

My Home Life

Quality of life in care homes

A review of the literature

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Prepared for Help the Aged by
The National Care Homes
Research and Development Forum

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Preface

Help the Aged commissioned the National Care Home Research and Development Forum to deliver this project as part of its policy work relating to improving quality of care for older people. More specifically, the project relates to a proposed new programme of work looking at the quality of life of older people who live in care homes. The aims of the proposed new programme are to deliver accessible tools and information resources to care home managers, staff and commissioners which will be utilised within their daily work to optimise the quality of life of older people within their care.

This preparatory project, designed to inform the larger programme of work, reviews and collates research and experiential evidence from a range of stakeholders about what specific practices or factors can impact upon the quality of life experienced by older people living in care homes.

Aims

The specific aims of the project are:

- to deliver an initial base of evidence (research and experiential) about what quality of life means to older people living in care homes and what specific practices, behaviours and attitudes have an impact on the quality of life of older people
- to provide evidence (research and experiential) as to how older people in care homes can be supported to have a voice in delivering improvements in care-home practice
- to demonstrate through the process of this work that knowledge can be harnessed from older people, care-home staff and researchers in this field and that these groups can work collaboratively to improve the quality of life of older people
- to capture the voices of those who are living in care homes expressing their views of a vision for social care in care homes and consider how their input might influence practice within the future.

Help the Aged

Help the Aged is committed to improving the quality of life for older people in care homes, as part of its overall vision and mission.

The **Help the Aged vision** is of a future where older people are free from the disadvantages of poverty, isolation and neglect, so they can live with dignity as valued, respected and involved members of society.

The **Help the Aged mission** is to secure and uphold the rights of disadvantaged older people in the UK and around the world. Working with them, we will research their needs, campaign for changes in policy, and provide services to alleviate hardship today and prevent deprivation tomorrow.

National Care Homes Research and Development Forum

The National Care Homes Research and Development (NCHR&D) Forum was established in 2003 to provide a platform for practitioners and researchers to network and to share information and ideas arising from their work. Members believe that the forum has the potential to bring together a wealth of knowledge and talent and could exert a considerable influence on future research agenda for long-term care for older people. In the short time that the National Care Homes Research and Development Forum has been in existence it has facilitated networking between 112 researchers and practitioners involved in care-home work. The Forum was recently awarded Economic and Social Research Council (ESRC) funding to run a seminar series (Transitions in Care Homes: meeting the demands of the 21st century) to facilitate the exchange of national and international ideas and experiences in order to inform and plan for future joint undertakings in research and development in care homes. Since the NCHR&D Forum's inception, it has become evident that a common theme within members' individual work is the desire to make a difference to the experiences of those living and working in care

homes. This commitment is evidenced by the way in which 57 members have volunteered to share their knowledge and expertise to inform this preparatory document, mostly regardless of financial remuneration. Contributions to the work have included sharing of information (databases of reference material plus articles and reports), authorship of chapters and critical reading of draft material by an expert panel.

This unique collaborative project has been led by Julienne Meyer (Professor of Nursing: Care for Older People, City University).

Other chapter leads include:

- Professor Jan Reed (University of Northumbria in Newcastle)
- Dr Sue Davies (University of Sheffield)
- Belinda Dewar (Consultant Nurse for Care Homes in Scotland; formerly of Queen Margaret's University College, Edinburgh)
- Fiona O'May (Queen Margaret University, Edinburgh)
- Dr Jackie Bridges (City University London)
- Caroline Nicholson (City University London)
- Dr Hazel Heath (freelance researcher)
- Jenny Dudman (freelance researcher).

In particular, Hazel Heath has played an important role in editing the document, Sue Davies in sharing her original database of references on quality of life/care in care homes (pre-2000), which was then updated (post-2000) by Belinda Dewar, Fiona O'May and Jenny Dudman, drawing in part on the AgelInfo database. The project team is most grateful to the Centre for Policy on Ageing for agreeing to give access to the AgelInfo database to NCHR&D Forum members for the purposes of this project. Belinda has also worked with colleagues in Scotland to obtain articles from older people about their experiences of quality of life in care homes.

Format of the work

The focus of the work is on quality of life, but recognising the links to quality of care. An

appreciative inquiry approach has been taken to focus on positive messages, rather than poor practice. The review builds on earlier work (Davies, S. (2001) 'The care needs of older people and family caregivers in continuing care settings', Chapter 5 in M. Nolan; S. Davies; G. Grant (eds) *Working with Older People and their Families* Buckingham: Open University Press). A stakeholder conference was held in London (29 June 2006) to tease out recommendations for the care-home sector, government, regulatory bodies, professional bodies, NHS and social care agencies, voluntary organisations and educationalists (research and teaching). The report begins with the context (Jenny Dudman), followed by two chapters overviewing issues related to quality of life (Jan Reed) and quality of care (Sue Davies and Hazel Heath). The evidence is then reviewed under a number of headings including: transitions into a care home (Fiona O'May), identity (Jackie Bridges), creating a sense of community (Sue Davies and Christine Brown-Wilson), shared decision-making (Sue Davies and Christine Brown-Wilson), health and care responses (Hazel Heath), end-of-life care (Caroline Nicholson), keeping the workforce fit for purpose (Julienne Meyer) and, finally, promoting positive cultures in care homes (Belinda Dewar). Throughout the document key issues are specified, best practice is identified, educational resources highlighted and illustrative quotes provided.

The authors would like to thank the following 57 members of the National Care Homes Research Development Forum for their input to *My Home Life*, either by sending material for consideration or by offering to act as an expert panel member.

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In a Care Home

Mrs J. L. Sealey

They are not always what they seem
 These tired, broken bodies
 Beneath the thin white hair
 Behind faded watery eyes
 Through cracks in the fragile shells
 We may glimpse histories
 Of long, eventful lives.

Here the wartime Spitfire pilot
 Still strains to stay alert, aware;
 And those once-famous dancer's feet
 Move endlessly to and fro
 In time to some remembered choreography.
 While another's hands trace out the plans
 He drafted for a new town's grandeur
 His neighbour's lips silently dictate
 Important Civil Service memoranda.

Others were less publicly honoured
 Yet honourably toiled – mining coal,
 Nursing the sick, teaching generations
 of children
 How to live well and reach their goal.

What is it that goes amiss
 As age takes over the body?
 Surely what these women, these men
 Have achieved, have been, have seen
 Should somehow remain manifest,
 Not be forever lost
 In their forgetting, their silences?

Part 1

Context and concepts

1 Context

Jenny Dudman

1.1 Historical influences

'In the main the story of long-term care is a positive one which charts the progress made in medical science and social care. But it also reveals how much more could be done, how much more progress could still be made, and how many more hopes could be fulfilled...'

(Kirkwood and Astle 1996, pp5–6)

Long-term care for older people in the UK began over 300 years ago and was nurtured through Poor Laws in the Victorian workhouses, but it was not until the early twentieth century that 'old and infirm' people began to receive what could be described as institutional 'care' designed to meet their needs. Fundamental in the development of long-term services has been the distinction between health care (originally defined within the National Health Service Act 1946) and social care (the National Assistance Act 1948), based on the explicit assumption that it is possible to distinguish between 'the sick or infirm' (people with health needs who should receive care from the NHS) and 'the frail and old' (people with social needs). This somewhat arbitrary distinction has been crucial in that the former received care free of charge while the latter would be called upon to pay. It also determined the development of long-term care provision during the 1950s and 1960s in that nursing and residential provision have different histories. 'Health' units, along with the newly emerging specialty of geriatrics, developed within units vacated by provision for infectious disease or, later, maternity services. 'Social' provision developed in 'Part III' accommodation run predominantly by local authorities.

During the 1980s and 1990s, changes in funding from the then Department of Social Security opened a door to new providers, and the bulk of older people's long-term care provision moved into the independent sector (private, i.e. for profit, and voluntary, i.e. not for profit). As a consequence, the 1980s saw the development of regulation through the Registered Homes Act 1984 with a small percentage of homes dually registered to offer both residential and nursing places, and also to the immense debate about

'perverse incentives' towards residential care leading to further changes in funding arrangements through the NHS and Community Care Act 1990. It is important to note that, at this point, specialist support from multidisciplinary teams within NHS units was lost to the majority of older people living in care homes, including access to consultants in old age medicine (geriatricians), occupational therapy, physiotherapy, speech and language therapy and others, subsequently not costed into the care provided. Following the fragmentation of long-term care across the statutory, voluntary and private sectors there is evidence of ageism in policy development over the years, where old age is depicted as a problem evidenced in the management of decline in the attitude to long-term care, rather than one requiring a dynamic, positive approach to ensure that older people lead a fulfilling life (Hurtley 2004). Since devolution, services have developed differently around the UK, with some areas, particularly in Scotland and Northern Ireland, retaining more NHS-provided continuing care.

Ownership of care homes falls into either the local authority or the independent sector. Local authority homes are publicly funded and managed and are largely in the residential care sector. In the independent sector care homes can be owned by charities or other voluntary organisations or can be privately owned by anyone from large for-profit companies down to small, one-person businesses. Since the mid-1990s there has also been a rise in the number of care homes which are 'dual-registered'. These again tend to be mainly in the independent sector (Bajekal 2002).

The Care Standards Act 2000 saw the terms 'nursing homes' and 'residential homes' replaced by 'care homes' for institutions which provide accommodation together with nursing or personal care. Care homes for older people are now categorised by the type of care they provide, nursing or personal, and by ownership. Care homes (personal) provide broad personal care only, whereas care homes (nursing) are intended for those people who need regular or constant nursing care (Bajekal 2002, Froggatt 2004).

For ease of reference, the terms ‘nursing home’ and ‘residential home’ are used in this report.

1.2 Care homes in the UK today

It is estimated in the *Healthcare Market Review* (Laing and Buisson 2004a) that there are about 486,000 places in care homes across the UK, which comprise:

private nursing care	164,300 places
private residential care	182,000 places
voluntary nursing care	15,000 places
voluntary residential care	49,700 places
public provision (including NHS and LA)	74,600 places

It is difficult to get accurate data, corresponding to provider type, for each of the constituent countries of the UK but the breakdown for each country is roughly as follows:

- England has about 749 care homes (both residential and nursing) in the local authority sector, 10,462 in the private sector and 1,640 in the voluntary sector (National Care Standards Commission 2004).
- Scotland has 185 care homes in the local authority sector, 643 in the private sector and 152 in the voluntary sector (Scottish Executive 2005).
- Wales has 140 care homes in the local authority sector and 550 in the private and voluntary sectors (individual figures are not available for the latter categories) (National Assembly for Wales 2003).
- Northern Ireland has 47 care homes in the local authority sector, 107 in the private sector, 23 in the voluntary sector and 77 which are dual-registered (Department of Health, Social Services and Public Safety 2004).

It is also difficult to get accurate data on the breakdown of numbers of care homes, either residential or nursing for each of the countries. Figures from the DH show that, in England, in 2002, there were 24,000 residential care homes, 5,200 private nursing homes and 2,280 dual-registered homes (DH 2002b). In Scotland, in

2002, there were 605 residential care homes and 558 private nursing homes, although the nursing homes cover all client groups and not just those for the older person (Scottish Executive 2003). No figures were available for Wales or Northern Ireland.

Over the past 20 years the balance between the different types of provider has changed, with a shift from the public to the private sector. The number of homes owned by local authorities has fallen drastically, from over 85,000 in 1994 to 44,200 in 2004 (Office of Fair Trading 2005, National Care Standards Commission 2004) and the private sector is now the major provider (Bebbington et al 2001). Within the private sector, while the proportion of beds supplied by the major for-profit providers has increased over the past 10 years, from 6 per cent to more than 22 per cent of the total, 54 per cent of homes are still single home businesses and 8 per cent of small businesses have two or more homes (Office of Fair Trading 2005).

Size and facilities

The average care home in the UK has about 30 places, although there are wide variations, from those with 2–3 places to some with over 100 beds. Residential homes tend, on the whole, to be smaller than nursing homes, with 24 compared to 44 beds (Office of Fair Trading 2005). A survey of care homes in 21 local authorities by Darton et al (2003) found that the majority of local authority homes and just over half of the voluntary homes were in purpose-built premises, whereas the majority of private residential homes, dual-registered homes and nursing homes were in buildings which had been converted for the purpose. However, with the growth in ownership of care homes by the large major providers, there has been a corresponding growth in the numbers of purpose-built homes in the dual-registered and nursing-home sectors. There are also a small number of care homes which have been recently regulated for three or fewer residents. These are usually in the proprietors’ own home.

The *Building Capacity and Partnership in Care* document (DH 2001) provided a positive

challenge from the government, recommending greater involvement of the independent sector at the planning stage of developing new facilities, with the aim of regenerating the sector. In reality this was difficult to implement, partly due to the complications arising from the fragmentation of the sector and a lack of political will, limiting the potential for joint forward planning and provision of care homes where they are needed.

A study of 673 homes in 21 local authorities by Netten et al (2001) found that 89 per cent of beds in local authority and voluntary residential homes were in single rooms. In private residential homes it was 69 per cent and in dual-registered and nursing homes it was 65 per cent. However, the reality is that these rooms may be as small as 10 square metres in area, which is notably smaller than those of a typical student room or prison cell (Hanson et al 2003). (Comparisons are illustrated in figure 1.1.) There were found to be washbasins in the bedrooms of 88 per cent of homes. Approximately 50 per cent of private residential homes and 40 per cent of voluntary residential homes, dual-registered and nursing homes had en-suite showers or baths in at least some of the bedrooms and about 60–70 per cent of homes in the independent sector had en-suite toilets.

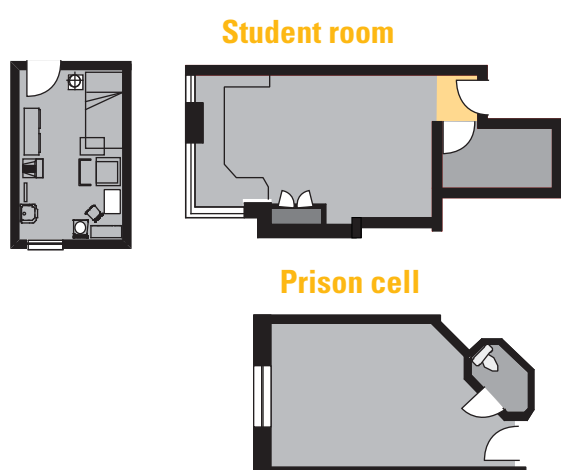


Figure 1.1: Older people living in care homes may have as little personal space as 10 square metres. A typical student room and prison cell are also illustrated to the same scale for comparison. (Source: *Profiling the Housing Stock for Older People*, Dr Julienne Hanson, Reader in

Architecture and Urban Morphology, UCL; co-investigators Leonie Kellaher (Director, Centre for Environmental and Social Studies in Ageing, UNL), Professor Mike Rowlands (Professor of Anthropology, UCL); researchers Dr John Percival, Dr Jean-Sebastien Marcoux and Reem Zako)

Demand

Over the past 20 years the demand for care-home places has been influenced by both demographic trends and government policy (Office of Fair Trading 2005).

Until 1993 there was a rapid expansion in the number of care homes. In fact, between 1983 and 1986 the number of independent care home beds rose by 242 per cent (Netten et al 2001). This was fuelled by both an ageing population and by open-ended income support funding. This meant that anyone with less than a specified amount of savings received full state benefits, which would pay for their care-home fees, without assessment or further means-testing. This encouraged people to opt for private residential care and equally encouraged many people to open private care homes (Andrews and Kendall 2000). In 1993, this period of expansion came to an end with the transfer of state funding to cash-limited local authority budgets, as a consequence of the NHS and Community Care Act 1990. Since then, across the UK, capacity has fallen by 15.5 per cent from its peak in 1996. Demand has also fallen by 12.4 per cent during the same period (Office of Fair Trading 2005).

More recently demand has been held in check by a temporary reversal of population ageing during the years 2001–4 (Laing and Buisson 2004a), although from 2005 it is believed that population ageing will again become the main driver of demand until the middle of the 21st century. The number of people aged 65 and over in the UK has been projected by the Government Actuary Department to grow from 9.3 million in 2000 to 16.8 million in 2051, an increase of 81 per cent (Wittenberg et al 2004), and for those aged 85 years and over almost to quadruple, from 1.1 million (1.9 per cent of

population) in 2004 to 4.2 million (6.5 per cent) (Laing and Buisson 2004a). These estimates require there to be a major upward revision in assumed life expectancy and could, in turn, result in a substantial increase in demand for long-term care in the future, as rates of disability and dependence escalate rapidly with increasing old age (Laing and Buisson 2004a). Wittenberg et al (2004) go so far as to suggest that over the next 50 years the number of places would need to expand by about 150 per cent.

However, it is difficult to accurately predict future demand as it is influenced by opposing forces (Laing and Buisson 2004a). Demand is not only dependent on people's state of health, developments in health care and the treatment of certain diseases: it is also influenced by government policy, which at the present time is placing the emphasis on providing alternative forms of care in people's own homes (Office of Fair Trading 2005). It should be noted that very little is known about the benefits and costs of care at home *versus* care in a residential setting. Mottram et al (2002) attempted to assess this issue through a systematic review, yet they were able to find only one study, a randomised controlled trial involving 112 people in the US, the findings of which showed no significant differences between the two groups. However, due to the magnitude of the predicted demographic pressures, there is bound to be a need to see some expansion in the care-home sector in the mid- to long term (Laing and Buisson 2004a).

Occupancy rates

Nationally, care homes have an occupancy rate of over 92 per cent. Laing and Buisson's (2004b) most recent survey of care homes found occupancy rates in 2003 to be 91.8 per cent for all for-profit homes (compared with the average of 90.4 per cent recorded in 2002), 92.3 per cent for private residential homes and 87.7 per cent for dual-registered homes. The Social Policy on Ageing Information Network (SPAIN) (2005) argues that this is well above the optimal level and suggests that we are actually experiencing a bed shortage. 'Spare places' are needed if the

care sector is to be responsive and equipped to cope with the range of care needs that it is called upon to deal with, such as permanent residence, short-term respite placements and discharges from the NHS or intermediate care. Spare capacity is also needed to ensure provision of choice and to allow for 'local provision' so that the older person does not have to be moved away from their family and friends. SPAIN believes optimum occupancy should therefore be only 90 per cent.

Number of places

The number of care-home places varies widely across the UK. For example, London has only two-thirds of the places which would be expected for the proportion of older people in the population; whereas Northern Ireland has about a quarter more places than would be expected (Office of Fair Trading 2005). In England there are approximately 460 places per 10,000 population age 65 and over. London has relatively fewer places (313/10,000), which is just over half the number of that in the North West (578/10,000) (National Care Standards Commission 2004).

Such regional variations may be a result of an adequate supply of non-residential services, or alternatively, could represent a real shortage (National Care Standards Commission 2004). If the latter were the case, it could mean that individuals are placed far away from their home, family and friends. For example, while a survey of care homes in London by Henwood (2001, for the King's Fund) showed no evidence of insufficient care-home places, it did note that places were not always in a location of choice.

A number of organisations have highlighted the shortage of places for those with specialist care needs. The survey by Henwood (2001) highlights the serious shortage of services in London, including residential care, for those with mental health problems, including dementia and depression. SPAIN (2005) suggests that at present there are pronounced local and regional shortages of care-home places, especially for those with specialist care needs, such as mental health problems. And while the Office of Fair

Trading (2005) acknowledges that some homes provide a range of more specialised services in areas such as dementia care, mental disorders and physical disability, the number of these is actually limited, resulting in limited choice for consumers. For example, in Scotland, of the 980 care homes currently registered, only 20 are specifically for those with dementia (Scottish Executive 2005) and in England, of 13,000 care homes, about 3,000 are for those with dementia (Office of Fair Trading 2005).

1.3 Residents in care homes

Age and health status

The proportion of older people who live in long-term care is small (4 per cent) and is very much age-related (Bajekal 2002). Age Concern (2004a) cites the percentages of people living in a care home or long-stay hospital as:

- 0.9 per cent for ages 65–74
- 4.3 per cent for 75–84-year-olds, and
- 20.7 per cent for those aged 85 and over.

Women residents tend to be older, at an average age of 85.6 years, compared to 83.2 for men (Office of Fair Trading 2005). People who move to live in nursing homes tend to be slightly younger than those who move into residential care (Netten et al 2001).

Bebbington et al (2001) identified a range of illnesses associated with admission to a care home, the most common being dementia, which was reported in about 38 per cent of residents. Arthritis was reported in 32 per cent of cases and cardiovascular disease and stroke in around 20 per cent. Other factors included respiratory disease, deafness, depression, fractures and blindness. Stroke and malignancy were more frequently reported amongst admissions to nursing than residential homes, whereas those placed in residential care were characterised by a history of arthritis, deafness or a lack of motivation.

Some degree of cognitive impairment is also widespread among those who move into care homes. Only one-third of residents are classified

as intact or borderline and over a third have severe impairment. Levels of cognitive impairment are higher in those cared for in nursing homes, although large numbers of severely impaired people are cared for in residential homes (Bebbington et al 2001).

Further discussion of the health of care-home residents, and the implications of this for service provision, is offered in Chapter 8.

Care homes also have a significant role to play in end-of-life care, a role which will continue to grow as the population ages. Each year approximately 21 per cent of people over the age of 65 who die do so in care homes. By comparison, 4 per cent of the UK population die in hospices, whose role it is to specifically provide care for terminally ill and dying patients (Froggatt 2004). However, as the National Council for Hospice and Specialist Palliative Care Services argues, it is not possible to make comparisons between hospices and, for example, nursing homes, in terms of bed costs, as this would not be comparing like with like (National Council for Hospice and Specialist Palliative Care Services 1995).

Further discussion of the role of care homes in end-of-life care is offered in Chapter 9.

Very little is known about the extent to which existing services are used by people from black and ethnic minority origins. The numbers of older people from these groups in the general population is small. In 1996 they comprised less than 2 per cent of all people over 60 and fewer than 1 per cent of those over 75. In the survey by Bebbington et al (2001) 1.2 per cent of those surveyed were from an ethnic minority group. The study highlighted significant differences in reasons for admission and health status between those from the ethnic minorities and those from the white British population. They found that, in general, those from the ethnic minorities were more likely to be younger, male, living with their family prior to admission, have a higher incidence of cognitive impairment, dementia and incontinence and be more dependent. They were also more likely to move into a home for a mental health problem, or problems with their

housing or carers, rather than for a physical health problem.

Reasons for entering care homes

While people generally enter care homes because they can no longer live independently, they do so for a wide variety of reasons, of which physical and mental health problems predominate. A report by the Office of Fair Trading (2005) identifies a number of reasons for admission and it should be borne in mind that many residents are experiencing more than one problem at the time they move into the home.

Physical health problems	69%
Mental health problems	43%
Functional disablement	42%
Carer stress	38%
Lack of motivation	22%
Present home physically unsuitable	15%
Family breakdown (including loss of carer)	8%
Rehabilitation	6%
Fear of being a victim of crime	4%
Abuse	2%
Loneliness or isolation	2%
Homelessness	1%

(Office of Fair Trading 2005)

From their study Bebbington et al (2001) were able to identify a number of characteristics, common to people who become long-stay residents. Typically they were over 80 years, female, unmarried, living alone, living in a house rented from the local authority or housing association, receiving income support and housing benefits, receiving attendance allowance, living in a poorer neighbourhood, had multiple disabilities and had a limiting longstanding illness.

According to Bebbington et al (2001), admissions come from a number of sources which include:

- 29% from private households
- 6% from sheltered housing
- 13% from other care homes, and
- 51% from hospital.

Prior to any admission the person will have undergone an assessment of their care needs. In the past such assessments were usually carried out by social services, independently of any other bodies which may have had a responsibility towards the person. But since the introduction, in 2004, of the Single Assessment Process for Older People (SAP), all the agencies in England that assess social care, health, housing and other needs are required to work together to avoid duplication (Age Concern 2005a).

Wales has a unified assessment process and care management system for older people in place.

Scotland has introduced a Single Shared Assessment.

In Northern Ireland assessments are undertaken by an integrated health and personal social services (Office of Fair Trading 2005).

If a person approaches a care home directly, it is the responsibility of the home, since the implementation of the minimum standards, to carry out the assessment. But this is not the same as a SAP assessment. Older people who are funding their own care are, under Charging for Residential Accommodation Guide (CRAG) regulations, entitled to have their needs assessed by the local authority, even though the local authority is not then obliged to arrange services, unless the person is unable to do it and has no one willing to do it for them.

Dependency

People who move into nursing homes have higher levels of dependency than those who go into residential care (Bebbington et al 2001). Overall 75 per cent of care-home residents are classified as being severely disabled (Office of Fair Trading 2005, Bajekal 2002). Prevalence of severe levels of disability is, as one would expect, highest in nursing homes (91 per cent) and lowest in residential homes (70 per cent). The prevalence of severe disability is also significantly higher for women (79 per cent) than for men (70 per cent) in care homes (Bajekal 2002).

Across all care homes 57 per cent of women and 48 per cent of men need help with one or

more 'self care' tasks (Office of Fair Trading 2005). Needing assistance with dressing was most common, followed by help with using the toilet, transfers from bed or chair, washing and feeding. For each task, higher proportions of women than men needed assistance (Bajekal 2002).

1.4 The regulation of care homes and standards

Attempts have been made over the past 20 years to improve standards in care homes. The Registered Homes Act (DH 1984) gave greater powers to both local and health authorities in the regulation of care homes, both private and voluntary. However, according to Nazarko (2000), as the legislation was vaguely worded and open to interpretation, it resulted in health and local authorities all applying different standards. The need for national standards was recognised and, in 2000, new legislation aimed at improving the standards of care provided by all care services was introduced across the UK. In England and Wales this was through the Care Standards Act 2000 (DH 2000); in Scotland through the Regulation of Care (Scotland) Act 2001 (Scottish Executive 2001); and in Northern Ireland through the Health and Personal Social Services Act (Northern Ireland) 2001 (Department of Health, Social Services and Public Safety 2001).

The major consequence of all this legislation has been the introduction of National Minimum Standards. Standards have been drawn up by the Department of Health, the Scottish Executive and the Welsh Assembly to cover a variety of client groups, including care homes for older people (Laing and Buisson 2004a). These standards apply to seven key areas: choice of home, health and personal care, daily life and social activities, complaints and protection, environment, staffing and management and administration. However, as Laing and Buisson (2004a) point out, there are significant variations between the different countries in terms of the standards, for example, in room size and numbers of shared rooms.

Independent regulatory bodies have been set up in each country to apply and monitor these standards. In England, this role has been assigned to the Commission for Social Care Inspection (CSCI). For Wales, the relevant body is the Care Standards Inspectorate and, for Scotland, the Care Commission. In the case of the CSCI, inspections originally took place at least once or twice a year. However, changes have already been made to this process, starting from 1 April 2006. These changes see a reduction in the frequency of inspections, from twice a year to 'at least once in every three years'. There will be three types of inspections:

- key – a thorough, unannounced inspection
- random – short and targeted
- thematic – following up on national or regional issues such as medicines management.

An annual quality assurance assessment is also being introduced, in which the provider will be required to assess the service it is providing, together with the publishing of quality ratings, although this will not take place until mid-2007 (CSCI 2006)

The role of the inspectors is to rate a home's performance against each standard, on a scale of 1 to 4. Where regulations are not being met the provider is asked to draw up an action plan and the inspector monitors the provider's progress in rectifying the breaches in regulations. If there is a serious disregard of the standards, or they are continually flouted, enforcement action is taken, with the ultimate sanction being cancellation of a home's registration (National Care Standards Commission 2004, Care Commission 2004). However, even since the setting up of these bodies, quality of care remains an issue. For example, the National Care Standards Commission reported that in 2002/3 only about 50 per cent of care homes for older people met or exceeded their standards for a simple and accessible complaints procedure and protection of the person from abuse. During these years they received 12,685 complaints. Between April 2003 and March 2004, 64 per cent of complaints received by the

Scottish Commission were related to care homes and for the same period, the Care Standards Inspectorate for Wales received an increased number of complaints against care homes, the majority relating to basic care provision (Williams 2005).

1.5 Staffing and skill-mix

The Royal College of Physicians, Royal College of Nursing and British Geriatrics Society (2000) emphasised the importance of access to relevant health professionals, in particular stating the need for positive care for people with dementia and depression. This was swiftly followed by a significant collaborative report, *Care of Older People in Care Homes: a comprehensive interdisciplinary approach* (2001), which echoed the need for more robust professional input, skill-mix and a more research-based approach to improve health outcomes of older people in care homes (Hurtley 2004).

However, there is very little accurate data regarding staffing levels or skill-mix within the care-home sector. The survey by Netten et al (2001) found that in the case of residential homes there is approximately one full-time member of care staff for every three places and one part-time member of care staff for every 2.5 places. Dual-registered and nursing homes have higher levels of full-time staffing, with one full-time member of care staff for just over every two places, but similar levels of part-time staff as the residential homes.

This study also found that, for all types of home, staffing levels for both care and nursing staff tend to be highest in the mornings, falling off slightly in the afternoons and again in the evening. At night both dual-registered and nursing homes have at least one member of staff on duty, with the majority having three. Private residential homes have the lowest numbers, with 51 per cent having only one staff member available at night. Most local authority and voluntary residential homes have two staff on at night.

Their survey also revealed the number of staff with nursing qualifications to the number of

places. In dual-registered and nursing homes it was the equivalent of just over one registered nurse to every four places. Private residential homes had one to ten places and local authority and voluntary homes had one to 20. A survey by the Royal College of Nursing (2004) of RCN members working in care homes revealed that registered nurses make up less than a third (30 per cent) of the employed nursing staff, although this figure did vary from 15 to 48 per cent. There appeared to be no significant difference between privately owned homes or those which were part of a chain. Netten et al (2001) also found that 55 per cent of local authority homes employed at least one social worker; however, they were less likely to employ nurses. For private and voluntary homes about 20 per cent employed social workers.

From their 2004 survey, the English Community Care Association, P and G Professional and Laing and Buisson argue for a skill-mix review, as they feel this would relate to better care delivery, as staff numbers and qualifications are matched to care needs and improved care provision. Furthermore, they contend that staffing notices are outdated and a national dependency tool is required with a new negotiated skill structure. They recognise the need for cross-learning opportunities for staff, relatives and residents and would like more partnership working with the NHS.

National Minimum Standards have been set for staffing levels and skill-mix. In terms of staffing levels they require staffing numbers and the skill-mix of qualified/unqualified staff to be appropriate to meet the assessed needs of the residents, the size, the layout and the purpose of the home. A formula has been devised by the Residential Forum (2002) proposing a range of 16 (low dependency) to 20 (high dependency) care assistant hours per resident per week. Yet this applies only to new homes and those seeking a variation in registration and the rules are not rigidly being applied. No guidance has yet been published regarding qualified nursing input in the case of nursing homes. However, those care homes which were operational before the introduction of the Care Standards

Act are being advised to maintain levels set by health authorities, although this would be difficult to enforce. Henwood (2001) expresses concern that the reduction seen in residential care homes for those with mental health problems may be due, in part, to these standards, which are calling for higher staffing levels and expertise than previously needed.

Recruitment and retention of care-home staff, both qualified and unqualified, is a major issue, especially in areas where the cost of living is high – for example, in London and the South East (Henwood 2001). A study by Netten et al (2003a) found that a lack of qualified nursing staff was the factor most frequently cited for care home closures. It is felt by some that the introduction of the National Minimum Wage has not helped this situation, as it has brought into line the wages of the care sector with other much less stressful and demanding work. Netten et al (2003a) argue that that without marked increases in care staff wages, which is something that care homes can ill afford at present, recruitment and retention will continue to be an ongoing problem. The English Community Care Association, P&G Professional and Laing and Buisson (2004) argue for more government action to respond to demography and the implications.

Over the years concerns have been expressed regarding the quality of care provided in care homes, with calls for higher levels of training and qualification among care assistants. Little is known about current levels of training for care assistants, who in the past have been seen as largely untrained, poorly paid and difficult to recruit (CPA 2001). Netten et al (2001) found that two-thirds of homes in their survey had staff with NVQs or BTEC awards, with many other members of staff working towards such qualifications. Another survey by the CPA (2001a) of 1200 independent sector and local authority homes found that at least 20 per cent of all care assistants had some form of additional training qualification: for example, at NVQ level. They also found that while there was no shortage of training across the country, availability was uneven and the quality of the

training was not known. Some homes were found to have well developed strategies, while others had glaring gaps. They found the not-for-profit homes had a more thorough and comprehensive approach to staff training. They also discovered that the vast majority of homes believed that training had benefited both quality of care and staff morale.

Yet the training and education of care home staff is important if one is to ensure that carers are able to fulfil their role with both 'competence and sensitivity' (Fitzpatrick and Roberts 2004). A number of authors have tried to identify the qualities and knowledge needed by care-home staff. O'Kell (1995) believed that carers need personal warmth, patience, sensitivity, the understanding of client's needs, the ability to provide competent care and the ability to promote client choice and independence. An even more detailed list of core knowledge and skills is identified by Fitzpatrick and Roberts (2004). This list includes knowledge of the ageing process, good communication skills, an ability to promote independence and autonomy in activities of daily living, identifying and meeting nutritional needs, managing incontinence and constipation, maintaining skin integrity, medicines management, managing mental health issues including dementia and depression and encouraging participation and involvement of older people and their families.

Within the National Minimum Standards there was also a requirement, by December 2005, for there to be a minimum of 50 per cent of care staff to be trained to a minimum of NVQ level 2 or equivalent and for all homes to demonstrate staff training and development. However, by 2004 only 22 per cent of private and voluntary care homes, in England, had achieved this target, with progress among the remainder variable, with the majority in the 10–30 per cent range (Laing and Buisson 2004a).

Workforce issues are discussed further in Chapters 10 and 11.

1.6 Funding issues

The cost of residential and nursing home care is divided between the state and the individual, with the amount each has to pay determined by means-testing. Over the past three decades there have been some significant changes to the way care is funded. For example, in the 1970s a quarter of older people in residential care homes were funded by the NHS, but by 1995 this figure had reduced to 10 per cent (Netten et al 2001). Also, 1995 saw the introduction in England and Wales of 'continuing care' packages, whereby a person who does not need to be cared for in an acute hospital but has a high degree of ongoing health care needs receives fully funded care, paid for by the NHS (House of Commons Health Committee 2005, Age Concern 2005b).

One of the most recent government policies to impact on care-home fees has been the decision, in the case of England and Wales, to make nursing care 'free' to everyone, but not 'personal' care. In Scotland the decision was taken that both personal and nursing care would be funded by the state.

While Wales adopted a single Registered Nursing Care Contribution (RNCC) of £105/week and Northern Ireland £100, England adopted 3 bands: high/£125, medium/£77.50 and low/£40. In Scotland the rate was set at £145/week personal care allowance, plus an additional £65/week for nursing care, although the person does lose their entitlement to Attendance Allowance and the care component of the Disability Living Allowance (Laing and Buisson 2004a). However, the RNCC is not the same as fully funded NHS care (RCN 2006).

NHS-funded nursing care allocations to English primary care trusts are £89 per funded resident/week. Laing and Buisson (2004a) feel that this does not differ greatly from the actual cost of employing qualified staff to provide nursing in a care home, which they estimate nationally to be £106/week in 2004/5, although this is based on minimum staffing levels. It has been argued that the bands for low, medium and high contributions in no way cover the real

costs of providing nursing care (Henwood and Waddington 2005).

The inequity of long-term care funding for different groups such as people with dementia led to the 1999 Royal Commission on Long Term Care. The eventual outcome has resulted in increased complexities, exacerbating inequities and inconsistencies (Richards 2001). An example of this is the three bands of nursing care which are complex to implement and process. There are also concerns that people are being incorrectly assessed for RNCC funding, when in fact they are actually entitled to a fully funded NHS package (RCN 2006). This issue will be addressed following the Grogan case in January 2006. One of the findings of this was that the eligibility criteria used to assess Mrs Grogan were 'fatally flawed', partly as a result of linking fully funded NHS care eligibility to the RNCC bands. The judge called on the Department of Health to produce clear guidance and direction to the NHS to prevent this situation from continuing (RCN 2006).

Initially the NHS-funded nursing payment was made direct to the care-home provider. However, this saw many care homes raising gross prices and then giving the residents a fee reduction, which was often less than the NHS-funded nursing payment. Following complaints from consumer groups the government has changed the regulations so that the value of the RNCC is now transparent to the consumer (Laing and Buisson 2004a).

A cross-sectional survey of over 11,000 residents in 617 care homes in 21 local authorities in 1996 (Netten et al 2001) found that nearly 70 per cent of residents were publicly funded to some extent. In the private sector about one-third of residents in residential homes and a quarter in nursing homes were self-funding. Of those who were publicly funded, 14 per cent had originally been self-funding on admission and had then become eligible for public funding (Netten et al 2001, Joseph Rowntree Foundation 2002, Williams 2005). The latest review by Laing and Buisson (2004a) found that in April 2004 61 per cent of independent

care-home residents were having their fees paid by local authorities and 33 per cent were self-funders. In Scotland 40 per cent are funded wholly or partly by private means and 52 per cent are funded wholly or partly by local authorities (Scottish Executive 2003). No figures were available for Wales or Northern Ireland. The numbers paying their own fees does vary greatly across the UK, from 50 per cent in Surrey and Sussex and 57 per cent in Edinburgh, to 17 per cent in North-East London, Durham and Tees Valley SHAs and 11 per cent in the Shetland Islands.

If the baseline fees paid by the Local Authority do not cover the entire cost of the fees charged by the care home, it is possible for a third party, often a family member, to pay a 'top up'. Williams (2005) states that there is a lack of information about the extent to which third parties pay 'top-ups', or the amount typically paid. However, the Office of Fair Trading (2005) estimate that around 35 per cent of those receiving state funding are also being topped up by a third party.

There appears to be some disparity in the fees charged by care homes for older people when compared to other types of care homes, such as, for example, those providing care to younger disabled adults (NCSC 2004). Fees for the majority of care homes for the older person are between £200 and £400 per week, with small numbers charging between £400 and £700 per week, although in London and the South East significantly higher fees are charged (NCSC 2004). By comparison, while the majority of care homes for younger disabled adults are charging about £300 per week, significant numbers are charging £400–£1,500 per week. Also, a small number of homes are charging over £3,200 per week (NSCC 2004).

In addition it has been found that those older people paying their own fees are often charged more. Laing and Buisson (2004a) estimate that self-pay fees are around £50-100 higher than the local authority fees, for similar services and amenities. This suggests that a number of providers are subsidising the inadequate levels

of funding they receive from local authorities by cross-subsidy, whereby those funding all their care pay the real cost plus a premium on top.

Other ways around this shortfall include some organisations accepting less than is necessary to cover costs, while in the case of some voluntary organisations they may use their charitable income to 'top up' the fees (Fair Rate for Care for Older People 2002). The practices of care homes charging higher fees to those older people who fund themselves, or of relatives being required to top up fees paid by the local authorities, have resulted in a 'super-complaint' being made to the Office of Fair Trading (SPAIN 2005, Office of Fair Trading 2005).

Funding is a continual problem, with local authorities claiming that central government funding has been inadequate over a long period of time and Ministers maintaining that councils are provided with sufficient funds to enable them to carry out their duties. SPAIN (2005) believes that this problem stems from the baseline determining care-fee levels which was set at the time of the Community Care Act 1990. It argues that insufficient money was transferred from the DHSS to local authorities, due to the underlying assumption that all that older people in care homes required was accommodation and physical care to cover their basic needs. In addition, there are concerns from within the sector about meeting the targets of the NVQ training in particular, as the training burden is not reflected in the fees (English Community Care Association, P&G Professional and Laing and Buisson 2004). While local authorities have received increased allocations, it remains open to debate whether these increases have been sufficient to cover the additional pressures of demand, wage costs and inflation (Laing and Buisson 2004a, SPAIN 2005). It is now hoped that the Single Assessment Process will go a long way to redressing this balance, with the funding of care based on the total needs of the older person and not determined by how much the local authority can pay (SPAIN 2005)

Key influencers on the future strategic development of the sector, in priority order, are:

- government funding of social services residents
- regulation
- self-funding market
- public perceptions
- growth in public sector provision.

Politics, population demographics, staff availability, ability to gain planning permission for developing alternative models of care, assessment and commissioning practices are also key influences (English Community Care Association, P&G Professional, Laing and Buisson 2004).

1.7 Care-home closures

Since the reforms to community care in the 1990s, many care homes have been forced out of business. In England and Wales, Age Concern (2004b) reports that there has been a steady decline in the number of care-home places, since a high point in the mid-1990s. Between December 2001 and April 2003, 745 care homes in the independent sector closed. The DH (2002b) also reports that between 2000 and 2001, 5 per cent of residential and nursing homes closed. In Scotland there is a similar picture, with 146 care homes closing between March 2000 and March 2005.

Care-home closures are associated with a number of factors (Netten et al 2003b). These include home size, occupancy levels, numbers of homes owned by the provider, whether the home is purpose-built, the proportion of single bedrooms, the provision of en-suite facilities and whether the building is single-storey or has a lift.

Factors which owners of closed private and voluntary homes feel contributed to their closure include low levels of fees paid by publicly funded residents, the cost implications of the national minimum standards, disillusionment with the long-term care sector, retirement, increases in running costs such as wages, the expectation that future local

authority fees would not cover costs and problems with recruitment and retention of staff (Netten et al 2003b, DH 2002b).

Closure is usually precipitated by a number of factors. However, in a study carried out by the DH (2002a), where a single cause was identified it was usually related to the low level of local authority fees. Nursing-home closures were particularly associated with difficulty in recruiting nursing staff and a skills shortage. In the case of residential homes, closures were associated with local authority pricing policy and the cost implications of implementing the minimum care standards (DH 2002b). The latter is one reason which has been given for the decline in the number of local authority care homes. Many of the local authorities are unable to raise the funds necessary to carry out remedial work, as the government has restricted the amount they can borrow (McFadyean and Rowland 2002, Fair Rate for Care for Older People 2002).

Unless the effect of market forces, such as the cost of meeting the minimum standards, high land and building costs, and the problems of recruiting staff begin to be tackled through, for example, improvements in fees paid by local authorities, the likelihood is that, for the time being, care homes, especially the smaller ones, will continue to close (Netten et al 2003b, SPAIN 2005).

1.8 Summary

- The development of care homes since the mid 20th century has been strongly influenced by the legislative distinction between healthcare and social care.
- Comprehensive statistics on care homes (for example, size, facilities, occupancy rates) have not historically been recorded by governments but some information is now available through care home regulatory bodies, market analysts Laing and Buisson, and large-scale surveys conducted, for example, by the Policy Social Services Research Unit, Canterbury.

- Care-home provision varies around the UK but the shortage of places is acute in some areas, particularly for people who have dementia.
- People who live in care homes are commonly aged 80 and over, with multiple and complex healthcare needs consequent to dementia, arthritis, cardiovascular disease, stroke or combinations of these.
- Independent regulatory bodies which apply and monitor minimum standards are now established across the UK.
- Recruitment and retention of care-home staff is a major issue, particularly acute in some areas, and there are calls for skill-mix guidance to be reviewed.
- Care-home funding is also a major issue. Government funding procedures vary around the UK and some are currently under review, specifically the funding of registered nursing and continuing NHS healthcare in England.
- Reduced state funding alongside increasing costs has led to a growth in care-home closures and providers continue to express concern about inadequate funding.
- Key influences on the future strategic development of the sector include government funding of social services, regulation, self-funding residents, public perceptions and any change in public sector provision.

1.9 Conclusion

Long-term care in the UK is diverse and complex, with multiple stakeholders who fund, regulate or provide a range of services. If the older people who live in care homes are to achieve quality of life, major issues such as state funding and staffing must be addressed by all concerned.

1.10 Glossary of terms used in Chapter 1

Care homes (personal) Previously known as residential homes, these homes provide personal and social care. Nursing and medical care is provided by primary care, through GPs and district nurses.

Care homes (nursing) Previously known as nursing homes, these homes provide personal, social and nursing care. Qualified nurses are employed to provide nursing care and medical care is provided through GPs.

Dual-registered homes These homes provide both personal and nursing care. Their advantage is that unlike residential home clients, those who later require nursing care will not need to move to a different home.

Continuing NHS health care A package of care arranged and funded solely by the NHS. In the case of a care home, health, personal and accommodation costs are all paid by the NHS.

2 Quality of life

Jan Reed

2.1 Perspectives on quality of life

Quality of life is notoriously difficult to define, as it pervades a range of aspects of everyday life in significant and complex ways. Quality of life can also go by a range of other names, such as well-being, satisfaction with life, or happiness, which makes it difficult to be clear about the nature of quality of life and how it can be supported. In the middle of this ambiguity, however, quality of life is a key concept, and whether we can be precise about it or not, we can see how important it is that the quality of our lives is as high as possible, that is that it is maximised in all circumstances and in all dimensions.

The importance of quality of life is reflected in the number of studies and papers there are about it. Looking at these papers, however, suggests some points that need clarification:

There may be some tensions between normative or universal ideas of quality of life, and individual ones. While normative ideas, that is, the general ideas we have about what is 'normal' quality of life for everyone, may be easier to use in tools for assessing quality of life; they may be based on simplifications of experiences, and may not fit individual cases. Individual measures may reflect individual perceptions more explicitly, but they may also be time-consuming and complex to apply. An example would be SEIQUOL, a self-evaluated quality of life tool, which asks for individuals to rank the areas of life that they feel are important to them, and give each area a score – a process that can be lengthy and complicated. These different areas may vary from one person to another. One person, for example, may feel that family life is very important to them, and another might not, so a universal approach might not reflect this diversity. This would contrast with universal or normative ideas of quality of life, which are based on the idea that quality of life is the same for everyone, and that priorities and the importance of different domains are shared across populations. Universal models of quality of life, then, have a resonance across cultures but will not reflect individual differences.

There may also be tensions between age- or environment-specific quality of life and general quality of life issues. Following on from the point above, there is a paradoxical need to think critically about any assumptions we might make about quality of life being different for older people in care homes than it is for anyone else, yet a need to think through their specific circumstances, needs and preferences. We might think, for example, that older people and people in care homes may have different ideas about quality of life, but this is not necessarily the case. As Gerritsen et al (2004) suggest, there is no evidence that quality of life for nursing home residents is 'fundamentally different' (p612). Indeed, to assume that it is different may be to support a set of assumptions about older people and care-home residents which distinguishes them from everyone else – in effect saying that they are different from everyone else, younger people or people who do not live in care homes. Not only is this not supported by any evidence, but it also opens the door to the use of stereotypes in thinking about older people. None the less we may need to take generational experiences and living contexts into account when looking at the quality of life of residents of care homes.

2.2 Quality of life and quality of care

Quality of life is often confused with quality of care, which is the way in which care is delivered and the standards that it meets. Separating quality of life from quality of care is a difficult process, especially as the two are interconnected. If care is of a high standard, it can support and promote quality of life. Nevertheless, quality of life can be independent of quality of care. Quality of life may be high while quality of care is low: that is, people may feel fulfilled and happy even if the care they get is poor or non-existent (they may not even need or want it). Conversely, people may have a high quality of care, in that it meets a number of standards, but have low quality of life. While quality of care is important, and something that professionals may want to think about carefully,

it is not necessarily the key contributor to quality of life. (See also Chapter 3.)

2.3 Dimensions of quality of life

Quality of life can be made up of a number of different dimensions, and in order to understand and raise quality of life, it is important that these dimensions are differentiated from each other and the differences understood. Dimensions may include physical, social or psychological aspects of quality of life (Gerritsen et al 2004) and under these headings it may include things like pain, isolation or anxiety, for example. While each of these might be a separate dimension of quality of life, it may also be that they are connected – that pain can restrict activity and lead to isolation, for example. As Gerritsen et al suggest, therefore, it is important that we understand the connections between these dimensions and how they interact with each other. We may also need to think outside the boxes we are most accustomed to by appreciating the importance of dimensions outside our own area of expertise. As health professionals, for example, we might think of quality of life as having solely a health dimension: that is, if people have health needs we regard their quality of life is directly and only dependent to this, whereas some other domain, such as money or environmental concerns, may be more or just as important. We need to think widely about quality of life and its dimensions, rather than just about the areas with which we are most familiar.

A report published in *Caring Times* in 2004 considered the insights into the consumer dimensions of quality of life. This included research commissioned by a large provider reinforcing former Office of Fair Trading fieldwork findings in *Older People as Consumers in Care Homes*, published in 1998. OFT cited the most frequent attributes of homes from a resident's perspective as: kind and helpful staff, a friendly atmosphere, the care and companionship received. In addition to these attributes, residents cited as basic concerns affecting how they feel about their home: having their own room, living in a building that 'feels

cared for', and receiving well cooked and presented food. In the same report further research conducted by the social services care home contracting team in Northern Ireland, using a series of focus groups, listed the same aspects, with some additional topics that reflected 'users' concerns' to inform their future contracting. These included the quality of activities, opportunities for getting out of the home, kind and knowledgeable staff, an accessible room and staff continuity.

This discussion suggests that quality of life is an area that is too complex and ambiguous to discuss or apply to practice. Taking these problems into consideration, however, there is still a body of research and debate which can inform and shape the way that we can think about quality of life for older people in care homes. This work can be used to investigate our central questions – what do we know and what can we do?

2.4 Quality of life in the literature

There are a number of ways in which researchers and writers have approached the topic of quality of life in the literature on this subject.. Some have focused on quality of life for very specifically defined groups of people: for example, people with dementia, or people with cardiac problems. Others have focused on broader areas: for example, physical functioning or social expectations. Some of this work is based on models of need, sometimes using hierarchical models such as that developed by Maslow (1943) which present some needs as essential to be met before others can be. A needs-based approach can easily be driven by professionally determined ideas about needs, based on professional models and capacities.

Some writers have explored quality of life from distinct professional perspectives such as nursing or medicine. What few have done, as Gerritsen et al (2004) have argued, is to look at quality of life from the perspective of older people themselves: that is, in terms of what is important to them. As Gabriel and Bowling (2004) contend, professional and academic views of

older age have suggested that later life is a time of decline and dependency, and this thinking has 'inevitably under-estimated the quality of life of older people' (p676).

This approach involves moving away from a needs-based view to a preferences perspective: in other words, paying attention to what people say they want, rather than what they (or others) say they need. This may involve relinquishing professional models of quality of life based on needs as defined by professionals. While these may have a sound basis in research or experience, they can also be imposed on older people, and driven by professional concerns or constraints. Thinking about preferences means having a much more 'older person-based' perspective on quality of life – to find out what people's preferences are means talking with them about their views, rather than relying on models from others. This would include looking at the things that older people in care homes think will improve or maintain their quality of life. These preferences may not be achievable in the resource constraints of the care home, but it will mean that exploring preferences generates discussion and thinking about possibilities.

From work with people experiencing profound communication difficulties due to dementia Lawton (cited in Thompson 2005) concluded that quality of life assessment for people with dementia should include both subjective and objective factors. Subjective quality of life refers to psychological well-being, whereas objective quality of life refers to external/environmental factors such as physical safety, privacy, and freedom from barriers. Four dimensions of quality of life are outlined:

- 1 Psychological well-being:** affective states including depression, anxiety, agitation, happiness and contentment
- 2 Objective environment:** refers to structured or routine events and includes architectural environmental features
- 3 Behavioural competence:** refers to a person's behavioural abilities including functional ability, physical health, behaviour and cognitive ability

4 Perceived quality of life: the person's own perception of their quality of life.

Kitwood and Bredin's indicators of well-being through sensitive and detailed observation of people with dementia has further been developed in the well-being and ill-being profiling (Bradford Dementia Group 2002).

For older people living in care homes, then, there may be some common experiences which can shape the discussion of quality of life. The first is that they are likely to have some experience of frailty (physical, psychological or social) which has led to them moving into a care home. The second point is that they are now living in a care-home environment, in which a number of dynamics operate, most vividly the dynamics of communal living where other residents and staff also have a place. Therefore ideas about the relative importance of quality of life may change and that supporting and enhancing quality of life may require different approaches. Frailty may mean that people review their ideas about the importance of different aspects of their lives – for example, physical activities may become less important, while social activities become more valued. Living in a care home may mean that some features of relationships, such as the availability of staff and access to fellow residents, may provide a context for moves to enhance quality of life.

From these discussions it can be seen that quality of life is a complex issue, and this complexity translated into the process of reviewing the literature in this field. Many papers can be identified through literature searching processes, but sorting them into groups that are manageable and which make sense can be a daunting task. Gabriel and Bowling (2004), for example, identified approximately 20 different quality of life themes in the data from a survey of older people's perspectives on quality of life.

Collapsing and streamlining these themes is a necessary but difficult task – necessary because in an unsorted form the themes are diverse and difficult to apply to practice, difficult because there is always the danger that important themes might be missed or subsumed

under another heading. At the risk of oversimplification, then, the themes on the quality of life literature have been divided into three basic dimensions – the environment that people live in, the activities they take part in, and the relationships that they have with others. These headings come from an analysis of the material that was found in the review process but is also evident in other summaries, for example, the literature review which resulted in Gerritsen et al's (2004) summary, and the study of older people themselves by Gabriel and Bowling (2004). The headings are:

- environment
- activities
- relationships.

Environment

Some work suggests that features of the environment in which people live has an impact on their quality of life. One aspect of the environment is its aesthetic appeal, that is, whether the setting is seen as attractive and appealing. As one resident said:

'It's a lovely home. I felt at home here straight away. It's just what I would have had if I'd picked the furnishings myself.'

This is an individual judgement – tastes differ, and what may be attractive to one person may be unappealing to another. This suggests that versatility and flexibility in decorating may be important for residents. Similarly important may be the opportunity for residents to bring possessions and furnishings to the care home, providing comfortable, usable and familiar possessions, to maintain continuity with previous lifestyles and environments.

Comfort is another dimension of the environment which may differ between individuals, depending on their preferences and their functionality. There may be some personal preferences for types of furnishing (for example, firm or soft mattresses for beds), which depend on personal choices, but other dimensions of comfort, such as accessibility and ease of operation, may need a careful assessment

of preferences and needs. Cook (2006) has described how a resident had set up a system of pulleys and levers to perform tasks such as opening windows and doors, and how this enhanced her comfort levels in the environment. This strategy, however, was developed by the resident without a lead from the care-home staff, and was subject to the different views and practices of care-home staff. If strategies for increasing comfort are to be maintained, then, there needs to be a careful assessment of needs and preferences, and an organisational response from the home.

Other dimensions of the environment may be easier to anticipate, such as safety. There is some evidence that residents of care homes value safety in their environment. This can involve facilities such as good lighting and appropriate handrails to maintain personal safety and reduce the possibility of injury, but there may also be priorities about security, such as the protection of belongings from loss or theft, as well as protection from assault. The response to these quality of life issues may be to develop systems of registering and recording possessions of residents and setting up systems of accountability with staff, so that any missing possessions are detected and investigated. More general responses may involve ensuring that doors to rooms can be locked and opened by the residents or at their request, and that entering residents' rooms is done only at the resident's request or with permission. Care homes may also need to ensure that premises are secure, and that visitors are identified by staff, and intruders detected. This may mean installing security mechanisms at main entrances, and ensuring that staff are aware of the importance of intruder detection. Staff, residents and visitors may also need to be aware of alarm systems and be able to operate them if needed.

Activities

Another dimension of quality of life in care homes is the way in which residents are able to participate in a range of activities. As one of the

older people said to whom Scharf et al (2005) talked:

'Being able to live comfortably and walk about... That's what it [quality of life] means to me anyway.'

Activity has been found to be important to residents in care homes, with some studies finding that organised activity can improve quality of life (Voelkl et al 1995).

These may be activities which maintain, expand or respond to areas of interest, such as new or existing hobbies. This means that staff need to be aware of existing activities and have thought through ways in which they can be maintained (for example, organising transport to venues and acquiring and adapting equipment). As one resident said:

'I was always very keen on the garden, and they've given me a room where I can get out easily and do bits and pieces.'

Staff also need to be aware of possible ways of developing new interests or extended interests, through being aware of sources of provision and support for residents. For example, a resident told us about a talk about local history:

'I was always quite interested, but going to that talk whetted my appetite, so I'm going to ask them to help me sort out all my documents, and maybe ask that man to come over and have a look.'

At an everyday level, residents may take part in some activities that they value highly, such as listening to the radio, or sitting in the garden. Hays and Minichiello (2005), for example, found that music was important to older people. Again, these preferences need to be acknowledged and supported, and strategies developed for making sure that they happen. This may be as simple as making sure that the radio is tuned to a resident's favourite programmes, rather than those that the staff like, or it may be more complex, such as organising people to accompany residents to the garden. If these efforts are not made, then residents may be left with little to do, with a consequent reduction in their quality of life.

Encouraging activity may require time, resources and energy. Activities may require time for staff support and care home resources such as equipment and materials. What may be crucial, however, is the energy that care homes may invest in exploring possibilities for activity, and in the process of rethinking ideas about residents. This may mean regarding residents as active rather than passive people, with a life full of possibility and potential. One resident talked to us about his reluctance to 'bother' staff:

'I used to go out for a drink every week, but I suppose that's all over now – they haven't suggested it, and I don't like to ask – it would be too much bother.'

On the other hand, when this was discussed with staff, it seemed that the process of visiting the pub was not a big problem:

'I didn't know that he went there. Actually, a few of our residents go there, and usually a member of staff goes with them, so he could go, quite easily.'

Relationships

The discussions above point to the importance of self in environments and activities, and this third heading, 'Relationships', points to the importance of the self in interaction with others. Much of this report deals in more depth with relationships with staff, particularly the ways in which staff can communicate more effectively with residents. What underpins these discussions is the idea of residents maintaining a sense of self as individuals who have social significance as people who relate to others. As one resident has said:

'I've always been very sociable, and it's nice to know that the other people here are too, and we're encouraged to mix.'

This can be extended to thinking about relationships with people other than staff, either previous or new relationships. Existing relationships may involve those with family and friends, relationships which have developed over time, and which have entailed a range of social positions which may be held dearly. Being a parent, for example, involves social positions of

responsibility and seniority which may bring a sense of loss if they are reduced. As one person said to Scharf et al (2005), giving presents to friends and family is important – when it was not possible this person felt ‘rotten’ (p34). Similarly, relationships with friends where residents have been confidants, sources of knowledge or known for their humorous conversation, may be important in maintaining someone’s quality of life. Maintaining these existing relationships may mean that care homes have to take care to be welcoming and hospitable for visitors, and respond to their needs as well as those of the residents. As friends and family members may also be frail and need support, this may mean making sure that homes are accessible and convenient, with social spaces, adequate facilities and support. Support with transport may be required for visitors too frail to use private or public transport, as may provision of easily accessible telephones or help with writing cards or letters to maintain contact.

Appreciation of old friends should not exclude the possibility of developing new relationships with other people. This may involve fellow residents, so staff need to be careful to provide a supportive environment for such interaction to take place: for example, social events and easily accessible meeting places. New relationships may also involve people from outside the care home, and staff should ensure that opportunities are available to residents through social exchanges and events involving people who live outside the care home.

2.6 Conclusions

This discussion has summarised some of the complex debates about quality of life for older

2.5 Summary

- Quality of life is notoriously difficult to define as it pervades a range of aspects of everyday life in significant and complex ways. It encompasses many dimensions and can be viewed from a range of perspectives.

- Comfort is important for care-home residents, who need to feel that their environment is attractive, supportive and safe.
- Care-home residents may need to continue past activities or to begin new ones. This support needs to be carefully planned and discussed with residents.
- Maintaining existing friendships as well as developing supportive friendships with other residents is important for residents and should be encouraged.
- Centrally, what constitutes quality of life is distinct for every person. In order to support and enhance quality of life we must seek to understand the priorities of each individual person.

people in care homes. This is a complicated area, where definitions of quality of life have developed in many traditions and have taken different forms. Amidst this complexity, one element remains central, and that is the importance of quality of life as each individual sees it. Enhancing quality of life is a process which starts with discussion with residents of their ideas about quality of life, and ways in which it can be supported. This may mean suspending assumptions and stereotypes about what older people want, and paying attention to what they say.

2.7 Recommendations

Staff should seek to understand each individual resident’s priorities for quality of life and address the key influences on this, such as the environment, meaningful activities and relationships, both through the care they offer and everyday life in the home.

3 Quality of care

Sue Davies and Hazel Heath

3.1 Perspectives on quality of care

Quality of care can contribute significantly to older people's quality of life but what constitutes quality of care in care homes is not clearly defined. Quality of care can be both an elusive and a dynamic concept. The concept of 'quality' is elusive because definition relies upon value judgements. The term 'quality of care' is dynamic because what is considered to be high or low quality changes over time and across settings to reflect prevailing social values of health and illness and also the expectations that people hold of services and practitioner-user relationships (Norman 1997, p27).

Traditional approaches have attempted to address what is a complex and multidimensional concept by reducing it to its component parts. In the search for definition, as Redfern (1993, p141) observes, there is a strong emphasis in the literature on an atomistic, reductionist approach which contradicts the holistic emphasis when describing the quality of, for example, a work of art.

Principles underpinning quality care have been identified as privacy, dignity, independence, choice, rights, fulfilment, recognition of individuality and diversity, expression of beliefs, safety, responsible risk-taking, citizens' rights, sustaining relationships with relatives and friends and opportunities for leisure activities (DH/SSI 1989, Centre for Policy on Ageing 1984, 1996). While few would challenge such principles, attempting to put them into practice in care homes without shared understanding runs the risk of them becoming mere buzzwords. Furthermore, as Nolan (1999, p66) argues, 'even if consensus as to a definition can be reached, what value do concepts such as autonomy and individuality have for individuals who might be both physically and cognitively frail?' Nolan warns (p67): 'to present benchmarks for quality which are either unrealistic, unachievable or simply inappropriate does nothing to enhance quality of care, and indeed might even hinder it. They are particularly important for staff who, if they set unrealistic or unattainable goals, are likely to become increasingly disenchanted.'

Standards against which to assess quality of care are widely used. Historically, approaches to quality assurance in care homes have emphasised structural characteristics of the home (such as room size and access to bathroom facilities), and physical outcome indicators of quality, such as the incidence of pressure sores, pain and infection rates (Abood 2002, Oldman et al 1998). While these elements are undoubtedly important, such approaches may fail to recognise the multidimensional nature of quality. They may also overlook some of the most important components of a quality service from the perspective of those who live in the home, and there is growing recognition that existing measures may not adequately reflect what is important to older people, their families and staff working with them (Robinson et al 2004, Kerrison and Pollock 2001).

Quality of care can be perceived and assessed in different ways by different stakeholders, according to their particular needs and agendas. Professional approaches are commonly rooted in the socialisation and linguistic traditions of a particular discipline and prioritise the achievement of their specific contribution to the service. In care homes, quality standards and measures are imposed within a strong regulatory framework enshrined in legislation. Independent sector providers, even those in the voluntary sector, have 'quality' priorities dictated by the fact that they run as businesses. Business support professionals such as lawyers or accountants will also influence 'quality' priorities, particularly, for example, in determining permissible levels of risk.

While acknowledging the consistency of the minimum standards against which care is monitored, the English Community Care Association, P&G Professional and Laing and Buisson (2004) voice concern about inconsistencies in inspection practices. Their report highlights the willingness of the sector to work in greater partnership with CSCI in terms of capacity planning, commissioning and staff regulation and argues for a consistent focus in outcomes measurement on the issues that affect residents' quality of life. This poses a particular

challenge since there is a growing body of evidence suggesting a disparity between the views of service providers and consumers about what constitutes quality care in care homes (Broussard 2001, Congdon and Magilvy 2002). Indeed, a key feature of the literature on quality assurance within care homes is that the voice of the consumer has been largely absent (Wagner et al 2001). The relatively small number of studies that have attempted to access service user views on continuing care services suggest that substantial investment is required in order to enable older people to have a voice (Mitchell and Koch 1997, Raynes 1998, Reed et al 1999). In particular, accessing the views of cognitively frail older people is a special challenge that requires time and skilled communication (Tester et al 2004). And yet such investment is essential if services are to be developed to be responsive to the needs and experiences of older people and their families.

The frustrations and challenges of attempting to develop measures of quality for health and social care are widely reported (see, for example, Rantz et al 1999, McCormack and McKenna 2001) and there is a risk of reducing 'quality of care' to what is easily measurable, to the exclusion of what is important (Briggs and Batchelor 2004). It has been suggested that 'quality' hinges largely upon perceptual and subjective influences that are not adequately reflected in standardised measurement tools (Kivnick and Murray 1997, Nolan et al 2001) and that quality measurement in care homes needs to find a way to include subjective interpretation of what matters to an individual (McCormack and McKenna 2001), with the emphasis on each person's potential to achieve his or her desired but realistic health choices. This is not to suggest that physical indicators of care quality (such as falls, pressure sores etc.) are not important; rather their significance for individuals needs to be part of the assessment.

Ultimately, quality of care can be seen as 'an abstract construct based on dynamic social interactions, the outcome of "negotiations" of various kinds between people from different social groups, each of whom holds particular

expectations and values and is more or less powerful according to the context of negotiation within which each operates' (Redfern 1993, p141). Approaches to assessing quality of care should recognise the complex, multidimensional nature of work in care homes and the range of stakeholder perspectives. They should be able to acknowledge the experiences of residents and relatives, the experiences of staff, the significance of relationships, and the interdependencies that exist in care homes. They should also have the capacity to consider the potential for both the interdependence and the reciprocity which can enhance quality of life for older people and those important to them.

A clear conceptual framework could offer a way forward in quality measurement (Tune and Bowie 2000).

3.2 New ways of thinking about 'quality'

Nolan (1999) argues that an appropriate framework for ensuring quality must:

- be sensitive enough to allow for individual variation
- afford a degree of specificity so that meaningful empirical indicators of key concepts can be identified
- be relevant to disparate groups of people who receive or provide care (or both)
- be easily accessible conceptually
- be capable of practical application.

Numerous approaches to quality assessment and improvement have been described in the literature, and the following have been selected for more detailed consideration on the basis that they appear to meet at least some of Nolan's criteria.

Caring in homes initiative – the Inside Quality Assurance package

One early attempt to involve residents and families in improving quality within care homes was the 'Inside Quality Assurance' package produced as part of the Caring in Homes

Initiative (CESSA 1992). Established in the wake of the Wagner review of residential care, the Caring in Homes Initiative comprised five action research programmes designed to address specific recommendations within the report (NISW 1993). The IQA programme aimed to develop a package for service review that was flexible enough to work in different types of care homes and accessible enough to enable home managers and proprietors to run the system themselves. It involved the development of 'quality groups' involving both 'insiders' and 'outsiders' who would meet together to discuss various aspects of life in the home. The initial task of each quality group was to write a report based upon interviews with residents and staff which covered seven topic areas: physical care, making choices, expressing feelings, the home as somewhere to live, knowing how things run, making links, and how the home feels to residents. Two simple questions were asked in relation to each topic: 'What is it like here?' and 'What needs to be different?'. Responses were then collated and fed back to residents and staff to check for accuracy. Finally, a report was developed with the purpose of identifying key issues and providing a basis for decision-making and action.

A detailed evaluation of the Caring in Homes Initiative in more than 100 homes is reported by Youll and McCourt-Perring (1993). They describe a range of experiences of using the IQA package, and identify implications for future efforts to involve older people and their families in quality assessment and improvement. For example, one consequence of the flexibility of the package was that different quality groups implemented the guidelines in different ways. This meant that service users were not always enabled to participate in ways that would make the most of their contribution. Staff assumptions about the capacity of residents to offer their views were a particular barrier. Membership of quality groups also varied between homes, and managers commented that it was difficult to find and recruit people with the time and energy to commit to the work. Staff were mostly enthusiastic about the process but, interestingly,

some staff felt strongly that IQA should also focus on staff needs, perceiving a direct connection between meeting needs for training, for example, and quality of care.

Most participating homes reported making changes as a consequence of the IQA process, often involving changes in the routine or the environment of the home, and many suggested that they planned to repeat the process. However, a significant proportion of homes failed to complete the process, suggesting that quality improvement initiatives were afforded a low priority. As the authors of the report point out, the effectiveness of any approach to quality assurance will depend on the extent to which the process is legitimised and supported by the philosophy, policies and practices of the organisation.

Qual A Sess

The Qual A Sess system was designed by institutions in Germany and the UK within the Concepts of Quality study funded by the EU Human Capital and Mobility Programme (Klein and Cook 1998). The system creates a process of continuous quality improvement within a care home. It involves residents, relatives and staff in the assessment of a home's current performance and in the development of action plans to promote improvements in the quality of care. Ten areas of service provision are assessed:

- policy and strategy
- people management
- processes – implementation and outcomes of operational policy
- information
- assessment and planning
- direct care and health services
- physical environment
- catering services
- interests and activities
- consumer satisfaction.

Qual A Sess incorporates an assessment of strengths as well as areas for suggested

improvement and consequently provides opportunities for positive feedback and encouragement. Klein and Cook (1998) note that the tool appears to identify standards and areas for improvement in a way that reflects the particular environment and culture within a care home. They propose that:

'alongside the regulatory structures that ensure that the appropriate environment is in place, processes for continuous quality improvement internal to care homes offer an approach to move standards beyond the bare minimum while tailoring the environment to the needs and preferences of those living in it.'

Reed et al (1999) describe their experiences of using the Qual A Sess system in 11 care homes for older people in the North of England. In addition to the obvious pleasure and satisfaction which residents derived from participating, the authors highlight a number of challenges in relation to:

- clarifying roles for participants
- interpersonal dynamics within the self-assessment teams
- practical concerns (timing of meetings, room layout, ensuring everyone can hear etc.)
- sustaining participation.

The authors conclude that skills in communication and assessment, and sensitivity to individual needs and problems, are required in order to facilitate meaningful participation from older people.

Box 3.1 The Qual A Sess quality management system

Qual A Sess is a self-assessment system that offers an alternative quality management approach.

It involves the regular and systematic review of those processes and standards in a person-

centred service which is essential to the achievement of quality as well as the satisfaction of the persons receiving the service, and its other customers. The self-assessment process allows the service to clearly identify and demonstrate its strengths and areas where improvements can be made.

Qual A Sess seeks to establish the quality of service by forming an opinion on the views of people receiving the service, their supporters (relatives, friends, advocates), management, staff and others who have an interest or concern in the service.

The system contributes to quality improvement and any concerns about the service and is able to assure quality by confirming that the standards and indicators of quality are being met, and by identifying where improvements can be made.

It provides a person-centred service with an agenda for action by identifying opportunities for continuous improvement. It demonstrates best value by:

- recognising that quality matters as much as cost
- value for money
- accountability and openness to people with an interest in the service
- regular monitoring and review.

Qual A Sess aims to:

- facilitate a discussion among management, staff, the persons receiving the service and other customers about quality in the person-centred service
- enable the service to evaluate its performance against the Qual A Sess standards and service user outcomes
- enable persons receiving the service, their supporters, management and staff to assess what the good-quality features are and to identify those standards and outcomes for service users that are not being met and can be improved

- implement a quality improvement plan consistent with the Qual A Sess standards and service user outcomes and best practice
- be able to demonstrate to those who need to know, the stakeholders, the quality of the person-centred service.
- provide a basis of consultation to establish whether the service meets the requirements of best value and value for money.

The advantages of Qual A Sess over its competitors

- The system's development was based on the European Quality Award and research into good practice in both the UK and Germany
- It is the only self-assessment system developed specifically for care services that has been subject to empirical research
- It is simple to use, requiring service users to give an opinion and tick a box
- It empowers service users as individuals within a group setting
- It gives service users confidence to give an opinion supported by others
- It gives service users the opportunity of saying what is good about the service and recommending where the service can be improved
- Service users can see where improvements are made
- It has been used within the Quality Protects programme (children) in Darlington
- It has been used by Essex County Council Domiciliary Care Service
- There is proven evidence of service improvement for service users

Information provided by Albert Cook,
Managing Director,
Bettal Quality Consultancy Ltd
(Cook 2006)

Observable indicators of nursing-home care

Concerned with the limitations of existing measures, a team of researchers at the University of Missouri-Columbia have developed the Observable Indicators of Nursing Home Care Quality instrument. Based on extensive qualitative research with both consumers and providers of nursing home care, it identifies seven dimensions of quality: care, communication, staff, environment, family involvement, home and central focus. Statements about each of these dimensions were developed into observable and measurable items and linked to Likert-type scales. The instrument is designed to be scored by an external observer following a walk through a facility, and is therefore relatively quick and easy to use. A version for consumers has also been published in a consumer guide to assist in decision-making (Rantz et al 2002).

International field tests of the instrument suggest adequate validity and reliability, although test-retest reliability measures were low when comparing diverse units within an organisation. The authors conclude that the instrument is most helpful in providing a broad indicator of care quality within an organisation and can be useful to staff in nursing facilities throughout the world to help them examine their quality of care and initiate and focus efforts to improve quality of care (Rantz et al 2002, 2005).

Exploring residents' views in aged care facilities

Individualised patterns of lifestyle are difficult to measure using standardised instruments. Consequently, Boldy and Grenade (2002) report a system whereby care-home residents identify what is important to them on an individual basis and then rate the home specifically on these dimensions. This allows assessors to determine the value that each resident attaches to a particular aspect of care. A comprehensive manual provides the tools for assessing the needs and concerns of residents using either a self-complete questionnaire or personal interview approach with either residents or their representatives. Summary forms for

collating information and suggestions for possible feedback and follow-up strategies are also provided.

The CARE profiles (combined assessment of residential environments)

Although a number of tools exist for assessing 'quality' within care homes, none of these considers the perspective of all those involved in creating a positive home environment. The CARE profiles attempt to do this by building on a model, developed by researchers at the University of Sheffield, known as the Senses Framework. Mike Nolan first developed this framework in response to the lack of a clear rationale for work with older people in long-

term care settings (Nolan et al 2001). He identified six 'senses' which he believed might provide direction for staff and improve the care older people receive. These are: a sense of security, belonging, continuity, purpose, achievement and significance (table 3.1). Further research has shown that these 'senses' are also important for family carers, and for staff working in care homes (Nolan et al 2002, Faulkner et al 2006). The researchers suggest that, through linking the experiences of older people, their families and staff, the Senses Framework has the potential to promote understanding of the feelings of others, and, as a result, to improve communication and the ability to work in partnership.

Table 3.1 The Senses Framework

A sense of security	
For older people	Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain, and discomfort. To receive competent and sensitive care.
For staff	To feel free from physical threat, rebuke or censure. To have secure conditions of employment. To have the emotional demands of work recognised and to work within a supportive but challenging culture.
For family carers	To feel confident in knowledge and ability to provide good care without detriment to personal well-being. To have access to adequate support networks and timely help when required. To be able to relinquish care when appropriate.
A sense of continuity	
For older people	Recognition and value of personal biography. Skilful use of knowledge of the past to help contextualise the present and future. Seamless, consistent care delivered within an established relationship by known people.
For staff	Positive experience of work with older people from an early stage of career, exposure to good role models and environments of care. Expectations and standards of care communicated clearly and consistently.
For family carers	To maintain shared pleasures/pursuits with the care recipient. To be able to provide competent standards of care, whether delivered by self or others, to ensure that personal standards of care are maintained by others, to maintain involvement in care across care environments as desired/appropriate.

A sense of belonging	
For older people	Opportunities to maintain and/or form meaningful reciprocal relationships, to feel part of a community or group as desired.
For staff	To feel part of a team with a recognised and valued contribution, to belong to a peer group, a community of gerontological practitioners.
For family carers	To be able to maintain/improved valued relationships, to be able to confide in trusted individuals, to feel that you're not 'in this alone'.
A sense of purpose	
For older people	Opportunities to engage in purposeful activity facilitating the constructive passage of time, to be able to identify and pursue goals and challenges, to exercise discretionary choice.
For staff	To have a sense of therapeutic direction, a clear set of goals to which to aspire.
For family carers	To maintain the dignity and integrity, well-being and 'personhood' of the care recipient, to pursue (re)constructive/reciprocal care (Nolan et al 1996a).
A sense of achievement	
For older people	Opportunities to meet meaningful and valued goals, to feel satisfied with ones efforts, to make a recognised and valued contribution, to make progress towards therapeutic goals as appropriate.
For staff	To be able to provide good care, to feel satisfied with one's efforts, to contribute towards therapeutic goals as appropriate, to use skills and ability to the full.
For family carers	To feel that you have provided the best possible care, to know you've 'done your best', to meet challenges successfully, to develop new skills and abilities.
A sense of significance	
For older people	To feel recognised and valued as a person of worth, that one's actions and existence are of importance, that you 'matter'.
For staff	To feel that gerontological practice is valued and important, that your work and efforts 'matter'.
For family carers	To feel that one's caring efforts are valued and appreciated, to experience an enhanced sense of self.
<i>Developed from Nolan et al (1996), Nolan (1997) and Davies et al (1999). First published in Nolan et al (2001). Reproduced with permission of the authors</i>	

The CARE assessment tools provide a profile of everyday experiences for residents, their relatives and staff within homes which can be used to highlight areas of good practice, and to indicate where change is required. Individual profiling tools have been developed for residents, their relatives and staff based on events and activities which were generally agreed to be essential features of everyday life. In completing the care tools, residents, staff and relatives are invited to indicate how frequently each of these events takes place, providing a profile of positive activities occurring within a care environment.

Early experiences of using CARE in different care homes has suggested that this approach can provide a mechanism for change (Faulkner et al 2006). Through careful feedback, staff, residents and family members can be helped to see things from each other's point of view, making for better communication. Furthermore, CARE provides an opportunity to celebrate all the good things within a particular home and to thank staff, residents and family members for their contribution. The authors propose that CARE can be used in a number of ways. However, it is likely to have most impact if the information produced is fed into an improvement cycle. In some care homes, this has involved residents, staff and family carers meeting together to plan and implement change. Other homes have fed back the results of CARE profiling in newsletters, providing opportunities for informal discussion about issues raised. Further research is needed to identify the impact of the CARE profiles on the experiences of residents, their families and staff.

3.3 Assessing quality of care for people with dementia

As the potential for enabling older people with dementia to maintain an acceptable quality of life has been recognised, methods for assessing the quality of care for people with dementia have been developed. Most of these approaches involve direct observation and recording of activity and interactions (Brooker 1995).

Currently, the most widely used tool for assessing the quality of dementia care is Dementia Care Mapping (DCM), which is based upon Tom Kitwood's theory of dementia (Kitwood 1997). DCM is being increasingly used in care homes to assess the quality of care for people with dementia and identify areas for improvement. It does not claim to provide a comprehensive evaluation of care, but to provide the service users' point of view through detailed, skilled and empathic observation of the person with dementia's activities and interactions with staff. Herein lies one of its main limitations in that it does not consider the experiences of family members or staff. However, it does complement assessment of structural factors of the care environment.

DCM has been revised several times since it was developed (Bradford Dementia Group 2005) and a new version, DCM8, has recently been made available (Surr et al 2006). The Dementia Care Mapping process involves briefing staff who work in the areas to be 'mapped' about the method, observation of participants with dementia within the setting, processing the analysed data, feeding back this information to staff, and using this to draw up an action plan for change (Bradford Dementia Group 2005). Observations focus on the well-being of residents and the actions of staff which promote or detract from this.

Most accounts of the use of DCM have been enthusiastic about its potential to raise awareness of poor practice (Brooker 2005), although there have been some suggestions that it can have a negative impact on staff morale, unless feedback is sensitively handled. Recent reviews of the efficacy of DCM, both as a tool to improve practice and as an outcome measure in research, have concluded that the method has acceptable face validity and reliability (Beavis et al 2002). However, these authors also conclude that other aspects of the validity of DCM remain unexplored. Given the time-consuming nature of the method, they argue that further evaluative research is urgently required. None the less, for people with severe dementia, who are sometimes no longer able to communicate verbally,

observational methods may provide the only way of gaining access to their experiences of care.

Another approach to promoting quality of care for people with dementia living in care homes is the Alzheimer's Society Person-Centred Standards (2001). Developed by the Royal College of Nursing in consultation with 20 care homes, the standards are grouped under six headings:

- person-centred care
- staff issues
- care processes
- life in the home
- relationships
- environment.

The standards are wide-ranging and based on a development approach to improving quality of care, which is both a strength and limitation. They offer a broad-based framework for teams to examine their values about care, to use as a quality checklist and to develop policies and procedures.

3.4 Summary

- Promoting high-quality care within care homes requires consideration of the views and experiences of all major stakeholders: residents, their families and staff.
- Making the lives of nursing home residents meaningful requires attention to areas often addressed under the rubric of quality of life (see for example Kane 2004) and it is essential that measures of quality of care go beyond meeting residents' basic care needs.
- A range of tools has been developed to assess and enhance quality of care within care homes. Research to evaluate their effectiveness is limited but they offer potential for development.
- Particular considerations are essential in assessing quality of care for people with dementia.

- The key to improving quality of care for care-home residents is likely to be as individual as quality of life itself (Kane et al 2003) and a person-by-person approach to determining what might make a resident appraise his or her quality of life more positively is essential.

3.5 Conclusion

The complexities of defining quality of care are clear from the literature but, ultimately, quality of care can be seen as the outcome of dynamic social interactions and 'negotiations' of various kinds between people from different social groups (Redfern 1993). New ways of thinking about 'quality' are emerging and this chapter considers a range of approaches. Approaches to assessing quality of care should recognise the complex, multidimensional nature of life in care homes and the range of stakeholder perspectives. Increasingly, the need for care homes to develop their philosophy of care in conjunction with all the key stakeholders is being recognised (see, for example, Stanley and Reed 1999). Quality initiatives are likely to be more successful if they acknowledge the entire care-home culture and are accompanied by positive (rather than punitive) incentives for providing a high quality of life and quality of care.

3.6 Recommendations

A clear conceptual framework could offer a way forward in quality measurement (Tune and Bowie 2000).

Developing philosophies of care in conjunction with all key stakeholders is to be encouraged. Key underpinning values are empowerment, mutuality and reciprocity.

Frameworks for ensuring 'quality' must be sufficiently sensitive to allow for individual variation, afford a degree of specificity so that meaningful empirical indicators of key concepts can be identified, relevant to all groups of people who receive and/or provide care,

conceptually accessible and capable of practical application.

A range of frameworks for assessing 'quality' is developing from which care homes can select the most appropriate for them. Some of the frameworks discussed in this chapter not only assess quality of care from a range of perspectives but also provide a mechanism for change.

As a supplement to regulatory strategies which concentrate largely on avoiding breaches of safety for residents (Kapp 2003, Davies et al 2002), voluntary, self-initiated efforts aimed at changing the entire nursing home environment from the inside should be supported.

Part 2
Care-home life

4 Transitions into a care home

Fiona O'May

4.1 Introduction

There is no doubt that the move from one's own home to a care home is a major, and often final, life transition. For many it may signify a decline in physical and mental health, a reduction in, or even the end of, independence, or be the corollary of the death of a partner. As such, the move can have negative connotations but, with appropriate planning and support, the transition can be managed so that it produces benefits, including improved quality of life. The extent to which this happens in practice, and the ways in which the transition can be facilitated, will be examined in this chapter.

At the time of Davies' (2001) work, most of the literature had concentrated on exploring the impact on residents and staff of moving to a care home, with a heavy emphasis on the importance of planning. Research by Reed, Payton and Bond (1998), however, has explored the move from the older people's perspective, and found that older people can be proactive in choosing to move into a care home, and choosing which one they prefer. Davies reported evidence that, where an admission is planned and where residents are involved in the decision-making process, the adjustment to care is easier. Little research had been conducted into the experience of the transition for relatives and carers of older people, and their needs both prior to and during the move. There is now a body of work which looks at the carer/family perspective (e.g. Ryan and Scullion 2000; Lundh et al 2000; Sandberg et al 2001; Gaugler et al 2001) and which will be the focus of this chapter, thus giving a clearer insight into the transitional process as a whole.

The decision to move into a care home can be particularly difficult when it is triggered by necessity rather than desire. Additionally, there is evidence that inappropriate admissions occur. In their retrospective audit of nursing home placements within three London boroughs, Bennett et al (2000) concluded that, while nursing home care was appropriate for 65 per cent of residents (n=157), 14 per cent were more suited to residential care and 17 per cent

to community care. This has obvious financial implications, but it also raises the question of whether people are being placed in nursing home care unnecessarily.

4.2 Decision-making

Ideally, any decision should be made jointly, where possible and relevant, between the older person and relatives/carers, with involvement and input from health and social care professionals and care-home staff. Within the decision-making process, Davies and Nolan (2003) identified three ways in which relatives reach a decision: 'making the decision', 'reaching the decision' and 'realising the inevitable'. 'Making the decision' is the most positive process, in which a relatively proactive and planned approach is taken in deciding that a placement is necessary. Less positive is 'reaching the decision', which occurs without a planned or rational basis, and the least positive is 'realising the inevitable', which usually occurs following a crisis, and can be regarded as making the best of the situation.

The partners of 7–10 per cent of care-home residents live in the community and the experience of moving into a care home will inevitably be traumatic and upsetting for both, particularly in relation to paying for care, in making sure their partners receive good-quality care and in obtaining information. This group of people does not fit into a definition of a carer, but their caring responsibilities may still exact a huge physical, emotional and financial toll (Bright and Clarke 2006).

Many carers continue to try to care for loved ones at home until they reach 'breaking point'. The decision for their loved one to go into a care home can then be taken out of their hands. Support from a 'navigator' or 'broker' in finding a care home can be helpful but, without this, distress can be exacerbated and can even lead to the choice of an inappropriate home (Argyle et al 2000, Bright and Clarke 2006).

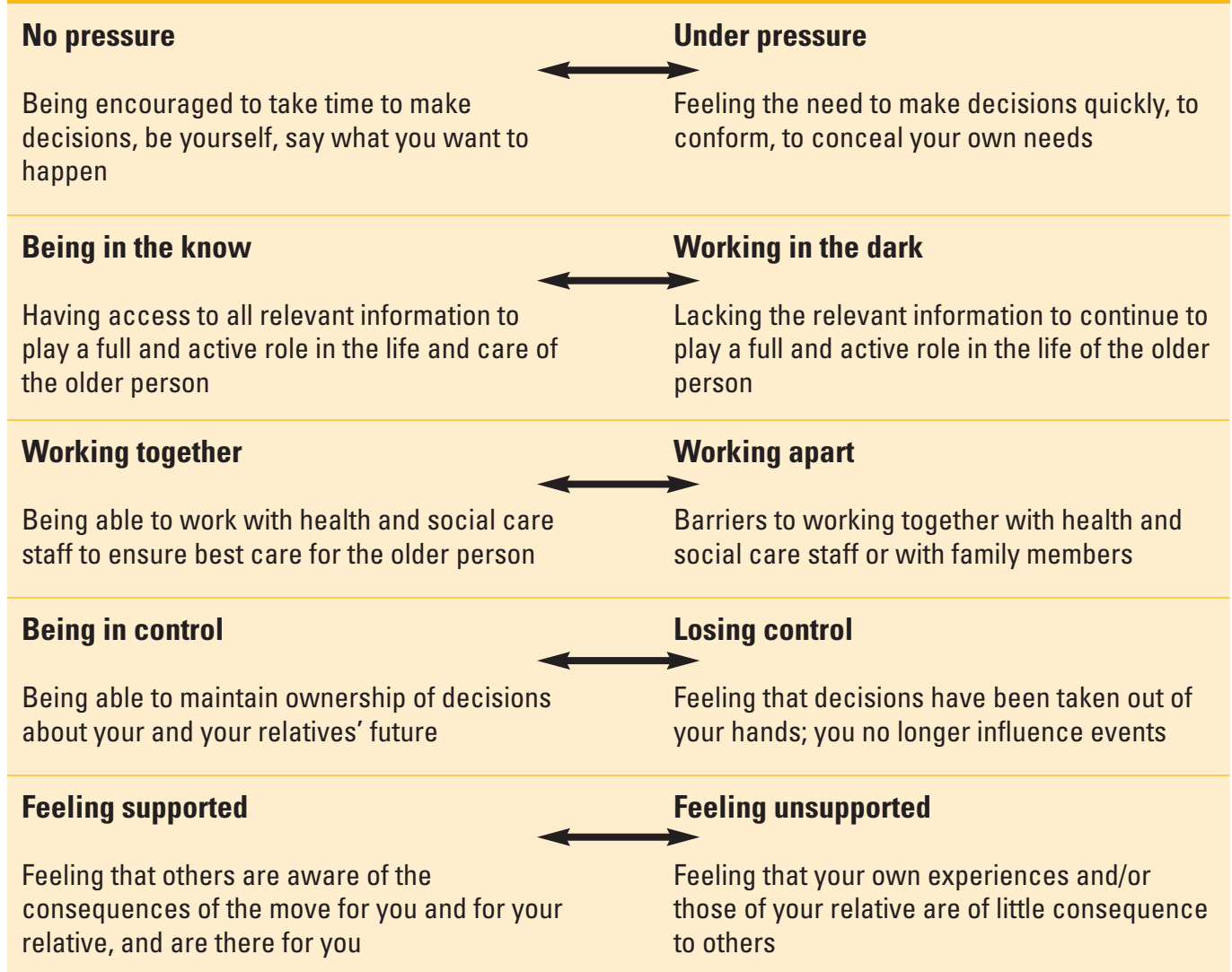
In making the transition, Davies and Nolan (2004) suggest there are three phases from the relatives' perspective:

- ‘making the best of it’
- ‘making the move’ and
- ‘making it better’.

These phases are sequential. They span the time from leading up to the move into the care home, the period immediately prior to and subsequent to the move, and lastly relatives’ efforts to engage staff in the homes and contribute to the life of the new resident on an ongoing basis.

Davies and Nolan (2003, 2004) developed a framework of five continuous dimensions which they found appeared to shape relatives’ experiences during each of the phases of care-home placement (see figure 4.1). These dimensions have a bearing regardless of where in the transitional process a carer/relative and older person might be, and will be used to explore the literature on managing transitions.

Figure 4.1 Relatives’ experiences during phases of a move to a care home



(Davies and Nolan 2003)

No pressure/under pressure

This dimension relates to being able to take your time, and voice your concerns and needs. The literature shows that the majority of admissions are made following a hospitalisation, or at a time of acute illness (Ryan and Scullion 2000; Lee et al 2002; Stilwell and Kerslake 2003), and, as a result, the older person and/or their relatives may have very little input in the decision-making process, which can be very traumatic:

'He was brought here from the hospital. He was never home again. It was a terrible shock, a terrible shock. I could never take him home again.'
(Ryan and Scullion 2000, p1191)

'Bill Connor tripped over some loose carpet in his kitchen. He was taken into hospital and, after a month, he went into a residential care home. He never went back home.'
(Counsel and Care 1999, preface)

As well as factors relating to the older person's state of well-being, carers and relatives often experience other stressors, such as their own state of health, other family responsibilities, work demands (Ryan and Scullion 2000; Davies and Nolan 2004) or ill-health.

Being in the know/working in the dark

This relates to being in possession of sufficient information to enable an informed choice. Research shows (Davies and Nolan 2004) that older people and their relatives are largely unprepared for the reality of care home life. You need information if you are going to make an informed choice. Too often, prospective residents and their carers do not realise that there is a plethora of information available to them, from a wide range of sources (family and social services, local authority, GP surgeries, voluntary organisations), and in several formats (written, verbal, visual, Braille, different languages).

A recent UK survey of 658 residents and/or relatives found that the majority (71 per cent) did not remember seeing any booklets or leaflets giving information about care homes, and over a quarter could not remember whether or not they had had sight of an inspection report before making their choice/decision (OFT 2005).

Every care home in the UK is registered with its nationally designated governing body (the Commission for Social Care Inspection [CSCI] in England and Wales, the Care Commission in Scotland, and the Department of Health, Social Services and Public Safety [DHSSPS] in Northern Ireland), who produce an annual inspection report. If not held in the individual home, these are available from the appropriate authority and often a local library. A problem is that information is rarely comprehensive, or held in one place. Additionally, there is a dearth of qualitative information: for example, information which would help older people decide which establishment's atmosphere would feel most like home to them. As Alzheimer Scotland (2003) highlights, you are unlikely to get opinions about specific homes from any of the above sources, and the following quote from a daughter trying to find a suitable home for her mother illustrates this point:

'The list he gave me, I didn't know which to start at. We looked at about eleven [homes]. What I don't agree with in these places... it's the lack of any grading system on the homes. You don't know what sort of place you were putting your relative in who you love. You don't know whose care you're putting them into – that's appalling! I mean you can go in and everything looks fine... of course it does! They're not going to do what they normally do. So where is the yardstick to measure these places by?'

(Davies and Nolan 2003, p441)

On the basis of earlier research carried out with the John Moores University, the Elderly Accommodation Counsel (EAC) developed a tool to address this issue (Titman 2003). Building on ongoing consultation with older people and by holding discussions and focus groups with residents and relatives, carers, care-home owners, local government staff and voluntary groups, EAC was able to compile a body of qualitative information relating to more personal and idiosyncratic aspects of living in a care home. Researchers established ten key areas of information that people felt they would need in order to make effective choices between care homes (see table 4.1):

Table 4.1 Key areas of information

Area	Detail
Staff attitude	Atmosphere; staff; resident interaction; philosophy
Structural issues	Rooms; garden; views; wheelchair access
Personal choice/ individuality	Flexibility with routines; choices over diet etc.
Living life/social interaction	Entertainment; transport; visitors
Personal identity	Personalising rooms; private phones etc.
Functional underpinning	Staff ratio; training; care plans; cleanliness
Specialist issues	Ethical; cultural; religious; medical; dietary etc.
Accessibility	Location; transport; nearness to relatives
Cost(s) added as needed	Inclusive (or 'all-in') fees <i>versus</i> basic fee with extra costs
Partnerships	With family, carers, agencies

(Titman 2003)

Combining this more individualistic, qualitative information with comprehensive factual detail relating to the care and facilities provided by each care home, enabled EAC to produce a *Care Options Directory*. This directory aims to provide potential care-home residents and their carers/relatives with:

- a tool to help people seeking care to establish their own priorities at the outset
- an up-to-date database of factual information about each UK home

- new qualitative descriptors to help people judge the likely suitability of those homes that are available to them.

This directory is now in the public arena and accessible from the EAC website (<http://www.housingcare.org>). Homes can be searched by postcode, town/county, home owner, and language/culture, with many more filters within each category. More detailed county guides for England, which give useful information and further sources of information, both general and local, are also available to purchase.

Help the Aged (2005), the Scottish Executive (2005) and Alzheimer Scotland (2003) have devised checklists to assist with the process of choosing a home (for a person with dementia). These focus primarily on practical issues but also cover personal and cultural aspects.

ACTION (Assisting Carers using Telematic Interventions to meet Older Persons' Needs) took an innovative approach to information provision through telematic technology (Hanson et al 2000). One programme, called 'Planning ahead', helps family carers and frail older people think about and plan for the future, giving information on long-term care services provided by social services or different types of care homes. Its key aim is to enable users to have direct access to education, information and support relevant to their individual needs. The web-based programme, viewed via either a personal computer or television, uses text-based information, video clips, maps, photographs and graphics. A simple decision-tree model helps older people and family carers think about ways of planning for the near or distant future (Hanson et al 1999). The programme can be used from home or before discharge from hospital.

Table 4.2 Benefits of the ‘break from caring’ and ‘planning ahead’ multimedia programmes

Education, information and support for frail older people and their family carers

Access to a wide range of materials from one central source

Promoting empowerment among frail older people and their family carers

Preventing crisis-oriented care

Exploding the myth that older people and new technology are incompatible

Complementing the work of professionals and other supportive services

NB Use requires careful timing and sensitive consideration of the issues for individuals all involved with someone’s entry into long-term care

(Hanson et al 2000, p718)

While this multi-national programme is still in the development phase, findings to date suggest that the ACTION technology helped frail older people and their family carers to obtain information at a time that was right for them, and to look at all potentially appropriate nursing homes in their area. They found this much more useful than simply looking at a list of care homes, and it also helped to minimise anxiety. The aim is for technology to complement the work of professional carers, and to benefit as many people as possible, by using cable television and a specific dedicated channel.

Working together/working apart

This dimension relates to the extent to which health and social care staff, residents and relatives work together. In reality, the way in which partnerships are developed, and the level of involvement of various stakeholders, vary

enormously. In one study, many family carers appeared to distance themselves from the decision to move their older relative into a care home, stating that the decision had been made by, or based on advice of, their GP (Ryan and Scullion 2000). Sandberg et al (2002) found that care staff in the community played a significant role in helping family carers, particularly partners, research the decision regarding placement. This role included recognising that placement is required (seeing the need), initiating and sustaining discussions about placement (sowing the seed and nurturing the seed), and legitimating the discussion.

The following quote is an example of working together. The relative had received sensitive support from a social worker regarding the decision to place his father in a care home:

‘He knew exactly what I was on about... He knew what was going on in here [points to head]. He knew what was going on in here [points to heart]. He was totally sympathetic. He listened to what we wanted to do. He knew that at that time – initially we were looking at this 24-hour care business – he knew that was not what I wanted, he knew why we were looking at it, he was still prepared to go through it all and came up with the numbers and we could have had it, the 24-hour care, and he was not the slightest bit fazed when I rang him and told him that we’d decided to go for the residential home. He’s been down to see my dad. A really, really nice bloke.’

(Davies and Nolan 2003, pp442–3).

A useful way in which to make an informed choice is the ‘try it and see’ approach, whereby potential residents are able to visit care homes and stay for a period of a few hours, or even a few days. In a study by Sandberg et al (2002) community staff arranged where possible for older people and families to visit a number of care homes to start to prepare for a move, but while this was useful in helping to give someone a feel for living in a home, it did not allow any element of choice. In Sweden it is not possible to select a particular care home; places are allocated solely according to availability. The

opportunity to ‘test-drive’ a care home is promoted by Methodist Homes (Kellaheer 2000). Kellaheer interviewed 100 residents in ten selected Methodist care homes in England. Over half the respondents knew the home through visiting or trial residential periods and had acquired sufficient understanding to decide on a move.

‘My wife died, my sister lived here. At home I was only seeing a few people. I don’t mind being on my own, but the arthritis... so I made up my mind and I told my nephew that I was going to try for here. I came for one week, which became three weeks, and the head of home said, “Do you like it here?” I stayed. I had to go and sell all my furniture. If I hadn’t known here, I should have stopped at home for as long as I could. I never thought there would be so much love and warmth in a place.’

(Kellaheer 2000, p9)

For many reasons, often practical in nature, trial stays are not always an option but, where available, they can be highly effective. However, it is as well to be aware that while a trial placement offers potential residents the opportunity to decide whether they feel the home is right for them, staff could possibly decide that the potential resident is not suitable for the home. Where relatives are asked to find an alternative placement, it can be difficult for them not to see this as a rejection of the older person, and to some extent of themselves. This also necessitates further searching for suitable accommodation (Davies and Nolan 2004).

Being in control/losing control

Maintaining control over decision-making is a key aspect of this dimension. The Office of Fair Trading (OFT) (2005) survey reported that, in the majority of cases (n=658), family members were involved in the decision-making process, either solely (37 per cent) or jointly with the resident (33 per cent), with 18 per cent of residents making the decision alone.

An example of an individual making the decision on her own is given below:

‘I made the decision myself. I decided to make it my home. I didn’t want to be a burden and I said, “I don’t want either of you to think that you have anything to do with this decision”, without there being a crisis. I’d applied, they didn’t even know. It’s kept the relationships good. We talked about the decision [that had already been finalised]. I hated to think that I was a trouble. I’m pleased – I’m proud. I’ve done this for myself.’

(Kellaheer 2000, p11)

A contrasting experience is shown in the following quote:

‘I didn’t make any decision about coming here. I was forced here. My flat was sold and then it all went haywire. I got no help from my children. For me it will never work out.’

(Kellaheer 2000, pp15–16)

Once the decision-making process is set in motion, events are generally ‘expert-driven’, which leads to a real, or sensed, loss of control and lack of involvement in decision making for the carer and older person alike (Sandberg et al 2001).

Advice to relatives to help them during the transition and enable them to maintain a sense of control over their own lives is given by Alzheimer Scotland (2005, p10) and shown in box 4.1.

Box 4.1 What might help cope with transition: advice from Alzheimer Scotland

- Try to take it easy until your energy levels rise again
- Give a structure to your day which may help you get through the difficult early months
- Not everyone is the same, but don’t fall into the trap of building your life around visiting the person in their new home. You need to build a new life for yourself which includes these visits
- Talk about your feelings to an understanding professional, to other carers, to a trusted friend or to supportive members of your family. Don’t bottle your feelings up

- Call the Dementia Helpline at any time to speak, in confidence, about how you are feeling (0808 808 3000)
- Speak to staff at your local Alzheimer service
- Try to persuade friends to drop in for a chat or to phone you regularly

Control and autonomy (self-determination) are different concepts; according to Coleman and O'Hanlon (2004) central to self-determination is the experience of choice, and not a mere perception of control over outcomes. Attitudes to control vary in people who live in care homes – some relish the relinquishing of control over some aspects of life, particularly when having too much control over life can lead to anxiety. This varies between individuals but the degree of frailty experienced will affect their ability and motivation to carry out tasks thus affecting their experience of choice and thus autonomy (Coleman and O'Hanlon 2004).

Feeling supported/feeling unsupported

This dimension relates to the perceived validity of feelings and emotions, and ways in which these can be supported. The move to a care home represents a transition not only for the older person, but also for the carer of the older person, who may be experiencing feelings of guilt, sorrow, loss, grief or anger.

'I was really hurt when she decided to go into a home, after all the years looking after her.'
Alzheimer Scotland (2003, p3)

'I was too wrapped up in concern and planning for her to be OK to think about how it would be for me. I had no idea what it was going to do to me – it was awful to be reduced from daughter and primary carer to visitor. It took a few months to come to terms with it.'
Alzheimer Scotland (2003, p25)

Sandberg et al (2001) highlight the importance and impact of support, from friends and/or professionals, who can help create long-lasting memories, but suggest that this is the exception rather than the rule. In their in-depth interviews with relatives, Ryan and Scullion (2000) found

an overall lack of support and awareness of relatives' needs on the part of professionals and staff, and a lack of planning concerning the whole placement process. There was no acknowledgement of the sense of loss, as illustrated by the following quote:

'I think there's a lot that someone could have said. "How are you feeling about this?"; "How is it affecting you?"; "Are you coming to terms with it?"'
(Alzheimer Scotland 2005, p11)

Care-home staff need to be aware of the factors influencing a relative's decision to move a relative to a nursing home and be sensitive to the range of feelings and emotions associated with this transition. Quite often relatives are asked to stay away for the first week or so to allow the person to 'settle in', but this is not good practice (Alzheimer Scotland 2005), as it denies the important role that the resident, the relative and staff members play during this crucial time. In the past, there was a strong tradition in professional health and social care services to 'take over' the complete care of the person going into long-stay care, with family carers viewed as no longer directly concerned with the care of the person. Although this is slowly changing, some staff may still be inclined to adopt a position of authority. However well-meaning, this can give relatives the message that their services are no longer required, which may further compound their sense of loss. Appropriate emotional support from staff, when offered, is much appreciated by relatives and carers, as shown in the following quote:

'They were lovely and that made me feel better. Because it is an emotional experience. I've been responsible for him for the last six years and to suddenly let go and hand him over to someone else... I shed quite a few tears over it... But you know, they've been so lovely, and that's helped. I feel now some of the staff are more like a friend.'
(Davies and Nolan 2004, p522)

Guidelines to assist staff in supporting adjustment for residents (and relatives/carers) were developed by Oleson and Shadick (1993, cited in Davies 2001, p82), who suggest that staff in care homes should:

- establish an understanding of the meaning and personal significance of the situation to the resident
- help residents to confront reality and respond to the requirements of the situation
- assist residents to sustain relationships with family and friends, as well as other individuals who may be helpful in resolving the crisis and its aftermath
- help to maintain a reasonable emotional balance by managing upsetting feelings aroused by the situation
- preserve a satisfactory self-image; maintain a sense of competence and mastery.

Many relatives wish to continue to care for their loved ones and staff should seek to offer them a sense of belonging and attachment to the care-home community. As highlighted by Gaugler et al (2001), developing caring partnerships is crucial if the resources of nurses and families are to be maximised to the benefit of care-home residents. Additionally, staff should collaborate with professional colleagues to help relatives cope with the changes in their lives and find new and meaningful roles. Staff should also consider establishing a support group for relatives.

There are some useful resources, such as those from Counsel and Care, which give advice for staff relating to new residents and cover a wide range of topics including understanding feelings of residents and relatives. See box 4.2.

Box 4.2 Good practice guidance: important things to know concerning new residents

- What resident wants to be called
- What they can do for themselves
- What they need help with
- What drinks they like and how they like them served
- The names of relatives and friends – those who visit and those in photographs

Their taste in alcohol

Information about lives (see section 5.3, Biographical approaches to care)

Whether they are open and chatty or quiet and reserved

Whether they like or dislike being woken up in the morning

How they like to have their hair done

NB Don't forget – people may change their minds over time.

Counsel and Care (1999) *Moving to Quality: 1*, p4

4.3 Summary

- Moving from one's home into a care home is a major life transition both for older individuals and for their carers, particularly if it is unplanned, but with appropriate planning and support quality of life can ultimately be achieved by both residents and relatives.
- The transition for residents and relatives can be eased if pressure on them is minimised, if they have access to all relevant information to enable them to play a full and active role in the life of the home and, for relatives, in the care of the older person, if they are able to work with staff, are able to maintain ownership of decisions about the future and feel that others are aware of the consequences of the move for them and their loved ones.
- Guidance for potential residents and relatives is available on choosing a care home, the information to seek before making a decision, and in how the transition can be managed: for example, Help the Aged (2005), Scottish Executive (2005) and Alzheimer Scotland (2005).
- Guidance on how to ease the transition of moving into a care home is also available for staff: for example, on information that can be sought from new residents and/or relatives.

4.4 Conclusions

The transitions intrinsic to an individual's move into a care home can be viewed from a range of perspectives, some of which have been discussed in this chapter. The frameworks and models offered can help older individuals, relatives and staff to understand more the ways in which the transition is impacting upon them and how best to manage this.

The involvement of all stakeholders, planning and choice are fundamental if the transition is to be made as smooth as possible. Using these elements, Nolan et al (1996) suggested that there are potentially four types of placement: the positive choice, the rationalised alternative, the discredited option, and the *fait accompli*. The preferred option is positive choice and planning is crucial in this, even if the move is unexpected.

The move into a care home may not always be permanent and, increasingly, homes are offering respite care and/or rehabilitation (see, for example, Hart et al 2005). Although the presence of more transient residents can impact on the feelings of those who are likely to remain in the home long-term, it reinforces the fact that care homes can no longer be assumed to be the 'final resting place'.

There are also broader perspectives to be acknowledged. The care of older people who become ill, disabled, frail or vulnerable should be viewed as a responsibility for society in general, rather than solely of individuals and families. In addition, it is important to raise awareness among people of all ages that living in care homes, as a style of both housing and care, can be a positive option.

Finally, although the initial transition into a care home can be seen as complete once the person feels settled in the home, in reality further transitions begin. These are explored in Chapter 5 in terms of maintaining a sense of identity, in Chapter 6 in terms of adjusting to a different type of community, in Chapter 7 in terms of sharing decisions and in Chapter 8 in terms of maintaining health and functioning.

4.5 Recommendations

A culture of communication and the sharing of information should be promoted as this enables all stakeholders to be involved in decision-making processes (see Chapters 6, 7 and 11 for further discussion).

The frameworks offered in this chapter can be shared with older people, relatives and staff to raise awareness of how the move into a care home is impacting upon them and therefore what actions they could take to deal with this. The frameworks could also be developed, through research, into tools which could ultimately be used by practitioners to facilitate transitions.

A framework for good practice in supporting all stakeholders could be particularly helpful in situations where an older person's move into a care home is instigated by a crisis.

Care-home service providers could use the existing guidance on moving into a care home from Help the Aged (2005), Scottish Executive (2005) and Alzheimer Scotland (2005) as a basis from which to develop their own resources to assist older people and relatives in choosing a care home. Meaningful qualitative information, such as personal testimonials and information on philosophies of care, could also be included.

Initiatives that encourage a proactive approach to decision-making – for example, facilitating trial visits to care homes – should be developed.

All stakeholders, including service providers and regulators, staff, older people and their advocates could consider how they can share good practice and how they might promote living in a care home as a positive choice for housing and care – for example, through publications.

5 Working to help residents maintain their identity

Jackie Bridges

5.1 Introduction

Maintenance of identity is closely linked to self-esteem and perceptions of quality of life in old age (Davies 2001; Tester et al 2003; McKee et al 2005), so is an important area to explore in care-home settings. Moving to and living in a care home can serve to undermine one's identity or sense of self in a number of ways (Peace et al 1997).

Firstly, the process of transition from one's own home to a care-home setting can involve a series of losses, including changes to existing relationships and a move away from a personally meaningful environment (Forte et al 2006; Chaudhury 2003; Tester et al 2003; McKee et al 2005).

Secondly, the health issues that may have prompted the move to the care home may also impact on an individual's ability to maintain their identity. For instance, physical disability may affect an individual's ability to attend their usual place of religious worship, while cognitive impairment may undermine an individual's ability to recall significant individuals and events that could provide a sense of identity in the present.

Thirdly, the features of the care-home environment may further erode a person's sense of identity. Physical features can include the provision of homogenous facilities such as communal lounges and bedrooms decorated in the same way, and the relative absence of private physical space in which to undertake intimate activities. Organisational features can include the presence of institutional routines that dictate what happens when, and the degree to which staff have detailed knowledge of the requirements of different social groups defined, for example, by religious or ethnic affiliation or sexual orientation (Ashburner 2005; Forte et al 2006; Chaudhury 2003). Chaudhury (2003) notes that 'the majority of long-term care facilities are "nonplaces" that afford few links with one's personal or cultural past' (p88). In contrast, Colman and O'Hanlon (2004) argue that despite the losses of a familiar lifestyle and environment potentially leading to a 'dislocation' of identity, a complete loss of identity or control

does not necessarily result, and that many older people remain remarkably resilient in defining themselves in a way that subjectively distinguishes their own person from that of others (core goals, interests, personal characteristics and behaviour).

From the literature she reviewed, Davies (2001) identified that working to help residents maintain their identity was one of the key themes for improving the experience of older people living in care homes. Since this review, a number of papers have been retrieved to suggest that work in this area continues to develop. Davies identified the importance of locating the care of older people in the context of their whole life development, and the publication of a number of initiatives since then to promote biographical approaches to care and person-centred care underline the importance of her message. Much of the literature reviewed here is anecdotal, reporting on the success of various initiatives to improve care in this area without the support of formal evaluation. However, the lack of evidence is to some extent outweighed by the detail given on these clearly thoughtful and creative person-centred initiatives. This detail provides clear guidance for practice. Where research has taken place, it has in the main been qualitative in approach. Staff interviews are often used as an evaluative measure although older people and their families are rarely involved in evaluation.

The literature reviewed here identifies a number of strategies to overcome the threats to identity associated with living in a care home. These are often presented as 'person-centred' care, at which the next subsection looks in more detail.

5.2 Person-centred care

Person-centred care is one of the national standards set out in the *National Service Framework for Older People* (Department of Health, 2001) and is an approach advocated in care-home literature to overcome the threats to a person's identity associated with living in a care home. Person-centred care can be interpreted in a number of different ways, as

is apparent throughout the growing body of literature on the subject (Ashburner 2005, Dewing 2004, McCormack 2004). There are still theoretical concerns about what is meant by person-centred and personhood (the central attribute of being a person). In the meantime, it is clearly the work of Kitwood that has driven much of the practice and policy initiatives in dementia care for older people in the UK. Building on Kitwood's work (Kitwood and Bredin 1992; Kitwood and Benson 1995; Kitwood 1997), Brooker (2004) defines person-centred care in dementia as encompassing four elements. As will be apparent, these elements may be generally applicable to care for older people as a whole, including those living in care homes. The four elements are:

- valuing people with dementia and those who care for them
- treating people as individuals
- looking at the world from the perspective of the person with dementia
- a positive social environment in which the person living with dementia can experience relative well-being.

(Brooker 2004)

Tobin's work (1991) can be used to add substance to the concept of person-centredness. Tobin argues that maintaining personhood in old age is the primary psychological task of older persons and that in the oldest old (generally aged 85 and over) preserving self-identity is central. He suggests that older people maintain personhood by utilising both rational coping and less rational mechanisms. Each of these two clusters has four kinds of coping. The rational cluster consists of engaging in meaningful activities that affirm the core self; control in the here and now; dealing with contractions of the environment future time, and with relationships to make life more manageable; and comparison of own functional status with peers who function less well or who have died. The less rational cluster consists of magical mastery and ignoring reality; increased aggressiveness combined with passivity; functional paranoia; repetitive and

selective reminiscence to define the core self. Tobin's research suggests that older persons do generally maintain personhood well into old age and, when this is ultimately threatened, by factors associated with becoming the oldest old, the focus is on achieving stability of self-identity.

Person-centred care can encompass a range of strategies from dementia care mapping (audit of quality of psychosocial environment from the perspective of the individual with dementia) to individually tailored occupational activities (Ashburner 2005). However, the commonest approach mentioned in the literature is some form of biographical approach to care.

5.3 Biographical approaches to care

A biographical approach to care was the commonest approach to person-centred care identified in the literature reviewed. It can include one or more of the following:

- reminiscence as the sharing of memories
- life story as an individual approach to share information about a person's life usually (although not necessarily) in the form of a scrap book or booklet
- autobiography – a comprehensive account of a life where the subject is the sole author
- oral history – mainly done in groups, whose main concern is the retrieval of past experiences and its recording or preservation
- life review as the process of going over a person's life with a view to understanding or 'unpacking' certain events.

(Goldsmith 1996)

Many older people experiencing chronic illness and disruption of their familiar life patterns and former self-images need help to reconstruct the past and find meaning to reconstruct the present (Sidell 1995). It is therefore important to provide opportunities that allow older people to establish themselves as a person in the face of this disruption. Taking a biographical approach aims to understand 'what matters' to the

individual, including their values and wishes (Wells 2005). The value of such approaches may be two-fold. Firstly, the review of one's life story to date and its integration into the present and the potential future may be therapeutic for the individual resident. Secondly, the process and outcomes of such work can enable staff to get to know individual residents well and to work with residents in tailoring the care accordingly.

A randomised controlled trial found only limited evidence of the effectiveness of reminiscence in promoting the well-being of nursing home residents with dementia (Lai et al 2004). However, a qualitative study using interviews and focus groups with older people in residential care, carers and staff found that reminiscence activity could have a powerful impact on identity maintenance in older people (McKee et al 2005). McKee et al found that sharing past and present lives through talk was a key aspect of developing relationships between residents and staff, and between residents. In addition, everyday talk about the past offered intergenerational benefits, enabling older people to preserve their identity and their role within the family context through being 'central to the transmission and preservation of family folklore' (McKee 2005, p121). However, tensions were also identified that could impede reminiscence such as the potential for reminiscence to prompt distress in older people and the potential lack of skills and time from staff in dealing with this.

Biographical approaches to care: examples of good practice

A biographical approach is not just about staff gathering information about the resident but involves the resident and their family in the process of gathering and reviewing the information, and in negotiating how care is to be delivered to ensure it is helpful and appropriate (Davies 2001; Wells 2005). Good examples of initiatives follow.

Wilson (2004) developed a training programme aimed at introducing person-centred approaches to care for social care staff (including senior staff) working in residential and day-care settings

for older people. Programme content included values and attitudes including societal discrimination against older people and power and disempowerment within service settings; the values and principles of person-centred working and planning; components of a person-centred approach including life stories, giftedness and dreaming; essential lifestyle planning including gathering and sorting information; learning to listen, rituals and routines and writing support plans; and tools for connecting with the wider community.

'It jogged me into thinking about clients as individuals again – because you can become quite stale.'

'It made me do a lot of thinking about myself and the way I approach residents.'

Training course participants
cited by Wilson (2004)

In an action research study aimed at developing person-centred care in a care home setting, participants developed a booklet called *Getting to Know You* aimed at supporting ongoing biographical work with residents (Ashburner 2005).

'I think we have made progress. Before, it was just about doing the work but now we are talking with our residents. I think relationships are better and with communication there has been a big shift, and now there is respect and now we knock on the doors and we ask if we can borrow things. For example, a resident is improving and he is speaking more and as he starts to talk I can understand him more. This is because we are talking to him and we are stimulating him.'

'Their behaviour is connected to their biography, and talking to their families... their behaviour is connected to their past. There was a lady we used to put to bed, and she would cry and cry and then I sat with her, and just gave her a bit of time. Then I worked out that if I gave her a pillow case this seemed to settle her. I told my colleagues. Talking to her family, she used to live next door to my Nan, and she used to work in a laundry and this is where the biography helps.'

Staff members cited in Ashburner (2005)

Memoraid is an alternative resource that can be used to document biographical and other personal information and has been particularly developed for use with people with memory or communication problems. It includes guidance and sections on personal history, world events during the life of the individual, life events, calendar for recording events of importance to individual (e.g. family birthdays, Wimbledon week), photographs, family tree, significant connections (people, animals, places), spiritual preferences and personal preferences for drinks, food, clothing, bed, bathing, skin, teeth, nails, hair, communication, activity, entertainment and interests, favourite things and preferences not recorded elsewhere, and other information. (Detail on Memoraid can be obtained from Memoraid on 020 7740 1344 or Memoraid@Munro.co.uk.)

An approach that used 'place' as an explicit reminiscence theme by using residents' home-related photos and narrative information successfully triggered memories in care-home residents with dementia (Chaudhury 2003). One such example is reproduced here:

'Oh, mealtime was the only way you could see everybody... Everybody was home from school or whatever activity they attended. You didn't have fast food and stop-off joints. Oh yes, I can see this – my mother is saying, "Come in, come in, girls. Betty, Lucille, come in and set the table. It's time to do that." We come in and get the dishes out and set the places for everybody. "Is so-and-so gonna be here tonight?" "Yeah, he's gonna be here." And so there is a place set, and if some unexpected stranger or company got in or if somebody happened to be dropping in at that time, the preacher could come in. Then you move the plates around and put another setting on the table. The head of the family will sit there and Mother will sit closest to the stove where she could replenish the dishes, the serving dishes, and each child had a different place. It is a long table of mahogany with rounded corners. Almost ten people can sit there. Yes, very definitely. Everybody will have his or her seat. And "Get out of my seat", if you sat in the wrong seat.'

Resident cited by Chaudhury (2003, pp92–3), with permission of copyright holder Haworth Press

Box 5.1 Felix's story

An evaluation of a training programme that introduced person-centred approaches and philosophy to staff included the following account from a staff member who had attended the course:

'Felix has always been a witty man with a great sense of humour. He was a keen golfer and used to love going out for rides in taxis or on the bus. Since his wife became unable to take him out, these trips had stopped. Felix now has severe dementia and over time, as his dementia has increased, his ability to communicate has decreased. Most of the time his conversation seemed not to make much sense to anyone.

'One morning a resident's wife was visiting and she and the key-worker were chatting about how things had been going, the lovely weather and her bus journey that morning down to the home. They talked about the things Felix used to enjoy doing, his love of music and how he used to like getting out and about. The conversation moved on to other things and a few minutes later, Felix, whom they had thought to be asleep, sat up and said that he missed going out on the bus.

'The two women were astounded as usually they got little back from Felix in conversation. However, once Felix had said this, the key-worker thought she should act on it straight away. It seemed like quite a simple thing to arrange. Indeed, she organised for Felix to go out with the day-care bus that very afternoon. She told Felix that he could go on the three o'clock bus and, astonishingly, he got himself ready with his jacket on to be downstairs at a quarter to three.

'Felix thoroughly enjoyed his outing and even though he appeared to forget it immediately afterwards, it was fantastic to see him take pleasure in something. He has been out a few more times since. He has also started to articulate more. For example, he has been able to express his anxiety about sometimes not recognising his visitors. His key-worker is now

able to support him by explaining them to him. By listening really carefully to Felix and giving him the time and space to go at his own pace, his life has become richer and his communication more meaningful.'

(Wilson 2004, pp9–10)

Other publications provide useful guidance:

Wells (2005) provides pointers to good practice. These include keeping the conversation person-centred and being aware of boundaries in judging topics for conversation. Wells also provides questions to have in mind that could inform conversation, observation and reflection (see box 5.2).

Box 5.2 Questions that acknowledge biographical and developmental influences

The person	Who is this person? What has been important to them in their life?
Values	What values can be distinguished from their life story?
Strengths	What are the strengths they have developed throughout their life?
Response to current situation	What is their response to the current situation? What changes have they made to manage the current situation? How have they managed at times of loss and change?
Network	What is their family and social network – who are they in contact with, how often?
Support	What support is there in their family and social network?

Emotional response to changes in relationships

How does the person feel about the changes in relationships following disability?

Perceptions of the future

How do they see the future?

Hopes

What would they like to achieve?

Working in partnership

Can they express the kind of help they would like?

(Wells 2005, pp61–2, with permission from Age Concern England)

Cole and Williams (2004) provide guidance on compiling life diaries with people with dementia. They cover confidentiality, security, timing the length of sessions to suit the client, recording and verifying findings from sessions, using illustrations such as photographs from local history books and sensory objects such as pressed flowers or something scented, and drawing the diary to a close. A booklet entitled *Why Make a Life Diary?* is available from the authors (Cole and Williams 2004). Other guidance can also be found in Killick (1998) and Killick and Allan (2001).

5.4 Other useful person-centred approaches

Other useful person-centred approaches, as follow, have been suggested in the literature to date.

Staff need to work to enable residents to 'be themselves': for example, in how they dress, items they choose to bring into the home and control over personal space (Tester et al 2003). Also helpful is a recognition that things, places, animals and ideas can be sources of security, belonging and self-identity for older people (Cookman 1996). Balancing the security of personal objects such as jewellery alongside residents' wishes to have constant access to and

use of them will require vigilance from staff and appropriate policies to be in place.

An important role for staff is in supporting residents to make new friendships and sustain current ones by introducing to each other residents who share similar backgrounds or interests, making existing friends welcome when they visit and supporting residents to stay in touch by writing letters on their behalf or enabling them to use the phone or email (Cook, Brown-Wilson and Forte in press; Cook 2006).

Staff making the time to chat with residents can be a simple yet effective strategy. Davies (2001) notes that even just 'popping in' to check residents are all right can be appreciated.

Ensuring that meaningful activities are available to residents is also of key importance (McKee et al 2005). What counts as meaningful activity for someone can range from engaging in the daily routine of the home, watching the view, engaging in hobbies, religious observance, singing or music. Just as important as organised activities is having the choice to opt out of them (Tester et al 2003). Activity organisers/providers may lead this type of intervention but all staff need to be committed to its provision. Charities such as NAPA provide a range of useful resources (see box 5.3).

Box 5.3 The National Association of Providers of Activities for Older People

NAPA believes that engagement in activity is essential to the maintenance of physical and psychological health and well-being. Many older people, through illness, disability or social isolation, experienced diminished health and well-being as a result of disengagement from activity. NAPA exists to put activity at the heart of care and to increase the status of activity providers.

It provides training, research and publications, regional groups, sharing days and a newsletter for members.

Staff working with residents to actively seek out individual ambitions and exploring how best to meet them may also be of benefit to individual residents. In one project that used a 'wishing tree' (see box 5.4), 'wishes' generated ranged from access to talking books to visits to the Highland Show (Lewin 2002). In another project, a training programme for staff resulted in staff identifying and helping a resident who had always wanted to learn to play the piano and others who wanted to learn new things, such as how to use a computer (Wilson 2004).

Involving key people and groups from the local community is another means of maintaining a person-centred approach. In one home, community education workers were invited to meet residents to discuss their interests and to run community education classes in the care home that were open to residents and other members of the community (Lewin 2002).

Exploring ways for individual residents to contribute to care-home life and/or the local community can also help. One example is of a resident offering to meet up with new residents as part of their orientation to the home (Lewin 2002). In the same home, it was proposed that residents visited local schools to talk about their life experiences and that the home produced a leaflet listing interests and topics that interested residents might offer. Using local museums provides another opportunity for interested residents to contribute to their local community. An example is the 'Thanks for the Memory' museum project (Horsham, West Sussex) that developed an exhibition using the reminiscences of older people in local care homes. This involved using the museum's themed handling boxes with items donated by the local population to trigger memories (several museums have now developed these loan boxes for their local population). Trained carers and activity staff facilitated sessions encouraging memories linked to various objects, from local people living in residential homes and day centres. Their memories were transcribed into witty and fun observations which were exhibited with the objects as part of the exhibition.

Exploring other ways for individuals to link with the wider community by, for example, joining relevant interest groups or participating in community activities that link to their interests and beliefs may also be of benefit. In addition, the internet offers other ways to 'reach out' from a care home setting by enabling links with the wider community and beyond, maintaining relationships with family and friends and providing opportunities to acquire new skills and knowledge. Many local Age Concerns have been setting up 'silver surfer' clubs at their local centres and provide training and resources for older people to develop their skills in this area. Details of this national initiative can be found on the web (<http://www.ageconcern.org.uk>). A small number of local Age Concerns (for instance Age Concern Neath Port Talbot) have actively promoted and facilitated computer use by care-home residents.

Also of benefit can be the provision of social opportunities through, for example, contact with resident or visiting pets (Baun and McCabe 2000), holding regular cocktail hours (Klein and Jess 2002) and providing music tailored to individual tastes through providing personal/portable music players and headphones (Burack et al 2002).

Establishing a forum for residents and their families may also help. Outcomes of one such forum reported in an action research study on person-centred care included setting up new services such as chiropody, speech and language therapy, physiotherapy and occupational therapy; environmental improvements including an improved door entry system, a relocated activities room and the designation of a new smoking area; and a number of initiatives to improve the quality of food and the range of social activities (Ashburner 2005).

Training staff in person-centred approaches to care is also of importance. Details of a course aimed at support workers working with older people can be accessed by contacting dforte@hscs.sghms.ac.uk. A further resource can be found in written guidance for care assistants working in care homes that

emphasises the importance of valuing personal belongings, sensitivity and knowledge of the individual when giving personal care, and promoting interests and activities (SCA (Education) and Help the Aged 1994).

Box 5.4 A wishing tree

'Six residents participated in the meeting with the wishing tree. The wishing tree, a structure made of wire and paper, was placed in the middle of the room. Leaves of coloured paper were given out and, in a group of two or three people, each person was encouraged to think of things they wanted for themselves. Each wish was then written on a leaf and hung on the tree. One resident was concerned that some wishes might be very private and it was agreed that these would not be displayed.

'One or two people fairly readily wrote what they would like to happen. In other cases, some general discussion about past activities led to the formation of a current wish. A range of wishes were expressed – to get books on tape, to have a regular visitor, to visit a relative's grave, to make what had once been an annual visit to the Royal Highland Show, to have more contact with children.

'Although staff in the home have generally friendly and open relationships with residents, some of these wishes had been entirely unknown to staff. It was felt by the Advisory Group that the visibility of the tree and the fact that everyone was involved appeared to "give people permission" to make their wishes known.'

(Lewin 2002, pp21–2)

Communication

Optimising communication between staff and residents will enable a person-centred approach to develop. This can be enabled through listening, observing non-verbal signs, using other aids such as Talking Mats™, gathering information over time and using cues such as

photos, personal object and visitors to stimulate develop conversation and interactions (Allan 2002; Wells 2005; Wilson 2004; Tester et al 2003). Consistent staff assignment is also important in this context, to optimise chances for staff and residents to get to know each other (Davies 2001). Careful assessment over time will enable staff to optimise communication with individual residents: for example, the time of day when they express themselves best, the activities that stimulate conversation and other forms of communication (Allan 2002). Residents with sensory impairments will need particular attention and strategies may include routine visual and hearing assessments, ensuring equipment is well fitted, positioned correctly and in good working order and paying attention to environmental conditions (Cook, Brown-Wilson and Forte in press). Resources for enhancing communication with people with dementia include Powell (2000) and guidance from the Social Care Institute for Excellence (2004).

5.5 Meeting the requirements of members of particular groups

We are all members of particular social groups defined by, for example, our gender, occupation, ethnicity, spirituality and sexuality. Membership of these groups may provide pointers for the care of individual residents but a person-centred approach will ensure that such care is appropriately targeted to meet individual needs. For instance, the Institute for Jewish Policy Research (2002) conducted a study using questionnaires to 5,000 Jews in Leeds and qualitative interviews (number not given) with care-home residents who were Jewish and their families across the UK. One finding was the variation in food requirements. Strictly Orthodox Jews require their food to be *glatt* kosher. Others may accept food that is kosher but not *glatt* kosher, while others' main requirement may be that the food is 'Jewish' rather than kosher (i.e. the food is familiar to the individual and perhaps links to their earlier life or family). A person-centred approach in this case will enable staff to identify and cater for an individual's dietary requirements while

understanding the context for choices made. Three key areas emerged from the literature reviewed in this area: ethnicity/cultural identity, spirituality and sexuality.

Ethnicity/cultural identity

Mold et al (2005a) have recently published the results of a systematic review on minority ethnic elders in care homes. They found a number of problems remain in ensuring the delivery of culturally competent care to this client group including staff training, and language and communication issues. Mold et al noted a general paucity of UK research regarding the needs of minority ethnic elders in care homes and the most effective ways to deliver care. A further review of best practice guidelines (Mold et al 2005b) resulted in a best practice framework (see box 5.5).

Box 5.5 Best practice framework for minority ethnic older people in care homes

Care management plans

Improve service user involvement in care decisions and ensure that services are sensitive to the needs of minority ethnic older people, e.g. regular resident meetings to assess both communal and individual needs

Service information

Increase the provision of information in various languages, styles and formats

Communication

Facilitate verbal and non-verbal forms of communication and social interaction between older people and care-home staff e.g. understanding the significance of hand and body language and facial expressions

Activities and interests

- Facilitate collaboration and involvement of local ethnic minority communities and organisations in the provision of care

- Ensure that social, religious and cultural preferences are accommodated in the occupation of leisure time
- Ensure adequate provision of the physical environment to support social, religious and cultural preferences

Alternatives to medication

Acknowledge and meet the needs of residents who wish to withhold and/or find alternatives to medication if they prefer or when conflict occurs with religious, social or cultural views

Cultural competency training

- Ensure that cultural competency training is provided, including knowledge of actual and potential service requirements of minority ethnic older people
- Facilitate staff knowledge of services which specifically cater for minority ethnic older people
- Integrate and support minority ethnic care-home staff

Cultural identity

- To improve the understanding and role of 'community', dress, food and language in maintaining cultural identity
- To increase the understanding of minority ethnic older people's expectations of insight of cultural beliefs
- Acknowledge different styles of end-of-life arrangements

*(Mold et al, 2005b, p604)
(British Journal of Nursing, with permission of Mark Allen Group)*

Examples of culturally competent care include:

- recruitment of staff from different ethnic groups so that workforce reflects local population
- staff training on cultural diversity and responding to racism
- access to translation services

- building design that takes into account needs of particular groups. This may include washing and toilet facilities of particular specifications; potential for segregation of male and female quarters; areas for prayer and meditation; and/or requirements relating to food storage, preparation and cooking.

(Mold et al 2005a, 2005b; Centre for Policy and Ageing 1996, Institute for Jewish Policy Research 2002)

Spirituality

There is increasing recognition that spirituality may not be the same as following a religious faith, although for some people this is their path. Indeed, spirituality is increasingly seen as the individual's search for meaning in his or her life. Therefore, meeting spiritual needs can encompass activities such as reading, expressive arts, music, walking and gardening, given that all these activities provide opportunities for creative meaning, gaining a sense of control, experiencing/expressing joy and nourishing the soul (Rose 1999 cited in Johnston and Mayers 2005). Jewell (2004) usefully defines spirituality as 'what gives continuing meaning and purpose to a person's life and nourishes their inner being' (p22).

MacKinlay has used the findings from her research involving in-depth interviews with independent older adults living in the community (2001) and those living in aged care facilities (2004) to identify six spiritual tasks of ageing: to search for ultimate meaning in life; to find appropriate ways to respond to meaning; to transcend disability and loss; to move and search from provisional to final life meanings; to find intimacy with God and/or others in the face of loss in long-term relationships; and to find hope. MacKinlay notes that these tasks serve as a dynamic process through which an individual may move 'maybe at times going back to revisit earlier experiences of life (reminiscence), perhaps reframing the meaning of these experiences, while at other times moving onwards' (2004, p83).

In a study that assessed older people's strength of belief, difficulties that occur and the support they receive, Colman (2004) found that personal spiritual experience is more significant than communal church life. He cites a correlation between losses and bereavement and the need for increased support in terms of spiritual education, and open discussion with peers as well as access to spiritual resources. He also expresses concern about the impact on older individuals of the declining influence of Christian religion in British society and the subsequent limitations in access to the spiritual resources once available to previous generations.

Box 5.6 Practice example: recommendations for care planning for people with dementia in Methodist homes based on spiritual needs

Love	to receive and give it
Hope	something to look forward to in this life and beyond
Faith and trust	someone/ something to believe in
Peace	security and tranquillity
Worship	something and someone of highest value in our lives.

(Albert Jewell, Senior Chaplain to Methodist Homes, 2004)

Orchard and Clark (2001) report on a postal questionnaire sent to 1572 care-home managers in Trent to investigate the perceptions and practice of spiritual care in care homes for older people. Forty-two per cent of managers responded. Those who responded showed a broad understanding of spiritual care, attributing a spiritual dimension to a range of social and emotional tasks. While the managers felt the home was responsible for providing spiritual care, some concerns were expressed over the

ability of staff to deliver this type of care. The authors concluded that there is much scope for improving the level of understanding among care-home staff about all aspects of spiritual care.

Some authors argue that the spiritual needs of older people with dementia merit a particular focus (MacKinlay 2004, Killick 2004, Read et al 2003). Killick notes how involvement in the creative arts can enable communication, expressiveness and the continuance of personhood. He cites an interaction between Bob, a day centre attender, and Maria, a musician, to illustrate the power of music in unlocking language as well as providing stimulation and solace. Maria had just played some Bach on the keyboard for Bob:

Bob: *You touch the very... the little strings in the centre of my heart. What do you think of that now?*

Maria: *I touch the strings in the centre of your heart? Is that how you feel when you listen to music?*

Bob: *Oh yes, oh yes I do, yes. It's something you can't explain. That's the way it is. There's something in you, like, I suppose mental as well naturally, and I don't know, you can't explain it, that's the way it is.*

(Killick 2004, p147)

Good spiritual care in a care-home setting can include the following:

- provision of physical areas for prayer and meditation
- input from religious providers through regular services and visiting personnel
- enabling residents to attend places of worship or religious events outside of the home
- staff training on spirituality; and
- providing meaningful opportunities for life review or other form of biographical approach

(Centre for Policy on Ageing 1996, Orchard and Clark 2001, Sapp 2004, Johnston and Mayers 2005)

Albans (2003) offers meaningful and detailed practical guidance on other aspects of care that can help meet people's spiritual needs. Areas covered include mealtimes (attending to presentation and atmosphere in which meal is eaten, manner in which help is given), activities programme (as opportunity to link residents to wider world and boost self-worth), celebrations for personal or national events, attention to the spiritual aspects of personal care and contributions that can be made as death approaches. Hammond and Moffitt (2000) also offer detailed advice on a spiritual approach in helping with activities of daily living, and provide a framework to use in developing a spiritual profile for including in a person's existing care plan.

Two UK organisations are a useful resource in the spiritual aspects of care:

MHA (Methodist Homes for the Aged) Care Group provides a range of homes, training programmes for staff and leadership through conferences and seminars in this field (Albans 2003, Heeks 2004, Jewell 2004).

The Leveson Centre provides a focus for interdisciplinary study of ageing, spirituality and social policy through publications, seminars, conferences, research and networking.

Sexuality

Forte et al (2006) note the many challenges and opportunities in care homes for residents to maintain intimate and sexual relationships. They identified through a review of the research that there are a number of barriers to residents' sexual needs being identified and met. These barriers include the public nature of much of the living space and the intimate nature of personal care that can challenge an individual's sense of privacy, dignity and choice. Forte et al identify the impact that the move to a care home can have on existing relationships, lifestyle and sense of self, and emphasise the importance of staff recognising these vulnerabilities and working alongside residents to create 'a sense of welcome and community' (p447). They also note, however, that attitudes of staff towards

discussions and expressions of sexual needs can be negative, and emphasise the need for training and education that is thoughtfully delivered and pays attention to the residents' and the staff members' psychosocial needs.

Other good-practice examples identified in the literature include:

- establishing a sensitive approach to a couple's need for intimacy using skilled observation and emotional literacy
- offering/encouraging privacy for visiting relatives
- negotiating with resident couples whether or not they wish to share a room
- providing small sofas where couples can sit together
- staff to consider the type of humour they use and to guard against patronizing behaviour, smiles, salacious remarks or laughing at the residents
- putting an equal opportunities policy into practice (see box, for example) to ensure that these facilities are available to all, regardless of disability (including dementia), sex, gender identity, age, sexual orientation, marital or parental status or HIV status
- educating other residents whose misconceptions and prejudices may be interfering with another resident's right to express their sexual identity
- considering how work is allocated, as far as possible, to meet an individual resident's preferences for sexuality and gender of carer. In situations where a resident's behaviour is particularly challenging, staff preferences may also need to be considered
- using sensitive strategies to address overtly 'inappropriate' behaviour
- encouraging open discussion among staff and residents to ensure that residents' sexual needs can be accommodated rather than ignored.

(Heymans 2003, Springfield 2002, Hurtley 2005)

Special consideration may need to be given to some residents, for instance, those with dementia. A sensitive and respectful approach will be needed from staff to ensure that one person's need for sexual expression does not lead to coercion of vulnerable others. Gordon and Sokolowski (2004) provide a case study of two residents with dementia embarking on an intimate relationship and the ethical considerations that were reflected upon to ensure the best interests of both residents.

Box 5.7 Example of an equal opportunities statement

(Name of home or company) is committed to a policy of equal opportunities, in the employment of our staff, the deployment of volunteers and in the care and services provided to older people.

(Name of home or company) considers it to be the responsibility of every member of the organisation to ensure that this policy is applied, by:

- ensuring equality both of opportunity and access for all persons to the services provided by *(name of home or company)*.
- ensuring that no person or group of persons applying for a job or for use of services of the organisation will be treated less favourably than any other person because of their class, colour, religious beliefs, race, ethnic or national origin, disability, sex, gender identity, age, sexual orientation, marital or parental status or HIV status.

(Springfield 2002)

(with permission of Nursing and Residential Care, Mark Allen Group)

5.6 Support for staff

In addition to training managers and staff to develop new knowledge and skills, other forms of support may also be needed. Care that is not person-centred can result from individual and

organisational psychological defences to protect staff from the pain and anxiety associated with emotionally traumatic nursing work (Menzies 1977). Establishing person-centred care must therefore include a great deal of support for staff in addressing these anxieties and breaking down these defences. In one study, this included group clinical supervision for all staff, action learning for senior nursing staff, introducing dementia care mapping, and building networks between the home and other organisations including the NHS Trust of which it was a part, the Department of Health and the Royal College of Nursing (Ashburner 2005).

'And before we had nobody to turn to and you had to stand up for yourself. They just smashed you. There was nobody to fight your own battles. If a relative said something was wrong then there was nobody there for the staff... the relatives were always right. We felt demeaned. We had to fight our own battles. You gave us some support. It has helped me feel like a human being, no longer the lowest of the low. With these meetings, if I feel aggrieved I bring it along... The patients were not responsible – there was just nothing for staff.'

(staff member cited in Ashburner 2005)

Cotter (1998, 2002a, 2002b) highlights how nurses will need to be supported in taking on board psychosocial aspects of care, and this is reflected by other authors who argue that the creation of space for reflection, the recognition and valuing by others of the work they do and the development of participative, non-hierarchical strategies for change and service development may be of benefit and give staff other ways of dealing with the difficulties of the work they do (Cotter 1998; Zagier Roberts 1994; Halton 1994). Moreover, working participatively may require increased support for those in a leadership position, because staff becoming empowered to voice their different views may lead to conflict which the leader may be ill-equipped to resolve (Cotter 2002a).

5.7 Summary

- There are a number of threats to identity associated with living in a care home and staff should seek to learn about older individuals in the context of their whole life development so that residents have opportunities to integrate past and present life experiences along with their priorities for the future.
- Person-centred care, including for those living with dementia, encompasses valuing individuals and those who care for them; treating people as individuals; looking at the world from the perspective of the individual and creating a positive social environment in which the person can experience relative well-being.
- Optimising communication between staff and residents will enable a person-centred approach to develop.
- A biographical approach to care involves the resident, family and staff in the process of gathering and reviewing information and in negotiating how care is to be delivered in order to ensure it is helpful and appropriate. It can include the sharing of memories, life stories or autobiographies, oral histories or life review.
- Other person-centred approaches that help residents to maintain identity recognise the importance of sustaining current friendships as well as making new friendships, and also the importance of relationships with possessions, places, animals and ideas.
- Intrinsic in the personal identity of individuals are aspects of gender, occupation, ethnicity, spirituality and sexuality.
- Culturally 'competent' care can be enhanced by recruiting staff from different ethnic groups, staff training on cultural diversity and responding to racism, access to translation services and building design that encompasses the needs of particular groups.

- Spirituality is seen as a search for meaning in people's lives, for example through prayer or meditation, reading, expressive arts, music or gardening.
- Review of the literature identified a range of barriers to residents' maintaining intimate and sexual relationships, which can be overcome through challenging misconceptions and establishing a sensitive approach to the need for intimacy.
- Establishing person-centred care should recognise the emotional effects on staff and offer support in addressing personal anxieties, valuing others and working participatively.

5.8 Conclusions

As is evident, ensuring that care-home residents maintain their identity is a multidimensional challenge. What is clear from the literature in this area is that one size does not fit all. Each resident in a care home will have different needs and requirements that may be informed by, but not determined solely by, their membership of certain social groups. Getting to know individual residents and their families requires a biographical approach to care and this in turn will inform a person-centred and tailored approach to their care. A person-centred approach is not just the individual practitioner's responsibility but a philosophy for the whole organisation, evident from staff selection through to design of the physical environment.

Of equal importance is the need for managers and staff to be adequately supported in developing person-centred approaches to care and a recognition that delivering this type of care, while being immensely rewarding, can also provoke anxiety and discomfort as staff come to terms with the emotional nature of their work.

While the evidence base for biographical and/or person-centred approaches to care is growing, there is a paucity of research supporting the use of many of the other examples of good practice used here. In particular, the voices of older people and their families are absent from much

of the evaluation that has taken place. More research is needed to inform the development, implementation and evaluation of initiatives aimed at preserving the identities of care home residents. This will add to the growing evidence base for improving the overall quality of life in care homes.

5.9 Recommendations

This chapter has suggested a range of ways in which person-centred approaches can be put into practice. Such approaches are to be encouraged and shared.

Training staff in person-centred approaches to care should be promoted. Courses, guidance and other resources are available.

Further research is needed in order to develop and evaluate person-centred approaches to care, and particularly research which incorporates the views of older people and their families.

6 Creating community within care homes

Sue Davies and Christine Brown-Wilson

6.1 Introduction

'How does one keep from "growing old inside"? Surely only in community. The only way to make friends with time is to stay friends with people... Taking community seriously not only gives us the companionship we need, it also relieves us of the notion that we are indispensable.'

Robert McAfee Brown

'There can be no vulnerability without risk; there can be no community without vulnerability; there can be no peace, and ultimately no life, without community.'

M.Scott Peck

'Living together is an art.'

William Pickens

Moving to a care home entails many losses. In particular, the loss of ties to the communities that an older person has been part of can be hard to bear. However, life within a care home has both personal and community dimensions (Brown and Thompson 1994) and the transition can be eased if this represents simply a move from one community to another (Davies 2001). Creating a sense of community within a care home is therefore a goal to which residents, their families and staff can all aspire and contribute. Before we consider ways in which this can be achieved, it is important to be clear about the meaning of 'community' and why this is so important.

6.2 Beyond the idea of home

For many years, the ideal put forward as a basis for residential care settings has been that of 'home' (Peace and Holland 2001). However, many commentators have questioned the appropriateness of attempting to make care homes 'like home', even if it were possible, given that 'home' is usually associated with family, shared memories, and comfortable familiarities (Stafford 2003, Peace and Holland 2001, Savishinsky 1991). Home promises autonomy, a sense of security over the long term, and being able to age in place if one so chooses (Maddox 2003). These characteristics are difficult to replicate even within the smallest of care

homes, raising questions about whether the care home as 'home' model may have run its course (Peace and Holland 2001). Furthermore, representing the care home as 'home' to prospective residents may not be helpful if this raises expectations that cannot be met.

Lily Robinson, a nursing home resident interviewed by Gubrium (1993), discusses what the concept of home means to her:

'No place, no hospital, no nursing home is like your own home, not to me... Peace of mind, I think, at home makes you different. You run your home. These people here run the nursing home. At home, you're the overseer. You take care of everything, and I think that more like a whole being. Here, you're just a part. When you're home, you're whole. You're a whole person. You're taking care of everything, and everything comes to you by your means, and it makes you feel more at home.'

(Gubrium 1993, pp128–9)

This quote is very telling, as it reveals the importance of ensuring that residents feel that they do have a say in 'running the home' as well as enabling residents to feel that they are part of a whole – the care-home community. Rather than trying to make care homes more home-like, the alternative objective of creating care homes as 'communities' may offer a useful way forward.

6.3 What is 'community'?

Definitions of 'community' within the literature are many and varied; however, a number of shared ideas and characteristics have emerged. These include the notions of membership, influence, integration, need-fulfilment, emotional connection, commitment to the collective good and celebration (Macmillan and Chavin 1986, Roberts 1993). Davis identifies the essential attributes of community as consciousness, common values, intention, interdependence/inter-connectedness and affirming, and stresses the importance of learning and development, and a clear integration between part and whole (Davis 2000).

A sense of community and belonging is of particular importance to older people from minority ethnic groups or from 'traditional societies' where older people are seen as valued members of the family with a vital role to play. Here the well-being of society as a whole is more important than contemporary Western values that focus on the pursuit of personal well-being and individual happiness (Coleman 2004).

While these attributes seem entirely consistent with our understanding of what makes a good care home, being part of a community can also pose challenges. Drevdahl (2002), for example, makes reference to the contradictions inherent within the concept, in that a community can be both home (a location of refuge and familiarity) and border (a place of peril, difference, and unfamiliarity). Community life is not always easy and straightforward, and becoming part of a community often involves hard work (Reed and Payton 1996). Ultimately, any 'community' is likely to mirror the complicated, complex and often conflictual relations existing in any environment where people live and work in close proximity to each other. In order to create a positive community, the relationships between members need to be considered an important priority within everyday life.

6.4 How do we create community within care homes?

If we assume that 'community' provides an appropriate model for care homes, with the potential to promote quality of life and quality of experience, how do we create communities within the diverse organisations providing continuing care for older people? Our interpretation of the literature suggests six broad processes to which staff, residents and their families can all make a contribution.

These are:

- understanding and respecting the significance of relationships within care homes
- recognising roles, rights and responsibilities
- creating opportunities for giving and receiving

- creating opportunities for meaningful activity
- building an environment that supports community
- committing to shared decision-making.

Each of these will now be considered in more detail. Shared decision-making is considered in detail in Chapter 7.

6.5 Understanding and respecting the significance of relationships within care homes

There is now a wealth of research identifying interpersonal relationships as key determinants of experiences within care homes, for residents, their families and for staff (Powers 1992, Grau et al 1995, Bowers et al 2001, McGilton et al 2003). Bowers, for example (Bowers et al 2001), found that residents' definitions of quality centred on the intricacies of their relationships with their care providers, and on the consequences of care for physical comfort and sense of self. Grau (1995) also found the quality of interpersonal relationships with staff members to be the most important aspect of quality of care for nursing home residents. Recurrent themes within interview studies involving residents of care homes highlight the importance to relationships of continuity of staff, adequate communication, staff responsiveness, dependability and trust, and a degree of personal control (Rantz et al 1999, Bowers et al 2001, Edwards et al 2003). Residents of care homes are living with an increased risk of dependency and vulnerability and therefore require dependability and reliability from their care providers, as well as empathy and responsiveness to their needs (McGilton et al 2003). Continuity of carers and a supportive environment in which to work are crucial factors in ensuring that care providers relate effectively with residents.

There is also evidence that relationships with residents and their families are key factors in shaping the work experiences of staff within care homes (Moyle et al 2003). For example, nursing assistants have identified their relationships with

residents as the most important work issue and their major reason for staying in the job (Parsons et al 2003). A study of relationships in care homes found close relationships between residents and staff and suggested that lack of attachment was a strong predictor of staff burnout and turnover (Sumaya-Smith 1995).

Numerous studies have also demonstrated the importance of relationships to the experiences of family members following an older person's admission to a care home (see, for example, Davies and Nolan 2004, Hertzberg et al 2001). Contrary to popular wisdom, most family members are keen, often desperate, to maintain their relationship with the cared-for person and seek to work in partnership with care-home staff in order to achieve this (Sandberg et al 2001, Kellett 2000). Staying involved means establishing new relationships with staff, and with other residents and their families. Spousal caregivers, in particular, have described how they find new meaning in their relationships following the move and great satisfaction in visiting (Davies 2003, Kellett 1999). However, experiences vary and in some homes family members are viewed as 'interlopers' and 'adversaries' whose intrusions are tolerated to varying degrees (Stafford 2003, Davies 2003). The extent and nature of family involvement is closely related to the quality of staff-family relations (Hertzberg and Ekman 2003, Sandberg et al 2002), although often relatives feel that they have to take the initiative in establishing relationships with staff (Davies and Nolan 2006, Hertzberg and Ekman 2003).

In dementia care, Adams (2005) acknowledges that person-centred care highlights the needs of the person with dementia at the expense of the rest of the family. He suggests that the notion of relationship-centred care goes some way to address this, but tends to neglect the rest of the family and society as a whole. Adams argues for a clear definition of relationships, outlining how they develop, and argues that dementia care should be set in a broader framework that fully understands the relationship between dementia and the rest of society in order to meet individual, family and organisational needs.

The concept of relationship-centred care is receiving increasing attention in the literature. In an attempt to put relationship-centred care into operation, Mike Nolan and a team at the University of Sheffield have developed the Senses Framework, which attempts to capture the important dimensions of interdependent relationships necessary to create and sustain an enriched environment of care (Nolan et al 2006). The Senses acknowledge the subjective and perceptual nature of the key determinants of care for older people, families and staff. These are shown in Chapter 3, table 3.1. Identifying what creates the 'senses' for individuals is likely to lead to more positive experiences of care home life.

Relationships between residents

One area that has received relatively little attention is that of relationships between residents. Some studies suggest that older people in care homes value opportunities to develop relationships with other residents (Mattiasson and Andersson, 1997; McDerment et al 1997; Raynes 1998; Tester et al 2004). However, where residents show signs of dementia, other residents may be more discriminatory (Reed 1999). Mattiasson and Andersson (1997) asked 60 older people residing in nursing homes in Sweden to assess the quality of their care. The responses pointed to the significance of their social relationships in the home, with the majority of residents indicating that it was important to make new friends, and to have a 'nice time' with other residents. These older people wanted to engage in social relationships with fellow residents but found that opportunities were limited in the nursing home setting (Mattiasson and Andersson 1997). This may be due to the range of physical, cognitive and sensory impairments that older people in care homes experience. The impact of sensory impairments on the lives of residents routinely goes unacknowledged. However, visual and hearing impairment prevents older people identifying usual cues in social conversation with other residents, as the following excerpt indicates:

‘Cause I am not a good mixer. I’ll tell you what happens. I used to go down to the sitting room, which is beautifully decorated with lovely armchairs and lovely furnishings and photographs. Really nice – you couldn’t get it more homely. They keep changing things around, which makes things worse for me. Never mind. They will introduce me to somebody and I can sit and talk with them for a little while, not very long. I can’t always understand what they are saying. And the next day, I wheel myself straight past them and they think, she’s a bit stuck up there. And they don’t speak to me and I don’t speak to them [laughter]. We are like bits of kids, oh dear God. To think that I have come to this. I have been talking to a woman for ages and the next day I wheel myself past her because I cannot see her and I don’t recognise her.’

(Cook 2006)

This example indicates the difficulties faced by residents who seek to develop or sustain relationships with others when other residents are not aware of the problems they face. However, this does not always need to be the case. In another home Gwen, a resident with hearing and visual impairment, described how care staff positioned residents in the communal lounge so that she could be involved in conversations:

‘There are two people I sit near and I can hear to talk with. Everyone else is so far away. I would be lost without them. I can talk to Freda because I can hear her. She keeps me up to date. I usually have to ask her what’s for dinner. There can be somebody next door to Freda and I just can’t hear them. I should feel lost if there wasn’t the three of us. If Betty and Freda weren’t here, I would be lost.’

(Christine Brown-Wilson, forthcoming PhD)

Powers (1992) observed how residents developed social networks that included each other, staff and families. On the basis of ethnographic work in a small number of care homes, she suggests the following typology:

- institution-centred networks where ties were simple, concentrated on the institution and of low intensity

- small cluster networks containing small cliques of residents who regularly spent time together, sharing confidences with each other
- kin-centred networks where relationships focused on family who visited regularly. These residents found it difficult to accept relationships within the home
- balanced networks with a wide range of contacts including residents, staff and families. These networks showed the greatest interconnectedness.

(Powers 1992)

In spite of evidence demonstrating the importance of these networks, Davies (2001) found that staff did not always make the most of opportunities to support and encourage relationships between residents, as one relative described:

‘but I do think they could encourage the ones who talk to sit together and they don’t always do that. If they did that and a member of staff sat with them they could talk about anything. He has a newspaper – I always take the Sheffield Star, so he has something to talk about.’

Interview with daughter of resident
(Davies 2001)

Other studies have noted that staff are often unaware of relationships that exist between residents (Reed and Payton 1996). This may have an important impact on the daily experience of older people in care homes. Cook et al (2006) also highlight the importance to residents of being able to maintain long-standing friendships following the move to a care home. On the basis of longitudinal interviews with eight older people, she describes how residents implemented a range of strategies to sustain their relationships with these people.

Many homes perpetuate rotating staff assignment to residents in the belief that this makes scheduling easier and ensures that ‘challenging’ residents are shared equally (Stafford 2003). However, with consistent staff assignment, relationships can flourish leading to improved quality of care and lower staff turnover (McGilton et al 2003, Rantz et al 2003,

Teresi et al 1993, Burgio et al 2004). Without consistent staff who have detailed knowledge of a resident, individualised systems of care (for example, those aimed at promoting continence, preventing pressure damage and promoting good nutrition) become much harder to implement and maintain (Rantz et al 2003). Furthermore, studies have shown that relatives and their families appreciate continuity of staffing (Davies 2003, McDerment et al 1997, Raynes 1998). Naturally, situations will arise where individual members of staff might feel they need a break from caring for a particular resident; similarly residents and/or family members might experience difficulties in their relationship with an allocated staff member. However, when such difficulties arise, they can be dealt with on an individual basis, rather than disrupting established relationships.

6.6 Negotiating roles, rights and responsibilities

Each person who has a connection to a care home, whether as a resident, a visitor or a member of staff, has the potential to make a unique contribution to the community that results. However, this requires each individual to be clear about their role within the community, what they can expect in terms of their personal rights, and the responsibilities they each have.

There is growing acceptance of the notion that care homes for older people develop a distinctive 'culture' which creates and shapes experiences of care for residents, their relatives and staff (Rowles and High 2003, Davies 2003, Anderson et al 2003). The culture that develops is the result of a complex interplay of factors and it is important to recognise that residents, staff and family carers all contribute (Stanley and Reed 1999, Davies 2003). Environmental and organisational factors also play a part. There is some evidence that the culture within a home can be modified through a planned change approach, resulting in improved outcomes for residents (Anderson et al 2003, McGilton et al 2003, Aveyard and Davies 2006). However, as previously discussed, this requires a conceptual

framework that identifies the potential contribution of all the major stakeholders and provides clear indicators for development.

Residents

The role that residents can perform within a care home has received little attention in the literature. The task that residents face in order to 'fit in' to a care home following a move has already been described (see Chapter 4). However, the work does not end there as the challenges of communal living continue, particularly with residents who may have very different needs (Reed 1999).

Writing from his experience of being a nursing-home resident, John Fletcher suggests that staff need to permit greater resident participation in the home and listen to their views more (Fletcher 2000). However, this suggests an equal responsibility for residents to consider the contribution they might make. He writes:

'Many people entering care homes still have an ability to make some contribution to their environment and this should be encouraged wherever possible. For one thing, if they are given a purpose in life, through participating in the affairs of the home, this can boost their morale, which can subsequently have tremendous effects on their health. Moreover, their expertise will contribute to the well-being and reputation of the home. Indeed they can also serve as an early warning system to management if things start to go wrong.'

(Fletcher 2000, p116)

So residents can make an important contribution to a care home community. But what about their rights within these environments? The Office of Fair Trading raised a number of concerns in relation to the rights of residents of care homes (OFT 2005). In particular, the review found that most residents were unaware of whether they had a contract with the home providing their care. Furthermore, half the residents surveyed said they had received no information about complaints procedures, although 28 per cent identified that they had experienced

dissatisfaction at some point during their stay. The report recommends that all residents should have a contract that is clear about the responsibilities of the care home, sets out fair terms for when fees will be reviewed, and states what would happen in the event of a change of circumstances for either the older person or the home. The report also recommends the establishment and evaluation of advocacy services to support older people in the process of resolving complaints.

Relatives

The difficulties family caregivers experience during the transition to nursing home care have already been described (see Chapter 4). However, many relatives are able to establish a new role in the life of the older person within their new environment and studies have demonstrated that family carers can make a vital contribution (Nolan and Dellasega 1999, Davies and Nolan 2006, Sandberg et al 2001). Family involvement personalises and humanises the life of a resident (Rowles and High 2003). It provides residents with a link to their own life histories and to the world outside which might otherwise be lost. Sandberg et al (2001) termed the process of maintaining an active role once the care had been transferred to the care home as 'keeping'. This involves maintaining the previous relationship between family care giver and resident, supporting the resident to maintain previous interests or social contacts and making sure that the care received by the resident is adequate and appropriate (Sandberg et al 2001).

Once older people are settled within care homes, family care-givers have been identified as a resource on a number of levels; from providing direct care to supporting staff with additional information to meet the needs of the older person (Hertzberg and Ekman 2003). While registered nurses acknowledge the importance of relatives in meeting the needs of residents, they do not always fully acknowledge their contribution (Hertzberg and Ekman 2003). Furthermore, numerous studies have shown that family members rarely have the opportunity to discuss and negotiate the role that they would

like to play within the home (Davies and Nolan 2004, Ryan and Scullion 2000a). In interview studies, relatives describe a range of roles. Recurring themes include acting as an advocate for the older person, maintaining continuity, helping staff to get to know the resident, monitoring care, and being part of the community within the home.

'I have a lot of contact with the other residents because I like them. And I've got to know them all by name – I mean, my mother's neighbours, Ellen Partridge, she's ninety-two. Little Lady Alice, she's ninety-seven. Elsie, she speaks French, and I say to her, you know, "Bonjour", and she, oh she's so pleased that somebody can speak a little bit of French, and she responds to you in French.'

Gerald, son (Davies 2001)

Relatives also describe an 'on call' role and highlight the importance of establishing and maintaining a relationship with staff (Keefe and Fancey 2000). Direct involvement includes providing emotional and physical support, providing personal comfort and importantly, providing a link to the local community.

'Residents in long-term care facilities were often vibrant members of their families and communities. To assume that they are no longer interested in the outside world is to deny them the right of citizenship. Family members who continue to engage and inform the resident of current events contribute to fostering the resident's identity and purpose.'

(Keefe and Fancey 2000, p240)

Family members frequently introduce or maintain activities oriented towards engaging or re-engaging their relatives in familiar aspects of their lives (Rowles and High 2003). However, often they require encouragement to make use of their talents and skills in this way. Burton-Jones (2001) provides some excellent ideas for ways in which staff can involve relatives and friends in the life of the home and this book is a valuable resource. It is clear that in their approach to relatives, practitioners in health and social care have enormous potential to influence whether relatives experience home entry as a positive choice (Nolan et al 1996, Ryan and

Scullion 2000a). As with many experiences of health and social care, it is often very small acts that make a difference. For example, a spouse interviewed for a study on relationships in care homes (Brown-Wilson, forthcoming PhD) described how staff were supportive of their preferred seating arrangements when she visited:

'We have two chairs together but we have no divine right to that corner but it does make it nice to be like that. It's important for me to know where we are and when I go to know we will be there. There's no reason why we shouldn't be accommodated in that respect as it doesn't adversely affect the other residents.'

(husband) (Christine Brown-Wilson, forthcoming PhD)

Families who feel secure in their relationships with staff, may be more likely to become involved:

'I tidy Ernie's wardrobe and the staff say to me, they don't have to do too much because I keep it so nice, so I can help like that you see. If they need to change him, they can always find clean clothes.'

(wife) (Christine Brown-Wilson, forthcoming PhD)

Staff can also enhance the experience of visiting by working together with relatives: for example, offering refreshments, joining in when conversation is obviously flagging and arranging furniture so that visitors have somewhere to sit:

'And they are very sensible people there, they never sit two people together. They always leave a chair in between so relatives can walk straight in and sit down. And the carers, there's always somebody there – one carer can always move along if someone hasn't been spoken to for a bit, and can walk along and have a few words with them, and that is what I like. And there is always... I never have to get a chair. There's always one there. And there's always one there for the carer, which is a very good idea.'

Edwin, husband (Davies 2001)

However, several studies have found that relatives are often left to their own devices to manage their visits with little input from staff (Davies 2001, Ross et al 1997). An example of

one activity that care homes could use to nurture and support relationships between residents and their community dwelling spouses is described in box 6.1.

One particular area where tensions often arise between residents, their families and staff lies in decisions about risk-taking. For relatives making the difficult decision to move a loved one to a

Box 6.1 Practice example

At the Bradbury Centre, manager Lorna Brown and her staff regularly organise 'couples evenings' for residents with a community-dwelling spouse. Pre-dinner drinks are served in the lounge, followed by a three-course candlelit dinner accompanied by soft music. The meal is prepared separately by the kitchen staff and served by Lorna and her staff. Many of these residents have advanced dementia and can no longer communicate easily with their spouses. The communal nature of the meal ensures that the conversation flows and that couples can spend an enjoyable evening in the company of others.

nursing home, a primary consideration is often their physical safety (Kapp 2003). However, staff within care homes are often concerned to ensure that residents are not unnecessarily restricted in their movement and choice of activities. Furthermore, there is evidence that a focus on risk-averse environments can act against quality of life (Parker et al 2004). Ryan (2003) suggests that residents and relatives must appreciate the fine balance between rights and risks that will continually have to be negotiated in a client-centred environment, and this is an area where regular discussion and clear documentation of decisions is essential.

Staff

It could be expected that staff within care homes would have a clear understanding of their role and responsibilities. However, this is not always the case, with many care homes adopting a task-centred approach within job descriptions.

As a result, staff are often unclear about the therapeutic direction for their work, and yet this is essential if they are to experience job satisfaction (Hansebo and Kihlgren 2002). Being clear about the goals of care for individual residents and having the skills and opportunities to assess whether these goals are achieved can contribute to shared understanding of staff roles and the nature of the work.

A key responsibility for staff is to ensure that residents and their families are treated equitably, which is an essential component of quality for residents (Campbell 2003). This is important since there is evidence to suggest that staff perceptions of individual residents influence their approach to care. Hantikainen (2001), for example, found that staff approached challenging behaviours of residents in different ways, depending upon their perception of that behaviour. Two broad perspectives were identified:

- behaviour as a problem that needs to be controlled (with the focus on consequences of behaviour, irrationality of behaviour and injustice of behaviour), or
- behaviour as something that has to be learned to live with (with the focus on adequacy, ability of the older person to cope and avoidance of judgemental attitudes).

Furthermore, these perspectives were found to have a crucial impact on decision-making, in this case in relation to restraint use. Staff need to be aware of their reactions to and perceptions of individual residents, and how these might influence their decisions about care (Campbell, 2003). Furthermore, Hantikainen suggests that determining the balance between rights and responsibilities of older people and nursing staff requires general as well as situation-specific discussion, based on ethical awareness. Once again this highlights the importance of regular, open and honest communication between residents, their families and staff.

Staff have an important negotiating role within the care home and this often involves the creative use of strategies to avoid conflict, as the following quote illustrates.

'When it's nearing time for me to go, he carries my bag to the door and he won't let me go without that. It's our ritual, it is, as we say fond farewells. It's special for both of us. Sometimes, "our friend" might come up and that's when she gets a bit rude, so the staff don't fuss, they guide her away and no one is upset. Anything that spoils our routine upsets me.'

(wife) (Christine Brown-Wilson, forthcoming PhD)

Much of the recent literature illustrates clearly how demanding and complex the role of staff in care homes has become, particularly if the outcome of such labour is to be therapeutic rather than simply custodial. A recurring theme within recent literature is the need to acknowledge the emotional component of work with older people and family caregivers if true partnerships are to be created. Gattuso and Bevan (2000) for example suggest that emotional labour includes the blurring of 'public' and 'private' in women's experiences and maternal models of care. This is consistent with the idea of 'mother wit', a philosophy which care workers draw upon to help them care for residents based upon their own child-rearing experiences (Diamond 1992, Anderson et al 2005). Gattuso and Bevan also argue that the welfare of the recipient of gerontic nursing is linked to the well-being of the nurse carer but that a cultural change is needed so as to recognise and value emotion work. These arguments resonate with Brechin's (1998) assertion that any analysis of care must address the experiences of all those involved so as to tease out the tensions and pressures which mitigate against good care in order to help identify and build appropriate support.

In addition to recognition of the emotional labour involved in their work, staff need to work in a safe environment, with adequate resources, and with access to the skills to meet the needs of residents and their families. They also need to feel that they are appreciated by residents and their families (Campbell 2003) and by their managers and other staff (Wicke et al 2004, Perry et al 2003). Atkin et al (2005) highlight the significance of simple acts of recognition, such as

a thank-you card, in making staff feel valued and significant. The following quote made by a care assistant in a study of relationships in care homes also demonstrates this:

'She [resident] is nice enough to say to us that "I'm well looked after and I know I'm very lucky" and you only need someone like that to say something like that and you think it's all worthwhile, and that makes you want to go the extra mile without her having to ask for things. You want to put yourself out for her.'

Anne (care worker) (Christine Brown-Wilson, forthcoming PhD)

Poor communication between staff and family care-givers has been highlighted as a major barrier to family involvement within nursing homes (Hertzberg and Ekman 2003, Sandberg et al 2001) with conflicting values and goals identified as a contributing factor (Nelson 2000, Pillemer et al 2003). Several studies have shown a mismatch of expectations between staff and relatives (Davies 2001, Hertzberg and Ekman 2003, Ryan and Scullion 2000b), yet these expectations are rarely expressed and clarified. Kellet (2000) highlights the need to create possibilities for productive information exchange leading to opportunities to negotiate mutually satisfying care through the development of comprehensive care plans.

The potential for relationships built on partnership between staff and family caregivers to make a positive difference to experiences of care has been demonstrated (Nolan and Dellasega 1999, Davies 2001). Dewar et al (2003) supported staff in identifying and implementing strategies to enhance relatives' involvement in long-term care settings – for example, the provision of protected times for staff to speak with relatives, with consequent improvements in communication. Pillemer et al (2003) report on a series of workshops for staff and relatives which also resulted in improved communication. However, in both these studies, it was acknowledged that considerable time and commitment are required from the organisation, the staff and the relatives to make such initiatives a success. The question of

sustainability within long-term care environments has therefore been raised (Pillemer et al 2003). It is crucial to make sure that participants are able to see the benefits of their involvement for both themselves and others (Aveyard and Davies 2006). Rowles and High (2003) go even further in calling for a new perspective on the nursing home as a 'family-focused institution' (p200).

6.7 Creating opportunities for giving and receiving

The importance of relationships in creating community within care homes has already been considered. Another component is the extent to which members of the nursing-home community feel that they are able to make a contribution to these relationships and to the community as a whole. Social Exchange Theory holds that reciprocity in relationships is essential to well-being, and a number of studies have found this to be important for residents of care homes (Ghusn et al 1996, Roe et al 2001, Davies 2001). Roe et al (2001), for example, found successful and positive caring experiences where care providers and older people formed friendships that provided mutual companionship and support. They describe reciprocity between care providers and elders, where they took an interest in each other's lives, time was spent talking and there was a vested interest in each other's well-being. However, finding opportunities for reciprocity can be difficult for frail older residents. Diamond (1992) describes how one resident achieved this:

'Many [residents] were involved first and foremost in their own caretaking. Grace DeLong taught us how to situate her in the wheelchair, how to get the sand out of her eyes, how to adjust the hand braces, how to place the bedpan. In her jovial yet commanding manner, she was an active participant in her care. And she was fond, as well, of getting us out of her way. "I'm fine now that I'm in the chair. You go tend to the other girls. I can take care of myself." Moreover, she tended to talk to her somewhat confused roommate,

especially in waking her, talking her through getting dressed, and guiding her down the hall.'
(Diamond 1992, p92)

One study (Grasser 1996) explored the extent to which nursing assistants in nursing homes recognised residents' attempts to reciprocate. Nursing assistants identified a variety of caring behaviours on the part of residents which were considered a means to achieving reciprocity; however, opportunities for engaging in them were seldom created. The author concludes that in-service education is needed to enable staff to recognise opportunities for reciprocity. Sometimes residents may want to make things easier for the staff by fitting in, for example, with the timing of a bath. This could be an important aspect of reciprocity that should be recognised by staff.

Taft et al (2004) describe the innovative use of oral history to provide residents of care homes with opportunities to share their knowledge and experience. Nursing home and community residents participated in a project to discuss memories of World War II, and reciprocal benefits were experienced by participants and listeners alike. The pleasure experienced by care providers in listening to older people reminiscing about their experiences was also expressed in a study of student nurses experiences of learning to care for older people:

'I find that older people are very interesting. They have vast experiences of life. I find talking to them is like reading a good history book. I love hearing them recollecting and comparing life to our modern society. I have found myself consulting and tapping in to their vast knowledge of the past.'

Student nurse (Nolan et al 2002)

As previously mentioned, numerous studies have demonstrated the importance to residents of the relationships they develop with other residents (Tester et al 2003/2004, Reed and Payton 1996, Powers 1996, 1992) – relationships that provide obvious opportunities for giving and receiving. Where staff appreciate and respond to the ties and affection that develop between residents, the effects can be profound.

In an interview, one resident described how she had been able to help a close friend, also a resident, at the time of her death:

'She'd been very poorly for a couple of days, and in the middle of the night, the staff came and woke me up and said, "We think Betty hasn't got long. Do you want to come and say goodbye to her?" So I put my dressing-gown on and went down the corridor and they left me with her. I climbed on the bed next to her and put my arms around her and told her what a good friend she had been to me. She died in my arms.'

(research in progress, Davies 2006)

This experience, sensitively managed by staff, contrasts sharply with that described by another resident who continued to mourn the death of a friend several months after the event:

'He went to hospital and nobody would tell me anything. I couldn't get any information. After about a week, they said, "Oh, he died last Friday – didn't anybody tell you? Well, I would have gone to the funeral, but it had already happened. So I wasn't even able to say goodbye to him.'

(research in progress, Davies 2006)

The need for sensitive care at the end of life is considered further in Chapter 9.

Pets provide another opportunity for residents to give attention and affection, while also providing comfort to the resident and a topic for conversation. Several studies have identified the positive impact of pets on residents' well-being (Steed and Smith 2002, Edwards and Beck 2002, McCabe et al 2002, Savishinsky 1992). One recent study, for example, found a significant, positive change in mood for those receiving visits from volunteers with a dog compared with a visitor alone (Lutwack-Bloom et al 2005). Richeson (2003) also found that sessions of animal-assisted therapy decreased agitation and increased social interaction among nursing home residents with dementia.

Caring and reciprocity need to extend between staff as well as residents (Jervis 2002). Relationships are enhanced for residents if caregivers are reliable, empathic and consistent in their approach (McGilton et al 2003).

Box 6.2 Resource: Pets as Therapy (PAT dogs)

This charity has 90 area-co-ordinators managing volunteers with 'vetted' (for temperament) dogs who visit a range of care establishments providing stimulation and companionship and an opportunity to 'relieve sickness, suffering and distress'. It provides an enjoyable experience, especially for animal lovers: 'Joan was overjoyed when she put out her hand and felt the fur of the lurcher who had come to visit her. Joan chatted away happily for some time, and when it was time for us to go, told the volunteer how much she had enjoyed the visit and how she would be counting the days to the next one.'

Harrop (2004) www.petsastherapy.com

However, in order to develop and maintain such relationships, care providers must be supported in their work environments. The value of teamworking and mutual support in care homes has been clearly demonstrated (Wicke et al 2004, Davies 2003). Yet in some homes, relationships between nurses and nursing assistants have come to mirror doctor-nurse authority structures, typified by inequality and lack of collegiality (Jervis 2002, Valentine 1996).

Moyle et al (2003) identified that staff gained satisfaction from residents' appreciation of the work they do for them.

RN: *They are always very appreciative and they always say "Thank you". It makes you feel that what you are doing is not taken for granted.*

EN: *At night when I am feeling stressed I get quite a few hugs and kisses from them.*

If residents are unable to, or choose not to display such appreciation, this may have serious consequences for the morale and job satisfaction of staff (Moyle et al 2003). In such situations it becomes even more important for managers to provide adequate recognition and feedback for their staff. Family members can also play an important role in ensuring that staff

receive positive feedback. Feelings of recognition and a sense of achievement are important motivators for care assistants (Pennington et al 2003, Cronin and Becherer 1999) and studies have shown that staff place high value on simple acts such as private verbal feedback and recognition from peers, residents and families (Atkin et al 2005).

Chou et al (2002a) considered the components of staff satisfaction in residential aged care in a cross-sectional survey of 70 facilities in Western Australia (n=983). Five aspects of staff satisfaction were examined; personal job satisfaction, workload, team spirit, training, and professional support. Professional support was shown to have a positive effect on all aspects of staff satisfaction that were measured. The authors conclude that care staff should be provided with a sufficient level of support, which involves enabling them to voice any concerns and receive appropriate guidance from supervisors.

Family-friendly initiatives have also been suggested to contribute to positive work experiences and workforce stability (Monahan and Hopkins 2002). With increasing family commitments expected to affect a large proportion of the workforce, the need for amenable working conditions must be a priority for employers.

Relatives find meaning and satisfaction in the opportunities to continue to care for an older person following admission. Many relatives also make an important contribution to the lives and daily experiences of other residents, their families and staff (Davies et al 2006; Ryan and Scullion 2000a). On the basis of an ethnographic study involving working as a nursing assistant within three nursing homes, Timothy Diamond, a professor of social policy, describes this crucial contribution:

'Family members brought other things, tidied up the rooms, and made contacts with others over the course of their visits. To watch these wives and daughters and nieces and husbands circulate through the halls, with their particular greetings for particular people, remembering a birthday, a

nickname, a specific problem with sickness, was to see them create an integral part of the social fabric of these homes.'

(Diamond 1992, p142).

However, Hertzberg and Ekman (2003) found that staff tended to recognise only 'hands-on' notions of care, making relatives' contribution to residents' psychosocial well-being difficult to acknowledge and reward. Concerns about privacy and confidentiality can also act as a barrier to giving and receiving care and attention.

6.8 Creating opportunities for meaningful activity

'I like to be busy but not for busy's sake; it has to be for a purpose. It helps when you do it with others, you can talk with them and it helps you get through the work faster.'

Irene (resident) (Christine Brown-Wilson, forthcoming PhD)

Recreation, social and community activities and personal development are key domains in quality of life at all ages. However, in spite of evidence to suggest the protective effects of purposeful and meaningful activity for older people (Baum 1995, Ballard et al 2001, Kiely and Flacker 2003), observational studies suggest that older people living in care homes continue to spend much of the time in passive inactivity (Davies et al 2005). According to Ballard et al (2001), for example, almost 50 per cent of residents' time is spent asleep, socially withdrawn or inactive, with only 14 per cent spent in some form of communication with others. Only 3 per cent involves constructive activity. Pruchno and Rose (2002) found that the most frequent activities for residents were watching television (12 per cent of waking hours) and resting (20 per cent). However, this study also found that nursing home residents spent more time engaged in recreational activities and less time watching television than frail older people living in their own homes. They conclude that there are recreational opportunities available in care homes that may actually make these living environments preferable for some people.

Meaningful activities do not just happen. They require support from everyone involved as the following example shows:

'In the summer time when they're in the garden, they were all just sat there in the sunshine and then I decided we would have a sort of flower-arranging competition so I picked all the flowers and went and got about five vases and got the tables in front of them and they looked at me as though to say, "Do I have to do this?" And then W said, "Well, I've only got one hand," and I said, "Come on, of course you can, you're going to be in this competition," and I sorted out the colours of the flowers so they looked reasonable and I fetched them a little pot, and they were all sticking so many flowers in their little pot and they were all looking at what each other had done. Then I fetched Matron and I said, "Matron, can you come and judge this competition?" and she picked out one she liked best and I think we had a little prize for who'd won. When we finished, I took each vase and put it into each of their rooms for them, so when they went back upstairs, it was there for them and it wasn't wasted. Then they got chatting and talking about it afterwards, which made communication between that group and I think that's so important.'

Anne (care worker)

The benefits of meaningful activity to health and well-being in later life, including advanced frailty, have been demonstrated (Richards et al 2005, Zimmerman et al 2005). Marshall and Hutchinson (2001), for example, reviewed 33 studies evaluating the use of activities with people with Alzheimer's disease, including music, art, reminiscence, physical activity, life review, reading and games. The review provides evidence that purposeful organised activity can make an important contribution to the quality and quantity of activity and can promote social interaction in formal care environments. In a longitudinal study Brooker and Duce (2000) found higher levels of well-being for residents engaged in reminiscence therapy and group activities than unstructured time. McKee et al (2002) also examined the impact of reminiscence activities on quality of life for residents and found a positive impact on morale and emotional

well-being. However, care staff within this study also expressed concern that social care (talking, listening and sharing) is not recognised as ‘real work’ within caring organisations.

The arts can be a valuable communication and expressive tool. An art therapist working in a care home for people with dementia described art as ‘physical’ although it communicates emotional and spiritual elements: ‘When a mark is made it does not disappear like a thought disappears.’ Art provides an opportunity for older people experiencing loss and preparing for death to communicate and be heard (Byers 2004). Likewise, a dance and movement therapist recounts the way movement and dance helped older people to resolve and integrate painful memories that even in the late stages of life threaten to engulf and restrict quality of life. ‘The past is ever present’ and it is important for older people to be able to tell their story (Bunce 2004). Dramatherapy can be used for social engagement, validation of feelings, orientation and reminiscence or just for fun (Langley 2004).

Studies have demonstrated the benefit of musical activity for older people (Goodall and Eppers 2005, Hagen et al 2003, Remington 2002). Hagen et al (2003) examined the effects of musical exercise for residents of long-stay wards in the UK. Three separate units were non-randomly allocated to a control group or to a

musical therapy or occupational therapy group. Both groups receiving occupational therapy and music therapy showed improvements in physical and cognitive functioning. These effects were not sustained when the programmes were discontinued, suggesting that activities need to happen continually to be of ongoing benefit.

Unfortunately, many staff and family members are unaware of the kinds of activities that frail older people, particularly those with cognitive impairment, will find enjoyable and meaningful and there is an expectation that activities must be highly structured, usually involving groups of people. On the contrary, one-to-one activities for a short period of time may be more appropriate and beneficial. These might include looking at a newspaper or magazine together, singing or listening to music. This is a role for families and volunteers as demonstrated in the following quote:

‘There’s never anyone to have conversations with them, the staff are all so busy. That’s why I come at dinner time because you get to know them and then if they go into their rooms. I would never see N if I didn’t come at tea time. A different face for conversation, isn’t it? Well, I say, I’m doing this and I’m doing that and W will pick up on it. And I bring my grandchildren, they’re twins, and I’ve been bringing them in since they were that big [very small] and she will ask me about them. Whenever I come in and W’s got a visitor, I will hear her say, “Oh, that’s A and she’s got these grandchildren, these twin little girls,” so I think she must get something out of it. I talk about where I’m going and where I’ve been and then it gives them something to think about. and the next time I come, they’ll say, “Oh, did you so-and-so?” and they sort of remember and that’s nice.’

(niece) (Christine Brown-Wilson, forthcoming PhD)

None the less, the increasing frailty of residents does limit the range of possible activities and staff need to be creative in order to engage residents effectively. The availability of skilled advice and support in this respect is paramount (Green and Acheson-Cooper 2000); however,

Box 6.3 Good practice guides

Useful practical guide books, suitable for developing reminiscence work in care homes, have been produced by Age Exchange in London. These include:

Reminiscing with People with Dementia: a handbook for carers by Errolyn Bruce, Sarah Jodgson and Pam Sweitzer.

Reminiscence in Dementia Care, edited by Pam Sweitzer, and

The Reminiscence Handbook: ideas for creative activities with older people by Caroline Osborn)

few care homes have regular access to an occupational therapist and activity co-ordinators are often seen as a low priority, in spite of evidence to suggest that they make a major difference to quality of life for residents (Pearson et al 1992).

Tools are available to help staff and families decide which activities might be appropriate for an individual with cognitive impairment. For example, the Pool Activity Level Instrument (Pool, 2002) involves completion of a structured checklist which indicates whether the person is operating at one of four activity levels: planned, exploratory, sensory and reflex. Activities suitable for each level can then be identified (box 6.4). Marshall and Hutchinson (2001) highlight the importance of ensuring that activities are tailored to the individual needs and likes of residents and there are obvious links to the use of biography and life story work. Cultural sensitivity is also an important component of planning activities (Mold et al 2005, Laird 1979).

There has been a great deal of interest in recent years in the potential for multi-sensory environments such as Snoezelen rooms to enhance well-being for older people, particularly those with dementia (Cox et al 2004, Baker et al 2003). However, a review of the literature concluded that overall multi-sensory stimulation

Box 6.4 The PAL (Pool Activity Level) Instrument for occupational Profiling promoting independence in dementia care

This tool was designed to assist carers providing activity-based care to improve independence and help people with dementia to achieve optimal functional performance. It was developed by an occupational therapist and influenced in its early development (1999) by a best-practice project in partnership with Surrey Social Services (see Chapter 10). The instrument includes a checklist which helps to identify an individual's activity level according to four categories (level of function):

planned	orientated to obvious goals
exploratory	more concerned with the process of an activity rather than the goal
sensory	concerned with the impact on own senses
reflex	sub-conscious responses to direct stimulation.

Jennifer Wenborn, a clinical research fellow in occupational therapy, has researched the validity and reliability of the checklist section of the instrument as part of a PhD at University College London. A project carried out in a care home with a history of poor resident-focus, in particular a lack of activities for residents, resulted in a rise in staff morale, more satisfied relatives and improved well-being of residents. Given a focused, structured approach that encourages staff to get to know the functional abilities of residents, personal attention was given towards achieving goals that aided independence and quality of life.

(Pool 2002)

is no more effective than any other form of activity. Two exceptions are aromatherapy and bright light treatment, which appear to be effective in alleviating agitation and sleep disturbance for people with severe dementia (Burns et al 2002). It is possible that the most therapeutic aspects of any activity within a care home lie in the opportunities they provide for social interaction (Davies et al 2005).

Few studies have addressed the impact of providing meaningful productive activities for care home residents although a number of studies have highlighted residents' need to 'feel useful' (Mold et al 2005). This clearly links with the notions of giving and receiving considered in the previous section. For this to happen, individuals need to engage in meaningful activities, not just during the few hours of programmed events, but through regular opportunities to participate in general housekeeping chores such as assisting with

mealtimes and folding laundry (Brooker 2001). The need for productive engagement within the care home was vividly expressed by two ladies, Gertrude and Sarah, in conversation with one of the authors:

Gertrude: *Well, it's like a hotel here, they won't let you do anything. We're waited on hand and foot.*

Sarah: *But we're not used to it, are we? We've all worked all our lives, we were caterers at the local school – dinner ladies, we were!*

SD: *So are you ever able to help out with the cooking here?*

Sarah: *Oh no! That wouldn't be allowed. It's against health and safety, they say.*

In another home, the staff had gone to extraordinary lengths to ensure that residents could have access to a greenhouse, the registration and inspection unit having originally argued that this represented a safety hazard to residents. A student nurse on placement at the home described the benefits to one resident, Tom, of being able to continue to grow tomatoes, which were then enjoyed by residents and staff:

'One gentleman here, he suffers with dementia and short-term memory loss, and I got a particularly good rapport with him while I was here at Byron Lodge. I got to know about his past life, and he enjoyed gardening. So we've got a greenhouse here, so we encouraged him to grow some tomatoes. My day often included taking him down to the greenhouse to tend to his tomatoes. And he used to like going for a walk as well, and we used to go for a walk around Wath and come back. It didn't matter to me that he forgot within minutes what we'd done, because he enjoyed doing it while we were doing it and I got a lot from that.'

Student nurse (Nolan et al 2002)

Being creative in relation to day-to-day events is likely to increase opportunities for meaningful engagement beyond those available in organised activities. Volunteers and family can enrich the range of activities on offer. However, regular input of volunteers within care homes is rare;

for example. Green and Acheson-Cooper (2000) found volunteers in only four of twenty homes studied. An example of the effective involvement of volunteers is described by Marken (2004), who reports on the Dining with Dignity programme, which integrates care-home residents, staff, community volunteers and occupational therapy students to improve residents' nutritional intake. Volunteers are trained to provide one-to-one assistance during meals and to promote a positive dining experience through social interaction and participation.

A number of studies demonstrate the significance of mealtime experiences to quality of life in care homes (Lengyel et al 2004, West et al 2003). Mealtimes represent the familiar, distinctive patterns of family life and bring comfort and security, especially at times of stress (Evans et al 2005). People use food to cope with emotions and express feelings, celebrate triumphs, reward hard work, and gain a sense of companionship (Grodner et al 2000). Traditions surrounding food consumption can also provide a powerful link to identity (Evans et al 2005): when traditional foods are unavailable, we lose one way to reinforce our identity, with potential consequences for our quality of life.

Within a care home, each mealtime is a unique process to which residents and staff are central (Gibbs-Ward and Keller 2005). Introducing some variety into what can become a very routine activity can enhance the quality of the experience for all concerned. For example, in an observational study of 27 residents, Mallott et al (cited in Beck 2001) showed that making a meal in the dining room where residents could observe the food preparation, smell the food cooking, and choose their favourite food resulted in residents with dementia eating significantly more and staying in the dining room longer. Occasional takeaways, parties and celebrations, and themed meals provide variety and give residents something to look forward to. Yet often such activities are constrained by extremely limited food budgets.

The literature suggests that food service has largely become identified as a non-nursing duty and a task that should be completed as quickly as possible, and by the least-qualified members of staff (Pearson et al 2003). This conflicts with the evidence that social interaction at mealtimes has the potential to promote well-being and that mealtimes need to be actively managed in order to ensure adequate nutritional intake for all residents. Evans et al (2005) provides one idea for making mealtimes more enjoyable and ensuring that individual preferences are recognised. [box 6.5]

6.9 Building environments for community

The physical environment in which we live makes an important contribution to our quality of life (WHOQoL 1998). Furthermore, the layout and fabric of a care environment can have significant consequences for the way in which

Box 6.5 Practice example

One way to focus the attention of staff and residents alike is to designate the occupants of one dining room table each week as 'hosts' and provide a colourful sign for their table. At intervals during the week, serve everyone in the dining room a favourite food selected by each 'host' as a reminder of home. Ask someone from recreational therapy, occupational therapy or social services to write down a brief story from the resident about the special food, add the resident's name, print in large letters and post on an easel at the dining room entrance when that food is to be served. Serve the food first (using a special plate) to the resident who requested it, commenting on how good it looks and making the occasion fun. Both nutrition and socialisation are addressed through this simple adaptation of the 'Resident of the Month' strategy commonly used to reinforce self-esteem of nursing home residents.

(Evans et al 2005)

Box 6.6 Good practice guides

These developed from a three-year action research project known as Growing with Age (GWA), run by the National Association of Providers of Activities for Older People (NAPA). This was funded by the Big Lottery Fund and ran from 2002 to 2005, focusing on exploring possibilities for greater links between residents and the communities (people and facilities) in which they live. The GWA vision was: 'Imagine a world where the local residential home or sheltered housing scheme was a hub of community activity in an area, with doors open to a wealth of interesting experiences inside and outside the home – a place that people enjoy visiting rather than dread that they might end up there.'

Key recommendations

(see Chapter 12 for detail)

- Developing links with local community organisations
- Developing an integrated team approach to activity provision
- Developing support, supervision and training for activity organisers

Practice guides:

- 1 Developing Community Links
- 2 How 'Community Aware' Is Your Care Setting?
- 3 Getting Out and About
- 4 Creating links between care settings and local faith communities.

NAPA also produces a factsheet with practical ideas for visitors called '101 ideas for things to do visiting a relative in a care home'.

www.napa-activities.net

relationships develop and are maintained (McKee et al 2003, Davies 2003). Proximity of communal spaces to areas where staff spend

their time for example encourages conversations 'in passing' (Davies 2003). McKee et al (2004) identify more than 300 relevant building features that affect quality of life for residents of care homes, based upon the research literature, care industry standards and professional guidelines. These features cluster into ten resident domains (privacy, personalisation, choice/control, community, safety/health, physical, comfort, cognitive, awareness and normalness, and one staff domain (provision for staff). McKee et al (2004) developed an assessment tool, the Sheffield Care Environments Assessment Matrix (SCEAM), and found both positive and negative associations between these domains and measures of resident well-being.

Design features that support links with the local 'community' have also been found to be important, such as being located on a public transport route, having access to local services and shops within a quarter of a mile, and a space for family gatherings. Features that support residents' awareness of the outside world, such as weather-protected seating outside the main entrance, can also increase residents' sense of connection with the local community (Parker et al 2004).

Marshall (2001) suggests consensus in relation to a number of design features for appropriate environments for people with dementia that are relevant to care homes. These include small size, a familiar, domestic, and homely environment with scope for ordinary activities (for example, kitchens in care units, washing lines, garden sheds), unobtrusive concern for safety, safe outside space, and controlled stimuli, especially in relation to noise. Special care facilities with an emphasis on an ecological model of care (offering more choice, meaningful activity and privacy than traditional settings) have been shown to improve outcomes for residents with dementia (Reimer et al 2004).

Older people living in care homes have described how connection to the outdoors played a key role in their quality of life for many reasons (Chalfont 2005), including sensory stimulation,

providing opportunities to engage with neighbourhood and community, contact with wildlife, fresh air, physical exercise, having a pleasant view, stimulation for conversation and reminiscence. However, a lack of mobility aids and transport, poor location and architectural design, restrictive care practices and lack of social involvement from family carers may act as constraints on the extent to which residents of care homes are able to connect with nature, and with the outside world generally. In response, a number of commentators have called for transformation of care home environments into human habitats that enable residents to thrive within a therapeutic environment (Bergman-Evans 2004, Ruckdeschel and Van Haitsman 2001).

The Eden Alternative, developed by the physician Dr William Thomas (1995; 1996) is the most comprehensive model available for environmental transformation of nursing homes (Tesh et al 2002) and has been introduced in numerous homes across the US. The Eden Alternative (box 6.7) is intended to transform the physical, interpersonal, psychosocial, and spiritual environments of a facility, as well as the organisational culture. Research conducted in facilities pioneering the Eden Alternative suggests that, in addition to improving quality of life, implementing the Eden model may provide a variety of more tangible benefits, such as decreases in medication use, infection rates, accidents, pressure ulcer rates, and staff turnover (Thomas, 1996). However, other studies have found that within some organisations adoption of this model is taking place at a very superficial level and this may be masking its true effects (Hinman and Heyl 2002, Tesh et al 2002).

In a commentary on nursing home environments, Barba (2002) describes a vision of what is possible:

'Currently, many nursing facilities have thriving environments, where companionship, variety, and spontaneity are part of a nurturing setting... These thriving environments are attractive and home-like, designed to fully meet both physical and social needs. Each person has

Box 6.7 The Eden Alternative

Thomas conceived the Eden Alternative when he noted the isolation and inactivity of nursing home residents. He looked to nature for an 'alternative' to the sterile environment in which many nursing home residents live. Thomas suggested creating a 'human habitat', a home where the milieu is diverse, spontaneous, and natural. He saw residents having the opportunity to participate in caring for themselves, other residents, and their surroundings in an enhanced environment.

Elements of the enhanced environment included decentralisation of management structure and team care delivery to empower the staff and place decision-making authority as close to the resident as possible. The introduction of many and varied plants, daily children's activities and resident animals comprise the other components. These individual elements are not new in nursing homes, whereas the comprehensive approach is.

The Eden Alternative is based on the belief that caregivers in nursing homes will treat residents the way the caregivers themselves are treated. If caregivers feel nurtured and cared for, they will nurture and be caring toward the residents. If caregivers feel valued, they will value the residents. Toward those ends, decision-making in the Eden Alternative model is moved to the residents and to the employees closest to the residents—the nursing assistants. The traditional top-down bureaucracy in health care facilities is transformed to a team model, where staff members are empowered to accept responsibility for managing themselves and their assignments. Staff from the various departments form teams who co-operate in making decisions about everything in the work environment, resolve conflicts and share duties and responsibilities. Staff make their own schedules and their own assignments. Members of the team handle families, staffing problems and all aspects of their units.

(Barba 2002)

privacy, but not isolation. Residents can exert some control over the design and organisation of their environment. Each person's room is furnished with personal belongings to maintain continuity, a sense of ownership, and a feeling of home. Planned activities are aimed at helping each member of the nursing home community achieve a degree of success. There are numerous opportunities for residents to take on various social roles within individual limits, enabling them to remain involved in continuing relationships to the greatest extent possible, and to get pleasure from each day.'

(Barba 2002, p5)

Such environments do currently exist within care homes in the UK. The challenge for the future is to ensure that every older person who needs to move into a care home can expect a similar experience.

6.11 Conclusion

With the shift to larger care homes dominating the market, the care home as 'home' model may have run its course, and the search for an alternative vision to support successful ageing in communal long-term care environments is a priority. It is increasingly recognised that each care home develops a distinctive culture, which determines the degree to which individual

6.10 Summary

- Representing a care home as 'home' may not be helpful if it raises expectations that cannot be met. Rather, homes can aspire to create a sense of community to which residents, their families and staff contribute.
- Community encompasses notions of membership, influence, integration, need fulfilment, emotional connection, commitment to the collective good, and celebration. Key attributes include common values, interdependence/inter-connectedness and stress the importance of learning, development and a clear integration between part and whole.

- A wealth of research now exists to identify interpersonal relationships as key determinants of the experiences of residents, families and staff in care homes.
- Every person who has a connection to a care home potentially makes a unique contribution to the community but this requires each individual to be clear about their role, what they can expect in terms of personal rights and their responsibilities.
- Creating opportunities for giving and receiving – between residents, staff and family members, among residents and with animals – contributes to relationships and engenders an overall sense of community within care homes.
- Meaningful activity, recreational opportunities, expressive arts or one-to-one activities can make a significant contribution to the overall living environment in care homes.
- The building design and physical environment make an important contribution to the sense of community and the relationships within this, including access to a choice of communal areas, individual rooms where residents and guests can enjoy privacy and gardens providing safe access to fresh air.
- Relationships with the local community and links with local organisations are important in maintaining residents' quality of life and easy access to transport is essential for relatives who may be frail.

expectations are met. However, the dominant culture commonly reflects a particular pattern and set of values. Competing alternatives acknowledged within the literature include the medical model, the business model and the hotel model. However, we propose that the care home as community model currently offers most promise for ensuring that the needs of all stakeholders, residents, their families and staff, are reconciled and met as fully as possible.

This model requires attention to six key processes:

- understanding and respecting the significance of relationships within care homes
- recognising roles, rights and responsibilities
- creating opportunities for giving and receiving
- creating opportunities for meaningful activity
- building an environment that supports community
- committing to shared decision-making (see Chapter 7).

In order for these processes to be enacted, the literature suggests that all stakeholders must recognise and accept the important role they have to play in contributing to the community within the care home. There is a need to consider the whole family of a resident as members of the extended community, as Rowles and High (2003) suggest, to create family-oriented institutions. Within this broad philosophy, it is essential that individual needs and desires, particularly in relation to the extent to which an individual wishes to be involved in decision-making, must guide practice. The importance of effective leadership, management and the availability of expert advice in achieving a positive care-home community are paramount, and are covered in other chapters within this review. However, access to sufficient resources, particularly in terms of staff time, is essential. Our understanding of the techniques and strategies that are most effective in promoting quality of life within care homes for older people suggests that these often require a high level of knowledge and skill, and are demanding in terms of resources, both economic and personal. These factors are incompatible with the often low level of resources that are afforded to many care homes. Until those who work closely with older people needing long-term care are valued and rewarded in a way that recognises the complexity and skill involved, it is unlikely that the potential for ensuring optimal quality of life will be achieved.

The following quote captures the essential elements of the community model described here:

'Any group of people who live and work together develop a certain way of being, a commonly held set of values and traditions, essentially a culture. In an environment that accommodates vulnerable people, it is especially important that this culture is accepting, inclusive and positive... traditions evolve through celebrations and recurrent events. A sense of identity and role comes from individual and group responsibilities in various activities. This is the process by which a community is built. It is such an important function that it must include everyone, even the most impaired, in a positive and affirming manner.'

(Zgola 1999, p173)

6.12 Recommendations

The following recommendations may be helpful to staff, residents and family members attempting to create community within their care homes.

Care-home managers should ensure that policies are 'user'- and 'family'-friendly and that every opportunity to engage relatives and members of the local community in the life of the home is capitalised upon.

New homes should be designed with the layout which most effectively supports relationships, including access to a choice of communal areas in close proximity to each other and close to staff areas.

Proximity to bus routes and level access are important considerations for family members who may themselves be ageing.

Residents, family members and staff should have easy access to outside areas, which should be safe, and provide access to plants and wildlife. A covered outside area should be provided to give access to fresh air during inclement weather.

Communal rooms should have sufficient seating to allow visitors and staff to sit close to residents and should include sofas to allow hand-holding and cuddling.

Individual bedrooms, sufficiently spacious to allow residents to receive visitors in private, are a fundamental requirement to maintaining relationships, particularly for residents with a community-dwelling spouse.

Owners and managers of care homes should seek wider involvement from members of local communities and voluntary organisations.

Recreational and educational activities in the care home need to be flexible and adaptable to the changing needs of residents and their family members. Staff and family members should be encouraged to recognise the value of one-to-one and group activities. Expert advice on suitable activities should be available in every care home.

Staff members need to be encouraged to perceive a role in supporting and facilitating family visiting both by recognising when families need privacy and joining in with conversations when appropriate.

The potential for resident 'adoption' programmes involving local volunteers should be explored so that residents who do not have regular visitors are not disadvantaged. Such developments could be the responsibility of activity co-ordinators working in partnership with residents and family members.

7 Shared decision-making in care homes

Sue Davies and Christine Brown-Wilson

7.1 Introduction

'All over the place... there is constant pressure to make people feel that they are helpless, that the only role they can have is to ratify decisions and to consume.'

Noam Chomsky 1928–

'You can't talk about a kind of democracy unless those who are affected by decisions make those decisions.'

Casey Hayden 1940–

'Good plans shape good decisions. That's why good planning helps to make elusive dreams come true.'

Lester R, Bittel,
The Nine Master Keys of Management

The way in which decisions are made within care homes provides an important focus for attempts to promote quality of life and high-quality care. Indeed, it has been suggested that it is the myriad of decisions that create the culture within a home and ultimately determine each resident's daily lifestyle and quality of life (Rowles and High 2003). On the basis of ethnographic study in a number of care homes, these authors describe four broad types of decision within these environments (table 7.1).

Table 7.1 Types of decisions in nursing homes

Authoritative Relatively immutable, externally imposed by government or legal statute, or determined by corporate or facility administrative policy (e.g. arrangements for regulation and inspection)

Given A set of taken-for-granted decisions which define the cultural environment within each home and sustain norms and expectations regarding the conduct of everyday life in the facility (e.g. handover report involves all grades of staff)

Negotiated Largely individualistic decisions resulting from interaction between various stakeholders (e.g. a relative negotiates with a care assistant that certain items of her mother's clothing will be dry-cleaned, a resident agrees to wait until another resident has been helped)

Reflexive Autonomous decisions made by individuals through a process of self-deliberation (e.g. a care assistant decides to remain beyond the end of her shift to stay with a resident who is dying, a relative brings flowers for the communal lounge)

(adapted from Rowles and High 2003)

Decisions are made on many levels and are of many types. Some decisions are very remote from residents, their families and staff, even though they impinge on their daily experiences. Other decisions are made on a daily basis within the home and may be autonomous or negotiated. All these decisions have important implications for the extent to which the needs and wishes of all members of the care-home community are reconciled and respected. It might therefore be assumed that decision-making within care homes would be an important focus for research and practice development. However, the search strategy for this review revealed very little information that considered decision-making processes, and most of the articles identified related to decision-making at the end of life (see, for example, Pasman et al 2004, Forbes et al 2000).

The desire to be involved in decisions, both at a personal level and more widely, is likely to vary between individuals (Crain 2001). In many cases it will fall to staff members to identify the extent to which a resident or a family member wishes to participate and at what level. This poses a challenge if no formal structure is in

place to involve older people, their families and direct care staff. In order to create opportunities for shared decision-making, staff need to see this as a priority and as a positive component of their work.

A related issue is the extent to which residents, their families and staff feel they are involved, or have control, over decisions that affect them and literature that has explored this from the perspective of each of the main stakeholder groups will now be considered. This chapter concludes with an overview of a number of initiatives that have attempted to promote shared decision-making, including the perceived impact on quality of life and quality of care.

7.2 Resident perspectives

Maximising the extent to which the older residents of care homes are enabled and empowered to exercise choice is increasingly accepted as essential for quality of life (Kane et al 1997, Boyle 2004). Furthermore, the extent to which residents are able to exercise choice and control has a direct influence on the relationships they develop within the home, with staff and each other (Brown-Wilson forthcoming). Most studies have examined the impact of involvement in decision-making at the macro level, for example, making the decision to move into long-term care and choosing a care home. However, the continuing importance of maintaining personal control in day-to-day activities as far as possible has also been demonstrated (Bamford and Bruce 2000, Tester et al 2003).

An understanding of the link between a resident's perceived real choice over aspects of their daily lives and the potential for preventing depression in long-term care settings is important (Boyle 2005). In this study comparing quality of life, autonomy and mental health in residential and nursing homes in England and Northern Ireland, residents expressed a sense of powerlessness over their everyday lives in homes that reduced their sense of control through the imposition of regimented routines, restricted scope for decision-making and

diminished sense of freedom. This resulted in feelings of hopelessness and the development of depression. Although the National Service Framework for Older People (DH 2001) states that mental health should be promoted in older people, including those in care homes, it makes no mention of the importance of supporting autonomy to prevent depression.

To some extent, routine and order are important to many older people because they increase the predictability of events and so allow them more control over their lives. However, because frail older people, particularly those with any degree of cognitive impairment, may find it difficult to express their wishes, they are particularly at risk if care routines become inflexible and fail to respond to individual needs and preferences. Graneheim et al's (2001) account of interactions between care staff and Ruth, an older woman with dementia residing in a nursing home, provides a powerful example of ways in which staff can unknowingly restrict a resident's choices at the level of negotiation.

'Care providers disregard Ruth's will by neglecting her opinion. They do not consult her concerning private matters, they act in contradiction to her spoken wishes and sometimes they ask what she wants but act before she answers. Care providers discuss how to solve the situation on a particular morning while Ruth is listening. Their alternatives are either to take her to the bathroom, put on her trousers and put her into the chair restrained by a belt, or to try to get her to bed and wait and see. They decide to try the second alternative. In this situation Ruth chooses the third alternative and creeps under the bed cover. Another morning a care provider offered her breakfast in bed and Ruth seemed to be pleased. When the care provider brought the breakfast she put the tray on a table beside the window and Ruth got up, fetched the tray, put it on her bed and started to eat. Other examples of disregarding her will are when care providers sit by her bed although she has asked them to leave, put sugar in her yoghurt even if she says, "No, thank you" and shampoo her hair a second time although she has asked the care provider to stop.'

(Graneheim et al 2001)

There are numerous opportunities for negotiation and shared decision-making in the minutiae of daily interactions between residents and their carers. Much of this goes unwitnessed and it is difficult to be certain about the extent to which older people are involved in these micro-decisions. Some studies of interactions between staff and residents in long-stay care settings have found alarming levels of personal detractions by staff (see, for example, Perrin 1997), whereas other studies document highly skilled and sensitive interaction aimed at enabling the older person to retain as much control as possible (e.g. Davies 2003).

Communication difficulties that might inhibit residents' involvement in decision-making have already been discussed (see Chapter 6). Studies have shown that many staff within care homes feel inadequately prepared to care for residents with communication difficulties (Norwood-Chapman and Burchfield 1999, Meehan et al 2002). However, a number of evaluation studies have demonstrated improvements in communication following structured intervention programmes (Williams et al 2003, Dijkstra et al 2002, Proctor et al 1998, Jordan et al 1993, Buckwalter et al 1991). Murphy et al (2005) describe the use of 'talking mats', a low-technology communication resource to help frail older people, including those with dementia, to express their views and feelings. This technology has proved particularly useful in identifying factors that promote and inhibit quality of life for frail older people living in care homes (Tester et al 2003).

Patterns of interaction between staff and residents also encourage or inhibit resident involvement in decision-making. For example, Williams et al (2005) caution against the use of 'elderspeak', a style of speech often indistinguishable from baby talk featuring a slower rate of speech, exaggerated intonation, elevated pitch and volume, greater repetitions, and simpler vocabulary and grammar than normal adult speech (Kemper 1994). Although use of 'elderspeak' may be a well-meaning strategy on the part of staff to attempt to communicate effectively with communication-

impaired residents, many residents find this demeaning (Williams et al 2003). Furthermore, use of elderspeak may infer that older adults are incompetent and dependent, and is unlikely to encourage residents to express their views and opinions.

Cathy Butterworth, an inspector for the Commission for Social Care Inspection (CSCI), provides a useful summary of reasons why the older residents of care homes are not always adequately involved in decisions that affect them (2005). First of all, she suggests it takes time for attitudes to become embedded. Stepping back from a controlling role may not always be comfortable for staff (Tutton and Ager 2003), who feel a need to balance this approach with the duty of care to keep residents safe. Secondly, involving service users in a meaningful way is not as easy as it may first appear. Reed et al, for example (1999), provide a powerful description of the challenges of attempting to involve residents in setting care standards, demonstrating the importance of recognising older people's priorities if true partnerships are to be created (some further examples of approaches to involving residents in decision-making are included in section 3.2). On a one-to-one level, many residents of care homes tend to defer to the opinion of a health professional and skills are needed to enable them to express their views. Thirdly, professionals may need to spend additional time with service users discussing and exploring their options. In the time-starved environments characteristic of many care homes, it is easier and faster to assume what an older person would like than to truly establish their wishes. Finally, Butterworth suggests that nurses and carers must possess the knowledge to be able to give service users adequate information and the skills to explore sensitive and serious issues, such as preferences at the end of life.

Taken together, the available evidence suggests that many older people residing in care homes desperately want to be involved in the decisions that affect them, both on a daily basis and at a wider level both inside and outside the home. However, this needs to be assessed on an

individual basis. Enabling residents to make active choices is likely to involve some degree of risk-taking on the part of staff and family. For some family members, a safe environment for their relative is one without risk (Nay and Koch 2006) and regular communication between all parties is essential to ensure that risk-taking becomes an accepted aspect of care-giving. Furthermore, staff must feel supported by their managers to adopt a risk-taking ethos.

Recent legislative changes in both England and Scotland have implications for the involvement of older people with cognitive impairment in decisions that affect them. In England, the Mental Capacity Act (Department for Constitutional Affairs 2005) is aimed at increasing involvement in decision-making for people with impaired mental capacity and assumes that everyone has capacity until established otherwise. The Act raises questions about the use of proxies to make decisions on behalf of an older person and introduces the idea of a mental capacity advocate – an independent consultant who has responsibility for representing the older person's views and is not a paid member of staff. However, important questions about how 'capacity' is defined and determined are not fully answered within the Act. In Scotland, the Adults with Incapacity Act (Scottish Executive 2000) is a legal framework that has implications for how decisions are made and is relevant to nursing homes in Scotland. The Act covers the decision-making process for those who have been assessed as incapacitated to make decisions in identified areas and affects matters such as treatment plans and financial decisions. Also the Mental Health (Care and Treatment) Act (Scotland) (Scottish Executive 2003) offers a framework for decision-making in areas such as advance statements and named persons. Both pieces of legislation have codes of practice that must be adhered to when making decisions and it is important that staff within care homes are familiar with these.

7.3 Relative involvement

A growing body of evidence is suggesting that family caregivers appreciate attempts by formal

caregivers to create partnerships with them and recognise their knowledge and experience (Lundh et al 2003, Davies and Nolan 2006). However, evidence also suggests that such positive experiences are not yet the norm and that care staff do not always acknowledge and draw upon the expertise of family caregivers in planning and implementing care for older residents (Naleppa 1996, Hertzberg et al 2001). This is in spite of evidence demonstrating the benefits for all concerned of involving family members (Pillemer et al 2003, McDerment et al 1997, Specht et al 2000, Aveyard and Davies 2006).

A growing sub-group of older carers are those supporting a relative in a long-term care setting. These are mostly spouses, although some are filial carers – mainly daughters. Many of these former carers struggle with their changed situation and status and report feeling a sense of loss, grief, guilt, sadness, loneliness and even anger when their relative moves into a care home. Support from care homes varies, and some do not recognise the contribution the former carer could make to the ongoing care of their relative. However, some provide support groups and encourage relatives to become involved in life within the home. This might include fundraising activities, helping with gardening, outings and projects. Homes that recognise the needs of a former carer tend to treat them as a partner in the process of care (Davies 2001b). Recognising and using carers' knowledge of their relative's needs and preferences is very important in care planning, particularly when the resident has dementia. Valuing relatives involves considering them as co-consumers of the service, and enabling them to be fully engaged supporters of good care.

The degree to which relatives are able to participate in shared decision-making will depend to a large extent on the relationships they are able to develop with staff. On the basis of interviews with 48 relatives who had experienced the admission of a close family member to a care home, Davies (2001b) identified four types of relationship. These were:

- partnership care ('working together'); reciprocal relationships, with clearly established responsibilities and with staff recognising a relative's need to contribute to and monitor care
- substitutive care ('getting on with it'); where relatives perceive gaps and deficiencies in care and attempt to fill these gaps themselves
- submissive care ('putting up with it'); relatives respond passively, fitting in with the routines and expectations of the home; they find it difficult to raise issues with staff for fear of causing problems in their relationships with them
- confrontational care ('battling it out'); relatives perceive no alternative but to continually register complaints about care standards on behalf of the older resident.

Not surprisingly, the most positive experiences were described when family members were able to work in partnership with staff, confident that their views and opinions would be taken into account. Ron, for example, described his experience of the staff at the home where his wife is resident:

'There's only one thing I've been a bit concerned with, and that is she doesn't seem to be awake at all at the moment. I'll have to talk to Steve about it. I think she needs to have the medication reduced. She's spending too much time asleep. Steve will see to that and the doctor or the nurse will sort that out. Because he said quite openly, anything or any problems you want to talk about, do talk. So I'm quite happy.'

Ron, husband (Davies 2001b)

Rigid policies and inflexible rules are likely to have repercussions for partnership working and shared decision-making. Indeed Nelson (2000) suggests that most complaints in nursing homes result from the bureaucratisation of care and a clash of value systems. Whereas family members are concerned with issues of autonomy, better service, and individualised care, the facility's value system might seem to be more concerned with efficiency, profit, risk management and proper care as well as other medical, managerial

and professional prerogatives. Nelson argues that, although these goal sets are not always in conflict, the provider's concern for the individual resident's interest is inherently limited by facility priorities and the need to sustain managerial power and control. He suggests that resident advocates are essential in order to achieve an appropriate balance which meets the needs of the older person, their family and the organisation.

High and Rowles (1995) describe the notion of progressive surrogacy: with increased length of stay, residents progressively participate less in decisions concerning their lives and families continue a high level of involvement in the decision-making process and in some cases actually increase their involvement. They suggest that this might provide a more realistic goal as a resident's cognitive awareness declines:

'If autonomy is only conceptualised as direct and totally independent decision-making by an individual, then increasing or enhancing autonomy is generally not a realistic goal for nursing home residents who experience deteriorating health and cognitive decline. On the other hand, surrogate decision-making, actualised in the form of progressive surrogacy is not antithetical to autonomy if grounded in the richness and complexity of social interdependencies, including the positive features of delegated, assisted and extended autonomies.'

(p113)

In some instances, the stated 'philosophy' of a care home, often prepared by senior staff, with or without consultation with residents and their families, may not filter down to care staff (Wright 2000). Davies (2001b), for example, found that what residents and their relatives could expect was often left to the vagaries of individual members of staff:

SD: *'Are you ever able to have a meal there [with your wife]?'*

'Well I used to have. There you used to be, it just depends who's on. They'd say, "Would you like a dinner, Jim?" and I'd say, "Yes, please". But they

never asked me for ages, about twelve months since I had one. I'm not bothered.'

Jim, husband (Davies 2001b)

The majority of partners of residents in care homes participating in the 'Moving Stories' research, investigating the impact of admission into a care home on residents' partners (Bright and Clarke 2006) said they were still able to contribute to practical care tasks, whereas others adopted a visiting role to help their partner remain in contact with life outside. Most were content with the extent to which they were involved, in terms of how much they wanted or were able to be.

One contributor explained:

'Physically I am not strong enough [to do more practical care tasks]. After three hours a day doing what I can I am mentally, physically and emotionally exhausted.'

Another said:

'My wife has Alzheimer's disease and she seems to get upset when I am with her, but if there is anything else I can do I am very willing to help. I am 88 years old.' (p37)

Although many partners expressed continuing devotion they struggled with how to redefine their relationship.

For families to make a successful contribution to the continuing care of their relative they need to have the opportunity to be fully involved in all aspects of care, including assessment, planning, implementation and evaluation of care. However, Ryan and Scullion (2000a) found that family members regarded care plans as a nursing issue, suggesting low levels of engagement in the process. These findings highlight the potential for educating relatives and staff about the potential value of involving relatives in care planning. To encourage continued family involvement, care staff need to recognise, and respond to, the family's need for information about the changing needs of the resident, in a process of continuing dialogue and negotiation. There is certainly evidence that relatives want more information about the condition, illnesses and limitations of the older person (McDerment et al 1997, Rantz

et al 1999, Davies 2001). Relatives may also need information and guidance from staff in relation to decisions which they make on behalf of nursing-home residents (High and Rowles 1995). Aveyard and Davies (2006) found that encouraging relatives to contribute to wider decisions about the home through the mechanism of an action group helped relationships to develop, and as a consequence, staff became more aware of the contribution that relatives made to care.

Hertzberg and Ekman (2003) have suggested that at times it is hard for staff to feel confident about working in partnership with relatives. While staff might welcome relatives' contributions, they may also feel a need to retain a position as 'clinical experts'. This requires careful facilitation, so that relatives' involvement in decision-making does not threaten staff members' sense of significance. For such feelings to be overcome it is important that staff commit time to building trust and relationships with relatives. Ashburner et al (2004) also found that staff members felt threatened by external attempts to promote person-centred care within a nursing home for older people. The key to achieving change in this environment appeared to be the development of relationships over a period of time.

7.4 Staff involvement in decision-making

Although there is a clear need to shift the balance of power in decision-making in care homes to include residents and their families more effectively, there is a parallel need to ensure that all staff are able to contribute to decisions which affect them. At the reflexive level (Rowles and High 2003) many staff within care homes display a remarkable level of decision-making skill. This is captured in Diamond's ethnographic account, describing the work of nursing assistants in US care homes:

'Nursing assistants went about trying to organise their day as best they could. It took continual mental work to balance the tasks from above with the contingencies of the moment... The

official tasks were difficult, sometimes unpleasant, and took some skill. But there was a host of unspoken, unnamed demands, before, during and after the tasks, that presented problems, both physical and emotional. If the orders from the rational plan had parcelled out the tasks into a time-motion calculus that made sense in the abstract, carrying out the order continually came up against the unplanned, fluid and contingent nature of everyday tending.'
(Diamond 1992, p143)

This complexity of decision-making is recognised by Anderson et al (2003), who describe a process of self organisation in care homes, involving care staff in identifying priorities and negotiating these priorities with others to deliver responsive care that meets the needs of staff, residents and families. This is highly skilled work and affording care assistants a degree of autonomy in decision-making at the level of individual work management has benefits, as long as adequate senior support is available (Gruss et al 2004).

Studies have also shown that participation and empowerment of staff are essential elements of a positive working environment (Banaszak-Holl and Hines 1996, Anderson et al 2005, Davies 2003). Furthermore, studies of staff job satisfaction in care homes suggest a relationship between job satisfaction and a sense of being involved (Atkin et al 2005, Hall et al 2005). Participation in decision-making by all grades of staff has also been associated with improved outcomes for residents on a range of measures (Flesner and Rantz 2004, Rantz et al 2003). A number of initiatives aimed at increasing staff involvement in decision making within care homes have been evaluated. For example, Yeatts and Seward (2000) explored the effects of self-managed work teams (SMWT) in reducing staff turnover in nursing homes by increasing the level of involvement that staff have in planning tasks. The introduction of these teams was shown to reduce employee turnover by increasing job satisfaction. The authors conclude that involving nursing assistants in decision-making, even at a basic level, appears to confer

upon the employee a new dignity and self-respect.

Banaszak-Holl and Hines (1996) found that nursing aide turnover in a sample of 250 nursing homes in the USA was significantly reduced by their involvement in interdisciplinary care planning meetings. Involvement in such meetings was suggested to give nursing aides greater responsibility and authority in resident care and provide them with a formal communication channel to use when needed. Similar approaches have been used to encourage staff to manage their own work rota.

7.5 Involving other agencies

There is growing recognition of the need to link the community within a care home to the world beyond by increasing 'institutional permeability' (the exchange of people, services and communication) (Rowles and High 2003, Rowles and High 1996). This relates both to members of the public, including local community groups, who may wish to volunteer their services, and to statutory service providers within the NHS and local social services. Most UK care homes are located within the independent sector and staff can be isolated from wider professional networks and expertise, although there are also pockets of excellence and innovative work. None the less, concerns have been expressed about how agencies work together to ensure that the long-term care needs of older people living in care homes are met. A joint report of the Royal College of Physicians, the Royal College of Nursing and the British Geriatrics Society published in 2000, for example, highlighted how the health needs of older people in care homes are often overlooked and suggested a need for more interdisciplinary collaboration to achieve change (RCP, RCN and BGS 2000). Goodman et al (2003) describe the uncertainty concerning the role of district nursing in care homes for older people and call for greater clarity about their possible contribution. There is also potential for greater involvement of Community Mental Health Nurses in promoting mental health for residents

of care homes (Mason 2006). This is discussed further in Chapter 8.

In recognition of the potential for joint working and shared learning, statutory service providers and commissioners of long-term care services throughout the UK are beginning to set up services aimed at supporting staff in independent sector care homes through building closer and more effective working relationships. Many of these initiatives have the ultimate goal of enhancing quality of care for residents and their families through developing confidence, skills and knowledge among care-home staff. A range of approaches is in operation, including dedicated specialist posts and multidisciplinary teams aimed at intensive case management (Hayes and Martin 2004), outreach work from established services (Crotty et al 2004, Proctor et al 1998, Salgado et al 1995) and the initiation of self-help through the creation of supportive networks (Meehan et al 2002). To date, evaluation of these initiatives is limited and this is an area requiring urgent investigation. One promising scheme is described in box 7.1.

Box 7.1 Specialist care homes support team

A primary care trust (PCT) in Sheffield has established a specialist development team to intensively support staff and residents of care homes. The overall goal is to build capacity for staff to effectively manage the ongoing health and social care needs of residents in order to avoid unnecessary admission to hospital or, where hospital admission is appropriate, and in the best interests of the resident, to avoid an unnecessary prolonged hospital stay. The team consists of two full-time specialist nurses, a full-time specialist occupational therapist, a part-time (0.2 WTE) general practitioner with special interest in older people and a part-time (0.5 WTE) administrator. The specific aims of the initiative are to:

- build closer and more effective relationships between care homes and primary, secondary and community health services, intermediate care services, social services and voluntary agencies
- develop confidence, skills and knowledge among care home staff to take a proactive approach to chronic disease management
- identify best practice and effective ways of working to support the monitoring and early detection of changes in health
- support the development and implementation of new ways of working which support making the most effective, timely and efficient use of available resources to avoid hospital admission
- develop confidence, skills and knowledge to manage end-of-life care needs
- develop confidence and skills among care home staff to maintain or enhance the physical, emotional and social wellbeing of all residents.

The team faces the challenge of gaining the voluntary commitment of staff working in each individual care home. Identifying opportunities within each home and developing an understanding of the unique culture of individual homes has been important. Methods used to influence change include:

- action learning sets both across and within individual homes
- formal training sessions both across and within individual homes
- networking with and capitalising on the skills and knowledge of other professionals from within North Sheffield PCT and other organisations
- facilitating networking across homes
- working with all levels of staff
- clinical audit
- providing *ad hoc* advisory support.

(Johnson 2005)

7.6 Moving towards shared decision-making in care homes

The research reviewed here suggests that partnership working has the potential to strengthen relationships in care homes and promote positive experiences for all concerned. A number of studies have evaluated the effect of focused interventions aimed at enhancing partnership working. The Family Involvement in Care (FIC) intervention, for example, was designed to help family caregivers of nursing home residents with dementia negotiate and establish a partnership with staff caregivers. It comprises four elements (box 7.2).

Box 7.2 Elements of the Family Involvement in Care (FIC) Protocol

- Orientation of a primary family caregiver to the facility and the proposed partnership role
- Education of the primary family caregiver for involvement in resident care
- Formation and negotiation of a partnership agreement
- Follow-up and evaluation with the family member.

The activities family members agreed to perform ranged from the simple provision of information about the resident to active participation in physical care and recreational activities. Activities were chosen by family members from a manual, which provided the rationale for each intervention together with guidelines.

In experimental studies the FIC has been found to slow residents' rate of deterioration (Jablonski et al 2005) as well as enhancing the caregiving experience of family members and improving nursing home staff attitudes toward family members (Maas et al 2004).

In a largely qualitative evaluation, Lundh et al (2003) explored the impact of an educational intervention within a care home in Sweden, working with both staff and residents' families. The findings of this project highlighted how partnership working promoted mutual understanding of the needs of relatives and staff and an appreciation of each other's contribution. All of these studies, however, found difficulties in maintaining improvement beyond the period of the project and there is a need for sustainable interventions that become part of the culture of the care home. One such intervention is described by Aveyard and Davies (2006). This involved setting up an action group involving relatives, staff and representatives of external agencies, at a nursing home for older people with dementia (box 7.3). Evaluation of the project suggested that the work of the action group had encouraged staff and relatives to

Box 7.3 The Support 67 Action Group

67 Birch Avenue in Sheffield is a nursing home providing care for up to 40 older people with dementia. Since 2001, researchers at a nearby university have been working in partnership with staff, residents and relatives at the home with the aim of developing care practice and creating a positive environment for living, working and learning. The main guiding principle is to ensure that all participants – residents, relatives and staff – feel that they are valued members of the home community.

The project is using an action research approach to plan and evaluate developments. Initially, questionnaires were completed by staff and relatives and these provided the basis for discussion at a series of staff awaydays. A feedback report highlighted areas that would most improve the experiences of residents, relatives, staff and students and this was circulated to everyone involved. Following the identification of needs and priorities, an action group was established to take ideas forward. The Support 67 Action Group meets monthly and includes relatives of

residents and representatives of all staff groups within the home, including domestic and catering staff. Senior managers of the care trust and housing association jointly responsible for managing the home also attend, ensuring that decisions can be implemented quickly. Achievements to date include:

- establishing an activities programme for residents, including assessment of each individual's abilities and interests;
- production of a booklet for relatives aimed at easing the transition to life within the home;
- setting up an information and support group for relatives;
- developing resources to support student nurses on placement at the home;
- creating safe garden areas.

Early evaluation suggests that the partnership project has enhanced communication and provided a renewed sense of purpose and achievement for relatives and staff alike.

(Davies et al 2005)

7.7 Summary

- There are numerous opportunities for negotiation and shared decision-making in the minutiae of daily interactions, and the way in which the myriad of decisions are made creates the culture which ultimately determines residents' daily lifestyle and quality of life.
- From their ethnographic research, Rowles and High (2003) identify four main types of decisions: authoritative (externally imposed); given (taken-for-granted decisions which define cultural environments and sustain norms of conduct); negotiated (largely individualistic decisions resulting from stakeholder

interactions); reflexive (autonomous decisions made through self-deliberation).

- Evidence suggests that many older people in care homes desperately want to be involved in the decisions that affect them. Maximising the extent to which residents are enabled and empowered to exercise choice is increasingly accepted as essential for quality of life. Particular attention needs to be paid to residents who live with cognitive impairment or communication difficulties.
- For families to make a successful contribution to the continuing care of their relative they need to be offered opportunities to be fully involved in all aspects of care including assessment, planning, implementation and evaluation.
- Although there is a need to shift the balance of decision-making power in care homes to include residents and their families more effectively, there is a parallel need to ensure that all staff are able to contribute to decisions which affect them.
- There is growing recognition of the need to link the community within a care homes to the world beyond by increasing the involvement of local community groups and volunteers, statutory service providers and local social services.

recognise and value each other's contribution, as well as creating a powerful voice for change.

7.8 Conclusions

In order for care homes to function as true communities, where everyone's contribution is recognised and valued, all stakeholders – residents, their families and staff members – need to have the opportunity to be involved in the decisions that affect them, to the extent that they wish to be involved. We suggest that the typology of decision-making described by Rowles and High (p1) provides a useful framework for thinking about the decisions that

affect experiences within care homes and that providers should consider how to ensure that residents, their families and staff members are actively involved at each level and that everyone has the opportunity for their voice to be heard.

7.9 Recommendations

Care staff should be encouraged to consider residents and relatives as expert partners in care unless this is contrary to the relative's or older person's wishes.

Residents and relatives should be involved in the initial assessment of the older person's needs and the proposed plan of care should be negotiated and agreed with all parties. The use of biographical methods of assessment can be particularly valuable and is a practical method for involving family members in assessment and care planning.

Care staff should ensure that residents and relatives are provided with opportunities to express their concerns and anxieties around the time of admission and at regular intervals.

Shared decision-making in relation to an individual resident's plan of care requires regular, planned reviews involving the home manager, named nurse, key-worker, resident and family members.

In order to encourage continued family involvement, staff must recognise and respond to the family's need to be educated about the changing health needs of the resident. Regular review and discussion could provide a vehicle for these activities.

Accessing user views and feeding these views into a change process should be a priority. The establishment of a group involving residents, relatives and staff to enable all stakeholders to feed their views into an active change process should be a requirement of registration. Care-home staff should facilitate opportunities for groups to meet regularly. Notes of meetings, including action points will help to ensure that appropriate follow-up takes place. Creative ways of disseminating information from such discussions are necessary to ensure

that everyone is aware of decisions and developments. (See also information on the Caring in Homes Initiative in Chapter 3.)

Methods for disseminating information to all members of the care-home community, such as a regular newsletter, have the potential to ensure that everyone feels involved and creates ownership of identified problems and solutions.

Primary care organisations should establish multidisciplinary teams to work with staff and residents within care homes in order to support staff to develop their skills and knowledge. Such teams will provide a link between homes and ensure access for residents to the full range of services available locally.

8 Health and healthcare services

Hazel Heath

8.1 Introduction

Health is integral to quality of life and ill-health or disability can compromise its achievement. Older people living in care homes can enjoy considerable quality of life but most need healthcare support in order to do so. The gradual re-designation during recent decades of older people's long-term care services from 'health' to 'social' masks the fact that many residents have substantial healthcare needs and, while some needs may be met within the homes, most will require input from doctors, pharmacists, therapists, specialist nurses and other services outside the home.

This review of the literature reveals fundamental areas for concern: for example, that some residents are not receiving services to which they are entitled under the National Health Service and that others, particularly those who fund their own fees, are being charged for services that should be provided within the NHS. Obtaining general practitioner services is problematic in some localities and specialist medical services are not widely available. Therapy input to care homes is particularly sparse, and without this older residents' potential for maintaining their independence or for regaining lost functioning can be limited.

While such problems are clearly widespread there would appear to be enormous potential for improving health support and services to care-home residents. Newly developed guidance or standards for best practice and a broad range of resources are now available. In addition, some localities are developing innovative specialist and multi-professional services which ensure that older care-home residents receive the healthcare they need.

This chapter highlights the major health issues for older people living in care homes and summarises the findings of research into the healthcare services currently available to them. The subsequent sections offer details on resources, standards, guidance for best practice, care schemes and a range of innovative models which provide positive examples of how services could be developed for the future.

8.2 The healthcare needs of older care-home residents

Older people who live in care homes have high levels of healthcare need, largely determined by chronic, progressive disease and resulting in multiple disabilities. In the spring of 2006 the Continuing Care Conference (CCC) undertook what it described as 'the biggest census of care-home residents ever undertaken in the UK'. It surveyed a population of 40,843 residents in 751 BUPA care homes. (The response rate was 79 per cent and 93.7 per cent of respondents were long-stay residents.) The survey reports that:

- 82 per cent are 'confused' or 'forgetful', 'depressed' or 'agitated'
- 73 per cent are incontinent
- nearly half of residents are both immobile and incontinent, and
- over three-quarters need help with their mobility or are immobile.

In terms of specific clinical diagnoses, over two-thirds of the residents in the survey have neurodegenerative disease such as dementia, stroke or Parkinson's disease.

These results not only indicate high levels of healthcare need but also that the dependency of residents living in care homes is increasing. Bowman et al's (2004) survey of 16,043 people resident in 244 BUPA care homes (25 per cent residential and 75 per cent nursing) across the UK identified that:

- 78 per cent had at least one form of mental impairment. Only 22 per cent were said to have a normal mental state; 64 per cent were 'confused' or 'forgetful'; 20 per cent were reported to exhibit challenging behaviour; 19 per cent were described as 'depressed' or 'agitated'.
- 71 per cent were incontinent.
- 27 per cent were immobile, confused and incontinent. (There was considerable overlap in dependency between residential and nursing care. Only 40 per cent of those in

residential care were ambulant without assistance and 46 per cent were incontinent.)

- 76 per cent of residents required assistance with their mobility or were immobile.

In terms of specific clinical diagnoses, over half of the people in this survey had neurological disease such as dementia, stroke or Parkinson's disease.

The survey authors highlight that medical morbidity and associated disability, rather than general frailty and social needs, had driven the move into a care home for over 90 per cent of residents, and they conclude that it is unlikely that the needs of people with such levels of dependency can practically be met in the community.

The increasing dependency of care-home residents is confirmed by other studies. For example, Netten et al's (2001) longitudinal and cross-sectional surveys conducted for the Personal Social Services Research Unit identify that residents are increasingly more dependent than a decade ago, particularly with regard to cognitive impairment and the ability to perform self-care tasks such as washing.

The average age of residents would now appear to be 83.6 years (CCC 2006).

8.3 Providing adequate healthcare

Despite the substantial health needs of older people living in care homes, the literature is unequivocal that there are wide variations, both nationally and within individual localities, in the delivery of healthcare services to care home residents.

During the 1980s and 1990s when the provision of long-term care widely shifted from NHS continuing care sites to independent sector homes, as the Royal College of Physicians, Royal College of Nursing and British Geriatric Society taskforce (2000) highlighted, 'the transfer from hospitals to care homes [was not] accompanied by significant transfers of medical resources to the community'. Consequently 'care-home residents have often become the medically dispossessed in spite of their complex health

care needs, which may contribute to avoidable ill-health and acute hospital admissions' (para. 2.9). The taskforce members concluded: 'it is a paradox that older people with the greatest needs for consistent, creative and effective care now live in care homes denied the traditional essence of interdisciplinary geriatric care' (para. 2.4).

There is a growing body of research evidencing the limited medical, multi-professional and specialist gerontological input into care homes (summarised in table 8.1) and it is worth noting that the studies reported here are rigorous and comprehensive. For example, O'Dea et al's (2000) survey had a high response rate (96 per cent) and respondent homes were deemed to be representative of the national picture of ownership, size and occupancy.

The research also reveals some fundamentally important issues concerning equity of access to NHS services for people who live in care homes. It is disturbing to see evidence that some older care-home residents are paying for services that to patients in acute hospitals or their own homes are provided free of charge under the NHS. Even more disturbing is evidence that self-funding residents are paying disproportionately more for services than residents funded by local authorities.

The realities of the lack of NHS service provision to older people in care homes, and the lack of acknowledgement of the ongoing inequities, prompted Jacobs and Glendinning (2001) to describe this as 'an invisible issue'.

Additional issues identified in the research were that NHS and community information systems did not always record information on the input to nursing homes and there were no overall databases which recorded private input.

Table 8.1 Research identifying healthcare service input in care homes

Research	Findings
<p>Telephone survey of nursing homes in one London health authority: 49 homes with 1,541 residents (<i>O'Dea et al 2000</i>)</p>	<p>Only 27% of residents had access to all healthcare services. Two homes with 43 residents received no regular GP visits, no specialist nursing advice or therapy services, i.e. little or no contact with any health services other than the nursing provided by the home. Six homes with 90 residents received GP visits and chiropody service with no other nursing or therapy services.</p> <p>Only one home reported any routine involvement of a local geriatrician, who liaised once a month with the home's GP</p> <p>During the year of the survey, less than 1% of residents had received 'hands-on' care from a district nurse, mainly those who were catheterised, needed leg ulcer dressings, or had wounds or burns. The most frequently accessed specialist nurses were tissue viability, diabetes, palliative care, continence and stoma care nurses.</p> <p>17/49 homes, 19% of residents, had made no use of specialist nursing services during the previous year.</p> <p>Only 6% of residents had been seen by an NHS physiotherapist for assessment and advice. One-quarter of homes had made no referrals to either NHS or private physiotherapy services in the previous year. 41% of homes used NHS assessment and advice only; 22% used private services only; and 12% used both types of provider.</p> <p>Two-thirds of homes using private physiotherapy levied an extra charge to residents for this.</p> <p>30/49 homes had no speech and language therapy (SLT) in the past year and no home used a private SLT. Overall only 2% of all residents received this service and no regular service was provided to any home.</p> <p>All homes had access to chiropody services, with one-third using NHS services only, a third using private services only and a third using both. The homes using private services tended to be larger.</p> <p>The over-75 check, introduced as part of the 1990 GP contract, was carried out in only one in five homes</p> <p>23 homes, 36% of residents, could recall no planned medication reviews in the last year. Regular reviews were carried out in about half the homes.</p>
<p>Postal survey of 400 nursing homes in England, Scotland and Wales (<i>Barodowala et al 2001</i>)</p>	<p>Only 10% of residents received physiotherapy, mostly through private physiotherapists employed by the nursing homes, and only 3.3% of residents received occupational therapy. There was a marked difference in physiotherapy provision between those homes employing a private physiotherapist (35.7%) and those homes not doing so (3.9%). This illustrates that most of the physiotherapy provision was non-NHS.</p> <p>Barodowala et al (2001) defined OT provision as that provided by a trained OT as opposed to a social/activities organiser. Only 3.3% of residents were currently receiving OT treatment and 5.8% had received OT during the previous six months.</p>

Research	Findings
<p>Telephone survey of 765 nursing, residential and dual registered homes across 72 English PCG/Ts (Glendinning et al 2002)</p>	<p>Identified extensive variations in homes' policies and local GP services.</p> <p>8% of homes paid GPs for services to residents.</p> <p>Larger homes were more likely to receive services over and above GP core obligations.</p> <p>Few homes had direct access to specialist clinicians. Glendinning et al (2002) identified that 83% of homes could contact a geriatrician and 92% a psychogeriatrician when needed, in both instances usually via the resident's GP. Only 5% of homes had direct contact with a geriatrician and 12% a psychogeriatrician.</p> <p>Glendinning et al (2002) showed regular medical and medication reviews and regular home-based surgery consultations are additional services which arguably acknowledge the higher levels of illness and dependence of home residents, compared with that of many older people living at home. All these services were significantly more likely to be provided to homes which paid GPs than homes which did not.</p>
<p>Qualitative interviews: 27 homes in England (Jacobs and Rummy 2002)</p>	<p>The findings revealed extensive variation in local GP services.</p> <p>Few homes had direct access to specialist clinicians.</p>
<p>In-depth qualitative face-to-face and telephone interviews: 42 homes. England (Jacobs 2003)</p>	<p>This study investigated the perceptions and experiences of home managers and GPs of the provision of general medical services for older residents. Although, in theory, most homes endorsed the principles of patient choice and continuity of care, in reality many were registered with only one or two GP practices, thus limiting choice. Contracts between homes and GPs may provide opportunities for improving medical care but do not guarantee additional services. Visits on request formed the bulk of GP workload in homes but can be hard to obtain for residents. Regular weekly surgeries were preferred by many homes but have additional workload implications for GPs.</p>

In addition, surveys suggest that the level of NHS services has diminished. O'Dea et al (2000) identified a decline in the previous ten years from when the Office of Population Censuses and Surveys audited the use of services by residents in communal establishments. Seventeen per cent of older residents in private homes in the OPCS survey had seen an NHS physiotherapist in the last year, compared with 6 per cent in the O'Dea et al survey, and 25 per cent had been treated by a community nurse

compared with less than 1 per cent in O'Dea et al's survey.

General practitioner services

The responsibility for providing medical services lies with general practitioners and, in principle, care-home residents are entitled to register with the GP of their choice and to receive general medical services within NHS provision. While many older care-home residents do receive such services, this is by no means the case for all.

The research literature identifies some key issues.

- Due to the shortage of GPs in some areas, particularly where large or numerous care homes increase the demand, there can be problems in obtaining GP services, particularly for new residents, and also in obtaining temporary GP cover for residents admitted for short-term respite care (Janzon et al 2000).
- If individuals move out of the catchment area of their own GP, or if the home operates a policy of registering all residents with one GP, new residents may be forced to register with the GP who serves the home (O'Dea et al 2000).
- Many GPs now contract with care homes to charge a fee or 'retainer' for their services to residents, which they argue are over and above the 'general medical services' for which the NHS contracts with them.
- Additional costs to homes in the form of GP fees or retainers are commonly passed on to residents. This results in residents being charged for GP services that individuals living in their own homes receive with NHS funded provision.
- Because local authority fees and top-up payments are limited, self-funding residents may be charged more for such services.

From the PSSRU national survey, Glendinning et al (2002) conclude that the extensive variation in homes' policies and local GP services raises serious questions about patient choice, levels of GP services and, above all, equity between residents within homes, between homes and between those in homes and those in the community. There were wide variations in the numbers of GPs providing services to individual homes and this was not entirely dependent on home size. Eight per cent of homes, mostly nursing homes, paid local GPs for their services to residents. Larger homes were more likely to encourage residents to register with a 'home' GP. Homes paying local GPs were more likely to receive one or more additional services, over and above GPs' core contractual obligations. In

O'Dea et al's (2000) research, all respondent homes had a GP whom they considered to be the home doctor. All homes said that they allowed residents to register with a practice of their choosing but nearly all (47/49) reported that residents register with the home doctor. This study found that 20 per cent of homes had no regular GP visits. Eighty per cent of the homes received regular visits from their GP and 20 per cent had visits by request only. Daily visits occurred in the two largest homes, one with 200 beds and the other with 150 beds.

Although GPs should not charge patients for general medical services, the General Medical Services Committee (GMSC) of the British Medical Association has argued that the medical care of frail older people in care homes falls outside GPs' core terms of service and should therefore be excluded from their contractual obligations (GMSC 1996), particularly where an increase in the numbers and size of care homes within a locality has a disproportionate impact on GP practices. As a consequence many care homes pay retainers to GPs. Glendinning et al (2002) found that fees ranged from under £500 to over £5,000 per year (commonly £1,000–£1,999).

A survey of homes run by charitable, voluntary and benevolent organisations (VOICES/ACO/OBRA 2001) showed that about a third of responding homes were paying retainer fees to GPs on top of the normal NHS fees and allowances paid to GPs. These retainer fees were normally introduced at the request of the GP and could amount to £150 per resident per annum, the average being £41 per resident per annum. Although many of these GPs were providing additional services, such as regular surgeries on the premises, others were providing these services within their basic remuneration from the NHS. Some GPs included the provision of core NHS GP services within the retainers charged to homes. Since the response rate to this survey was only 42 per cent it may have attracted responses from organisations that were concerned about paying retainers to GPs. Nevertheless, residents in these homes are likely to be contributing indirectly to their medical care through their fees to the home. This raises issues of equity and there

are suggestions that GPs' fees should be paid by health authorities rather than the homes themselves. Dealing with large numbers of GPs presents inherent difficulties relating to co-ordination of care and duplication of GP effort.

In Jacobs' (2003, p116) qualitative study, GPs were divided concerning the desirability of contracts. Some felt that the extra workload involved in caring for residents should be remunerated and that this would enable them to offer better-quality care. Others, however, believed that this additional remuneration should be coming from the NHS, and that contracts had the potential to alter the doctor-patient relationship, 'because really the contract's between you and the patient, not you and the home' (GP).

Jacobs (2003) argues that recognition of the additional workload for GPs working in care homes is necessary and that this should be accompanied by additional NHS remuneration. Glendinning et al (2002) conclude that in areas where homes experience difficulties in registering new residents with already overburdened GPs, there may be no option but to register all new residents with a GP with whom the home has entered into a contractual arrangement. Indeed there may be advantages in homes building close working relationships with one or two GPs who are committed to the home and its residents and may offer a wider variety of services. As businesses, homes are usually forced to recoup the cost of GP fees from residents. Therefore a significant number of residents are contributing toward the cost of general medical care which is provided to everyone else under the NHS and to which they have contributed all their lives.

A two-year project funded by the Department of Health and conducted by the Association of Charity Officers (2005) reported on good practice in GP healthcare for older people in establishments managed by charitable organisations. It found that the quality of provision across the UK was variable; some GP practices appeared better managed than others and were more 'efficient, efficacious and effective', borne out by the provision of 'palpably

better care within core funding than others who are charging additional fees through retainers'. Recommendations included regular GP medication reviews, encouraging consultants with an interest in older people to develop services in care homes and abolishing retainer fees.

Retaining a resident's contact with his/her existing GP provides valuable continuity in the care of a frail person who has experienced the major life change of admission to a care home, often following a spell in hospital. Some GPs go out of their way to ensure continuity of care, as this interview with a home manager illustrates:

HM: *'I've had one recently come. Now her GP in fact doesn't want to change. He said he'll come and see her. He's the only one and he's out of the area.'*

Q: *'But he's prepared to travel over?'*

HM: *'Yes, because she's over 90 and she's always been under him and he said "I'll come to keep an eye on her. I would like to come".'*
(Jacobs 2003, p114)

Box 8.1 Practice example: a GP service to care homes

A Weston-super-Mare GP practice developed a project to reduce the pressure on their services to care homes while improving quality. Key features included dividing all care homes between the town's practices. All the patients in each home (with their agreement) register with a single practice. A team of GPs and nurses initially visit each home to re-register patients, review their health and medication and establish home-based notes from the computer system. Practice nurses visit fortnightly to review patients who have developed problems. Funding for this initiative was recommended from the commissioning of a 'Local Enhanced Service'.

The research literature shows that access to other healthcare professionals for older people living in care homes is limited in many localities.

Specialists in medicine for older people

The work of specialist geriatricians appears to have shifted markedly to acute care (RCP, BGS, RCN 2000). Glendinning et al (2002) identified that 83 per cent of homes could contact a geriatrician and 92 per cent a psychogeriatrician when needed, in both instances usually via the residents' GP. Only 5 per cent of homes had direct contact with a geriatrician and 12 per cent a psychogeriatrician. In O'Dea et al's (2000) survey, only one of 49 homes reported any routine involvement with a local geriatrician who liaised once a month with the home's GP.

Primary care nursing and specialist nursing

For people living in care homes without nursing, any nursing needs that residents have are the responsibility of the primary health care nursing services. Specific clinical needs among older people in care homes without nursing include continence promotion, prevention of infection, pressure ulcer prevention and care, dental health, diabetes care, visual problems and palliative care. Approximately one-third of residents in residential homes have a continence problem. In Goodman et al's (2003a) study, all participant district nurses agreed that people who would previously have been assessed as needing nursing-home care were now being moved into residential homes.

In a study to explore the actual and potential contribution of primary care nurses in residential homes for older people, Goodman et al (2003a) found that district nurse contact was variable and unpredictable. DNs had regular contact with residential homes for discrete nursing tasks, but appropriateness of referrals and input was not agreed. Some of their work was felt to be preventable (for example, tending to superficial wounds caused by poor moving and handling) and DNs' involvement was felt to be greater where staff were less aware of anticipatory care, e.g. in preventing constipation. Focus group discussions revealed that DNs found their work in residential homes problematic and indicated a lack of consensus about their role. The data suggested that uncertainty about providing care in a setting that

straddles the health and social care, public and private divide, and anxieties about managing their workload overshadowed their acknowledged concerns about the older people in the homes. DNs provided training in the homes, which was felt to be valuable. Some homes paid for this, others did not. O'Dea et al (2000) similarly reported that during the year of their survey, less than 1 per cent of residents had received 'hands-on' care from a DN, mainly those who were catheterised, needed leg ulcer dressings, or had wounds or burns.

Box 8.2 Practice example: the development of specialist expertise among nurses in care homes

Some larger homes and care-home groups encourage their RNs to develop specialist expertise: for example, in moving and handling, tissue viability, wound care, bowel care, continence and nutrition. This means that there is always a nurse in the home or group who can advise and teach on these aspects

(Heath 2006)

The specialist nurses most frequently accessed by care homes would appear to be tissue viability, diabetes, palliative care, continence and stoma care. O'Dea et al's (2000) survey found that about one-fifth of homes had made no use of specialist nursing services during the previous year.

The survey conducted by the Continuing Care Conference (2006) identified that 90 per cent of care-home residents had a medical reason for seeking specialist nursing care.

In 2000 the RCP, RCN, BGS taskforce recommended the development of gerontological nurse specialists to co-ordinate the healthcare of older people in homes and a range of new Older People Nurse Specialist roles is emerging.

Box 8.3 Practice example: specialist nurse support to care homes

In January 2004 managers and clinicians at Newham PCT responded proactively to the finding that 10 per cent of acute admissions to the local over-75 medical service were from care homes. They developed and introduced a specialist nurse support service for local care homes with a view to preventing and monitoring avoidable accident and emergency (A&E) attendances and acute care admissions. The service was initially piloted (from August 2005) with two out of the six local care homes and overseen by a local steering group representing a variety of stakeholders.

The role is explicitly not to undertake tasks for which care-home staff do not have the skills but to work directly with staff in anticipatory care planning and in learning new skills. For instance, where a resident would previously have been hospitalised owing to a blocked urinary catheter, Eunice (the specialist nurse) will work with care-home staff to set out a plan for changing the new catheter before it blocks. She will also visit the home to change the catheter if (as can be common with female staff and male residents) care-home staff do not have the skills to do this themselves. However, rather than changing it herself, she will involve a care-home nurse in the procedure and, where skills are lacking among the staff, will look to arranging suitable training packages and acting as practice supervisor as staff acquire new skills. Often Eunice goes beyond the call of duty in ensuring that staff take on new skills: for example, driving them to a training course for administering flu vaccines.

Eunice is a district nurse with a range of specialist skills. She can visit a resident in the care home and carry out ECG, pulse oximetry, a bladder scan or urinalysis. She also screens the documentation of all individuals who attend A&E from care homes and follows them up where a specific clinical or training need is identified. Referrals are made to local

specialist nurses (e.g. respiratory, tissue viability) and other professions as required. Specialist medical input from a local care of the elderly consultant has been recently introduced, as has a second specialist nurse, with a view to extending the cover of this service to all local care homes.

(Dr Jackie Bridges, City University, February 2006)

Box 8.4 Practice example: specialist older people's team support to care homes

The Community Health Support Team Model comprises older people's specialist nurses (OPSNs), a mental health lead nurse, pharmacist, part-time old age psychiatrist, two consultant geriatrician sessions per week, and three sessions per week from one consultant nurse.

Pre-admission assessment is carried out by the dedicated OPSN rather than primary care nurses in order that older people's needs for healthcare can be identified. The OPSN in part directs the work of the rest of the CHST and a priority for the team is to support primary care services in addressing the specialist healthcare needs of nursing-home residents through regular specialist clinical review, together with support for practice development. Regular meetings with local social services departments and relevant professionals from local NHS trusts complete a network of local communication with major stakeholders.

Clinical governance priorities include:

- determination and review of the NHS contribution to nursing care for care-home residents
- resident health outcomes including pressure ulcers, falls, nutrition, manual handling, depression, recognition of dementia

- mental health assessment
- evidence-based prescribing
- end-of-life care
- influenza immunisation
- management of specific diagnostic groups.

Training programmes – for example, on medication management, continence and pressure ulcer prevention – have been provided for nursing-home staff.

Evaluation of this service concludes that the OPSN role is key in maintaining an effective interface between primary care and independent sector care homes.

(Hayes and Martin 2004)

Therapy services

In theory, homes can access NHS services or use private providers but, with the relocation of long-term care services from NHS to the private sector during the 1980s and 1990s, the provision of these services became problematic. This can result in older nursing-home residents having less access to physiotherapy and such services than those living in their own homes. In practice, the NHS provides no regular ‘hands-on’ physiotherapy service to nursing homes, but patients can be referred by GP, consultant, district nurse or other therapist for assessment and advice (O’Dea et al 2000).

As the research in table 8.1 shows, access for care-home residents to physiotherapy and occupational therapy is limited (Barodawala et al 2001). Some homes, particularly larger nursing homes, make use of private physiotherapy services and there is a marked difference in physiotherapy provision between homes employing a private physiotherapist and those who do not. In fact, most of the physiotherapy provision identified in surveys was non-NHS and O’Dea et al (2000) identified that two-thirds of homes using private physiotherapy levied an extra charge to residents. This again raises equity concerns if the costs are reflected in fees charged to residents.

Occupational therapy input is particularly sparse (Barodawala et al 2001) and the consequences of the lack of expert advice can be seen in unnecessary dependency and in the high rates of immobility-related complications (Sackley et al 2004). The costs can be seen in high rates of readmission to hospital and increased GP workload (Groom et al 2000). OT input can make an enormous difference in older people’s everyday functioning, and therefore to their quality of life (Sackley et al 2001, Sackley and Dewey 2001, Sackley et al 2004).

Speech and language therapy is virtually non-existent in most homes, as O’Dea et al (2000) identified.

Chiropody/podiatry can be essential in maintaining older people’s ability to walk and most homes seem to have access to podiatrists although, again, many of these are not provided under the NHS (O’Dea et al 2000).

8.4 Priority health needs

Particular issues identified in the literature concern residents who have mental health conditions such as dementia or depression, are in pain, are at risk nutritionally or of falling, experience continence problems or need medication. The following sections deal specifically with these issues. They highlight findings from the literature alongside ideas, standards, guidance, resources and practice development initiatives that could contribute towards enhancing healthcare services for older care-home residents in the future.

Box 8.5 Resources: best practice statements

Best practice statements provide advice and guidance to nurses and allied health professionals on the most effective ways in which to deliver care. They address healthcare issues where there are recognised instances of variation in practice and promote the delivery of consistent levels of healthcare for patients no matter where they access services.

The statements themselves comprise:

- the best evidence available at the time
- agreed opinion
- examples of good, as well as innovative, practice.

The statements are developed using a systematic process that includes:

- the involvement of NHS Scotland staff and service users gathering and reviewing the best supporting evidence available at the time
- the study of examples of current practice
- widespread consultation with healthcare professionals and the public.

Each statement is reviewed after three years and, if necessary, updated.

Best practice statements are being developed through NHS Scotland and Glasgow Caledonian University
http://www.nhshealthquality.org/nhsqis/qis_display_search/

Examples of best practice statements are identified throughout this chapter.

Mental health

As recent surveys demonstrate (Bowman et al 2004, CCC 2006), the mental health needs of older people living in care homes are complex. A broad range of therapeutic interventions are now available to older people with mental health needs but the extent to which these can be accessed by older people who live in care homes varies. Interventions available in better-quality homes include activity-based therapy (such as music, art or exercise), reminiscence, reality orientation, validation and multi-sensory stimulation (Snoezelen). There are, however, a much broader range of therapies which experience and anecdotal evidence suggest are not generally available to those who live in care homes. These include psychotherapy, psychodynamic therapy, cognitive-behavioural therapy and counselling (Minardi and Hayes 2003a, b).

Box 8.6 Resources: mental health

Advice on interventions to promote mental health in older people and Department of Health guidance on promoting integrated mental health services for older people are described in the Resources section.

Dementia

The Alzheimer's Society estimates that three-quarters of people living in care homes have dementia and emphasises that these people are among the most vulnerable members of society. Generally, people with dementia move into care homes when their needs become either too complex or too expensive for them to remain in their own homes but research into how well their needs are met within care homes is limited (Hancock et al 2006).

In a study to identify the unmet needs of people with dementia in care and the characteristics associated with high levels of need, Hancock et al (2006) assessed 238 people in residential homes using the Camberwell Assessment of Needs for the Elderly (CANE) tool. They found that the environmental and physical needs of residents with dementia were usually met. Unmet needs included sensory or physical disability needs (including mobility problems and incontinence), mental health, and social needs such as company and daytime activities. Although unmet needs were not related to either the severity of dementia or the level of the resident's dependency, they were associated with psychological problems, such as anxiety and depression. The authors conclude that mental health services and residential-home staff need to be aware that many needs remain unmet and that much can be done to improve the quality of life for residents with dementia.

The Alzheimer's Society supports this view. It acknowledges that dementia may cause a person in a residential home to behave in ways that are bewildering and upsetting, both to themselves and to those caring for them. However, the kind of care that they receive can make a big

difference to their behaviour and their quality of life.

Box 8.7 Resources: dementia

The Alzheimer's Society has developed information on standards of care in care homes and training on quality dementia care. Details are given in the Resources section of this report.

Depression

Depression is estimated to affect up to 40 per cent of older people who live in care homes and often goes unrecognised (Audit Commission 2000, Brown et al 2002). Yet the literature offers clear indicators on how this can be addressed.

In terms of everyday care, research by Boyle (2005) in Northern Ireland suggested that long-term environments which constrain older people's autonomy contribute to the development of depression. This could suggest that environments that promote autonomy help to prevent the development of depression. Research by Mann et al (2000) suggested that staff responses to individual physical needs and, moreover, a concerted effort to improve physical health care, might reduce the prevalence of depression in care homes and thus enhance quality of life. Even with individuals where the recognition of depression is complicated by dementia, rapid recognition, appropriate diagnosis and treatment can result in a reduction in depression, as Payne et al (2002) found one year after people with dementia moved into a long-term care facility in the USA.

Box 8.8 Resources: depression

Advice on recognising depression with dementia and details of Best Practice Statements on depression relevant to care homes are offered in the Resources section.

Pain

The high prevalence of pain amongst older people in long-term care facilities has been described as a global public health issue (Cowan et al 2003a). While pain is an individual experience and amenable to intervention, when left unattended it can considerably reduce overall quality of life.

Older people living in care homes experience pain particularly from musculoskeletal disorders alongside the range of other health conditions common in later life, and pain can be severe. In the USA, Teno et al (2004) found that 3.7 per cent of more than two million people in nursing homes experienced daily pain that was at times excruciating. More than one in five of those with daily pain that was excruciating at times had a diagnosis of cancer. Nearly two-thirds of persons with this level of pain were no longer independent in activities of daily living. Many authors highlight the multiple and interrelated problems caused by the inadequate treatment of pain in older people and these are particularly relevant to care-home settings. Consequences include impaired mobility, decreased socialisation, anxiety, sleep disturbances, impaired posture, impaired appetite, impaired memory, depression, impaired bowel and bladder function, impaired dressing and grooming. In France, Pickering et al (2001) surveyed over 200 individuals aged from 65 to 98 to determine the effect of pain on recreational activities, especially physical activities. They found that the intensity and daily experience of pain are both obstacles to participation in physical activities, especially for the oldest residents. The findings also show that participation is linked to autonomy and quality of life.

It would appear from the literature that a significant proportion of older people do not receive adequate pain treatment, including effective interventions for chronic pain. This was reflected in a small-scale study of UK care homes (n=68) which identified a 39 per cent prevalence of chronic pain among resident older people, although 69 per cent of homes did not have a written pain management policy and 75 per cent did not use a standardised pain assessment tool (Allcock et al 2002).

Box 8.9 Resources: pain

Advice on assessing and managing pain in older people is detailed in the Resources section.

Box 8.10 Practice example: emerging service models for pain

Healthcare services in some localities include Pain Management Centres with expert multidisciplinary Chronic Pain Management Teams. These provide a comprehensive and integrated service to meet the complex needs of people living with chronic pain, helping in managing their pain and thus improving their quality of life. Such services can include consultant-led and nurse-led outpatient clinics, multidisciplinary assessment clinics, physiotherapy, clinical psychology, pharmacy advice and pain management programmes. Pain management services also commonly link with palliative care services.

The research suggests that pain assessment and management in care homes could be improved with multidisciplinary expert input and staff education. Could such input be offered to homes through local pain management teams?

In such an initiative it would be important for older people to be offered appropriate information, the opportunity to make decisions about their pain and, if appropriate, that they are facilitated to become active partners in their own pain management.

Independent pain consultancy teams are now developing in some localities. Pain Consultants Ltd provides training and advice on reducing the impact of pain in older people. Pain Consultants Ltd, Bullrush House, Twitchell Road, Great Missenden, Buckinghamshire HP16 0BQ. Tel: 01494 866997. Web: www.painconsultants.co.uk

Nutrition

In recent years under-nutrition has been reported as a widespread problem in care homes and the causes are numerous. From their literature review, Cowan et al (2003b) report that physical causes are partly attributable to body changes and disorders that occur with increasing age. Other factors include impaired vision and hearing, dementia, confusion, depression, and sensory loss (taste and/or smell). Specific illnesses or disabilities, such as stroke, Parkinson's disease and swallowing disorders also contribute to nutritional problems. There is also increased risk from drug-induced nutrient deficiency due to pre-existing nutritional status, chronic illness and polypharmacy. The effects of medication can reduce appetite or sensory awareness and compromise nutrition. Certain drugs interact with the absorption and metabolism of nutrients. There are also organisational factors: for example, if residents are not helped to eat, or if there is a lack of screening, or a failure to recognise malnutrition. Under-nutrition can contribute to physical and psychosocial problems including infection, poor wound healing, skin problems, pressure sores, apathy and depression, and mental confusion (Morrell 2003).

Information on how nutritional care in homes can be improved is now widely available in the form of nutritional standards, educational support and examples of good practice.

Box 8.11 Resources: nutrition

Advice and resources to support nutrition are detailed in the Resources section.

These include:

- Department of Health minimum standards for nutritional needs in care homes
- best practice statements on nutrition for physically frail older people
- best practice statements on oral health

- advice on dental care for older people who live in care homes, from the Relatives and Residents Association
- information, including a quality improvement checklist, to assist care homes in improving the delivery of meals, from the Commission for Social Care Inspection
- a multidisciplinary training initiative including awareness-raising sessions, a training package and workbooks
- a learning unit on optimising nutrition in care homes, devised by a multidisciplinary team at Queen Margaret University College, Edinburgh.

Box 8.12 Practice example: social mealtimes and quality of life

A recent study in the Netherlands (Nijs et al 2006) suggests that providing a convivial and social environment at mealtimes improves the quality of life and physical performance of nursing-home residents. The researchers assessed the effect of eating together (family-style mealtimes) on the quality of life of nursing-home residents without dementia. Their theory was that quality of life, physical performance and body weight would remain stable among residents offered family-style mealtimes but would decline in those receiving the usual pre-plated service.

A total of 282 residents in five Dutch nursing homes took part in the study. Each nursing home had a control ward and an intervention ward. The control wards maintained the pre-plated service, while the intervention wards introduced social family-style mealtimes. All meals were similar in weight and nutrient content. The intervention lasted for six months and results were adjusted for age, sex, and length of stay.

Family-style mealtimes improved quality of life and prevented a decline in physical performance and body weight of residents.

These results support earlier research that found family-style mealtimes improved the mood of nursing-home residents with dementia. Although this study excluded residents with dementia, the authors believe that the conclusion they drew may be extended to all nursing-home residents.

This was a simple intervention that did not need extra staff, or increase workload or costs, say the authors. With motivated staff, this programme is easy to achieve on a low budget.

(Kristel Nijs, PhD Fellow, Wageningen University, Division of Human Nutrition, Wageningen, Netherlands; email: kristel.nijs@wur.nl)

Box 8.13 Practice example: mealtimes for people with dementia

Peace and quiet have been put on the menu for dementia residents sitting down to meals at a UK care home. The St Nicholas care home in Netherton, Liverpool, is ensuring residents eat in a calm atmosphere, free of distractions, so that they can focus their attention on enjoying their meal. During mealtimes a 'Do not disturb' sign goes up outside the dining room. To preserve the social atmosphere of people coming together to have a meal, visitors to the home such as doctors and district nurses have been asked to avoid going to see residents while breakfast, lunch and tea are served. To cut the noise level, the television and radio in the room, which has a lounge area, are switched off. Staff members are allocated to serve specific residents and keep track of their needs.

Kathy Vogel, manager of the home's dementia unit, said the introduction of 'protected mealtimes' had made an 'unbelievable difference.'

Dr Graham Stokes, BUPA Care Service's head of mental health, said, 'Healthy people can be

distracted from eating if there is noise and disturbance around them. The staff at St Nicholas care home have made extra efforts to minimise distractions for residents burdened by dementia who may be particularly prone to such distraction. The result has been that residents are eating more of their meals. This simple measure illustrates how meeting the nutritional needs of care home residents is more than a matter of providing wholesome fare.'

Dr Clive Bowman, BUPA Care Services medical director, said: 'We make considerable effort to support the nutrition of our residents. This is a really sensible yet simple initiative that supports our care for residents with dementia. People with dementia can be 'on the go' burning up a lot of calories throughout the day and eating well is key to avoiding health problems caused by poor nutrition. Providing an environment that residents find conducive to eat is an important part of care. It's a practice that will be shared by other homes which provide dementia care and demonstrates BUPA's positive approach to care.'

The success of the St Nicholas scheme is being monitored by the local primary care trust, the part of the NHS which purchases care for the community. It is looking at the potential to expand the initiative.

Continence

Continence is a major issue in care homes, with approximately three-quarters of residents categorised as 'incontinent' (Bowman et al 2004, CCC 2006). Continence care urgently needs to be improved. The Royal College of Physicians' analysis (RCP 2005) of care for older people with urinary and faecal incontinence in England, Wales and Northern Ireland revealed poor access to integrated continence services, a lack of routine assessment, missing policies and documentation, inadequate staff training and a tendency to manage problems rather than seeking to cure incontinence. These findings were echoed in the results of an audit of continence care in care homes in England carried out by the RCN Continence Forum (Mangnall et al 2006).

This explored how continence problems were assessed and treated and the attitudes of care-home staff. Relevant documentation including clients' care plans was examined and the educational support available to staff working in care homes was identified. The audit identified many barriers to care-home residents accessing appropriate continence care including staff attitudes which viewed incontinence as normal in care-home residents. Documentation was generally poor and care plans did not usually reflect the assessment findings.

More positively, both audits identified 'a wealth of opportunity for improvement'. The RCP (2005) acknowledged the 'good continence knowledge' of specialist staff and Mangnall et al (2006) observed that care home staff were very keen to learn. The basic infrastructure to deliver better services now seems to be in place and there would appear to be 'enormous potential' for partnership working among care homes, local continence services and CSCI.

Box 8.14 Resources: continence

Resources to enhance continence assessment and management are detailed in the Resources section. These include:

- Department of Health national minimum standards for continence care and guidance on good practice in continence services
- the Royal College of Physicians' audit tool Continence Care in Older People
- details of a framework to assess the contextual influences on person-centred continence care.

Falls

Falls are another major issue in care homes. They reduce quality of life and can lead to death, with residents of care homes three times more likely to fall and sustain a hip fracture than older people living in their own homes. Risks can be reduced by introducing a range of

measures (Nazarko 2005, Skelton 2004). The most effective interventions include medication and nutritional reviews, environmental modification, appropriate walking aids and balance and strength exercises (NICE 2004). Exercise training can be provided by a range of practitioners including physiotherapists, chair-based exercise leaders, postural stability instructors and seniors exercise instructors. Specific guidance for care-home residents is available at: fallsprevention@health.qld.gov.au.

Various interventions to raise staff awareness in order to establish safer working practices through using a cross-profession risk assessment show early indications that prevention strategies can be used to reduce the incidence of falls (Mitchell 2004).

Box 8.15 Resources: falls prevention

Details of resources to support falls prevention are given in the Resources section. These include:

- a self-learning pack providing information on the causes and consequences of falls, maintaining a safe environment, and assessing and minimising risk
- a comprehensive guide and motivational video on preventing falls in care homes from Help the Aged
- a range of websites offering information and advice.

Box 8.16 Practice example: local falls champions and training

Local falls champions in Dorset, including nurses, occupational therapists and physiotherapists, provide on-site group training to a wide range of staff including those working in care homes. This includes information on current guidelines and evidence with experiential falls assessment package www.jackie-pool-associates.co.uk.

Medication in care homes

Medicines can make a huge difference to quality of life if they are correctly prescribed, taken and monitored. Research literature (e.g. O'Dea et al 2000, Glendinning et al 2002), recent press coverage (e.g. Burstow 2006), and recent reports (CSCI 2006b) all identify problems with medicines in care homes. The Commission for Social Care Inspection (2006b) reports that nearly half of homes (caring for an estimated 200,000 residents) are failing to meet national minimum standards for how they give people medication prescribed by their doctors to treat serious and other illnesses. The Commission highlights that people are given the wrong medication, someone else's medication, medication in the wrong doses, or no medication at all. CSCI also states that some staff members are poorly trained and records are not properly kept.

CSCI (2006b) recommends that:

- homes should review their policies and practices and monitor the workforce
- learning resources from the National Patient Safety Agency, not yet available in homes, should be actively promoted to the independent sector.
- councils should support homes through staff training and joint initiatives with primary care organisations.
- primary care organisations should acknowledge and act on their responsibilities to support healthcare provision within care homes
- new inspectorates should carefully consider how they will access pharmaceutical advice at local level.

8.5 Rehabilitation in care homes

There would appear to be considerable potential for re-enablement of residents in care homes. Indeed, Challis et al (2000) identified that many older people admitted to nursing and residential homes for long-term care have conditions which might benefit from rehabilitation. Narrow definitions of rehabilitation have tended to focus on time-limited programmes, but focusing on

optimising individual abilities and regaining lost functioning is more appropriate in long-term care settings. Research suggests that stroke survivors who enter a care home are more physically frail and cognitively impaired than those who return home and one study reported that only a third of stroke survivors resident in long-term care received treatment for secondary stroke prevention (Quilliam and Lapane 2001). A further study found that at six months after stroke, survivors resident in nursing homes were less likely to receive physiotherapy or occupational therapy compared with similarly disabled stroke survivors in hospital-based extended nursing care (Noone et al 2001). Another study identified that stroke survivors discharged to a nursing home had a significantly higher death rate in comparison with those who went home or to a rehabilitation facility (Lai et al 1999). Leeds et al (2004) found that, six months after hospital discharge, patients discharged home had a better functional improvement in activities of daily living and health-related quality of life than those in care homes. The authors question whether communication and discharge planning is of the same standard for stroke patients entering care homes as those going to their own homes. They conclude, however, that the outcomes in care homes are potentially remediable and could respond to better rehabilitative efforts and increased social support and encouragement.

Box 8.16 Practice example: the benefits of introducing rehabilitation into care homes

Care homes

- develop reputation for pro-active care resulting in potential for higher fees
- gain a marketing edge by innovative, distinctive service
- can more easily attract residents and staff through their improved reputation
- will broaden their networks and access to other resources that will influence choice and quality of care.

- exert a positive impact on staff (enlightened attitudes, goal-directed practice resulting in job satisfaction and thereby staff retention)
- have the potential to win a larger share of the market by selling a better-quality service
- experience culture change, from task-orientated care to ability-focused practice
- experience reduced complaints
- reduce risk (falls, deformity, tissue viability)
- reduce dependency.

Staff

- experience enhanced motivation as the working environment is seen as 'moving forward', thus changing job expectations
- have better understanding of importance of maintaining function and raising the potential of individual residents
- enhance their skills
- experience enhanced job satisfaction.

Residents

- experience enhanced sense of well-being
- feel that more of their needs are being met
- experience greater sense of control and autonomy
- have enhanced confidence
- experience reduced levels of depression.

Relatives

- have opportunities to assist in therapy, encourage progress and understand the potential for improvement
- feel re-assured that their relative is receiving ongoing help from appropriate 'experts' to ensure a better quality of life while living in a care home.

Ability-focused care is a more constructive approach than 'the management of decline'.

(Pentland Healthcare 2000)

Box 8.18 Practice example: homes with effective rehabilitation services

Few care homes are currently able to provide the range of in-house services described below, but these serve as examples of what can be achieved given adequate resources.

The Royal Star and Garter Home for disabled ex-service men and women is a care home for approximately 180 residents. Facilities range from residential to high-dependency nursing, with input from psychology, social work, physiotherapy, speech and language therapy and occupational therapy.

Occupational therapy offers a range of assessments and one-to-one activities which concentrate on maintaining individual optimum function, and group activities to promote physical well-being, address cognitive deficits and encourage social interaction within a meaningful lifestyle through activity. The facilities comprise a main activity room which can be used for pottery, painting, collage and handicrafts, an adjustable therapy kitchen, a workshop to develop or continue an interest in DIY or hobbies, a quiet room and a computer area.

Case example

An 80-year-old man with a short-term memory disorder was helped to enjoy a meaningful life by being offered strategies which aimed to:

- *encourage self-maintenance: verbal and written reminders were developed*
- *tap into his past occupation (train driver), working on a model train project to encourage productivity*
- *offer leisure and recreation through pottery and group activities, such as bowls and discussion groups, which also promote social interaction.*

The service aims to provide structure, strategies, stimulation, skills, support, solutions, success (sense of achievement) and satisfaction (fulfilment).

Nightingale, a care home for the Jewish community, provides in-house integrated physiotherapy and occupational therapy and rehabilitation services for 300 residents, including a specialist unit for people with dementia. There is also a thriving activities department. Nursing staff refer residents to physiotherapy and occupational therapy services for mobility; falls; pain; walking aids; hip protectors/shoes; wheelchairs, seating and pressure cushions; aids and adaptations; environment advice; cognitive/perception; personal care and activities of daily living; hand function and splints. The therapies provide a range of treatments. There is also equipment provision, preventative advice and training for staff working on the various units.

Box 8.19 Practice example: developing a case for therapy in care homes

Pentland Healthcare 1998–2001

This multidisciplinary one-stop-shop was set up when under American ownership and linked to a large care-home provider, based on American therapy provision in care homes. It included physiotherapy, occupational therapy, speech and language therapy, dietetics and podiatry. Pentland began to develop a range of bespoke integrated therapy services to care homes as a business. Due to lack of funding resources the company closed, but not before developing a range of innovative projects, demonstrating the potential benefits of rehabilitation services.

These included:

- multi-disciplinary therapy screening for care home residents
- development of a stroke unit- slow stream and fast track rehabilitation
- slow-stream rehabilitation with minimum therapy input

- in-house staff training for restorative care workers to prevent dependency and optimise function, improve quality of life outcomes for residents and promote job satisfaction for staff
- early development of step-up, step-down and in-house rehabilitation
- restorative care programmes with a lead physiotherapist or occupational therapist to develop ability-focused care by maximising individual potential and well-being of residents. This involved carrying out assessments and care planning with nursing staff, teaching, coaching, advising and supporting staff to optimise health and prevent disability where possible.
- activity training for dementia units (NHS) and care homes (social services).

Case example

An 85-year-old gentleman who had suffered a right-sided stroke five years previously had no use of his left arm and was barely able to transfer using a wheelchair. He had previously been able to walk with a quadrapod stick but had lost his confidence. He had two physiotherapy sessions per week over six weeks (with occasional maintenance sessions), working on balance, weight transference and walking re-education, and transfer practice. Outcome: he can now easily and safely transfer from bed to chair, can independently brush his teeth and throw darts standing in the activity sessions. He now has the choice to walk safely with his quadrapod from his own room to the dining room.

Case example

A physiotherapist visited a care home to give restorative care advice after Mrs F sustained a fall. Although no injury was sustained, she was limping and appeared a little more mentally confused than normal. The physiotherapist trained the staff nurse and two care assistants in daily exercise for Mrs F in her room and in her bath. On telephone follow-up two weeks later the staff nurse said there was '100 per

cent improvement'. The staff were exercising Mrs F in her bath three times a week and supervising the other exercises on other days. They reported: 'She no longer limps and is generally less rigid. Although she has her up and down days, she is doing well cognitively, exercises on her own and does not complain of pain.'

(further information from Rosemary Hurtley, former Head of Therapy and Activity Development, hurtley@btinertnet.com)

8.6 Health promotion in care homes

Particularly as they experience more chronic illnesses than any other age group, older people can benefit from health promotion. Although many care homes aim to promote health, external support for this is largely absent (Chow 2003). A barrier to effective health promotion in long-term care settings, according to McBride (2000) has been the illness-based model of care. If, alternatively, residents are considered as individuals living in their own homes, offered information and helped to deal with changes in their own health, they could become more empowered to take responsibility for this (Chow 2003). McBride (2000, p18) describes health promotion as 'the active and purposeful bringing about of necessary challenges, marshalling required resources, and carrying out whatever activities are necessary to develop, sustain and increase healthy functioning'. Such activities include nutrition and weight control, exercise, adequate sleep, stress management, safety and drug management.

Screening can also help to promote health through early identification of changes or concerns. The annual health check for people aged over 75, introduced as part of the 1990 GP contract, offers such an opportunity, although O'Dea et al's (2000) research suggested this was carried out in only one-fifth of homes. There is potential for nurses with additional training to undertake screening and health promotion.

Box 8.20 Practice example: nurse practitioner service to care homes

Nurse practitioners have advanced skills in assessment and clinical decision-making. A full-time nurse practitioner offered regular open-access clinics within 28 nursing and residential homes (overall 343 residents) for the discussion of health concerns, health education, review and management of chronic disease and screening. In addition to organised home visits, the NP responded to calls for new acute health problems from 9am to 5pm weekdays. The NP also acts as a consultant to other nursing homes for particular problems. The NP work resulted in:

- a significantly lower number of GP contacts (surgery and home visits)
- significantly reduced cost of GP contacts
- reduced contacts with the district nurse, which tended to reflect an established pattern of visits (e.g. dressing chronic wounds).

The mortality rate was slightly lower in the study group than the control group. Twice as many patients in the study group felt that their health was better than it had been the year before.

The service also facilitated the identification of skin conditions, infections, falls etc. and allowed education and information to be targeted to the needs of the home staff.

If NP costs are included with primary care costs, the increased expense amounted to just under £2 per week per resident but, when overall costs are considered, the study implies that the increased cost of the NP service is offset by lower costs of other healthcare services.

(Soline Jeram, Consultant Nurse, Older People and Intermediate Care, Windsor Ascot and Maidenhead PCT)

Health can also be promoted through physical activity and there is strong evidence for the effectiveness of this in maintaining muscle strength and mobility, even in advanced age (e.g. a systematic review in Sweden by Rydwick et al (2004). Most homes would appear to provide exercise classes for residents. Barodawala et al (2001) found that nearly two-thirds of the homes provided exercise classes at least once a week and this increased to three-quarters in those homes with a private physiotherapist. In 32 per cent of the homes the staff had attended organised training sessions on rehabilitation during the preceding year.

Box 8.21 Resources: health promotion through activity

Resources described in the Resources section include:

- best practice statements on physical activity for dependent older people
- training programmes for health and care workers from the British Heart Foundation, which offers a range of learning materials and a supportive learning network.

Learning can also be a means of sustaining health, as well as providing novelty, interest and enjoyment. The Fourth Age Learning Report (NIACE 2000) suggests inter-agency collaboration and the need for further study into the impact of learning in health, and the wider social and community involvement of older people in the 4th age. Evidence suggests that there is no loss of brain capacity to learn, but rather that the brain's functions may 'get rusty' with disuse, especially as 'crystallised' intelligence (acquisition of specific skills and information, problem-solving and the ability to make judgements) continues to grow. Evidence also suggests that many older people wish to learn new things to keep their brains active.

The Dark House Venture Discovery Awards have been used in care homes to encourage older learners to try something new, and many

acknowledge activities as new learning (Brown 2005). Belonging to a group can be seen as both a motive and an outcome. Learning can help to improve health and reduce dependency (Dench and Regan 2000) and it also has the potential to empower older people (Brown 2005).

8.7 Summary

- Older people living in UK care homes have substantial and complex healthcare needs.
- Despite this, the evidence shows that these individuals are not receiving the healthcare services that are their right, and some are paying for services that should be provided under the NHS. Particular difficulties are experienced in accessing specialist old-age physicians and therapy services.
- The literature identifies a number of health issues where improving services must be a priority. These include mental health, depression, dementia, pain, nutrition, falls, continence and medication.
- 'Restorative' services to support rehabilitation and re-enablement in care homes are particularly sparse but there appears to be enormous potential for care-home residents to benefit from such input.
- Health can be promoted through spending time in personally meaningful and enjoyable ways, socialising and sharing, physical activity/exercise, and learning.
- Healthcare services for older people living in care homes ideally incorporate multidisciplinary, multi-agency specialist teams. Many localities are developing such services and this chapter has offered a range of examples.

8.8 Conclusions

This review of the literature has clearly identified that older people living in care homes have substantial healthcare needs, yet mainstream NHS multi-professional services are not universally

available to care-home residents, and are not always offered free of charge. This situation runs contrary to the stated intentions of national policies such as the NSF for Older People in England (DH 2001c, p16), the leading standard of which states that 'NHS Services will be provided, regardless of age, on the basis of clinical need alone'. It also raises issues of both access and equity. The additional workload for GPs covering large care homes or a number of homes within one locality needs to be acknowledged but, rather than allowing costs for GP, therapy, podiatry and other services to fall on residents, and particularly those who are self-funding, there are strong arguments for NHS services to reimburse homes for these extra costs.

GPs have found ways to maximise their input to care homes: for example, by giving advice on the telephone, sending practice nurses to 'triage' residents in order to determine whom the GP needs to see, assessing other patients when called to the home to see a particular patient, and running regular surgeries in the homes. Important in the efficiency of such services is that medical and care notes are available in the same location as the resident (Jacobs 2003).

Glendinning et al (2002) suggest two urgent priorities for primary care organisations: first, that their responsibilities for developing systems of clinical governance must extend to cover the range of services provided by GPs to residential and nursing homes; second, that these organisations urgently need to review the numbers of homes making payments to GPs and practices. These authors argue that primary care organisations' budgetary flexibilities enable them to make appropriate reimbursement arrangements for the additional care involved. Therefore, a system of remuneration from PCOs could provide a mechanism for improving the standards of medical care throughout the care-home sector without compromising patient choice. Bright and Clarke (2006) raise the issue of the legitimacy of residents paying for private physiotherapy or chiropody (necessary due to the absence of adequate NHS provision) which they suggest should be covered by a standard fee rate for each individual agreed at the outset.

Currently these services are not included in social service commissioning.

There are shortfalls in the availability of NHS services, particularly therapy services, to many homes (Jacobs and Rummary 2002). In some areas there appears to be such a shortfall in the capacity of NHS rehabilitation services that their extension to nursing homes may be unrealistic. There could, however, be potential to enhance professional rehabilitative input to care homes through the intermediate care agenda. In England, the NSF for Older People (DH 2001c) prioritises reinvestment in intermediate care services and builds on the expectation in the NHS Plan (DH 2000) that residential and nursing homes will play a major role in their development. Rehabilitation schemes have been developed in care homes; mainly the larger homes with appropriate rehabilitation facilities.

In 'a comprehensive survey of care home rehabilitation' Ward et al (2004) found that, although schemes primarily offered day rehabilitation to people outside the home, some also offered rehabilitation to permanent residents. These authors conclude that the use of care-home environments for rehabilitation could become an integral component of older people's rehabilitation provision. Another option would be for the NHS to develop community outreach rehabilitation teams that could support older people in care homes as well as in their own homes (Heseltine 2001).

Local initiatives are beginning to develop expertise among primary health professionals to specialise in the care of older people, supported by advice from geriatricians, psychogeriatricians, therapists and pharmacists. New nursing roles are also emerging and the Older People Specialist Nurses or Nurse Practitioners (described in boxes 8.3, 8.4 and 8.20) offer examples.

Overall, there would appear to be enormous potential for developing new roles and new ways of work in order to offer a range of multi-professional healthcare services to care homes. Such services could prove to be cost-effective. They could contribute significantly to helping

older people to maintain their health, functioning, potential for enjoyment and, ultimately, their quality of life.

8.9 Recommendations

It would seem to be timely for government, primary care organisations and older people's representative bodies to debate how funding for services into care homes is organised in order to ensure that the NHS funds the services which are its obligation to provide. This would reduce the pressure for older people to be charged for services they should rightly receive under the NHS.

Primary care organisations should review their provision in order to ensure that residents have access under the NHS to all services including general practitioner, specialist medical, specialist nursing, physiotherapy, occupational therapy, speech and language therapy, chiropody, all screening services and regular medication reviews.

Localities should strive to re-establish multidisciplinary and multi-agency healthcare support for older people in long-term care. This chapter has offered examples of such services and the new roles that are developing within these (boxes 8.3, 8.4, 8.19, 8.21). The document produced by the taskforce of the Royal College of Physicians, Royal College of Nursing and British Geriatrics Society in 2000 is also worth revisiting. It offers a range of suggestions and priorities for developing multidisciplinary services in care homes and includes details of the cost implications.

There would appear to be the potential to enhance rehabilitative input to care homes through developing intermediate care initiatives and examples of rehabilitation services are offered in the chapter (boxes 8.16, 8.17 and 8.18).

This literature review has identified a broad range of resources which could support and enhance healthcare in care homes, particularly the best practice statements, many of which were piloted in long-term care settings. Managers and staff should be encouraged to access and utilise these.

Box 8.22 Practice example: a multidisciplinary support team improving the health and well-being of people resident in nursing homes

In the Flintshire Local Health Group Multidisciplinary Support Team Project, each nursing-home resident has an initial comprehensive medical assessment by their registered GP and subsequent regular follow-up reviews at six weeks, six months and yearly. These provide an opportunity to offer proactive treatment and address any change in the health of the service user.

Medical records, including copies of clinical test results, are kept in the nursing home. At the initial assessment, a local health group pharmacist performs a full review of the medication regimen and can request blood tests for monitoring long-term therapies. Key benefits of the pharmacist involvement include increased communication between the GP, nursing home staff and dispensing chemist. This helps to prevent drug-related problems and unnecessary hospital admissions.

The physiotherapist is able to assess clients and ensure the provision of appropriate mobility aids. Clients ideally receive ongoing physiotherapy to ensure the best outcome. Education of staff, e.g. in promoting walking to the dining room, is highlighted as important.

The occupational therapist identifies specialised equipment needs and offers advice to promote independence.

The project also highlights training issues for the nursing staff, particularly in continence promotion, tissue viability and medicine management.

Although the primary concern of the project was to improve the health and well-being of residents, there were financial benefits. The total cost of the project including GP, pharmacist and nurse co-ordinator time, based on a pilot of 50 clients, was £10,545. A total

saving of £2,720 was made as a result of medication reviews.

Within its remit to prevent avoidable hospital admissions, the project linked closely to the local Rapid Response and Rehabilitation team. As a result of the project there was a 31 per cent reduction in admissions to secondary care over a nine-month period in one of the nursing homes, with a possible saving of over £33,000 in acute hospital care as a result of 165 bed days saved.

The project clearly demonstrated the benefits of improved multi-professional working for the health and well-being of people resident in nursing homes.

Similar projects have been piloted in other areas.

(Linda Green, www.jcn.co.uk, accessed 4 October 2005)

9 End-of-life care

Caroline Nicholson

9.1 Introduction

The provision of high-quality end-of-life-care for people living in care homes is both a necessity and a challenge. Currently 21 per cent of all deaths in people over 65 years in the UK occur in care homes, a figure set to rise (Froggatt 2004, SCIE 2004). Since 2000 there has been a burgeoning of research into death and dying in care homes, both within and outside the UK: Parker-Oliver et al (2004) review the evidence within nursing homes in the USA. Two British-edited collections now exist (Katz and Peace 2003, Hockley and Clark 2002), as well as reports and reviews of end-of-life-care for older adults in care homes (Froggatt 2004, SCIE 2004, Samson and Katz 2005). Published work also explores end-of-life care policy and practice for older people in all settings (Seymour et al 2005).

Due to the developing body of literature most of the research is, appropriately, either exploratory, that is, seeking to research the quality and nature of dying in residential homes (notably Froggatt 2001; Katz and Peace 2003; Komaromy 2003) or developmental, i.e. identifying and describing possible 'interventions' (Saysell and Routley 2004; Hockley et al 2005). Most literature on interventions addresses the development of service provision rather than direct resident-focused work.

Various definitions are relevant to care at the end of life (see box 9.1). Although these terms have been developed by organisations and working groups, there is no internationally or nationally agreed definition of terms (Froggatt 2004, p7). This ambiguity has the potential to create flexibility in care provision but also difficulties (Froggatt and Payne 2006).

The literature reviewed for this chapter is organised thematically, following the sequence of events faced by residents dying in a care home. It is noted that the multiplicity of loss (Holman et al 2004) and the complexity of dying are continuous processes that do not easily lend themselves to one phase of care, model of practice or set of recommendations. Hence, much of the literature presented in earlier chapters will illuminate and add to quality in end-of-life care in care homes.

Box 9.1 Definitions

Palliative care

'The active, holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.'

(National Institute for Clinical Excellence 2004)

End-of-life care

This term originates from North America and has been used particularly in the context of care for older people although its sense is not dissimilar to that of palliative care.

'End-of-life-care for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual beliefs and practices and encompasses support for families and friends up to and including the period of bereavement.'

(Fisher et al 2000, p9)

Terminal care

This is usually associated with the last few days or hours of life, and based upon the knowledge that the individual is dying.

Caution Care needs to be taken with the use of 'end-of-life care'. In Australia the phrase 'end-of-life care' is taken to mean the last few days of life, or terminal care.

This chapter is divided into four sections:

- Living and dying in care homes
- Preparing for dying

- Managing the last days of life and support following a death
- Particular challenges: specific groups and wider issues.

9.2 Living and dying in care homes

Within the literature there is considerable emphasis on the complexity of how residents face their last years. Yet understanding how to work with this dwindling trajectory (Lynn and Adamson 2003), has been difficult to extract from the literature. The subsections below go some way to explore such a process, namely:

- integrating living and dying in care homes;
- encouraging an open and supportive approach to end-of-life care;
- working with continuing loss.

Integrating living and dying in care homes

The slow-dwindling trajectory experienced by a majority of older people in long-term facilities is identified in a range of literature (Lyn and Adamson 2003, Katz and Peace 2003; Froggatt et al 2004, Seymour et al 2005, Davies and Seymour 2002). Underpinning this trajectory is the concept of frailty. Frailty is often used to describe the unstable state created by the combination of deficits or conditions that arise with increasing age (Nourhashemi in Coleman and O'Hanlon 2004, p154). Markle-Reid and Browne (2003) note there are no clear conceptual guidelines for establishing criteria to describe older adults as frail and question the notion that frailty is synonymous with those living in the fourth age. Frailty is multidimensional, resulting from the complex interplay of physical, psychological, social and environmental factors. Some work has sought to explore how this 'vulnerable state' may be worked with in care homes (Coleman and O'Hanlon 2004, Mitty 2004); however, little work examines the interface with end-of-life care.

The nature of multiple, often chronic, health problems, experienced by many older people over a period of time, make defining the point of

dying a difficult task (Froggatt 2001, Henwood 2001). The uncertainty concerning when an older resident is actually dying can lead to depersonalised, reactive and inadequate care (Sidell and Komaromy 2003, Kristjanson et al 2005). Current care-home literature emphasises normalising dying while maximising life in care homes (Nolan et al 2003). Much debate is needed to determine how this might be achieved, in particular the appropriate role of palliative care (Kristjanson et al 2005, Duggleby 2005, Katz and Peace 2003). There is consensus on developing a culture of care which values equally the dying and the living of older people.

Encouraging an open and supportive approach to end-of-life care

The majority of older people facing the end of life appear naturally to come to terms with their mortality. Fisher et al (2000) state that this awareness prompts a process whereby anxiety is reduced and there is an increasing acceptance of death. Such a process involves:

- an awareness that time is limited, with an increased preoccupation with identity – a focus on the past rather than the future
- a desire for the last chapter of life to be good
- a need for control over the end of life (Fisher et al 2000, p19).

Promoting end-of-life care in care homes requires an awareness and openness to such a process.

Encouraging and facilitating an open approach to the awareness of dying is a key theme within the care-home literature (Katz 2003b, Nolan et al 2003, Froggatt 2001) and in policy, e.g. the National Service Framework for Older People (DH 2001) (see Resources section in this report). However, the care-home culture does not always facilitate such a discussion on the awareness of residents' needs as they face the end of their life and the impact of a resident's death on other residents in the nursing home (Sidell and Komaromy, 2003). It is increasingly acknowledged that a person-centred approach, based on the individual needs of all those living

in a care home, is pivotal in the delivery of high-quality end-of-life care (Seymour and Hanson 2001, Nolan et al 2003). The growing literature describing relationship- and person-centred care in working with older people provides practical approaches for enhancing personhood and dignity and may provide a base for encouraging a greater open awareness of dying.

Box 9.2 Example of a greater openness towards death and dying in the nursing home following an action research study to develop nursing home staff's knowledge of palliative and end-of-life care

Yes, and instead of shutting people away – especially in the dementia unit, we used to put them in the sitting room with somebody standing outside the glass door that they couldn't leave – I don't do that at all now... we prepare them... and say, "So-and-so died and they're going away shortly".'

Evaluation interview with key champion-nurse
(Hockley et al 2005, p141)

Working with continuing loss

The experience and effect of accumulated losses for older people and staff in care homes receives little attention within the literature. Despite the rhetoric of end-of-life care most literature focuses on the defined terminal phase. It is often the accumulation of losses that become significant for a resident (Lloyd and Cameron 2005), staff and families (Holman and Jackson 2001). This has been termed living bereavement (Katz 2003a). Holman and Jackson (2001) highlight the continuing losses identified by staff that occur in a continuing care unit. These losses include the actual and anticipated death of a resident, changes in residents' health and independence, home and being part of the wider community, and altered intimacy in relationships and living circumstances.

Box 9.3 Case notes of Jack living in a care home: recognising and supporting living bereavement

Visited by his sister this afternoon. Sadly, their sister passed away unexpectedly yesterday. Apparently Jack was very close to her and will be absolutely devastated. We will support him as much as possible. Given a tray of tea to have with his family.

(Katz and Peace 2003, p137)

Working with loss requires a systemic approach whereby staff involved in this work are supported and valued (Ashburner et al 2004). Clinical supervision and support of the managerial leadership are important considerations in shaping care-home culture and thus in sustaining open awareness to dying within the living/dying continuum.

Summary from the literature:

- the importance of management in knowing the significance and consequence of losses for residents, family and staff (Holman et al 2004, Froggatt 2004, Moyle et al 2002, Lloyd and Cameron 2005)
- facilitating discussion of and documenting biographical approaches to care (Davies and Seymour 2002, Ashburner et al 2004) which can inform consequences and meanings. (For further information see Chapter 4)
- communicating clearly between staff and across disciplines (Komaromy 2003)
- collaborative approaches with the family (Davies and Seymour 2002)
- supporting staff through support groups and clinical supervision (Holman and Jackson 2001, Holman et al 2004)
- managerial and leadership development and support (Ashburner et al 2004)
- supporting residents, practical responses (Komaromy 2003).

9.3 Preparing for dying

The palliative care literature on preparing older people for dying in care homes falls into:

- specific interventions to support residents' choices and preferences for end-of-life-care
- supporting and improving care delivery through:
 - (i) establishing standards of care
 - (ii) education in the general 'palliative care approach'
 - (iii) collaborating with specialist palliative care providers.

Box 9.4 Palliative care approaches

(1) 'Palliative care approach'

- Provides relief from pain and other distressing symptoms
- Affirms life and regards death as a normal process
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help patients live as actively as possible until death and to help families cope during the patient's illness and in their bereavement
- Can be applied early in the course of an illness in conjunction with other therapies intended to prolong life, including investigations to better understand and manage distressing clinical complications.

(National Council for Palliative Care 2005)

(2) Specialist palliative care

Those who specialise in palliative care (consultants in palliative medicine, or clinical nurse specialists in palliative care – Macmillan nurses, highly trained in cancer care, are among these). Specialist palliative care is necessary for people who have unresolved symptoms or complex psychosocial issues, complex end-of-life issues, or complex

bereavement. It can be delivered in hospices, hospital at home or in care homes.

(Seymour et al 2005)

Choices and preferences for end-of-life care

The literature on preparing for dying mainly considers decision-making tools for individuals and mostly emanates from the USA (Froggatt et al 2006). Seymour et al's (2004) UK work is significant in eliciting views from older adults themselves about advance directives. Importantly, she concludes that the process of communication with older people and carers over time may be preferable to emphasising completion of advance directives. Such tools may reduce the number of inappropriate hospital admissions. Hospital transfers are known to be inevitable in some cases, and necessary due to medical needs and complications, but studies from the UK have found that such hospitalisations for dying patients may be both unnecessary and inappropriate (Katz 2004). A small number of studies have examined the hospitalisation of terminally ill residents from care homes (nursing) in the USA (Mezey et al 2002). In regions where nursing homes sought residents' wishes about transfer to hospital and end-of-life care, there were lower levels of hospitalisation, with residents preferring to die at home. Enhancing communication using advance care planning is therefore important to prevent inappropriate admission to hospital.

Useful information concerning decision-making includes the document *Making Decisions: helping people who have difficulty deciding for themselves. Planning ahead for the future* (Department for Constitutional Affairs 2003) available at <http://www.dca.gov.uk/family/mi/mibooklets/guide5.htm>. Both Help the Aged and Age Concern produce booklets relating to end-of-life care.

In the UK a number of initiatives are currently being developed in recognition of the need to improve end-of-life care. The Gold Standard Framework (Thomas 2003) (see box 9.6) is a tool that facilitates community health

professionals collaborating to assess, monitor and deliver care to people with advanced cancer. It is currently being piloted in nursing homes with older residents dying of any disease.

Box 9.5 Gold Standard Framework (GSF) in care homes

http://www.goldstandardsframework.nhs.uk/care_homes.php

The national GSF team undertook an action research study to implement and evaluate GSF within the care-home setting. Phase 1 of the pilot implemented the principles of GSF within 12 care homes nationally in 2004. A report was developed from phase 1, evaluating the process and making recommendations for future development of GSF in care homes. Phase 2 commenced in June 2005 with approximately 100 care homes (nursing) nationally, implementing GSF through an action research and evaluation process with the national GSF team and Birmingham University. A 'good practice guide' was to be developed at the end of phase 2.

The preferred-place-of-care initiative (Storey et al 2003) (see box 9.6) is a patient-held record that indicates personal preferences concerning place of care and death. It is currently being adapted to support care decisions made by residents in care homes.

Box 9.6 Preferred place of care (PPC): a nationally recognised tool for palliative care

The PPC originated in response to the NHS Cancer Plan (2000) and was originally designed as a measurement tool to evaluate the effectiveness of palliative care education for community nurses. The tool has been identified as helping professionals to record patients' wishes with respect to their place of care and death (<http://eolc.cbcl.co.uk/eolc>).

Although both the GSF and the PPC initiatives have received support from government and clinicians, the evidence underpinning these tools is not clear and their effectiveness in care homes is yet to be fully demonstrated. It is not clear how these initiatives will translate to a non-cancer setting. The culture of care homes is complex and merely introducing these tools into the system may create more tension and burden for staff who already feel undervalued and threatened by the increasing, often critical gaze of those from outside the care-home setting.

Practical advice for staff working in residential homes regarding the facilitation of discussion around end of life is available (Sander and Russell 2001).

Box 9.7 Practice example: a possible approach to facilitating discussion on a resident's end-of-life preferences

Once your resident has settled in, find an opportunity to open the conversation.

The greatest difficulty is knowing what words to use, so try working out your opening sentence in advance. This will give you more confidence, but if something comes naturally once you take the plunge, then so much the better. You might try something like: 'We usually ask all our residents if they have any anxieties about dying when the time comes. Is this something you would like to talk about?' Your resident will then be free to say as much or as little as they like.

You might also like to consider the following points.

- Record clearly that the topic has been raised so that the same question is not asked again
- Be prepared to drop the subject if your resident does not want to talk. The fact that you have mentioned the topic will make it easier for them to raise it at a later date if they wish to do so
- Record details such as preferred funeral arrangements

- Know how much of the conversation they are happy for you to disclose
- If your resident is confused or cannot communicate, it is still worth raising the issue. You may not get clear answers but you can still show that they will be supported by caring staff until the end.

(Sander and Russell 2001)

Supporting and improving service delivery

Establishing standards of care

The National Minimum Standards of Care Standard 11 in England (DH 2000, see Resources section) and the Standards in Specific Clinical Aspects of Care: Palliative Care for People who are Dying (Standing Nursing and Midwifery Advisory Committee 2001, see Resources section) embrace care-home provision. Key policy documents pertaining to standards of care have been summarised (SCIE 2004, Froggatt 2004). It is recognised that existing standards relating to care homes are vague; reference to details of end-of-life care (SCIE 2004) perhaps reflect the wider societal reluctance to face mortality. This may be less the case in Scotland where Standard 19 'Support and care in dying and death' (Scottish Executive 2005) of the Care Standards for Care Homes is now being supported by the development of Practice Statements for Care Homes, which will outline what these standards mean in practice.

Education in the palliative care approach

Education is the intervention most discussed in the literature. Research mainly clusters around ascertaining themes on which to base education and training. A number of written resources and training materials (see Resources section) have been developed since 2000. Evaluation of educational packages, although limited, indicates positive benefits in terms of staff knowledge and confidence (Katz et al 2000; Froggatt 2002, Fergus 2001). However, the long-term sustainability of these practices has yet to be fully explored. Local education initiatives, e.g. specialist nurses working alongside care staff on

specific cases (Froggatt and Houlst 2002, Hirst 2004) or district nurses working inside homes (Goodman et al 2003), may allow for a greater embedding in practice and wider cultural change.

Box 9.8 Macmillan Cancer Relief Foundations in Palliative Care: a programme of facilitated learning for care-home staff

This teaching resource, designed for staff at all levels, includes four modules: the principles of palliative care; communication; pain and symptom management; and bereavement care.

It was originally developed by Dr Jeanne Katz, Dr Moyra Sidell and Carol Komaromy, of the School of Health and Social Welfare at the Open University, following research funded by the DH into the type of palliative care training needed by care-home staff. Macmillan has developed the programme further into a self-contained education resource. Public Health Minister Melanie Johnson said: 'Research has shown that care-home staff need and want training to help them provide better end-of-life care for older people. This training pack is an excellent example of how the findings of this research have been applied in a practical way to improve services in palliative care.'

The resource has been made available through Macmillan's Professional Resources Quality Assurance Framework, including a rigorous peer review process. It enables care homes to address standard 11 of the National Minimum Standards for Care Homes for Older People.

*(Macmillan Resources
www.macmillan.org.uk/news)*

Collaborating with specialist palliative care providers

The absence of standards regarding the timing of, and access to, the provision of specialist palliative care to terminally ill patients is

discussed in the literature (Parker and McLeod 2002). The National Council for Palliative Care (2005) has produced a focus on care homes and identifies proposed actions for care homes, primary care trusts and strategic health authorities to improve collaboration in care. Examples of specific initiatives include:

- establishment of a specialist palliative care unit within a care home (Saysell and Routley 2004; Husebo et al 2004). Although small-scale, indications are that this intervention benefited both residents in the unit and residents in other parts of the nursing home
- linking Clinical Nurse Specialists with care homes to provide consultation in relation to difficult symptom management, support and facilitation of awareness around death and dying. There is little evaluation of the efficacy of this approach, although developmental work continues
- the Nursing Home Palliative Care link group run by Cheshire Hospices Education provides educative seminars, online support and a place to link with other care home staff (<http://www.che.org.uk>).

9.4 Management of the last days of life in care homes

The management of the last days of life for residents in care homes is influenced by a number of issues: care-home culture; facilitation of the dying process; and supporting staff, other residents and families following a death:

Care-home culture

Death and dying are often hidden and denied by the culture of the home (Reed et al 2002, Sidell and Komaromy 2003, Seymour and Hanson (2001). Home ownership, ethos of the home and characteristics of residents in the home can affect the provision of appropriate palliative care (Katz 2004). Literature suggests that care homes which are predominantly focused on personal care needs rather than nursing needs may be particularly challenged when providing end-of-life-care. The care manager is pivotal in

orchestrating the overall care and necessary procedures both during and after a death. (Katz et al 2000). Support and facilitation of care managers are vital if high-quality end-of-life-care is to be provided.

Key concerns arising from the literature for care managers in supporting care in the last few days are as follows:

- understanding and awareness of own attitude to death and dying and how that may influence decisions re care
- recognising and valuing the principles of palliative care and good dying
- ability and willingness to involve outside support. What are the local support services? How does the care home get access? (Katz and Peace 2003, ch7)
- facilitating open and sensitive communication. Acceptance that death is coming, yet recognising that some residents and/or family may not want to talk openly about the dying process. Family members might be reluctant to face the forthcoming death of their relative, which can create problems for staff and resident
- facilitating a supportive environment for families who may wish to be with their dying relative in the last days of life, e.g. comfortable chairs to sit in, refreshments nearby
- recognising the importance for the dying person not to be left alone and implementation of practices to enable this: e.g., enough staff on shift if a person is dying. Gross (2000) describes the use of volunteers to sit with dying residents either alongside or in place of a family member. However, this has resource implications
- recognising the need to support other residents when someone is dying. Within the literature residents expressed a desire to have a formal recognition of the death of a fellow resident, and considered bereavement support for both fellow residents and family members to be a valuable service (Katz 2004, Komaromy 2003)

- recognising the importance of supporting staff. Often tension can arise between professional and personal in care homes where staff have often become like ‘family’. (Katz et al 2001, Moss et al 2003)

Facilitation of the dying process

The notion of a ‘good’ death as an ideal in providing quality terminal care underpins practice. Age Concern (2002) highlights 12 principles of a good death (see Resources section). However, a good death can be achieved only if staff recognise and take the necessary responsibility in managing the process of dying. Current evidence suggests practice in nursing homes can be unsystematic (SCIE 2004) and can reduce terminal care to areas of pressure and meeting hygiene needs. The literature review undertaken for this chapter suggests that the quality of death cannot be separated out from care practices given within end-of-life care (Brazil et al 2004). There is much literature on the control of specific symptoms (see, for example, Fisher et al 2000) in order for comfort to be achieved during the dying process, but this is not included here.

A recent tool – an integrated care pathway for the dying (Ellershaw and Wilkinson 2003) – has been developed by specialists in palliative care in order to guide the individualised care of a person who is dying in the generalist setting such as care homes.

Box 9.9 The Bridges initiative: ICP (integrated care pathway) for care homes

Areas of care covered by the ICP

Comfort measures plus symptom control
 Psychological/insight measures
 Religious/spiritual support
 Communication with patient/family
 Communication with Primary Health Care Team

There are five sections to the pathway:

- resident/family initial assessment
- resident/family ongoing problems/focus
- interdisciplinary communication
- variance reporting
- guidelines, including management of pain and ‘last offices’.

Grief and Bereavement booklet/leaflet

Giving bad news and communication in palliative care

How to contact specialist palliative care services

Completed every four hours or more often if required, the ICP provides a framework for planning delivering and recording care.

(Hockley et al 2005)

The advantages of integrated pathways for older people who are dying in care homes include enabling good documentation, facilitating individualised care, encouraging proactive care, and bridging the gap between hospice and nursing homes (Hockley 2002).

Evaluative work on ICPs in care homes suggests that as after implementing the ICP documentation into eight nursing-home settings over a nine-month period, along with supporting staff in end-of-life care, staff:

- were more knowledgeable about palliative care issues
- communicated better as a team
- could talk more openly about death and dying
- recognised the last days of life and took more responsibility for the care when a resident was dying (Hockley et al 2005).

However, the same study highlighted that interdisciplinary communication was problematic, illustrating the complexity and challenges in co-ordinating care in this setting (Field and Froggatt 2003).

Supporting staff, residents and family following a death

The practical issues that have to be addressed following a death can reflect and, in some cases, help alter the culture of care in a home (Komaromy 2003, Page and Komoramy 2005; Berndt 2004). Berndt (2004) describes commemorative rituals that can be introduced within a care home. Instead of 'cleaning up' as quickly as possible after a death, time is given to focus on what has occurred. As a care-home community, staff gathered round the resident's bed in order to pause and remember before continuing with their work. Such an approach mirrors developments in hospices where relevant prayers would be said or a text read out following the death of a patient.

Respecting the body of a resident who has died, and maintaining their dignity, can be achieved in a number of ways:

- placing a favourite article of the deceased over the trolley, and allowing the body to be removed through the front door of the home (Berndt 2004)
- ensuring that the news of the resident's death is communicated sensitively to staff and residents. Some homes pin a photograph on the notice board, or place a flower in a vase or have a candle with a photograph nearby (Parker and McLeod 2002: 186; Katz and Peace 2003)
- providing opportunities for the home to stop for a moment of 'quiet' in order to respect the significance of the resident's life and death: e.g. bedside prayer (Berndt 2004)
- facilitating sharing memories of the deceased, e.g. a book of remembrance
- facilitating residents and staff in their personal acts of commemoration, e.g. a wish to attend a funeral, or plant a flower in the care-home garden.

Such commemoration facilitates mourning and powerfully voices the idea that remaining residents will be remembered when they die.

Box 9.10 A resident's view of the importance of marking a death

'I know now that how you remember and take care of my neighbours is how you will remember and take care of me.'

(Berndt 2004)

Practical issues include religious and spiritual practices concerning the body and bereavement (Katz 2004) (see also Chapter 5). Support after a death is complex as staff, residents and family may have ambivalent feelings. Families may feel relief at the easing of suffering but also loss at the death and ending contact with the home. Staff may wrestle with the tension between being a professional and being 'second family' to a deceased resident (Touhy et al 2005). Staff's own spiritual and personal beliefs and attitudes affect care following a death.

Literature that looks at what may help to support staff following a death is sparse. Nursing assistants within a staff support programme in an American nursing home identified the following as supportive practices (Burack and Chichin 2001):

- providing a place for staff to talk about their feelings and exchange ideas about this
- being able to attend the resident's funeral or memorial service
- being involved in discussion about a resident's care early on in the dying process
- having an opportunity to say goodbye to the family in some way. Some wanted to express this practically: for example, by cooking a meal.

Box 9.11 Good practice: collaborative learning groups (CLGs) following the death of a resident where the ICP documentation had been used

The CLG sessions fulfilled a number of roles which included:

- allowing people time to critically reflect on the care given to the resident who had died and learn what they might have done differently
- allowing the opportunity to teach about aspects of end-of-life care as it arose during the groups
- supporting those involved in caring for a resident who had died
- reflecting on the process of completing the ICP documentation
- understanding together how the ICP documentation might be further adapted to the nursing-home context.

(Bridges Initiative 2004, p50)

9.5 Particular challenges: specific groups

Dementia is often not recognised as a 'progressive life-limiting' disease, therefore open communication and awareness of dying may be limited (Henderson 2006). Literature on end-of-life-care and dementia within the UK is growing. In Scotland, Dumfries and Galloway commissioned a report to explore the needs of people with end-stage dementia. The report, based on a two-year study with managers, staff and informal carers, notes that discussions with family about end-of-life choices and preferences were very limited and restricted to the very terminal phase (Henderson 2006). The recommendations from the report provide a useful signposting for future research in this crucial and under-researched area.

Possible research in dementia care and end-of-life-care includes:

- interventions aimed at bridging the gap between specialist care and dementia care
- exploring and understanding further the experience of carers and people with dementia at the end of life
- exploring ways to work in partnership with informal carers

- training and development in needs of dementia patients in acute hospital settings and general residential care homes.

9.6 Summary

- There is no standardisation of definitions in relation to terminal care and end-of-life care. Research focuses on terminal care while end-of-life care is a more apposite focus for care homes.
- Care homes are complex systems where people are both living and dying. The dying trajectory for individual older people is often uncertain.
- There is a need to continue to develop a culture of care which equally values older people's dying as well as their living. Relationship-based care with the emphasis on personal need and dignity can facilitate this.
- Loss is multiple and complex in nature for residents, staff and families. All three groups need support.
- End-of-life practices rooted in the palliative care approach are helpful in supporting care homes but more evaluative work needs to be undertaken.
- End-of-life interventions need to take account of the culture of care homes if there is to be achievable and sustainable change. These include leadership and management of the home; internal support structures for staff and residents and external support structures, e.g. access and availability of a GP.

9.7 Conclusions

Care homes are complex systems within which people are both living and dying. Many are also experiencing multiple losses. There is a need to develop a culture of care that values older people's dying as much as their living, through, for example, relationship-centred care, in which,

with the support of residents, relatives and staff, the emphasis is on personal need and dignity. Encouraging and facilitating an open approach to the awareness of dying is a key cultural shift not just in care homes but in wider societal attitudes to ageing. In older age, it can be difficult to predict when someone will die; so promoting good end-of-life care should be integral to quality care in care homes. Practices and interventions rooted in palliative care, and support from specialist palliative care services, are helpful. Existing standards, frameworks and tools can help support good palliative care.

It is important that staff, family and fellow residents receive continuing support following a death: for example, through opportunities to discuss their feelings and to 'say goodbye', attending the funeral or memorial service, or through remembrance events.

Resourcing palliative care depends upon the care staff being nurtured (Seymour and Hanson 2001), yet working in care homes is often poorly remunerated and seen as low-status. Blame for poor care has often been placed on care-home staff, but this review highlights the responsibility that needs to be shouldered by our wider society for the pervasive ageist attitudes that still exist. Such attitudes are revealed in much of the end-of-life literature. It would be helpful to stimulate wider debate, discussion and research on how to blend best practice in palliative care and everyday work in care homes.

9.8 Recommendations

Further research is needed to examine the sequence of deterioration at the end of life, rather than simply the 'terminal' phase, to illuminate further the dwindling trajectory. This should include examination of the differing definitions relating to end-of-life care and how these are used across local, national and international boundaries.

Further research needs to be undertaken into the complexity of care within the care home system: emotional and social as well as physical.

More participatory research working with staff in care homes to identify and build on good practice is to be encouraged.

Further work is needed to address how the 'voices' of older residents in care homes, and particularly people with dementia, can be heard.

More evaluative studies on end-of-life interventions are required.

Further research is also needed into the decision-making regarding the transfer residents to hospitals in the last days of life.

Part 3

**Enhancing quality of
life in care homes**

10 Keeping the workforce fit for purpose

Julienne Meyer

10.1 Nature of the workforce

There is little reliable information about the size and structure of the independent care home workforce and local authority estimates are not easily verifiable. According to Eborall (2005) reasons why information about the social care workforce is so limited include lack of definition (overlapping boundaries), fragmentation (social care wide-ranging in its nature), range of employers (public and private), past change (change from public sector to private), official classification (difficult to extract data), present change (rapid pace, hard to keep up), new regulation (new systems not yet producing workforce data), and reliance on data collection methods which tend to produce unrepresentative data (self-completion and self-selecting samples). To deal with these issues, Skills for Care is calling for the future registration (GSCC) of managers and other segments of the social care workforce, sharing of information from the CSCI Registrations and Inspections Database and the use of a National Minimum Data Set for Social Care (NMDS-SC).

Despite the difficulties of accessing information on the workforce, estimates suggest that 50 per cent of the social care workforce in England (2003–4) working in care homes (including nursing staff), comprise 72,000 employed by the local authority and 390,000 in the independent sector (private and voluntary). Of the 390,000 staff (including support staff) working in the independent sector an estimated 47,000 are managers and supervisors, 288,000 are care workers and 36,000 are registered nurses (Eborall 2005).

According to Eborall (2005), in residential care settings the social care workforce is predominantly female (95+ per cent), part-time working is common (50 per cent) and settings for older people tend to employ older workers. Little is known about the current vacancy and turnover rate in the independent sector, but there is wide variation, both geographically and between individual authorities, with the highest in London (17.2 per cent). The lowest-paid care workers earn similar amounts to retail sector cashiers and

check-out operators, but 50 per cent of care workers earn more than the highest paid check-out operators, reflecting the wide pay range for care workers, depending on seniority, experience, qualifications, settings and employer types.

10.2 Expected qualification

The National Minimum Standard for Care Homes for Older People 31.2 states that by 2005 the registered manager should have a qualification, at level 4 NVQ, in management and care or equivalent, or in care homes providing nursing, be a first-level registered nurse and have a relevant management qualification (DH, 2003). Furthermore, Standard 28.1 requires a minimum of 50 per cent of trained members of care staff to hold NVQ level 2 or equivalent by 2005, excluding the registered manager and/or care manager, and in care homes providing nursing, excluding those members of staff who are also registered nurses. According to the CSCI (2005) the social care workforce qualification levels of staff in care services are also increasing, although there are many services that are not meeting the 50 per cent target for staff NVQ levels.

Eyers (2003) suggests that the current NVQ system of competencies do not meet the specific needs of older people in care homes and recommends a socio-health trained workforce, who can work across the health and social care system. This new level of Older Person Worker would focus on providing person-centred care, enabling older people living in care homes to have increased autonomy in their daily lives.

However, it should not be assumed that training of care staff will directly influence quality of life for older people in care homes. Low status, low pay and the low ratio of qualified to non-qualified staff, restricting opportunities for passing on skills, are all key factors likely to have an influence on care standards (Eyers 2000).

Further, as older people in residential care become older and have more need for care, it should not be assumed that qualified staff will want to pass on their skills to unqualified workers. Coffey (2004) describes a qualitative study undertaken to explore the perceptions of

nurses and care assistants regarding the provision of formal training for care attendants employed in the care of the older person in Southern Ireland. Data were derived from the research sample nurses (n=40) and care attendants (n=40) through the use of two research instruments (focus group discussions and a questionnaire containing open-ended questions). The study identified positive attitudes towards the training for care attendants by both nurses and care attendants but also a perceived link between the provision of training and blurring of role boundaries. This blurring of boundaries may have led to some registered nurses being disinclined to pass on their knowledge and skills to non-registered workers.

Spilsbury and Meyer (2004) suggest that for many years RNs have been ambivalent towards the HCA role and their training for nursing work (Cole 1989; Reeve 1994; Rhodes 1994; Girvin 1999; Warr 2002). Drawing on findings of HCA work in a UK hospital setting, using a multi-method approach (survey, interviews, participant observations, focus groups and documents), they describe the dynamic patterns of use, misuse and non-use of the HCA as a resource to patient care. This study has clear implications for managers, both in hospital and care-home settings alike. Spilsbury and Meyer (2004) argue that the competence of HCAs to carry out nursing work needs to be reassessed and that there also needs to be ongoing monitoring and supervision of their work to maximise, and further develop, their contribution to patient care and to ensure quality standards. Given the emphasis on expected qualification and quality of care standards in care homes, qualified nurses working in care homes need to be actively involved with the professional development of the non-registered workforce. Clearly, the changing nature of the workforce needs to be closely scrutinised, through research, to ensure quality of care/life for patients and residents alike. This is particularly important given emerging evidence that it is sometimes the more skilled work (e.g. discharge planning) that is being passed down from registered nurses to the non-registered workforce (Bridges 2004).

10.3 Modernising the social care workforce

Modernising the Social Care Workforce (TOPSS 2000) was the first comprehensive national training strategy to analyse the skill needs of people working in the social care sector in England and proposed an action plan to improve both the qualification base and the quality of training over the following five years. It was a response to the Modernising Social Services White Paper (DH 1998) and to the restructuring of further education (DfEE 1999) and higher education (Dearing Report) arrangements.

The strategy was placed in a vision of:

- a fully skilled and qualified workforce to meet:
 - the performance culture
 - National Service Standards
 - individual registration with the General Social Care Council
- a national qualifications framework matched to competences and job roles and underpinned by a comprehensive map of National Occupational Standards
- career pathways promoting lifelong learning through flexible training opportunities and Accreditation of Prior Experience and Learning
- modern partnerships between service users, carers, employers and training providers to ensure all training and assessment meet the skill requirements of responsive and high-quality services
- a tripartite approach for employers, employees and government to fund the necessary training to fill the knowledge, skills and qualifications gap outlined in the strategy
- a workforce which reflects the ethnic communities and diversity of background and perspectives in society as a whole.

Key themes to the strategy included:

- improving workforce planning
 - at local, regional and national levels
 - mapping existing skills and knowledge
 - predicting skill and knowledge shortages, gaps and skill-mix issues
 - recruitment and retention strategies
 - collecting data to meet national criteria, including equal opportunities
 - promoting best practice through inspection and review activities.
- modernising quality assurance of training outcomes
 - mapping training against National Occupational and Service Standards
 - benchmarking activity, e.g. via the National Training and Development Outcomes Index and the Quality Assurance Agency
 - working closely with awarding bodies including higher education institutions.
- roles and responsibilities
 - to achieve adequate resourcing of training and development by setting national levels of employer and employee contributions; seeking to influence government investment in the education and training of social care workers, greater influence over Training Support Programme (TSP) planning and Department for Education and Employment (DfEE) funding streams.
- partnership
 - to achieve joint and joined-up services
 - with carers and users to improve training outcomes
 - to ensure employees have the knowledge and skills to work collaboratively
 - to establish funding frameworks to achieve shared goals
 - to evaluate and monitor all training.

The social care workforce is currently under review by the Department of Health and the

Department for Education and Skills. It is recognised that to ensure the ambition of dignity in care, joined-up care, and healthy ageing (Philp 2006), it is vital that the workforce is skilled, dedicated, and valued and supported to do its best. A host of challenges, including multiple competitors for a limited pool of workers, the highly gendered workforce, the care responsibilities of the care workforce, and ethnicity, indicate that a more strategic approach is required. Similar strategies have been developed in other countries (for example, see Scottish Executive 2006), but it should be noted that these strategies have been developed in the context of a paucity of research on education and training in the social care sector.

10.4 Paucity of research on education and training in the care-home sector

While the care-home workforce is largely made up of care assistants, little is known about their education and training. The Lost Potential (SCA 1992) was a three-year study funded by Help the Aged which sought to raise the profile of care assistants through collecting information on staff, their training and experiences; undertaking training events; producing materials; and promoting the potential of care staff. Part of the project involved questionnaires being completed by 750 workers across the statutory, voluntary and private sectors. Findings suggest that much of the training was not only patchy but inappropriately targeted for this largely experienced, mature and committed workforce. Recommendations included: promotion of training for care assistants at NVQ level 2 and 3; more training on managing incontinence, working with dementia (including coping with aggression), anti-social behaviour, and medications; and development of specific training programmes for care assistants working at night. Further, it was recommended that the 'professional' aspects of induction, supervision and key-working are actively promoted by employers for care assistants in all sectors. Managers were seen as having an important responsibility for staff

development and training and were encouraged to provide in-house training events, by the use of staff meetings and through planned supervision sessions. It was suggested that managers might require advice, guidance and help on professional care, the role of managers as trainers, leadership, communication and effective management, and administrative and financial management. Guidance was also thought to be needed on good rota practice and management; and the newly created independent inspection units were seen as providing a structural means of systematic monitoring of standards of care.

Over a decade on, it is interesting to reflect on what has, or has not, been achieved. Unfortunately, the paucity of research monitoring the education and training of all levels of staff in the care-home sector makes any form of more informed comment difficult.

Given that most care homes are privately owned, the responsibility for staff development within care homes has not traditionally been the concern of the public sector. More recently this has been questioned. The advent of Project 2000, which saw the wholesale shift of nurse education into university settings, along with an early emphasis in training on health and the community, saw a widening of practice placements for student nurses, including use of care homes. Quality of care in care homes became of interest to educators interested in placing students in this new learning environment, leading to various forms of collaborative working. Pressure on acute beds also led to an interest in care homes developing intermediate care services, which required staff to develop new roles and re-skill through education and training. Trends towards integration of health and social care and blurring of roles across the interface of primary and secondary care also led to a renewed interest in the care-home sector. Further, the National Minimum Standards for Care Homes for Older People (31.2 and 28.1) also put the spotlight on the education needs of care-home staff. More recently, government funded initiatives, such as non-cancer palliative care in the community, has led to NHS staff working much more closely

with private care-home staff to raise overall standards, in this example with regard to end-of-life care. A growing research and development literature is emerging from this sector, but pre-2000 it was represented as only two sub-themes (effectiveness of training, teaching nursing homes) within an overall theme: improving the care experience/managing change in care homes (Davies 2001a). Post-2000, these sub-themes can be expanded into 'strengthening of management and leadership skills', 'enriched environments for learning', 'preparing the future nursing workforce', 'effectiveness of training' and 'creative learning initiatives'. However, once again, the literature on education and training in care homes is sparse, fragmented and made up of small-scale studies, largely qualitative in nature. While a body of knowledge cannot be claimed in this area, the studies none the less raise some important issues, worthy of consideration. However, it should be noted that education is part of professional practice and studies are likely to have been reported elsewhere that are relevant to this chapter.

10.5 Strengthening management and leadership skills

According to Moiden (2002), there is a strong body of evidence to support the strengthening of management and leadership skills in nursing homes. Research by Chambers and Tyrer (2002) examined the key operational management challenges for people who own and/or manage nursing homes and suggested that well-run care homes depend crucially on the skills and leadership attributes of the managers. Their role often combines that of lead clinician, operational manager, finance manager, marketing director, and advocate for residents and staff. Chambers and Tyrer suggested that staff management is a particular challenge because of the difficult market conditions. Although this was only a small-scale study (46 interviews carried out with a range of stakeholders, including residents, relatives, home proprietors, managers, social services staff and inspectors), almost all respondents felt that a nursing-home manager should have a nursing qualification.

In conclusion, the authors suggested that a national funded development programme was needed to produce a national cadre of competent care-home managers. They argued that management training needs to go beyond the requirements laid down by the National Care Standards Commission and should be complemented by local programmes across health and social care. Although recognising that some aspects of the care-home manager role are unique, they proposed that development activity in care homes should not be isolated from the rest of health and social care services. Good management and leadership skills are key to improving practice in care homes.

10.6 Enriched environments for learning

The culture of a care home directly affects quality of life for those within it (Reed and Payton 1997). This includes not only residents but also relatives and staff (registered and non-registered workers and learners). While quality of care is not necessarily the key contributor to quality of life, it is an important aspect of enriched environments for learning. This chapter highlights the importance of relationship-centred care, both as a therapeutic intervention and positive environment for learning.

Davies (2001b, 2003) describes three types of community within care homes for older people, the controlled community, the cosmetic community, and the complete community, arguing that the 'complete community' is consistent with the most positive experiences for older people and promotes 'best care'. In the 'complete community' objectives are enablement and partnership; care is person-centred and relationship-centred; staff work as an effective team with mutual appreciation and some blurring of roles; relatives are seen as integral members of the team; interdependence is an important value; and there are close links with the local community.

Tester et al (2000) found that quality of life for frail older people in care homes depended on four key inter-related areas: sense of self, the

care environment, relationships and activities. From the perspective of staff, Hurtley (2003) found that job satisfaction and motivation in care homes was based on a belief that the nature and quality of relationships between residents, relatives, staff, and management shape the culture of care. She found that job satisfaction and motivation of nursing and care staff were affected by seven key factors (see box 10.1)

Box 10.1 What motivates and provides job satisfaction for grass-roots staff delivering care in long-term settings?

- The understanding that individual, team and organisational health is interdependent
- A listening management, asking the right questions, along with the development of a learning environment for both staff and residents is necessary for the successful delivery of person-centred care and optimal well-being for both
- Key values, roles, knowledge and skills must not be assumed to be in place but actively modelled and taught to all levels of staff
- The well-being of staff is integral to the well-being of residents, with attention to the texture of the daily experiences of both
- Releasing empowerment and creativity within the workplace can negate the effects of stress and burnout
- Person-centred practice is centred on constructive positive person work aimed at enhancing open relationships and proactive management styles
- Realistic rewards are necessary to reflect the task significance of a formal carer's role to raise self-esteem and status both within the workplace and in wider society.

(Hurtley 2003)

Relationship-centred care provides not only a means for delivering quality of life for frail older people, but also a way of helping staff to gain job satisfaction and motivation. In addition, it provides an appropriate framework to evaluate the learning environment for students.

The idea of relationship-centred care arose from the discussions of a task force in the USA in the early 1990s (Tresolni and Pew-Fetzer Task Force 1994). The argument was made that this should form the basis for curricula across the caring disciplines (including medicine). The task force provided an indicative set of knowledge and skills upon which to base a relationship-centred approach. The importance of this approach is summed up as follows:

‘The phrase “relationship-centred care” captures the importance of the interaction among people as the foundation of any therapeutic or teaching activity. Further, relationships are critical to the care provided by nearly all practitioners and a sense of satisfaction and positive outcomes for patients and practitioners. Although relationships are a prerequisite to effective care and teaching, there has been little formal acknowledgement of their importance, and few formal efforts to help students and practitioners learn to develop effective relationships in health care.’

Tresolni and Pew-Fetzer Taskforce (1994, p11)

This model was further developed by Nolan et al (2001), who proposed that six senses (security, continuity, belonging, purpose, fulfilment and significance) underpin the notion of relationship-centred care. Nolan et al (2001) suggest that enriched environments for learning can be based on the Senses Framework. See Chapter 3, table 3.1 for a summary of the senses for older people, staff and family carers.

A criticism of the Senses Framework is the suggestion that there is a seventh sense missing: that is, the ‘sense of expertise’ (Anstey 2003). Anstey applied the Senses Framework to her PhD data, which focused on the involvement of older patients and their informal carers in the assessment of their own continuing care needs. Analysis of the data revealed that nurses were not being seen to contribute to the assessment

of patients’ continuing care needs. The failure of nurses to be more forthright in the multidisciplinary team was thought to be related to a lack of sense of expertise. Whether there is a seventh sense missing, or whether a sense of expertise is subsumed elsewhere within the Senses Framework, Anstey’s work suggests that education and training of nursing staff (registered and non-registered) might need to foster a better sense of expertise when caring for older people.

This body of work represents the most substantial work to date on enriched environments, although it continues to be empirically tested. For instance, current work is focusing on the development and testing of Combined Assessment of Residential Environment (CARE) profiles for residents, relatives and staff (Faulkner et al 2006). The CARE profiles have been developed through consultation with those living, visiting and working in care homes on what constitutes quality of care. Keeping as close as possible to the words used by participants in the study, these statements have been ordered in terms of priority and used to develop questionnaires for use with residents, relatives and staff to determine quality of care. Although still being tested, these CARE profiles have been used in development projects (Meyer et al 2004) as an educational tool to prompt care-home staff to reflect on practice and to consider ways in which the learning and care environment might be improved. Other work is being undertaken on the CARE profiles to see if they can be used as an outcome measure for quality of care over time.

Finally, learning is also important for older people. Little is known about older people’s experiences of learning and education over the course of their lives. Findings from the Growing Older Programme suggest that learning in later life is perceived to have a range of positive outcomes with the simple acquisition of new knowledge being least important (Withnall and Thompson, 2003). However, in residential homes, learning schemes are new and unproven. In a report on ‘Fourth Age Learning’ published

by NIACE (National Institute of Adult Continuing Education) a number of issues were raised with regard to learning in residential homes (Soulsby, 2000). Findings were based on a literature review and small-scale questionnaire complemented by a series of visits to a broad range of agencies offering learning to older people. Findings suggest that engagement with learning and similar activities enhances quality of life, lessens dependency and improves well-being. However, it was highlighted that learning communities in the residential sector are under-developed and would benefit from joined-up thinking. The report recommended that quality-monitoring systems in care-home settings should prominently feature intellectual stimulation. They postulated that 'active and engaged residents' might bring savings in medical and care costs and suggested the need for further research in this area.

10.7 Preparing the future nursing workforce

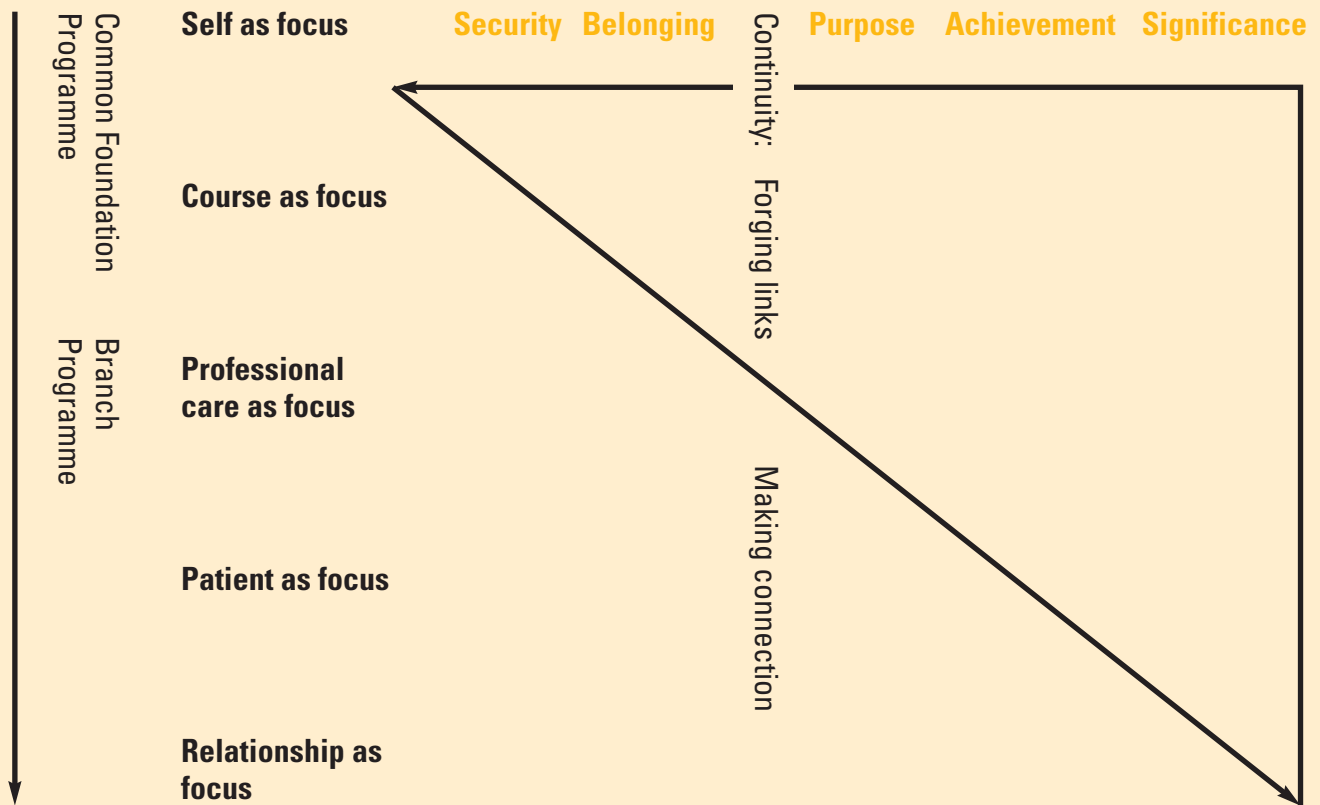
As stated previously, care homes are increasingly being used for student nurse placements. The AGEIN (Advancing Gerontological Education in Nursing) project highlighted the importance of positive clinical placement experiences (including the care-home sector) in shaping the attitudes of students towards working with older people (Nolan et al 2002). This study is significant not only in terms of its size (comprehensive synthesis of current knowledge in relation to caring for older people and their families and in-depth two-phase empirical study), longitudinal nature (3½ years), but also of its contribution to conceptual thinking in relation to enriched environments.

An emergent issue from this study was the far greater influence that the practice placement appears to have had on student learning and the subsequent desire of students to work with older people, compared with their classroom teaching. Seven case studies of positive practice placements (including one care home) were undertaken with the aim of identifying the cultural and organisational factors that positively

influenced the student experience. These factors were found to centre on the Senses Framework: security, belonging, continuity, purpose, achievement and significance. The AGEIN project has been further developed for a doctoral study (Brown 2006) and this work demonstrates that by establishing a high-quality experience for student nurses learning to care for older people it is possible to nurture positive perceptions of such work, thus making it a more attractive career option.

Brown (2006) also suggests that students have a number of different focuses (self, course, professional care, patient, and person) throughout the programme. Although these focuses are not discrete, they help to illustrate that while experiencing all the senses is important for student learning; one sense may have a greater prominence at a certain point in the programme than another (see fig. 10.1). This level of conceptual thinking provides a useful guide for teachers to assist students in their learning within the care home setting at various stages of training. At earlier stages, developing a sense of security is likely to be at the heart of student learning, given their focus on self and students' ability to meet the demands of the course. Later in their training, some will be able to develop a focus on relationships and more holistic forms of nursing and here a sense of significance is to the fore; the significance of the work, of older people, and their relationships with professional health care staff, family carers and others. This will be best achieved in enriched environments that foster relationship-centred care for residents, relatives and staff.

Figure 10.1 Influence of the senses on student focus



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However, as Brown (ibid) notes, creating an enriched environment is not serendipitous; it requires sufficient resources, solid leadership, continuity of staff, self-awareness and passion for gerontological nursing to create a care environment for older people that engenders excitement and enthusiasm in student nurses. This study provides invaluable information on the characteristics and facilitators of each of the six senses in both enriched and impoverished environments. The work could provide the basis for a new audit tool to measure the quality of the learning environment for students and staff, working in care homes. It could also be used to inform educational and practice development initiatives in care homes and developed as a guide for mentors in this setting. Finally, the study findings could inform how the CSCI inspects care homes in the future, as there are clearly essential links between the quality of the

learning environment, quality of care and quality of life.

If care homes are to be used as placements for pre-registration nursing programmes, enabling students of nursing to develop knowledge and skills in the continuing care of older people, there needs to be closer working between institutes for higher education and the care-home sector. Some excellent examples of this can be found (for example, Davies et al 2002). Davies et al worked with 40 care homes to improve student nurse placement experience. A working group was established to negotiate care-home placements for pre-registration students (see box 10.3 for terms of reference) and a strategy was produced that focused on the development of guidance notes for students and mentors (see box 10.4 for parameters for student practice and box 10.5 for selected learning opportunities). Other achievements of

the working group included identification of a designated liaison role, standardising link teacher support in nursing homes, and development of a programme of study days (see box 10.6 for summary of topics identified in the survey of learning needs and box 10.7 for suggested reasons for the success of the study day).

Box 10.3 Terms of reference for the working group – enhancing the student nurse experience

To monitor the need for care-home placements and identify and develop placements accordingly

To work closely with the inspection units to ensure that information held about the suitability of placements is correct

To provide consistent use of guidance notes in placements and develop these as necessary

To work with care homes to develop a programme of relevant study days and ensure access to post-basic education

To develop awareness in care homes of curriculum development

To promote research collaboration

To promote continuing professional development

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Box 10.4 Parameters for student practice

The mentor should be a qualified nurse

The student will negotiate off-duty hours

Students are supernumerary to normal staff requirements

Although students may participate in the delivery of care, they should not be viewed in a support worker capacity

Drug administration should take place under supervision of a qualified nurse at all times

Students should work within the university guidelines on safe practice regarding universal precautions (wearing gloves when in contact with body fluids) and moving and handling (a no-lifting policy)

Record-keeping – all student entries should be countersigned by a qualified member of staff

The student will be given the opportunity to conduct a development session for an individual or a small group of staff

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Box 10.5 Selected learning opportunities

To participate in client reviews

To work with the activity organiser to gain an understanding of the social needs of older adults

To examine the role of the inspection officer/team

To consider the establishment of staffing levels for the home

To explore the contribution of statutory health and social care services to care at the home

To develop a personal biography with a resident

To explore the perceptions and experiences of family caregivers in the care-home context

To appreciate the complexity of resource management in the care-home setting

To consider and compare funding arrangements for individual residents

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Box 10.6 Summary of topics identified in the survey of learning needs

Clinical issues

- Dementia
- Continence
- Nutrition
- Pain management
- Palliative care
- Tissue viability
- Stroke
- Diabetes
- Catheter care
- Care of stomas
- PEG feeds
- Parkinson's disease

Student issues

- Documentation
- Mentorship
- Clinical supervision
- Communication
- Curriculum

Research issues

- General research update

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Box 10.7 Suggested reasons for the success of the study day

- Staff felt valued
- Opportunity for professional update
- Opportunity to network and share ideas
- Involvement and interest demonstrated by the school of nursing

Structure of day worked well

No attendance cost for practitioners

Enhanced knowledge provides greater credibility with pre-registration students

Accessible and comfortable venue

Open not only to registered nurses but also senior carers

No limit on the number who could attend from each home

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In terms of preparing the future nursing workforce, consideration has also been given in the literature as to whether the newly qualified Project 2000 staff nurse is adequately prepared to work in the care-home sector. Runciman et al (2002) explored the views of nine senior nurse managers from nursing homes in one Scottish health board. Impressions were mixed, though generally favourable. Their perceived strengths (confidence, knowledge and questioning approach) and perceived limitations (practical and organisational skills) matched closely those of senior nurse managers in the NHS sector. Managers noted the significance to learning of the business and customer care ethos of nursing home care and of the exacting skill requirements of specialist and increasingly acute demands within this sector. They were also concerned about preceptorship and support for newly qualified nurses, identifying the availability of on-site round-the-clock experienced registered nurse cover as the preferred option for managers. The need for dialogue between sectors and with education providers was highlighted.

10.8 Effectiveness of training

The care-home sector tends to employ part-time and untrained care assistants, and while the great majority provide humane and empathetic care, inevitably the lack of training results in technical, attitudinal and coping deficiencies (Henwood 2001). The potential benefits of

training in long-term care settings for both staff and residents were indicated by Nolan and Keady (1996) following a comprehensive literature review. According to these authors, several studies indicate that after undergoing training, staff report increased competence, greater self-confidence, enhanced job satisfaction and morale and better teamwork. Others show that training regimes help to reduce the incidence of injury among staff, minimise sickness and absenteeism, and improve recruitment and retention. Several tangible benefits are also apparent for residents, such as a reduction in the use of sedation and restraint, more individualised care, and enhanced interactions between staff and residents.

Since this review, Clelland et al (2005) suggests that there is also other evidence of benefits to training care staff in homes including improved knowledge after training (Deakin and Littley 2001), assurance that care provision will be effective (Robertson et al 1999), improved practice and higher-quality care (Kenny 2002), and encouragement of problem-solving, reflection and motivation (Birnie et al 2003). These reviews provide many useful attributes that could be seen as indicators of the outcomes and effects of training programmes. In addition, Nolan and Keady (1996) suggest that the introduction of training programmes is complex and, if success is to be achieved, several systems need to be in place. Training needs to be embedded in a coherent programme of staff development and support. There is also firm evidence to suggest that training is most effective if combined with follow-up supervision 'on the job' (Stevens et al 1998). Further, a series of small-scale studies have shown that regular supervision increases creativity and personal accomplishment, decreases tedium and burnout, allows for a more positive assessment of patient's potential for rehabilitation, improves co-operation with colleagues and increases self-confidence (Brocklehurst 1997). A system of supervision for care and ancillary staff is recognised as particularly important for quality dementia practice (Kitwood, 1997). Moreover, Nolan and Keady (1996) suggest that a 'bottom-

up' approach, involving all trades and grades of staff at every stage, is more effective than a 'top-down' model. Staff must recognise the need for training, believe that it will result in change, and see benefit for themselves. This is more likely if training is related to an identified need, involves staff in the design, content and delivery of the programme, and is accorded value by management. However, in terms of identifying their own personal challenges and educational needs, caution is necessary, as nurses working in care homes tend to prioritise clinical nursing issues, such as pressure sore risk and medicine management, and indirect nursing issues, such as recruitment and retention of staff, rather than issues relating to quality of life (Morrell et al 1995). Lack of preparation for a managerial role has also been highlighted (Bartlett and Burnip 1998).

Given the above, resource constraints and difficulty of releasing staff to go off-site, creative learning initiatives delivered in the workplace appear to be the way forward. However, as will be seen, not all draw on what is already known in the literature about the effectiveness of learning in long-term settings. They are frequently one-off initiatives driven by enthusiasm and hampered by short-term funding, with little support for proper evaluation.

10.9 Creative learning initiatives

A number of creative learning initiatives have been developed for care homes which are designed to be delivered either in the workplace or as part of a community development initiative. As will be seen from the examples given below, they range from implementation of small-scale teaching packages on single topics to comprehensive educational programmes designed for all levels of staff working in a care home, in order to improve overall quality of care. Some initiatives focus on formal training requirements and lead to qualification, while others are more focused on development. All initiatives are led either by teachers and researchers in higher education or by service staff. Few are rigorously evaluated and no claim

can be made to a strong body of knowledge in this area. Interestingly, most designs have begun with what staff wanted or legislation proposed and no study could be found that focused on the older person's voice in determining the direct educational requirements for staff. The broad range of initiatives comprises a collection of unique studies that are difficult to theme more generally and hard to compare. The following are some of the better examples in practice.

Care Homes Training Collaborative

The Care Homes Training Collaborative (CHCH) commenced in January 2003 and was a two-year project funded by European Union, European Social Fund and Learning and Skills Council for London East (Meehan, 2004). The CHTC was aimed at care homes within three London boroughs where high staff turnover and a low skills base amongst staff was known to be problematic. The criteria for participating in the project were the receipt of training to either NVQ Level 2 in Care, Level 4 in Care/Registered Managers Award or the Assessors Award. Participants in the project were known as beneficiaries and were fully funded to undertake the training. The underlying principle of the project was to develop a work-based model of training and there was further funding to integrate e-based learning within this model. The team was led by a project manager and supported by three training facilitators/learning mentors, who had an allocated caseload of care homes. Forty-five care homes were recruited into the project, representing 1,259 beds. An in-depth care-home profile was carried out to identify training needs with each care home. Beneficiaries completed a diagnostic 'Skills for Life' assessment (Literacy, Numeracy and English for Speakers of Other Languages needs), together with a Personal Development Plan, an individual action plan and learning record plus a completed skills scan relating to their job role. This project was outcomes-driven (funding was dependent on beneficiaries registering for study) and this highlights the lack of research funding to systematically and comprehensively explore the impact of government education and training strategy on practice. While the project was a

success (in that it exceeded its original brief), data from the study remain unanalysed and it is not known whether beneficiaries translated their learning into practice to improve resident care or even whether they remained working in the care-home sector. Without providing evidence, the project lead claims the development of a sustainable network, improved standards of care, individual growth and development. The project lead also believed in the success of bite-sized programmes for delivering work-based learning and suggested that this was linked to the role of the education and training facilitator. Over the course of the project, 1,000 care-home staff were reported to have had meaningful contact time with the project team, all undertaken exclusively in the workplace.

Partnership with care homes project

This two-year action research project (Meyer et al 2006) was funded by the Regeneration Directorate within North East London Strategic Health Authority. The purpose of the study was to promote positive learning environments for staff and students working in care homes for older people, through workforce and practice development initiatives. Taking a Community of Practice approach, it explored the scope for shared learning and sought to foster closer working relationships and strategic partnerships between the care homes, the university and health and social care services.

The study was carried out in partnership with three care homes for older people (one independent, one NHS and one local authority) in an East London borough, with the overall aim of developing the skills and abilities of the workforce to further enable them to meet the care needs of their residents. The three participating care homes were working in partnership, together with other local health and social care resources, as a 'community of practice' to enhance learning and development and promote the integration of the care homes within their local community.

A multi-method approach to data collection was taken, including use of CARE profiles with

residents, relatives and staff (quality of life), staff profiles (training needs analysis), care-home profiles (contextual information), documentary analysis, semi-structured interviews and researcher field notes.

A number of action cycles emerged:

- to promote and support the implementation of person/relationship-centred approaches to care within the participating care homes and across the wider community of practice
- to promote teamworking within the participating care homes
- to facilitate leadership development and support for managers and deputy managers working in care homes within the community of practice.

Findings are informing the development of a number of educational tools for future use in the care-home and domiciliary sectors.

Care homes learning networks

The University of the West of England, Bristol, in partnership with local trusts, social services, local charities and TOPSS, received short-term funding from the Avon, Gloucestershire and Wiltshire Workforce Development Confederation to develop a care homes learning network (CHLN) for independent and voluntary sector care homes in the associated Strategic Health Authority (Wild et al 2005).

The aim was to improve and enhance the quality of care in care homes, develop the workforce, introduce research and support student placements. The project began with a scoping exercise (questionnaire and telephone interviews) with 29 stakeholders to explore their understanding of the term 'care homes learning network', expectations, views on relationships between independent/voluntary and public sector, sources of possible future funding, key elements for sustainability, and perceived main benefits. A facilitator worked with 13 care homes to establish learning contracts and deliver a six-month programme of topics (informed by government agendas) and delivered over two days a month. Members

were actively encouraged to follow evidence-based reflective practice and cascade their learning throughout their care homes. Key to the success of the network was a strong desire to have a 'voice in caring for older people'. This led to networking between care homes and the development of a regular regional care homes newsletter, care-home conferences/seminars, local care-home forums/groups, and increase in student nurse placements. A website (UWEonline Community Group) has been developed to allow discussion, information sharing, decision-making and access to other websites. The future of the network will be guided by the final data gathered from the completed evaluation form. Again, this initiative is driven by considerable enthusiasm, but lack of funding to resource the initiative and comprehensively evaluate its benefits should not be allowed to undermine its potential as an example of good practice. None the less, one needs to be mindful of some of the challenges in developing partnerships with the care-home sector, including poor documentation of needs, impact of bed closures, flaws in the new regulatory system, the need for new cultures of care, and lack of workforce data (Meehan et al 2002).

Allied health professional input

As stated before, there is limited published data concerning training effectiveness in care homes and even fewer regarding allied health professional (AHP) input (Clelland and McCann, 1999). Clelland et al (2005) report an interesting initiative that involved an Allied Health Professional Care Homes Training Team in the greater area of Glasgow. This study sought to elicit information and views from care-home managers and staff concerning staff training in care homes. Ten semi-structured interviews were undertaken with home management staff, which were thematically analysed. Some 648 care staff received training from the team in the ten care homes and those still working in the care homes (36 per cent) received a semi-structured postal questionnaire. The response rate was only 14 per cent, which highlights the challenge of using this type of survey method

within the sector. Findings emphasise the importance of early induction training, opportunities for career progression, tailoring training to need, benefits of training for both staff and the home, being accessible and approachable, appropriate level and content of sessions, identifying training gaps, and preference for time and place (afternoons and within the home). A number of changes were claimed to have been implemented as a result of training (see box 10.8).

Box 10.8 Changes implemented in the home, as a result of training

Impact generally

'The more training we've given the girls, the better it's been. The better the care's been... the place is starting to get a better reputation.' (9)

Impact of dietitians

'We implemented the tool and that did quite a lot for us. And we're much more nutritionally aware and we do food fortification and all that kind of thing.' (7)

Impact of speech and language therapy and dietetic training

'In relation to speech and language therapy, we now have a policy document and a leader, if you like, a nurse with a recognised responsibility to take referrals from all grades of staff, if they're having problems with a resident's dietary intake or their eating technique... It means problems with a resident's swallowing are picked up extremely quickly.' (3)

Impact of podiatry and physiotherapy

'Important that the residents wear shoes instead of slippers all day... I called the physio in, to help me do a risk assessment on a resident's bedroom... she recommended what we needed... what to do with her bedroom.' (1)

Impact of occupational therapy

'Absolutely... especially in the dementia unit, because wandering has absolutely halved... because people are being stimulated and they're being entertained, they've been involved in activities over 24 hours... and the appointment of a key worker to undertake this has really, really personalised the whole thing... the basis of our current policy came from the AHP team.' (3)

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Therapeutic activities

The National Service Framework for Older People states that older people in nursing homes should be able to choose to participate in group or one-to-one activities appropriate to their needs and interests (Department of Health 2001). The potential of older people in care homes to demonstrate the capacity for development is closely linked to the role of motivation within the provision of purposeful activity. There are strong positive correlations between both intrinsic and extrinsic motivation with levels of self-esteem, depression, life satisfaction and existential meaning in life. An activity-orientated lifestyle is a central theme in how many older people define themselves despite strong correlation between declining health and self-esteem, which includes the importance of hobbies, interests, social participation and a daily living routine. With dementia being the primary reason why so many people enter care, it is important to acknowledge the capacity for continued development within people who have dementia. (Coleman and O'Hanlon 2004). For example, life history work is considered a particularly relevant therapeutic activity to undertake with people who have dementia (Kitwood, 1997).

Mackenzie (2001) describes an action learning development programme for staff working in four nursing home units to assist staff in engaging patients with dementia in meaningful

activity. The participating staff included qualified and unqualified nursing staff working with a part-time activity co-ordinator, helping them to plan, reflect on and review learning tasks and work jointly with other staff to provide activities within the rota system. While staff gained confidence, knowledge and skills in activity planning over time, a number of lessons were learnt. First, staff found it hard to adopt new ways of working that were goal-directed, preferring to work more by instinct. Second, results were influenced by staff changes and highlighted the need for good communication. Third, individual activity plans needed to be incorporated into the residents' care plans. Fourth, in order to sustain change, all aspects of the organisation needed to be involved and attention paid to maintaining motivation and enthusiasm after the trainers had left. Finally, supervision was thought to be an important element for sustained improvement.

The College of Occupational Therapists (COT) and the National Association of Providers of Activity for Older People (NAPA) launched a partnership in 2005 to work together to make access to meaningful occupation a reality for older people. Both organisations promote courses and learning resources that share this aim and details of these are given in the Resources section at the end of this report.

Teaching packages on mental health

The National Audit Report – *Forget Me Not* (Audit Commission 1999) found that staff in care homes lack specialist skills in mental health. More recently, the first national UK survey of higher education provision related to dementia care found that educational provision for pre-registration nursing students is variable and too dependent on committed teaching staff (Pulsford, Hope and Thompson 2006). According to Furniaux and Mitchel (2004), the Alzheimer's Society believes that training is a major influence on the quality of care in care homes (Vaughan 2002), but recognises that insufficient training and experience in caring for older people with mental health problems can leave staff feeling unsupported and inadequately prepared

(Pritchard and Dewing 1999). With this in mind, Furniaux and Mitchel circulated 166 pre-teaching questionnaires (78, 47.5 per cent valid responses) to nurses and senior carers in 23 care homes in Gloucestershire requesting information on time in post, professional or vocational qualifications, training already received, ability to name measurement tools for dementia and depression, and training required. This led to the development of teaching packs on depression (assessment, causes and symptoms, treatment and management) and dementia (causes, assessment and treatment, and care planning). One hundred and thirty-seven post-teaching questionnaires were distributed following the pilot study teaching sessions (43, 31.3 per cent valid responses) to identify changes in knowledge and confidence levels of respondents in relation to caring for older people with dementia and depression. Although this study was methodologically weak (inappropriate use of unmarked scale as a response set for each question, and problems of using pre- and post- questionnaires to test knowledge), the study none the less highlights the importance of training tailored to educational need and clearly indicates the need for more mental health training for staff (only 6.4 per cent had received formal mental health education or held mental health qualifications).

AgeCare Awards programme

The AgeCare Awards programme is developing four levels or grades of awards, to cover the entire range of the sector's staff, from 'core skills' training (for care-assistants and ancillary staff), through 'supervisory' and 'specialist' levels, to a 'higher practice' grade for physicians and senior managers. The programme is fully compliant with TOPPS and CSCI requirements and courses are delivered through a series of structured workbooks, which are integrated with each home's own policies and procedures. The workbooks act as the portfolio of evidence needed to comply with NVQ requirements and, thereby, reduce substantially the administrative workload on candidates. The programme also allows for the use of alternative learning pathways, so staff with learning difficulties or

whose first language is not English can access training easily. All educational resources needed to complete the workbooks are supplied to each home as a core resource and ongoing support and advice is provided.

The programme places a very strong emphasis on quality and all of AgeCare staff are experienced nurses or care staff, as well, as qualified trainers. Their commitment and professionalism have been recognised in numerous awards, including being 'highly commended' in the 2003 National Training Awards.

AgeCare claims that its training programme enables it to provide a genuine career path for staff, helping with recruitment and retention as well as improving care for residents. It facilitates homes to establish their own in-house training capability, so that they are no longer reliant on external training providers (<http://www.agecare.org.uk/>). Researchers at the University of Sheffield are currently evaluating the implementation of the AgeCare Award programme, looking at all the training levels (and any variants and revisions of individual programmes) over three years. The evaluation comprises three evaluation activities that will focus on: (a) the training scheme as a set of linked vocational training courses; (b) the effects of the training on staff morale, commitment and satisfaction, and on care practice and resident outcomes; and (c) the costs and broader management implications of the introduction of the scheme in homes of different size and character. Intuitively, the AgeCare Award programme appears to be the most thought-through educational initiative leading to recognised qualifications for care home staff. It will be interesting to see if the evaluation confirms this.

Teaching care homes

The concept of a teaching care home originated in North America. Evaluation of teaching nursing homes in the USA indicates that the slower pace and less threatening atmosphere of the nursing home (compared with other health/care environments) facilitates effective teaching (Neil et al 1982; Mezey et al 1988). However, the

difference in traditions and culture suggest that it might be advisable to innovate rather than imitate US versions. With this in mind, the Teaching Care Home initiative in the UK was a joint enterprise from geriatric medicine, social work, and the charitable and private residential and nursing home sectors (BGS and RSAS AgeCare, 1999). It was recommended that each geographical district needs not just a single teaching care home, but a network of collaborating homes spanning the statutory, charitable and private sectors. However, it could be argued that the proposed model followed too closely a traditional medical model and withered on the branch. The idea was that there would need to be a co-ordinating centre, and in university settings this would ideally be a purpose-built home affiliated to the academic department of geriatric medicine, with multi-professional teaching and research faculty. Although it was suggested that formalised training programmes should be provided that match realistic job descriptions for all grades of care-home staff, the focus appeared to be providing greater opportunity for co-operative research and development across participating sites. While this elitist model did not take hold, the need for teaching care homes should not be ignored. Perhaps what is needed is accredited practice development units, that focus on improving quality of life in care homes for residents, relatives and staff. From what is known in the literature, such units should promote relationship-centred care and, as such, would provide the ideal environment for interprofessional learning at all levels.

In Sweden, Skog et al (2000) support the concept of teaching nursing homes. The results of a three-year participant observation study of learning dementia care in three contexts (day care, group dwelling and nursing home) demonstrated the importance of context, showing that the closer the relationship between trainee and patient, the more the patient seems to be the focus of learning, and the greater the value of practical training. This study revisits an important issue, namely, should practical learning reflect contemporary care or be an 'instrument of

reform'? (Gerdman 1989). The trainees' positive attitude towards the day-care setting (teaching ward) led the authors to suggest that the teaching nursing home 'could offer a supreme example of teamwork, minimising negative image, while strengthening the patient's position as a source of knowledge' (p156).

Learning and the fourth age

Learning is also important for older people. Little is known about older people's experiences of learning and education over the course of their lives. Findings from the Growing Older programme suggest that learning in later life is perceived to have a range of positive outcomes, with the simple acquisition of new knowledge being least important (Withnall and Thompson, 2003). However, in residential homes, learning schemes are new and unproven. In a report on 'Fourth Age Learning' published by NIACE a number of issues were raised with regard to learning in residential homes (Soulsby, 2000). Findings were based on a literature review and small-scale questionnaire complemented by a series of visits to a broad range of agencies offering learning to older people. Findings suggest that engagement with learning and similar activities enhances quality of life, lessens dependency and improves well-being. However, it was highlighted that learning communities in the residential sector are under-developed and would benefit from joined-up thinking. The report recommended that quality-monitoring systems in care-home settings should prominently feature intellectual stimulation. They postulated that 'active and engaged residents' might bring savings in medical and care costs and suggested the need for further research in this area.

10.10 Summary

- There is a paucity of reliable information about the size and structure of the independent care-home workforce.
- The changing nature of the workforce in care homes needs to be closely scrutinised

through research, in order to ensure quality of life and care for residents.

- A national training strategy for the social care workforce was issued by TOPSS in 2000 and the social care workforce is currently under review by the Department of Health and the Department for Education and Skills.
- Care assistants comprise the major workforce in care homes but little is known about the education and training they receive. There is some evidence that training enhances competence, self-confidence, job satisfaction, morale and teamwork.
- There is a strong body of evidence to support the strengthening of management and leadership skills in nursing homes.
- Care homes are increasingly being used for student nurse placements but creating an enriched environment requires sufficient resources, solid leadership, continuity of staff, self-awareness and a passion for gerontological nursing to engender excitement and enthusiasm.
- Learning is important for older people but learning schemes in care homes are new, and as yet their effectiveness is unproven.
- A range of creative learning initiatives have been developed for care homes which are designed either to be delivered in the workplace or as part of a community development initiative.
- This chapter highlights the importance of relationship-centred care, both as a therapeutic intervention in delivering quality of life for frail older people and also as a framework within which to evaluate the learning environment and help staff to gain motivation and satisfaction.

10.11 Conclusions

Research to date has been sparse, fragmented and small-scale, by nature. However, post-2000,

the emerging evidence seems to indicate the need for education and training to be relationship-centred and concerned with developing the whole of the care-home workforce on-site, as part of an overall quality improvement initiative, rather than external bite-sized educational inputs for individual personal and professional enhancement only. Registered and non-registered workers need to learn together, in order to make learning a force for change rather than a means of qualification. The importance of learning for residents must also be considered. Central to this process is the need for residents, relatives and staff to share their experiences of quality of life in care homes when living and working together. To date, research has focused too much on the perceptions of staff and policy to inform educational developments. The importance of context for learning should be noted along with the potential impact of positive placement experience on student attitudes to older people more generally. There need to be more dialogue and closer working relationships between care homes, the local community and institutions of higher and further education in order to enhance quality of life in care homes. The lost potential of care homes as a good learning environment for staff and students must be recognised, but poor investment in education and training makes teaching care homes an ideal to be strived for, rather than an immediate reality.

10.12 Recommendations

Ongoing research is needed to keep track of the education and training needs of the changing workforce in the care-home sector, along with research that shares lessons learnt from attempts to improve practice through education: for instance, action research.

Successful creative learning initiatives need to be strategically developed and supported to become part of mainstream practice.

Education and training need to be relationship-centred and concerned with developing the whole of the care-home workforce on site, as

part of overall quality improvement initiatives, rather than external bite-sized educational inputs for personal and professional enhancement only. Registered and non-registered workers need to learn together as a learning force for change, rather than a means of qualification.

The importance of learning for residents must also be considered. Central to the process is the need for residents, relatives and staff to share their experiences of quality of life in care homes when living and working together.

The potential of care homes to provide good learning environments for staff and students must be recognised and, in order to develop the necessary knowledge and skills among staff, there needs to be closer working links between local communities, institutes for higher education and the care-home sector.

Through encouraging increased financial investment, teaching care homes are an ideal for which to strive.

11 Promoting positive culture in care homes

Belinda Dewar

11.1 Introduction

A positive culture is characterised in health and social care as one where the ethos of care becomes and remains person/client-centred, evidence-based and continually effective within a changing health and social care context (Manley et al 2004).

Davies (2001a) describes three types of community within care homes for older people: the controlled community, the cosmetic community, and the complete community, arguing that the 'complete community' is consistent with the most positive experiences for older people and promotes 'best care'. In the 'complete community' objectives are enablement and partnership; person-centred and relationship-centred care; staff working as an effective team with mutual appreciation and some blurring of roles; relatives are integral members of the team; interdependence is an important value; and close links are made with the local community.

This chapter will examine the literature for evidence of some of these objectives which represent the 'complete community' in care homes. In particular it will examine staffing issues and teamwork, and their effect on resident outcomes, as well as research that has explored the impact of different interventions to foster relationship-centred care, and the impact this has had on staff and resident outcomes.

11.2 Effects of different staffing levels and skill-mix on quality of care

The availability of trained and well-motivated staff to meet the needs of residents is an important aspect of care-home culture. The issue of skill-mix is the topic of much debate in the care-home setting since recruitment and retention continue to be a major challenge. Davies' (2001b) review reported that there was a dearth of literature from the UK which considered the issue of skill-mix within the context of nursing homes and, in particular, the relationship between skill-mix and resident

outcomes. Much of the evidence at this time was inconclusive. One example from Australia (Pearson et al 1993) found that there was no relationship between the proportion of qualified nursing staff and quality of care or life for residents. However, the provision of in-service training and leadership style were found to influence quality of care.

Since 2000 there has been work which focuses on workforce and its relationship to outcomes within older people's care settings. There is a body of evidence that suggests a direct relationship between the registered nurse workforce and patient outcomes (West et al 2005).

In their review, Westwood et al (2003) found that an increase in registered nurse hours was related to a reduction in medication errors, patient falls, respiratory and urinary tract infections, skin breakdown and patient complaints. This review, however, did not specifically focus on care homes where the context of care may differ from general older people settings and make transferability of these findings difficult.

Lankshear et al (2005) found in their review that there were mixed findings regarding the relationship of registered nurses to resident outcomes in care homes. An important study by Schnelle et al (2004), which formed part of this review, was carried out in 21 nursing homes in the USA. They used 16 care measures to determine outcomes such as feeding, incontinence care, pain, and pressure sore development. They found that there was a significant difference in 13 of these measures when the nursing assistant hours were increased. This study was innovative in that it did not rely on data from extant data sources, but rather it gathered data from direct observations and interviews with residents. Using data from extant data sources, a technique often employed in examining the issue of skill-mix is problematic, as often this means that information on the two (or more) sets of measures may not be based on data that come from the same time period. In addition, data

from the extant sources may not be sensitive enough to pick up the realities of practice (Kane 2004).

Some of the findings from Schnelle et al's study did not show a positive relationship with increased staff and resident outcomes. Certain aspects of care were poorly implemented despite adequate staffing levels. Indeed Schnelle et al suggest that management practices and quality frameworks play a key role in the quality-of-care debate.

The majority of the work which looks at the relationship between staffing and quality of care in care homes has typically suggested a linear relationship e.g. as staffing increases, resident outcomes improve. However, Kane (2004, p253) argues that 'levels of staffing, expressed as bodies per resident, may not tell the whole story'.

As the profile of residents living in care homes has changed, in that older residents tend to be more frail, at the last stages of their life and often have multiple medical needs, the nature of work for staff may need to be carefully reviewed. Kane (2004) argues that there is a need to establish more clearly the specific nature of care in order that a more accurate profile of skill-mix can be determined.

The majority of the studies that have tried to assess the impact of the workforce on resident outcomes have focused on specific clinical indicators such as falls, infection rates, and incidence of pressure sores. Outcome indicators that refer to the social and emotional aspects of care have not been emphasised as key measures in these studies. Future work should explore a wider range of outcome indicators that would more accurately reflect the nature of care in these settings. In addition, we should value local knowledge which would include a clear understanding of the work that needs to be carried out and the roles and contributions of different types of workers e.g. activity staff, registered nurses, care workers, and domestic staff.

There is little guidance on what constitutes an ideal skill-mix ratio of registered to unregistered nurses (Spilsbury and Meyer 2001). Rather than

trying to come up with a numeric answer to the skill-mix debate within care homes, perhaps we need to think more in terms of key principles that would guide decision-making. The RCN is currently developing principles that could be adapted for care homes (RCN 2005).

In addition, it would be important to conduct periodic reviews of the current staffing level and mix, and measure this against workload and outcomes to ensure that skill-mix remains appropriate in the context of new policy directives and changes within the local care context.

Factors that affect team performance can include job satisfaction, levels of stress and burnout, managerial style and patterns of working. In a qualitative study about job satisfaction and motivation for staff in long-term care, Hurtley (2003) highlighted the importance of emotional health in the workplace and the interdependence of resident and staff well-being. She found that staff motivation can vary according to the type of residents, the team atmosphere and the leadership approach. Key findings included:

- a listening management, asking the right questions, along with the development of a learning environment for both staff and residents, is necessary to person-centred care and optimal well-being for both
- key values, roles, knowledge and skills must not be assumed to be in place but actively modelled and taught
- releasing empowerment and creativity within the workplace can negate the negative effects of stress and burnout
- realistic rewards are necessary to reflect task significance of the carers role.

Few studies have measured the impact that these factors have on resident outcomes. Understanding job satisfaction in care homes is essential in order that we can consider the best way forward in relation to recruitment and retention.

Redfern et al (2002) looked at the levels of work satisfaction and stress for staff and the quality of care and morale of residents. This study was a pilot, carried out in one care home, to test the applicability of various research tools. It found that job satisfaction was positively related to quality of care and that staff commitment to the nursing home is an important factor that may moderate the satisfaction-quality relationship. A larger study is recommended to test out further the relationship between work-related stress and morale of residents.

One of the problems with some of the satisfaction studies is that the majority have used survey tools. Moyle et al (2003) would argue that this approach is too narrow to use in long-term care in order to understand particular components of a job or characteristics of a worker. Moyle et al (2003) carried out a qualitative study in Australia with 27 nurses in two care homes. Key factors influencing job satisfaction included the satisfaction staff gained from resident gratification; constantly learning on the job; being an advocate for older people; collegiality and communication; and social interaction with residents. Understanding these more qualitative aspects of job performance could be important in recruitment drives.

The authors put forward recommendations that could influence recruitment and retention strategies that include:

- positive testimonials by carers to be used in recruitment marketing
- a values clarification exercise to be used during recruitment to establish congruence with the mission and values of the organisation.

They also propose a change in the attitude of employers, in order that:

- staff learning opportunities are regarded as a cost that could be recouped through staff retention
- flexibility to meet domestic requirements is provided.

In addition to the concept of job satisfaction other researchers have focused on the importance of teamwork in the care-home setting and have suggested that this may be subject to constraints different from other care settings. Wicke et al (2004) allude to this issue by questioning whether there are internal characteristics of for-profit nursing homes that make it difficult for effective teamwork to take place. They found in their study that staff were well aware of the aspects that contribute to effective teams, such as clear goals and opportunities for collaborative working, but these were difficult to realise in an organisation where there were few mechanisms for bringing about change or ensuring continuity of care. Some of the challenges to good teamworking were identified in this paper. They included part-time working, lack of team meetings, few written policies, and remote nursing management that operated in a vertical rather than horizontal structure.

There is no doubt that care-home work is physically emotionally and psychologically demanding. Several authors (James 1992; Nolan and Grant 1993) have commented on the emotional labour inherent in care-home work and have advocated approaches to teamworking that help staff in managing this aspect of their job. An example of one of the stresses of work that would come under the concept of emotional labour is the constant exposure to the more painful aspects of ageing. This may, for example, be of particular relevance for those people working with more cognitively impaired residents. Some resident attributes that staff have found difficult to cope with include aggression and hostility, stubbornness and unpredictability, and having little control over resident behaviour (Brodaty et al 2003). Resident behaviour and in particular assaults on staff were investigated in the USA by Gates et al (2002). From the 138 nursing assistants who were interviewed a shockingly significant proportion (59 per cent) reported that they were assaulted at least weekly. The nursing assistants felt that they lacked knowledge of how to decrease residents' agitation and

aggression. The extent to which people are supported to deal with emotional and psychological aspects of their job is questioned in Brodaty et al's work (2003).

It is increasingly being recognised that there is an interdependence between staff and residents (Gattuso and Bevan 2000) and that this needs to be considered when analysing factors that have an impact on moving towards a 'complete community' in care homes.

11.3 Promoting a positive culture

This section will examine some of the research that has been described in the literature that aims to promote a positive care culture in care homes.

A number of authors advocate that for successful cultural change there needs to be acknowledgement of the important part that each stakeholder plays and the interdependence of these roles (Ronch 2004, Davies et al 2003, Anderson et al 2003).

In a position paper from the world of social work, Ronch (2004) argues for a re-evaluation of the culture of institutional care. She states that 'cultural change is built by developing communities of practice where know-THAT knowledge is replaced by know-HOW knowledge' (p76). If the central focus is on tasks rather than relationships, this devalues the person providing the care as well as the resident. She states that we need to identify where staff and residents have needs in common and suggests that residents and staff have six mutual goals. These are to:

- feel safe
- feel physically comfortable
- experience a sense of control
- feel valued as a person
- experience optimal stimulation
- experience pleasure.

Ronch suggests that by looking at it in this way there is a reframing of the carer/resident

relationship, from 'doing-to' to relationship-building.

She describes three strategies that enable successful change to provide a quality service (shown in box 11.1). These were derived from previous success in the business world and have not been empirically tested in the care-home sector, so they need to be viewed with a degree of caution.

Box 11.1 Strategies that enable successful change to provide a quality service

Collaboration

Staff at all levels pooled their knowledge and created an 'inventory of solutions' which they could all draw upon

Narration

Telling stories about problems and solutions. Seen as a universal way in which to communicate principles and cultural values

Improvisation

Developing creative responses to the gaps in the real world of practice and the formal rules. These are particularly useful when devised with family members and residents who may have a different perspective.

Ronch (2004) argues that these three activities help to create a community of practice. She also advocates for 'celebrating the positive deviants' in the workplace and argues that a policy- or procedure-driven culture can have a negative effect on resident outcomes. In addition, she believes that we need to change the way we think about older people. The prevalent model in care homes focuses on chronicity which emphasises the debilitating effects of ageing and encourages care staff to take on the role of custodian. She believes that, in this approach, staff are devalued as much as the residents. She argues for adopting a lifespan development model whereby personal growth for both staff

and residents is valued and there is a shared commitment to ideas, values goals and management practices by residents, families and staff.

Aspects of this lifespan development model were evident in a study by Anderson et al (2003), who examined the relationship between management practice and resident outcomes. They introduce the idea of nursing homes in the USA as complex adaptive systems. Foote and Stanners (2002, p58) describe complex adaptive systems as 'a collection of individual agents, all of which have the freedom to act in ways that are not always totally predictable and whose actions are interconnected such that one agent's actions change the context for other agents'. These different agents/people, be they staff, residents, family members, other health professionals or policy-makers, interact with each other and are capable of spontaneous 'self-organisation'. In other words, we present particular behaviours to deal with the complex system.

The way in which we react to these complex challenges depends on three criteria:

- the rate of information flow
- the number and intensity of interactions among people; and
- the level of diversity of alternatives available for resident care.

There is a strong focus in this model on the importance of relationships, valuing different perspectives and fostering creativity, learning and innovation. The model would argue that there needs to be a different level of learning within organisations that challenges beliefs, as opposed to simply knowing facts or rules. This model is in sharp contrast to a top-down model of management.

Anderson et al (2003) hypothesise that a management practice that influences how people relate to one another will result in better resident outcomes. They identify four aspects of management behaviour that will have an impact on interactions between people in the organisation:

- open communication patterns
- participation in decision-making
- relationship-orientated leadership behaviour, and
- formalisation – the extent to which people are persuaded to abide by rules and procedures to ensure predictability and performance.

These aspects of management behaviour were measured using a range of validated tools. Data were gathered from 164 nursing homes to establish the extent to which these characteristics were evident in the organisation. The researchers then examined resident outcomes using minimum data set (MDS) data to assess whether evidence of these characteristics made a difference. The outcomes included prevalence of aggressive behaviour, restraint use, and complications of immobility and fractures.

The findings from this robust study suggest some very strong correlations between key characteristics of a culture strongly based on relationships and positive resident outcomes. Examples of this follow.

- Greater communication and openness (being able to say what you mean without fear of retribution) was related to lower use of restraints.
- Increased participation in decision-making by the registered nurses was related to lower prevalence of aggressive behaviour among residents.
- Formalisation (specifying work procedures and rules in combination with surveillance to ensure that they are followed) was higher in homes with a higher prevalence of complications and immobility.

What is interesting and innovative about this work is its specific analysis in relation to resident outcomes. The authors draw our attention to the importance of management practices as a lever for better outcomes. They argue that perhaps, previously, attempts to understand quality of life for residents in care homes have focused on analysing clinical processes, or the numbers and

skills of care providers. Anderson et al's quantitative data seem very convincing and, as a result, have great potential to influence policy. Recognising that this important study was carried out in the USA, it would seem timely to replicate this work in the UK.

There has been some work in the UK that has looked at culture and its relationship to staffing issues, as opposed to resident outcomes. In particular, Mozley et al (2004) identified three types of homes which were classified according to their 'regime type'. These are shown in box 11.2.

Box 11.2 Types of homes classified according to the type of regime

Positive

Homes which allow residents to act or choose things for themselves, show a positive approach to resident capabilities, allow residents a higher degree of freedom and choice. These homes have low conflict and high cohesion.

Mixed

Homes which have multiple regimes, allowing freedom and choice to residents but also employing regulation and control.

Restrictive

Homes which have low freedom and choice, show a narrow or restricted attitude to resident capabilities, and limit residents' freedom to think or act for themselves. These homes have high conflict and low cohesion.

Adapted from Booth's three-way classification of homes (1985, cited in Mozley et al, p112)

The data were explored for possible relationships between the homes' regime type and a number of other variables, such as job satisfaction and staff mental distress. No statistical differences were found with the majority of variables, with the exception of the restricted cultures, which had scores that indicated significantly higher work demand and

role conflict, and significantly lower job satisfaction and a climate of lower effort.

Booth's three-way classification has parallels with Davies' (2001a) three types of community. In Mozley et al's study, there was disagreement among the researchers about which category to place homes in. More work needs to be carried out to clearly identify the elements of these cultures, as identified by both Booth and Davies, if we are to understand their impact on both resident and staff outcomes.

11.4 Examples of good practice in promoting positive culture within care homes that impacts on the delivery of relationship-centred care

From the literature there are a number of American models that have recognised the importance of valuing the resident and staff in trying to promote a positive culture in care homes.

Stone et al (2002) conducted an evaluation of the Wellspring Model, which was introduced in 11 care homes in the USA in 1994. This model aims to enhance the quality of resident care and improve the working life of nursing-home staff.

Wellspring has an explicit approach to quality improvement that focuses on both clinical care and organisational culture change and has a specific set of processes for quality improvement. These processes are supported by a network of colleagues who work together to achieve shared goals, similar to the community of practice concept identified earlier by Ronch (2004). The model has six key elements, which are shown in box 11.3.

Box 11.3 Key elements of the Wellspring Model

- An alliance of nursing homes with top management committed to making quality of resident care a top priority.

- Shared services of a geriatric nurse practitioner who develops training materials and teaches two-day courses for staff from all 11 nursing homes about quality-of-care issues applying national clinical guidelines.
- Interdisciplinary 'care resource teams' that receive training in a specific area of care and are responsible for teaching other staff at their respective facilities.
- Involvement of all departments within the facility and networking among staff across facilities to share what works and what does not work on a practical level.
- Empowerment of all nursing-home staff to make decisions that affect the quality of resident care and the work environment.
- Continuous reviews by staff of quality-indicator performance data on resident outcomes and environmental factors relative to other nursing homes in the Wellspring alliance.

In their evaluation, Stone et al (2003) used both qualitative and quantitative methods and found the following:

- Rates of staff turnover declined or increased more slowly in Wellspring homes.
- Wellspring facilities performed better on annual inspections conducted by the state department of health.
- Some evidence suggests that Wellspring staff are more vigilant in assessing problems in quality and take a more proactive approach to resident care.
- Based on observation and interviews, Wellspring residents enjoyed a better quality of life and benefited from improved interaction with staff.
- No additional increases in net resources were required for the model's implementation, and Wellspring facilities generally had lower costs than other nursing homes.

Researchers and practitioners in the UK advocate a range of important variables to be in place if the provision of person-centred or relationship-centred care is to be successful. These include clinical supervision, action learning, critical incident analysis, effective appraisal systems, positive role models, and formal teaching (Davies et al 2003; Hockley et al 2005, McCormack 2001; Ashburner et al 2004).

Examples are cited below where some or all of these aspects have been incorporated into the model of change that seeks to promote a positive culture in care homes. Numerous other research and development projects have influenced thinking in this area but the discussion here focuses on those that have been carried out solely in care homes.

Davies et al (2003) conducted an action research study in a nursing home that aimed to promote a positive culture of care in a care home for people with dementia. Central to this work is the importance of the interdependence of staff, residents and their families and the need to consider all of their perspectives to reflect priorities in enhancing and improving care. The partnership project was based on the Senses Framework (see Chapter 3, table 3.1), which they argue helps to identify the important goals of care. The senses are security, continuity, belonging, purpose, achievement and significance. This framework is similar to the mutual goals identified by Ronch. The senses framework has been developed from extensive empirical work in care settings (Nolan et al 2002). Using this framework, staff and relatives worked together to identify areas of change in the care home. Activities included a relative support group, successful fundraising activities, developing a proposal for funding a part-time occupational therapist, and development of an activities programme. Outcomes for residents, relatives and staff included relatives finding it easier to approach staff, reduction in episodes of challenging behaviour, and an increase in visits by relatives to the home as a result of an enhanced sense of purpose.

In a study by Hockley et al (2005) the quality of end-of-life care was the focus of improvement in eight nursing homes in Scotland using an integrated care pathway (ICP). This project used an action research approach in order to promote collaboration between staff in nursing homes and the research team, and to empower staff in the practice so that they could develop a practice-based theory about end-of-life care that was relevant to them. The project used the following strategies to promote a culture in the care home that valued changing practice to achieve quality end-of-life care:

- the identification and support of two key champions in each home who would lead the initiative and help to enhance sustainability of the project once it had finished;
- the development of a community of practice that included researchers and practitioners, all of whom wanted to pursue the development of knowledge in relation to end-of-life care;
- the use of action learning sets for key champions in order to challenge espoused theories and theories in use;
- a values clarification exercise that set out to establish the beliefs and values of staff in relation to end-of-life care: the results of this were then formulated into an audit tool that staff could use to ascertain if they felt their organisation was meeting these goals;
- education sessions on the use of the ICP documentation to key champions and subsequently to all nursing homes;
- collaborative learning groups following a death in the nursing home for all staff;
- regular clinical support from a clinical nurse specialist (palliative care) and the study team.

Positive outcomes resulted, related to enhancing the quality of end-of-life care for residents – such as effective pain control and increased opportunities to talk about death. In addition to this, practitioners commented on their enhanced self-awareness, ability to challenge others, ability

to put together a persuasive case for change, enhanced teamwork, particularly with GPs, and opening up the nursing home culture so that talking about death and dying was not feared. As one nurse participant stated:

‘It’s a lot more relaxed and people aren’t so frightened... It’s been a really successful thing in bringing death and dying to the fore and not to be so frightened of it.’

This approach to getting evidence into practice had positive outcomes for the nursing-home culture.

Other studies that have focused on the development of person-centred/relationship-centred care in the care-home setting include Ashburner’s (2005) work. In her study the development of person-centred care in practice was built upon three main interventions: biographical interviews with service users and family members, clinical supervision for nurses and action learning for nurse managers. Baseline audit data on the quality of interactions and the quality of care were collected before and after the interventions. At the end of the study, findings showed improvements in person-centred care, the quality of nursing care provided, the quality of interpersonal interactions and the management of the home. The findings of this work identify the necessary systems of staff development (clinical supervision and action learning) required to build more enriched clinical environments in support of the delivery of person-centred care.

Staff in the UK studies cited above have been supported to develop relationship-centred care through initiatives such as action learning, collaborative action groups with staff and relatives, and clinical supervision. None of these studies has necessarily explored the challenges of building the relationships between residents, relatives and staff. It would seem that this approach could be important in addressing the potential imbalances of power that are said to exist between older people and formal carers (Killick and Allan 2001, McCormack 2001).

Dewar (2005) advocates, because of the potential power imbalance, mechanisms to

support practitioners and older people to develop skills in partnership working. Current work focuses on piloting an educational course for residents, relatives and practitioners in care homes (see box 11.4).

Box 11.4 Moving upstream together: an educational course for older people and practitioners

The aim is for older people and practitioners to work to:

- explore the culture of long-term provision for older people
- articulate the role they can play in bringing about change to improve the lives of older people in long-term care settings
- recognise the challenges to change and develop strategies for overcoming these
- the core elements of this course include exploring our beliefs and values, looking at culture, giving and receiving feedback and evaluating initiatives.

(Dewar 2006, work in progress)

11.5 Summary

- In a positive culture the ethos remains person-centred, relationship-centred, evidence-based and continually effective within a changing health and social care context.
- A 'complete community' is consistent with the most positive experiences of older people and 'best care'.
- Creating positive culture requires recognition of the complex and multidimensional nature of life and work in care homes.
- Interdependence is an important value.

- Homes should seek to promote enablement and partnership, person-centred and relationship-centred care through biographical and developmental approaches.
- Staff should seek to work as an effective team with mutual appreciation and some blurring of roles, and relatives as integral members of the team.
- Close links with the local community should be maintained.
- Effective leadership, management and the availability of expert advice are paramount in the creation and maintenance of a positive culture.

11.6 Conclusions

The evidence reviewed here suggests that the factors that help to promote a positive culture are multi-faceted. There is growing body of work that indicates that leadership and management practice can have an impact on resident outcomes. The strong message that unites these pieces of work is the interdependence of staff, residents and relatives, and any attempts to promote a positive culture within the care-home setting need to nurture these important relationships.

11.7 Recommendations

The development of cultures that support relationship-centred care is to be encouraged.

Through publications, organisations, groups and networks, existing initiatives that support the development of cultures supporting relationship-centred care should be shared and disseminated.

Research is needed in order to develop a clearer understanding of the nature of care and relationships in care homes.

The contextual influences on care in care homes should be further explored.

Workforce models relevant to care-home settings should be developed.

12 Conclusions and key best practice messages from the literature review

12.1 The care-home context

Older people's long-term care in the UK is diverse and complex, with multiple stakeholders who fund, regulate or provide a range of services. The development of care homes has been strongly influenced by the legislative distinction between healthcare and social care. Comprehensive statistics on care homes have not historically been collected but some information is now available through care-home regulatory bodies, market analysts and recent surveys. Older care-home residents are commonly aged 80 and over, with multiple and complex health and social care needs. Care-home funding is a major issue. Government funding procedures vary around the UK and some are currently under review, specifically the funding of registered nursing and continuing NHS healthcare in England. Reduced state funding alongside increasing costs has led to a growth in care-home closures and providers continue to express concern about inadequate funding.

Key influences on the future strategic development of the sector include government funding of social services, regulation, self-funding residents, public perceptions and any change in public sector provision.

If older people who live in care homes are to achieve quality of life, major issues such as state funding and workforce adequacy must be addressed.

12.2 Quality of life

Debates about quality of life may be complex but at their core each person defines quality of life for themselves as individuals. Integral to quality of life is what makes life meaningful, enjoyable and worth living. Any process seeking to enhance it therefore begins with discussion of individual ideas about quality of life, what contributes to this, ways in which it could be supported and the individual's priorities within these. For staff, this may mean suspending personal assumptions and stereotypes about what older people want, and paying attention to what they are saying.

12.3 Quality of care

Quality of care needs to be considered within the context of quality of life. Consequently the philosophies, strategies, everyday ways of working and evaluation mechanisms must be capable of encompassing a person-by-person acknowledgement of the priorities of individual service users. Evaluation of quality of care should also acknowledge that the broad range of stakeholders in care homes bring their distinct insights. New approaches to quality of care, its provision and its evaluation, are emerging, and these indicate positive routes to service provision in the future.

12.4 Transition into a care home

Moving into a care home gives rise to experiences of change, feelings of loss and assumptions about the future. This review has highlighted how a culture of communication and shared information can be created so that all stakeholders can be involved in the decision-making process. Resources are available which can assist decision-making in choice of a care home. These need to include meaningful qualitative information, such as personal testimonials, and information relating to philosophies of care. New initiatives could encourage a more proactive approach to decision-making, for example, facilitating trial visits to care homes. A new framework for good practice whereby someone comes into the care home following a crisis could be developed in order to support all stakeholders.

Key best practice messages

Recognising the effects of the transition

Moving into a care home is a major transition in life which may involve considerable losses, but with appropriate planning and support it can bring benefits and improved quality of life for both the older person and their families.

Easing the transition The transition for residents and relatives can be eased if pressure on them is minimised; if they have access to all relevant information to enable them to play a full and active role in the life of the home and,

for relatives, in the care of the older person; if they are able to work with staff; are able to maintain ownership of decisions about the future; and feel that others are aware of the consequences of the move for them and their loved ones. Information is available on how to choose a home and how to ease the transition of moving.

Care homes as a positive option Care homes as a style of both housing and care, can be a positive option, and entering a home can offer new opportunities. Initiatives that promote a proactive approach to decision-making, such as facilitating trial visits, should be encouraged.

12.5 Working to help residents maintain their identity

The starting point for helping residents to maintain their identity is getting to know individuals and their families through biographical approaches to care which, in turn, facilitate individually tailored relationship-centred care. Of equal importance is the need for managers and staff to be adequately supported to develop relationship-centred approaches to care and a recognition that delivering this, while potentially immensely rewarding, can provoke anxiety and discomfort as staff come to terms with the emotional nature of their work. More research is needed to inform the development, implementation and evaluation of initiatives aimed at preserving the identities of care-home residents. This will add to the growing evidence base for improving the overall quality of life in care homes.

Key best practice messages

The need for person-centred care

Staff should seek to learn about older individuals in the context of their whole life development (often established through a biographical approach) so that care can be tailored accordingly and residents have opportunities to integrate past and present life experiences along with their priorities for the future. This approach needs to be underpinned

by consistency in staff assignment to individual residents.

A variety of creative approaches To meet individual needs, the care home should devise a range of approaches including linking with local communities; thinking creatively about meeting communication needs; and being open to meeting particular spiritual, cultural, social and sexual needs sensitively.

Staff education and support A recognition that person-centred care can be emotionally demanding for staff and the provision of outlets for addressing anxieties and defences is important.

12.6 Creating community within care homes

It is increasingly recognised that each care home develops a distinctive culture which determines the degree to which individual expectations are met. However, the dominant culture commonly reflects a particular pattern and set of values. On the basis of the literature reviewed here it would appear that the care home as community model currently offers most promise for ensuring that the needs of all stakeholders – residents, their families and staff – are reconciled and met as fully as possible. In order for communities to be created within care homes, all stakeholders must recognise and accept the important role they have to play in contributing to these.

Key best practice messages

The importance of relationships

Communities are created through relationships between residents, family, friends, staff and the wider community. This involves understanding and respecting the significance of relationships within the home; recognising roles, rights and responsibilities; and creating opportunities for giving and receiving and also for meaningful activity.

The care-home environment The building and environment should support the community and the relationships within this, including access

Relationship-centred care is seen to be underpinned by six dimensions, developed by Mike Nolan and the team at Sheffield University as six 'senses' that acknowledge the subjective and perceptual nature of the key determinants of care for older people, families and staff:

- a sense of security
- a sense of continuity
- a sense of belonging
- a sense of purpose
- a sense of fulfillment
- a sense of significance.

Identifying what creates the 'senses' for residents, their families and staff is likely to lead to more positive experiences of care-home life.

to a choice of communal areas in close proximity to each other and staff areas as well as individual rooms where residents and their guests can enjoy complete privacy. Gardens providing safe access to fresh air, plants and wildlife can enhance quality of life.

Relationships with the local community

These are important in maintaining quality of life for residents, and links with local organisations, such as schools or voluntary groups, should be fostered. Easy access to transport, especially for relatives who are frail, is essential.

12.7 Shared decision-making

There are numerous opportunities for negotiation and shared decision-making in the minutiae of daily interactions in care homes, and the way in which the myriad of decisions are made creates the culture which ultimately determines residents' daily lifestyle and quality of life. Evidence suggests that many older people in care homes desperately want to be involved in the decisions that affect them and maximising the extent to which residents and their families are enabled and empowered to exercise choice is increasingly accepted as essential for quality

of life. Particular attention needs to be paid to residents who live with cognitive impairment or communication difficulties. This review of the literature identified a useful framework for decision-making (High and Rowles 1995). Residents and relatives should be involved in the initial assessment of the older person's needs and the proposed plan of care should be negotiated and agreed with all parties. Shared decision-making requires regular, planned reviews involving the home manager, named nurse, key-worker, resident and family members.

Key best practice messages

Involvement in decision-making In order for care homes to function as true communities in which everyone's contribution is recognised and valued, all residents (including those with cognitive impairment), their families and staff members need to have the opportunity to be involved in the decisions that affect them, to the extent that they wish to be involved. Methods for disseminating information to all members of the care-home community, such as a regular newsletter, have the potential to ensure that everyone feels involved and creates ownership of identified problems and solutions.

Decisions to influence change Feeding the views of residents and relatives into a change process should be a priority and establishing a group for residents, relatives and staff should be encouraged.

Ongoing shared decision-making through negotiation In order for quality of life to be achieved by residents in care homes, some decisions, such as the fine balance between rights and risks, will need to be continually negotiated by residents, relatives and staff.

12.8 Health and healthcare services

Older people living in care homes clearly have substantial healthcare needs, yet mainstream NHS multi-professional services are not universally available to them. In addition, some residents are being charged for services that are provided under the NHS to users in all other sectors. Primary care organisations should

develop systems to make appropriate reimbursement to homes for services which should be provided under the NHS, such as general medical services and physiotherapy. Primary care organisations should also be encouraged to develop new roles and multi-professional teams who can provide specialist expertise to older care-home residents and also ensure they have access to the full range of services available locally. Such teams could also support staff, residents and relatives in order that they develop their skills and knowledge: for example, in medication management, re-enablement strategies and health promotion. This review has highlighted a range of ways in which multi-professional support to care homes can be enhanced, and a variety of projects which demonstrate how this can be achieved.

Such initiatives contribute significantly to helping older people to maintain their health, functioning, potentials for enjoyment and, ultimately, their quality of life.

Key best practice messages

The need for health care Health is fundamental to quality of life and, without health, quality of life is unlikely to be achieved. Older people living in care homes have substantial and complex healthcare needs which require the full range of healthcare services.

Ensuring adequate healthcare services There is considerable evidence that older people in care homes are not receiving the healthcare services that are their right and some are paying for services that should be provided under the NHS. Primary care organisations should review their provision in order to ensure that residents have access under the NHS to all services including general practitioner, specialist medical, specialist nursing, physiotherapy, occupational therapy, speech and language therapy, chiropody, all screening services and regular medication reviews. Some areas have developed such services for care homes, including new roles, and there is potential to enhance professional rehabilitative input to care homes through developing intermediate care initiatives.

Health promotion Health can be promoted through spending time in personally meaningful and enjoyable ways, socialising and sharing, physical activity and exercise, and learning.

12.9 End-of-life care

There is no standardisation of definitions in relation to terminal care and end-of-life care. Research tends to focus on terminal care, while end-of-life care is a more apposite focus for care homes. Loss in care homes is multiple and complex in nature for residents, staff and families. All three groups need support. In addition, end-of-life interventions need to take account of the culture of care homes if there is to be achievable and sustainable change. End-of-life practices rooted in a palliative care approach are helpful in supporting care homes but more evaluative work needs to be done. Further research is needed into the process of dying, encompassing its emotional and social as well as physical elements, and into decisions resulting in residents being admitted to hospital during their last days of life. More evaluative studies on end-of-life interventions are also necessary, along with a broader debate on how to blend palliative care and care home practices.

Key best practice messages

Valuing living and dying Care homes are complex systems where people are both living and dying. Many are also experiencing multiple losses. There is a need to develop a culture of care which equally values older people's dying as well as their living, such as through relationship-centred care, with the emphasis on personal need and dignity, through which residents, relatives and staff are supported. Encouraging and facilitating an open approach to the awareness of dying is a key cultural shift not just in care homes but in societal attitudes.

A 'good death' In older age, it can be difficult to predict when someone will die, therefore promoting good end-of-life care should be integral to quality care in care homes. Practices and interventions rooted in palliative care, and support from specialist palliative care services,

are helpful. Existing standards, frameworks and tools can help support good palliative care.

Ongoing support It is important that staff, the family and fellow residents receive continuing support following a death – for example, through opportunities to discuss their feelings and to ‘say goodbye’, attending the funeral or memorial service, or through remembrance events.

12.10 Keeping the workforce fit for purpose

There is a paucity of reliable information on the size and structure of the independent care home workforce. The changing nature of the workforce needs to be closely scrutinised through research, in order to ensure quality of life and care for residents. This review has identified a range of creative learning initiatives in care homes which could offer indicators for future developments. Learning is important for older people but learning schemes in care homes are new and as yet their effectiveness is unproven. This review also highlights the importance of relationship-centred care, both as a therapeutic intervention in delivering quality of life for frail older people and also as a framework within which to evaluate the learning environment and help staff to gain motivation and satisfaction.

Key best practice messages

Identifying the need for education and training Ongoing research is needed to keep track of the education and training needs of the changing workforce in the care home sector, along with research that shares lessons learned from attempts to improve practice through education.

Education and training as integral to practice Creative learning initiatives need to be strategically developed and supported to become part of mainstream practice. Education and training need to be relationship-centred and concerned with developing the whole of the care-home workforce on site, as part of overall quality improvement initiatives, rather than external bite-sized educational inputs for

personal and professional enhancement only. Registered and non-registered workers need to learn together as a learning force for change, rather than a means of qualification. The importance of learning for residents must also be considered. Central in the process is the need for residents, relatives and staff to share their experiences of quality of life in care homes, when living and working together.

Care homes as learning environments

The potential of care homes as good learning environments for staff and students must be recognised and, through encouraging increased financial investment, teaching care homes are an ideal for which to strive.

12.11 Promoting positive culture

Creating positive culture in care homes for the future requires recognition of the complex and multidimensional nature of life and work in care homes. Person-centred, biographical and developmental approaches are essential. Homes should work to develop cultures that support relationship-centred care and to disseminate existing initiatives that support its development. A strong message is the interdependence of staff, residents and family members, and any attempts to promote a positive culture within the care home setting need to nurture these important relationships.

Key best practice messages

Defining a positive culture In a positive culture the ethos of care remains person-centred, relationship-centred, evidence-based and continually effective within a changing health and social care context. A ‘complete community’ is consistent with the most positive experiences of older people and ‘best care’.

Promoting a positive culture Creating a positive culture requires recognition of the complex and multidimensional nature of life and work in care homes. Interdependence is an important value. Homes should seek to promote enablement and partnership, person-centred and relationship-centred care through biographical and developmental approaches. Staff

should seek to work as an effective team with mutual appreciation and some blurring of roles, and relatives as integral members of the team. Close links with the local community should be maintained.

Leadership, management and expertise

Effective leadership, management and the availability of expert advice is paramount in the creation and maintenance of a positive culture.

References

1 Context

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12 Conclusions and key best practice messages from the literature review

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Appendix I Resources by theme

Managing transitions

Moving into a care home

A Positive Choice: choosing long-stay care for a person with dementia

Alzheimer Scotland (2003), Edinburgh
Guide to how to make decisions about or arranging long-stay care or choosing a care home for a person with dementia. Gives in-depth information on financial, legal and practical issues as well as looking at the subject from an emotional and personal perspective. Includes practical examples and lists useful support agencies.

<http://www.alzscot.org/pages/info/positive1.htm>

Care Homes: finding and paying for a care home

Help the Aged (2007), London
This advice leaflet provides information to help an older person and their relatives decide whether moving into a care home is the right choice for them.

Care Homes for Older People in the UK

Office of Fair Trading (2005), London
This market survey considers how well the care homes market serves people over 65 in the UK. Gives recommendations for all areas.

Care Options Directory

Elderly Accommodation Counsel, London
This online directory offers potential care home residents and their carers/relatives with:

- a tool to help people seeking care to establish their own priorities at the outset
- an up-to-date database of factual information about each UK home
- new qualitative descriptors to help people judge the likely suitability of those homes that are available to them.

Homes can be searched by postcode, town/county, home owner, and language/culture, with many more filters within each category. More detailed county guides for England, which give useful information and further sources of information, both general and local, are also available to purchase. The directory is accessible from the EAC website: <http://www.housingcare.org>

Help the Aged SeniorLine

This freephone national advice and information service is run by Help the Aged for older people, their relatives, carers and friends. Trained advice workers offer free, confidential and impartial advice on issues including community and residential care, welfare and disability benefits and agencies offering practical help. In Great Britain, call 0800 800 6565; in Northern Ireland 0800 808 7575. Lines are open Monday–Friday, 9am–4pm.

Letting Go without Giving Up: continuing to care for the person with dementia

Alzheimer Scotland (2005), Edinburgh
This booklet is for those who have been caring at home for a family member, partner or friend who is now in the later stages of dementia and where a decision has been made to transfer the person to a care home setting. It does not cover the process of decision-making or arranging long-stay care, or how to go about choosing a care home (these issues are covered in *A Positive Choice* – see above). Instead, the booklet looks at the impact of the move on the carer and the person with dementia. It aims to help carers establish new caring roles for themselves through visiting and working as partners with care home staff to help them understand the person with dementia and provide the best possible care in what is likely to be the person's final home.

http://www.alzscot.org/store/pages/Letting_go_without_giving_up166123028.htm

Life Story books

The Evergreen Unit at St Pancras Hospital, London, developed Life Story books to support and inform the care it gives to its patients. Where patients are able to contribute they do, but for many who have cognitive impairment and difficulty with verbal communication relatives are key to providing the information and are therefore actively encouraged to be involved in completion of the books. The Life Story books help staff to engage with patients who have complex needs and are used to inform many aspects of care planning, from personalising bedrooms to meeting personal needs in a way that respects the person's wishes and promotes their dignity.

The books, developed by staff on the unit including nurses, occupational therapists and a psychologist, are also a guide to providing meaningful occupation. All new staff are taught how to use the books during their induction process. The books are given to the relatives/next of kin when the person dies as a souvenir of the deceased. For further information, including the format of the life story books, see:

<http://www.scie.org.uk/publications/practiceguides/practiceguide09/ideas/ideas03.asp#ideaslifestorybooks>

Relatives and Residents Association

This charity supports older people living in care homes, their families and friends. The work of the association includes:

- providing support and information via a helpline
- carrying out project work on specific issues
- influencing policy and practice
- working with local relatives' and residents' groups in care homes.

The R&RA also holds regular conferences and produces a range of publications. Further information can be found at: <http://www.relres.org>

Residents and Relatives Association helpline

The helpline offers support and information on care homes. The organisation recognises that moving into long-term care is seldom easy and often means a momentous change in lifestyle connected with poor health and changes in relationships. Being informed is the key to making this transition as smooth as possible for all involved. The R&RA prides itself on taking time to listen and helping people work through the situations they are facing so that they are able to make informed choices. Tel. 020 7359 8136, Monday–Friday, 9.30am–4.30pm. Email: info@relres.org

Thinking about Moving into a Care Home?

Scottish Executive (2005), Edinburgh
This booklet is for people who may need to move into a care home and their carers and relatives. It explains:

- how your local social work service can help
- your right to have your care needs assessed
- your right to choose the care home you want to live in
- how the social service will work out how much you will pay towards the cost, and
- what will happen to your current home.

Download booklet at:

<http://www.scottishexecutive.gov.uk/Resource/Doc/114146/0027819.pdf>

Promoting a positive culture

Involving residents and relatives

Care Keys project

This project, funded by the Quality of Life programme within the European Union's Research and Development Framework V, involved six countries: Estonia, Finland, Germany, Spain, Sweden and the United Kingdom. It aimed to develop an effective tool for the management and performance evaluation of health and social care services for older people. The project placed particular emphasis on linking client preferences and quality-of-life objectives to the professional and managerial objectives of good-quality care.

Project website:

<http://www.carekeys.net/projects.html>

The Eden Alternative

Website co-ordinating attempts to introduce the Eden philosophy within care homes in the UK and Ireland. The Eden Alternative is a not-for-profit organisation dedicated to improving the experience of ageing and disability around the world. It aims to provide tools for improving the quality of life and for recapturing a meaningful work life. <http://www.eden-alternative.co.uk/>

Letting Go without Giving Up (see above)

Pets As Therapy

Pets As Therapy (PAT) is a national charity providing temperament-assessed/vaccinated PAT dogs and PAT cats with registered volunteers to hospitals, hospices, residential care homes, day centres, special needs schools and many other establishments. The animals provide comfort, companionship and therapy.

See <http://www.petsastherapy.org/>

Relationship-centred care and the Senses Framework

Nolan, M., Brown, J., Davies, S., Nolan, J., Keady, J. (2006), *The Senses Framework: improving care for older people through a relationship-centred approach*, from the Getting Research into Practice Series, University of Sheffield, describes the development of a conceptual framework for creating enriched environments of care for older people, including those in care homes. The report is based upon a four-year research project which explored student nurses' experiences of learning to care for older people in a range of care settings.

Available from Helen Mason, tel. 0114 2266851,
email h.c.mason@shef.ac.uk

Relatives and Residents Association (see above)

Promoting a positive culture

Developing positive practice in dementia care

Dementia care mapping: a quality improvement tool and process

Dementia care mapping (DCM) is a method designed to evaluate quality of care from the perspective of the person with dementia. Used in formal care settings such as hospitals, care homes and day care centres, it is based on the philosophy of person-centred care, which promotes a holistic approach to care that upholds the personhood of the person with dementia. This web page gives a brief description of dementia care mapping: what it is, what it can be used for, and contacts at the University of Bradford: <http://www.brad.ac.uk/acad/health/dementia/dcm/index.php>

Dementia: walking not wandering – fresh approaches to understanding and practice

Marshall, M., Allen, K. (eds.) (2006), Hawker Publications

This book is designed for those working with people with dementia in care homes, hospitals, day care centres and the community. It argues passionately that for people with dementia walking should be neither feared nor discouraged by professional carers, and especially not classified as challenging behaviour. Instead, walking should be viewed as an activity, fully understood, with significant potential and benefits.

<http://www.careinfo.org/books/>

Bradford Dementia Group

Established in 1992 at the University of Bradford to develop teaching, education and research in the field of dementia care, the group has been part of the Division of Dementia Studies since 2003 and comprises a multi disciplinary and multi-professional group engaged in a portfolio of activities. The mission of the group is to improve the quality of life and quality of care for people with dementia and their families, through excellence in training, education and research, recognising the key role played by practitioners and professionals. <http://www.bradford.ac.uk/acad/health/dementia/index.php>

Care-giving in Dementia: research and applications

Brunner-Routledge (2004), Hove

Each volume of *Care-giving in Dementia* integrates up-to-date neurobiological information about dementia with specific developments in care-giving, revealing the relevance of new research for professional caregivers. Multidisciplinary in focus, these collections also have a strong practical emphasis.

<http://www.amazon.co.uk/gp/product/1583911898/202-9140039-4711845?v=glance&n=266239>

Good practice guides: Bradford Dementia Group

Now under the editorship of Murna Downs, Chair in Dementia Studies at the University of Bradford, this series constitutes a set of accessible, jargon-free, evidence-based good practice guides for all those involved in the care of people with dementia and their families. The series draws together a range of evidence including the experience of people with dementia and their families, practice wisdom, and research and scholarship to promote quality of life and quality of care. <http://www.jkp.com/catalogue/index.php/ser/bradford>

The Importance of Food and Mealtimes in Dementia Care: the table is set

Berg, G. (2006), Jessica Kingsley, London

This book recognises that mealtimes are about much more than just re-fuelling. Using her extensive experience of working with older people with dementia, Grethe Berg explains how mealtimes can be used as opportunities for meaningful interaction, socialising and reminiscing, and useful forums for taking part in familiar tasks. The book considers the social significance of mealtimes and their role in maintaining patients' feelings of social attachment and well-being as well as the impact of the symptoms of dementia on food and mealtimes. It also explores different types of residential care and how mealtimes can be a focus of activity for patients. Also discussed are practical implementation strategies, considering variables such as building design, interdisciplinary collaboration, organisation of staff and residents, and staff participation and conduct at mealtimes. Practical strategies are suggested for care managers and carers to ensure that mealtimes are positive experiences for people with dementia.

<http://www.jkp.com/catalogue/book.php/isbn/1-84310-435-0>

Journal of Dementia Care

A multidisciplinary bi-monthly journal for all professionals working with people with dementia, this periodical aims to:

- provide a strong editorial commitment to improving quality of care for people with dementia in hospitals, residential and nursing homes, day-care and homecare settings
- raise the profile of all professionals working in this specialist field
- present the ideas and opinions of professionals working with people with dementia
- emphasise the value and importance of training for achieving quality care.

<http://www.careinfo.org/dementiacare/>

Working with Dementia: a handbook for care staff

Alzheimer Scotland (2004), Edinburgh

This handbook is for staff working in long-stay care settings that are home to people with dementia. This may be a hospital, residential or nursing home. The book has been produced by a carer who has experience of moving a relative with dementia from home into a residential setting and then on to nursing home care. A simple, easy-to-read resource for staff, the book covers the basics of:

- what dementia is
- admission into care
- how you can help
- challenging behaviour relating to dementia.

Single copies are free to care staff. Tel. 0131 243 1453; email alzheimer@alzscot.org;

or download it free of charge:

<http://www.alzscot.org/downloads/workingwithdementia.pdf>

Managed Care Network: Dementia Tayside Knowledge Exchange

The Managed Care Network brings together staff from NHS Tayside, Angus Council, Dundee City Council, Perth and Kinross Council, voluntary agencies, people with dementia and their carers. The Network not only aims to improve services but also to raise awareness and reduce the stigma of dementia. It has highlighted many gaps in services and identified four main priorities:

- early diagnosis
- education for staff, people with dementia and their carers
- involving people with dementia and their carers to ensure their expert voices are heard

- developing integrated care pathways for dementia.

<http://www.networks.nhs.uk/networks/page/792>

Switching on a Light: an introduction to life story work

This new DVD demonstrates what is meant by life story work and how this can be used with people with dementia. Filmed in a nursing home and using interviews with practitioners and people with dementia, it considers the benefits for those involved. The accompanying booklet gives more detailed information about getting started and the issues to be considered. An outline for a suggested training session is also included.

Price: £45.00. Orders:

<http://www.dementia.stir.ac.uk/>

UK Wandering Network

This network, funded by a grant from the Burdett Trust, is the first of its kind in the UK and has brought together researchers, development workers, practitioners and older people themselves to explore and debate the challenges associated with wandering and related behaviours among older people who have dementia. A useful website provides information on activities, publications and links to other websites.

<http://www.wanderingnetwork.co.uk/Welcome.htm>

Promoting a positive culture

Developing practice through collaboration

Everybody's Business: integrated mental health services for older adults – a service development guide

Department of Health (2005), TSO, London

Department of Health guidance on promoting integrated mental health services for older people: <http://kc.csip.org.uk/upload/SixKeyMessages1.pdf>

Joined-up Thinking, Joined-up Care

Scottish Partnership for Palliative Care (2006), Edinburgh

This report describes a Lottery-funded project to increase access to palliative care services for people with life-threatening conditions other than cancer. The full report can be downloaded from: <http://www.palliativecarescotland.org.uk/publications/Joined%20up%20thinking%20Joined%20up%20care%20Full%20Report.pdf>

Observable indicators of nursing home care quality

A series of measurement tools developed in the US and designed to assess the multidimensional nature of quality of life in care homes.

Further information:

<http://www.nursinghomehelp.org/OIQAL.pdf>

Professional and Practice Development Nurses' Forum Scotland

This forum brings together nurses and allied health professionals interested in professional and practice development issues for support purposes, networking and ultimately to influence practice throughout Scotland. <http://www.ppdnf.org/>

Relationship-centred care and the Senses Framework (see above)**Promoting a positive culture****Preventing abuse****Action on Elder Abuse**

AEA is a charity working to protect, and prevent the abuse of, vulnerable older adults. It was the first charity to address these problems and is the only one in the UK and in Ireland working exclusively on the issue. Although they cannot provide legal advice, helpline workers can provide information on the nature of elder abuse and indicate what action might be taken in response to abuse or to prevent it. Helpline open every weekday 9.00am–5.00pm: freephone 0808 808 8141 (UK); 1800 940 010 (Republic of Ireland).

Further information:

<http://www.elderabuse.org.uk/>

Additional resources***Bridging the Gap between Learning and Practice: an action learning approach to improving care practice***

Chapman, A. and Hosking, R. (2002), Stirling, Dementia Services Dementia Centre, University of Stirling

This guide for managers of care homes involved managers in its development. The project on which the report is based set out to explore why, despite training courses being rated as effective by participants, there is often no long-term change in practice. It also looked at other potential ways to improve the quality of care, instead of just providing more training courses.

Available from:

http://www.dementia.stir.ac.uk/publications/training_resources.htm

Culture Change in Long-term Care

Weiner, A.S. and Ronch, J.L. (2003), Haworth Press

This book discusses the theoretical and practical applications of culture change within the institutional long-term care setting. It examines existing models of 'positive cultures', emphasising philosophy, underpinning, and implementation. It gives an insight into theoretical frameworks for organisational change, of the changes that can occur in all members of the long-term care community, and of culture change in the context of broad organisational experience and cultural competence. Further information:

<http://www.culturechangenow.com/book-ccltc.html>

Educating for Dignity: a multidisciplinary workbook

This workbook is one of the products of the Dignity and Older Europeans (DOE) Project. One of the aims of the DOE project was to produce educational materials to aid interprofessional learning about the subject, throughout Europe. The workbook provides a brief outline of the theoretical model of dignity that emerged from the research, and four different sections based on the empirical findings:

- understanding dignity
- old age – what is it like to be an older person?
- dignity in care
- the impact of the system.

Download from:

http://www.bgs.org.uk/Publications/Publication%20Downloads/Educating_for_dignity1.pdf

Learning Organisations: self-assessment resource pack

This pack enables organisations to assess whether they are a learning organisation: that is, one that uses evidence-based practice and informed decision-making. Designed to help chief executives, senior managers, frontline staff, service users and carers, it was developed by practice development staff at the Social Care Institute for Excellence (SCIE) in collaboration with service users, carers and staff in social care. It is available as a series of cards in pdf and Word format from: <http://www.scie.org.uk/publications/learningorgs/index.asp>

Alternative formats available on request. For a free set of the cards email: publications@scie.org.uk

Alternative formats available on request. For a free set of the cards email: publications@scie.org.uk

Models of Delivery of Health Care to Older People in Long-term Care: a systematic review

Peet, S. (2004), The Research Findings Register, summary number 1297

The summary contains insights into models which service providers might find helpful.

<http://www.refer.nhs.uk/ViewRecord.asp?ID=1297>

The Wellspring Institute

Established in the US in 1994 to promote high-quality care in care homes, this organisation believes that:

- care decisions need to take place closest to the resident
- a substantial knowledge base is required by all staff to enable participation in decision-making.
- an empowered workforce increases resident and employee satisfaction and reduces staff turnover.

The Wellspring Change Model aims to involve all staff in decision-making. Educational modules are available. Further information:

<http://www.wellspringis.org/>

Maintaining identity

Maintaining identity for people with dementia

Aiding communication with people with dementia

SCIE (2004), SCIE Research Briefing

Available from:

www.scie.org.uk/publications/briefings/files/scare03.pdf

Dementia: walking not wandering (see above)

Bradford Dementia Group (see above)

Care-giving in Dementia: research and applications (see above)

Everybody's Business (see above)

Good practice guides: Bradford Dementia Group (see above)

The Importance of Food and Mealtimes in Dementia Care (see above)

Journal of Dementia Care (see above)

Working with Dementia (see above)

Managed Care Network: Dementia Tayside Knowledge Exchange (see above)

Memoraid

This resource can be used to document biographical and other personal information and has been particularly developed for use with people with memory or communication problems. It includes guidance and sections on personal history, world events during the life of the individual, life events, a calendar for recording events of importance to the individual (e.g. family birthdays, Wimbledon week), photographs, family tree, significant connections (people, animals, places), spiritual preferences and personal preferences for drinks, food, clothing, bed, bathing, skin, teeth, nails, hair, communication, activity, entertainment and interests, favourite things and preferences not recorded elsewhere, and other information. For details tel. 020 7740 1344 or email Memoraid@Munro.co.uk.

Switching on a Light (see above)

UK Wandering Network (see above)

Sign clinical guidelines No 86: management of patients with dementia

Scottish Intercollegiate Guidelines Network (2006)

This guideline considers investigations and interventions in which direct benefit to the person with dementia can be demonstrated. It covers all stages of dementia excluding mild cognitive impairment. The guideline does not address palliative care in advanced disease, risk or prevention. Download from:

<http://www.sign.ac.uk/pdf/sign86.pdf>

What Standards of Care Can People Expect from a Care Home?

The Alzheimer's Society (2005), London

Working both independently and in partnership with other agencies to improve the quality of dementia care, the Alzheimer's Society has developed quality standards for use in residential and nursing homes. This information sheet describes the kind of care that someone with dementia can expect from a care home and explains what action can be taken if problems arise. It suggests that a good care home should follow the principles of person-centred care, focusing on the person with dementia as an individual rather than as a patient with an illness and lost abilities. Rather than treating the person as a collection of symptoms and behaviours to be controlled, person-centred care takes into account each individual's unique qualities,

abilities, interests, preferences and needs.
http://www.alzheimers.org.uk/Caring_for_someone_with_dementia/PDF/451_carehomestandards.pdf

Working with Dementia (see above)

Working with people with dementia

A range of publications produced by the Alzheimer's Society, including some that are particularly relevant to older people with dementia living in care homes. Titles include:

Quality Dementia Care in Care Homes: person-centred standards

The Alzheimer's Society Book of Activities

The Alzheimer's Society's Guide to the Dementia Care Environment

Food for Thought practice guides

Further information:

http://www.alzheimers.org.uk/Working_with_people_with_dementia/Publications/index.htm

Maintaining identity

Maintaining dignity

Educating for dignity: a multidisciplinary workbook (see above)

Maintaining identity

Ensuring choice and involvement

In Focus: real voices, real choices

Commission for Social Care Inspection (2006), London

This report is based on a series of meetings at which adults who use care services told the Commission for Social Care Inspection about the things that concern them most. Available at:
http://www.csci.gov.uk/about_csci/publications/in_focus_real_voices_real.aspx

Creating community

Better mealtimes

Highlight of the Day? Improving meals for older people in care homes

Commission for Social Care Inspection (2006), London

This information bulletin is designed to assist care homes to improve the delivery of meals to older people, and in particular to improve their experiences of mealtimes in care homes. It highlights innovative ways in which care homes can provide a wholesome, appealing balanced diet in pleasing surroundings, at times convenient to residents. The bulletin links practice and workforce development to skills and knowledge in order to ensure a holistic approach. The quality improvement checklist suggests starting points for finding out people's likes and dislikes, encouraging and assisting older people to participate in decisions about meals and attractive presentation, with the back-up of good management processes, appropriate facilities and equipment and training.
http://www.csci.gov.uk/PDF/highlight_of_day.pdf

Involving relatives

Involving Relatives and Friends: a good practice guide for homes for older people

Burton Jones, J. (2001), Relatives and Residents Association, London

This book contains a wealth of ideas for enabling relatives and friends of older people who live in a care home to make an active contribution to life within the home. Further information:
<http://www.relres.org/publicationspages/PubInvolvingrelativesandfri.html>

Letting Go without Giving Up (see above)

Moving Stories

Bright, L. and Clarke, A. (2006), Relatives and Residents Association, London

This report explores the experiences of couples when one of them has moved into a care home. Drawing on the experiences of callers to the Relatives and Residents Association helpline, the report describes the practical and emotional difficulties they have faced. Further information is available at: <http://www.relres.org/pdf/MovingStoriesPressRelease.pdf>

Building networks

National Care Homes Research and Development Forum

Established in 2003, the NCHRDF provides a platform for practitioners and researchers to network and to share information and ideas arising from their work. Members believe that the forum has the potential to bring together a wealth of knowledge and talent and could exert a considerable influence on future research agendas for long-term care for older people. Membership is open to anyone with an interest in research and development in care homes. Contact: Professor Julianne Meyer, Professor of Nursing: Care for Older People, City University, London, email j.meyer@city.ac.uk.

Use of activity

Activities in Care Homes for People with Dementia: factsheet

North West Dementia Centre (2005)
Includes rationale for prioritising activity within care homes, together with suggestions and links to further resources http://www.pssru.ac.uk/pdf/MCpdfs/Activities_factsheet.pdf

The National Association of Providers of Activities for Older People

NAPA is a voluntary organisation and registered charity dedicated to increasing the profile and understanding of the activity needs of older people living in care homes, and equipping staff with the skills to enable older people to enjoy a range of activities. NAPA provides training and consultancy, and produces a range of publications, as well as campaigning to raise awareness of the activity needs of older people who live in care homes. Further information: <http://www.napa-activities.co.uk/default.asp?contentID=1>

The PAL (Pool Activity Level) Instrument for Occupational Profiling: promoting independence in dementia care

Pool, J. (2002), Jessica Kingsley, London
This tool was designed to assist carers providing activity-based care to improve independence and help people with dementia to achieve optimal functional performance. It was developed by an occupational therapist and influenced in its early development (1999) by a best practice project in partnership with Surrey Social Services. The

instrument includes a checklist which helps to identify an individual's activity level according to four categories (level of function):

- planned – orientated to obvious goals
- exploratory – more concerned with the process of an activity rather than the goal
- sensory – concerned with the impact on own senses
- reflex – subconscious responses to direct stimulation

Further information:

<http://www.jkp.com/catalogue/book.php/isbn/9781843100805>

Pets As Therapy (see above)

Successful Activity Co-ordinator Learning Resource (2nd edition)

Hurtley, R., Wenborn, J. (2005), Age Concern, London

Information, ideas and resources for those engaged in activities and leisure pursuits with older people in residential, nursing and care homes. This edition contains new material on the effects of bereavement; the significance of spirituality; falls; learning in older age; positive person work; multisensory stimulation; outings and social activities, spiritual activities; engaging people with dementia in activity; promoting physical activity; and involving relatives and the wider community. Topics include:

- the role of the activity co-ordinator
- successful group work
- challenges and opportunities that affect older people
- designing innovative programmes
- effective communication
- engaging people with dementia in activity
- themes, approaches and activities.

Further information:

<http://www.ace.org.uk/bookshop/index.cfm>

Improving health and healthcare

Collaborative working

Care of Older People in Care Homes: a comprehensive interdisciplinary approach

Royal College of Physicians, Royal College of Nursing, British Geriatrics Society (2000), London, Royal College of Physicians

This collaborative report emphasizes the need for more robust professional input, skill mix and a

more research-based approach to improve health outcomes of older people in care homes. Orders: <https://www.rcplondon.ac.uk/pubs/brochure.aspx?e=94>

Nutrition, hydration and oral health

Eating for Health in Care Homes: a practical nutrition handbook

The Royal Institute for Public Health
A handbook for owners, managers, chefs and other staff of care homes for older people, providing up-to-date advice on the nutritional needs of residents and suggestions on how to meet these needs in interesting new ways. Orders: <http://www.riph.org.uk/index13.html>

Eating Well for Older People

Caroline Walker Trust (2004), London
This report offers practical guidance for people who cater for older people in care homes, nursing homes or at lunch clubs, or who are responsible for community meals. This edition includes information based on developments including the National Diet and Nutrition Survey, the National Service Framework and the MUST screening tool. Orders: <http://www.cwt.org.uk/publications.html>

Help Us Stay Healthy: getting sufficient nourishment when going into a hospital or care home

NHS Quality Improvement Scotland (2005)
This leaflet provides useful guidelines that will help older people and their carers to make their expectations known when care is required. <http://www.nhshealthquality.org/nhsqis/files/nourishment%20G%20Cal%20companion%20statement%2005.pdf>

Highlight of the Day? (see above)

Hydration Best Practice: toolkit for care homes

Contains factsheets, checklists and advice to enable care home staff to improve water consumption for older people and staff. Download from: <http://www.water.org.uk/home/water-for-health/older-people/care-homes-toolkit>

The Importance of Food and Mealtimes in Dementia Care (see above)

Mealtimes and Nutritional Care

SCIE practice guide 09: Dignity in care
This section of the SCIE practice guide reviews the evidence relating to the importance of good nutritional care for older people in long-term care settings. <http://www.scie.org.uk/publications/practiceguides/practiceguide09/mealtimes/index.asp#keypoints>

Optimising Nutrition in Care Homes

This learning unit, developed by a multidisciplinary team, encourages practitioners to reflect upon and evaluate their own practice through work-based activities. It covers:

- the prevalence of malnutrition
- identifying residents at nutritional risk
- implementation of nutritional screening in care homes
- improving nutritional care of residents.

Successful participants are awarded a certificate for 10 credits at Level 3.
Partners in Active Continuous Education (pace), Queen Margaret University College, Clerwood Terrace, Edinburgh EH12 8TS.
<http://www.qmuc.ac.uk>
http://www.qmuc.ac.uk/pace/products/A_onch.htm

Working with Dependent Older People to Achieve Good Oral Health: best practice statement

NHS Quality Improvement Scotland (2005)
Good oral health is crucial to meeting fundamental human needs such as comfort, nutrition, communication and acceptable personal appearance. It is recognised, however, that oral care provision is a neglected area of practice. For example, there are few assessment tools that focus on the specific oral health needs of dependent older people. In developing this statement, the expert and project team brought together evidence to underpin daily and continuing care of the mouth and teeth for dependent older people.
<http://www.nhshealthquality.org/nhsqis/2475.html>

Falls prevention

Be Strong, Be Steady

This motivational video for older people, including those in care homes, is produced by Help the Aged. Its gentle programme of chair-based and standing exercises will help to strengthen muscles, increase flexibility and improve balance. £12. English plus Cantonese/Punjabi/Bengali editions.

Running time: 58 minutes.

Orders: tel. 020 7239 1946 or via

http://www.helptheaged.org.uk/en-gb/OnLineShop/Utility/Product.htm?CatalogNavigationBreadCrumbs=Getting%20Out%20and%20About;Exercise&CS_ProductID=N-26-01v&CS_Category=&CS_Catalog=Getting%20Out%20and%20About

Moving More Often

This training programme from the British Heart Foundation National Centre for Physical Activity and Health is for health and care workers and volunteers who work with frail older people and wish to promote physical activity and learning in a range of health, care and social settings. The programme is designed to promote physical activity, independence and well-being for older people, including those living in care homes. The Moving More Often learning network ensures that those interested are kept up to date with developments and learning as they occur.

The network connects a range of national organisations, related professionals in the health and care sectors, exercise teachers and activity leaders via a dedicated page on the website of the BHF National Centre, and through electronic newsletters, seminars, training and conference events. Further information: BHF National Centre for Physical Activity and Health, School of Sport and Exercise Sciences, Loughborough University, Loughborough LE11 3TU. Tel. 01509 223259.

Fax 01509 223972.

Email: bhfactive@lists.lboro.ac.uk.

<http://www.bhfactive.org.uk/older-adults/references.html>

Physical Activity for Dependent Older People: best practice statement

NHS Quality Improvement Scotland (2005)

These best practice statements are designed for developing and improving the care that older people receive and to promote effective

interdisciplinary teamworking. Download from: http://www.nhshealthquality.org/nhsqis/controller?p_service=Content.show&p_applic=CCC&pMenuId=0&pElementId=0&pContentId=2727

Preventing Falls: managing the risk and effects of falls among older people in care homes

Help the Aged (2004), Help the Aged, London
Available from: www.helptheaged.org.uk/slipstrips/practitioners

Preventing Falls in Care Homes

SCIE research briefing 1

Includes summaries of evidence and examples of good practice. Available from: <http://www.scie.org.uk/publications/briefings/briefing01/index.asp>

UK Wandering Network (see above)

Other websites of interest

<http://laterlifetraining.co.uk>

<http://extend.org.uk>

www.active-for-life.com

<http://balancemaster.co.uk>

Screening and immunisation

Administration of Flu Vaccine in Care Services

Scottish Care Commission (2007)

Information on the issues relating to administration of influenza vaccines in care homes, for the winter 2007–8. Download from: http://www.carecommission.com/index.php?option=com_content&task=blogcategory&id=62&Itemid=161

Pain management

Assessing pain in older people

Bird, J. (2005), *Nursing Standard*, 19, 19, 45–52

Particularly relevant to the management of pain for older people living in a care home, as is the following article.

Nursing management of pain in older people

Briggs, E. (2003), *Nursing Standard*, 17, 18, 47–53

Control of Pain in Patients with Cancer

SIGN (2000) publication no. 44

The guideline covers definitions and assessment of pain, the role of education and choice of analgesia. Download from: <http://www.sign.ac.uk/guidelines0/fulltext/44/index.html>

Continence care

Association for Continence Advice

The ACA is a membership organisation for health and social care professionals concerned with the progression of care for continence. It produces a regular newsletter and several publications for improving continence care. Further information: <http://www.aca.uk.com/>

National Audit of Continence Care for Older People

RCP (2005), National Audit of Continence Care for Older People, Royal College of Physicians, London

Includes a tool for auditing continence care.

http://www.rcplondon.ac.uk/college/ceeu/coop/naccop_audit2005.pdf

National Minimum Standards for Continence Care and Guidance on Good Practice in Continence Services

Department of Health (2000), TSO, London

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005851

Management of Suspected Bacterial Urinary Tract Infections in Adults: SIGN clinical guidelines no. 88

Scottish Intercollegiate Guidelines Network (2006)

Download from: <http://www.sign.ac.uk/pdf/qrg88.pdf>

Mental health

Depression and dementia: taking a dual-diagnosis approach

Manthorpe, J., Illiffe, S. (2006) *Nursing Older People*, 18, 2, 24–9.

Article containing advice on recognising depression with dementia in older people.

Best Practice Statement: working with older people towards prevention and early detection of depression

This best practice statement was produced by NHS QIS to offer evidence-based nursing guidance on prevention and early detection of depression in older people. In particular, the best practice statement informs care of older people who are moving to continuing care facilities such as community hospitals or care homes (nursing), older people awaiting hospital discharge or experiencing delayed discharge, or a comparable period of instability in their lives.

<http://www.nhshealthquality.org/nhsqis/1446.html>

Sharing decision-making

Everybody's Business (see above)

In Focus (see above)

Making Decisions: helping people who have difficulty deciding for themselves – planning ahead for the future

Department for Constitutional Affairs (2003)

A booklet designed to help adults (aged 18 and over) who may wish to make preparations for a future time when they may not be able to make their own decisions. This may be because of possible brain injury, dementia, mental health problem or other illness or disability which may affect their capacity to do things for themselves.

Available from: <http://www.dca.gov.uk/family/mi/mibooklets/guide5.htm>

Relatives and Residents Association (see above)

Talking Mats

Talking Mats is a low-tech communication framework involving sets of symbols. Developed to support people with communication impairment, the tool uses a mat with picture symbols attached as the basis for communication. It is designed to help people with communication difficulties to think about issues discussed with them, and provide them with a way to effectively express their opinions. Talking Mats have been used to help people with communication difficulties identify issues relevant to their quality of life. The following article describes the use of Talking Mats: Murphy, J., Tester, S., Hubbard, G., Downs, M. and MacDonald, C. (2005), Enabling frail older people with a communication difficulty to express their views: the use of Talking Mats[TM] as an interview tool. *Health & Social Care in the Community*. 13 (2): 95–107. Further information: <http://www.talkingmats.com/>

Keeping workforce fit for purpose

Workforce capacity

First Report for the Range and Capacity Review of Community Care Services for Older People: projections of community care service users, workforce and costs

Local authority models of community care have been changing, with a move away from care in care homes to more support for people in the community, to help them live as independent a

life as possible in their own homes for as long as possible. There are some concerns, however, that these changes in the pattern of care have developed unevenly and have resulted in a gap in provision for some people between NHS hospital care and care at home or in a care home. There is a need for new models of care to be developed to recognise this, with more intermediate rehabilitation taking place to maximise the independence of the older people involved. The range and capacity review being carried out by the Scottish Executive, in conjunction with health and local authority representatives and members of the independent sector, is seeking to address some of these issues. The review will also assist the short- and long-term planning of local partnerships by looking at the levels of community care services for older people over the next five, ten and 15 years, as a means of identifying the most effective way of developing and managing the market to meet future needs. The group aims to deliver recommendations on effective methods of developing and managing provision to meet future needs, and also to investigate different models of care.
<http://www.scotland.gov.uk/Publications/2004/07/19665/40321>

Training for dementia care

Care-giving in Dementia: research and applications (see above)

Depression and Dementia (see above)

Working with Dementia: a handbook for care staff (see above)

Training for end-of-life care

Death, Dying and Bereavement

BVS Training pack (£125 + VAT) video and CD-ROM
Contact: www.bvs-uk.com Tel: 0845 644 2866.
For more information: http://www.bvs.co.uk/product.asp?strareano=PRODUCTCATEGORY_1&intelement=25

Foundations in Palliative Care

Macmillan Cancer Relief
A teaching resource designed for staff at all levels including four modules: the principles of palliative care; communication; pain and symptom management; and bereavement care. It was originally developed by Dr Jeanne Katz, Dr Moyra Sidell, and Carol Komaromy, of the School of

Health and Social Welfare at the Open University, following research funded by the DH into the type of palliative care training needed by care home staff. Macmillan has developed the programme further into a self-contained education resource. The resource enables care homes to address standard 11 of the National Minimum Standards for Care Homes for Older People.
Macmillan Resources
www.macmillan.org.uk/news
Contact: Macmillan Resource Line
Tel: 01344 350310.
Online: www.professionalresources.org.uk

Palliative Care for the Elderly

St Columba's Hospice Education Department, Edinburgh

A four-module degree-level course that includes a double module entitled Assessing and Managing Symptoms in the Elderly at the End of Life.
Contact: Ish Warrilow, Education Personal Assistant, St Columba's Hospice.
Tel: 0131 5511381 x157. Direct line: 0131 551 7710.
Email: iwarrilow@stcolumboshospice.org.uk

Palliative Care in Aged Care

Flinders University, Adelaide, Australia
A postgraduate certificate/diploma course run by WebCT online, hence accessible for international students.

Palliative and End-of-life Care for Older People

British Geriatric Society (2006), Compendium Document 4.8
Draws together key principles for a 'good death'.
http://www.bgs.org.uk/Publications/Compendium/compnd_4-8.htm

Understanding Bereavement

Age Concern Understanding Bereavement Training Pack (£35), Author: Toni Battison.
Contact: Age Concern Books, Unit 6, Industrial Estate, Brecon, Powys LD3 8LA. Tel: 0208 765 7200.

Work-based Learning in Palliative Care: for practitioners in all general care settings including care homes

Royal College of Nursing.
Contact: Stephanie Schlingensiepen, Senior Fellow Practice Development/Gerontological Nursing, Royal College of Nursing Institute, 20 Cavendish Square, London W1G 0RN.
Tel: 0207 647 3657.
Email: Stephanie.Schlingensiepen@rcn.org.uk

Professional networks and grant-making bodies

Trusthouse Charitable Foundation

Grant-making trust prioritising projects concerned with older people, hospice and palliative care. Further information is available at: <http://www.trusthousecharitablefoundation.org.uk/obj.html>

Professional and Practice Development Nurses' Forum Scotland

This forum brings together nurses and allied health professionals interested in professional and practice development issues for support purposes, networking and ultimately to influence practice throughout Scotland. <http://www.ppdf.org/>

Scottish Gerontological Nursing Demonstration Project

This pioneering project based at Glasgow Caledonian University aims to promote evidence-based nursing care with older people. The project also seeks to involve service users and practitioners in setting the practice development agenda. Website includes links to publications and best practice statements: <http://www.geronurse.com/>

Training programmes and teaching resources (general)

Action on Elder Abuse (see above)

AgeCare Awards

The AgeCare Awards programme is developing four levels or grades of award to cover the entire range of the sector's staff, from 'core skills' training (for care assistants and ancillary staff), through 'supervisory' and 'specialist' levels, to a 'higher practice' grade for physicians and senior managers. The Programme is fully compliant with TOPPS and CSCI requirements and courses are delivered through a series of structured workbooks, which are integrated with each home's own policies and procedures. The workbooks act as the portfolio of evidence needed to comply with NVQ requirements and thereby reduce substantially the administrative workload on candidates. The programme also allows for the use of alternative learning pathways, so staff with learning difficulties or whose first language is not English can access

training easily. All educational resources needed to complete the workbooks are supplied to each home as a core resource and ongoing support and advice is provided. See: <http://www.agecare.org.uk/>

Bridging the Gap between Learning and Practice: an action learning approach to improving care practice (see above)

Eating for Health in Care Homes: a practical nutrition handbook (see above)

Educating for dignity: a multidisciplinary workbook (see above)

Handbook for Care Assistants (6th edition)
Phair, L., Benson, S. (2003), Hawker Publications
A practical guide to working with older people. <http://www.careinfo.org/books/>

How to be a Great Care Assistant

Hawkins, R., Ashurst, A. (2006), Hawker Publications

This care assistant's guide provides the specific information needed to complete the Skills for Care common induction standards. <http://www.careinfo.org/books/>

Learning organisations: self-assessment resource pack (see above)

What Standards of Care Can People Expect from a Care Home? (see above)

Best Practice Statement: working with older people towards prevention and early detection of depression (see above)

Provision of Activities in a Care Setting

This is the first sector-driven distance learning course initiated by BUPA Care Homes, developed with the Activities Adviser for BUPA and in conjunction with NAPA. It is aimed at those involved in supporting the quality of life for older people in care settings. The course is designed at level 2, as a distance learning option, to increase the individual's knowledge and skills in organising and carrying out activities. Contents include:

- the value of an activity service
 - planning and developing an activity service
 - delivering activities
 - monitoring and evaluating an activity service
 - human ageing, health and illness (optional unit)
- <http://website.ncfe.org.uk/index.php/root/qual-details?scheme=NP00078NT>

Supporting good end of life

Identifying needs

Death, Dying and Bereavement

BVS Training pack (£125+VAT) video and CD-ROM
Contact: www.bvs-uk.com Tel: 0845 644 2866
More information at: http://www.bvs.co.uk/product.asp?strareano=PRODUCTCATEGORY_1&intelement=25

End-of-life Care: promoting comfort, choice and well-being for older people

Seymour, J., Witherspoon, R., Gott, M., Ross, H., Payne, S. and Owen, T. (2005), Policy Press, Bristol
Report of a research project exploring older people's views and opinions on end-of-life care.
Orders: https://www.policypress.org.uk/catalog/product_info.php?products_id=1070&PHPSESSID=3b6d1993518840a57be67e47e69e7789

Lighting Up Lives

A report of palliative care needs of people with end-stage dementia living in Dumfries and Galloway 2004–6.
<http://www.alzscot.org/downloads/lightinguplives.pdf>

Preferred Place of Care (PPC): a nationally recognised tool for palliative care

Produced in response to the NHS Cancer Plan (2000), this was originally designed as a measurement tool to evaluate the effectiveness of palliative care education for community nurses. The tool has been identified as helping professionals to record patients' wishes with respect to their place of care and death. See: <http://eolc.cbcl.co.uk/eolc>

Understanding Bereavement (see above)

Training for palliative care

Foundations in Palliative Care (see above)

Work-based Learning in Palliative Care (see above)

Co-ordinating palliative care

Audit Questionnaire for Palliative Care

Hockley et al (2004)
This questionnaire can be used by care home staff to assess the quality of palliative care within the home. See: http://www.elib.scot.nhs.uk/SharedSpace/ccln/Uploads/2007/Oct/20071009104143_audit%20palliative%20care%20questionnaire.doc

Gold Standard Framework (GSF) in Care Homes

The GSF national team is currently undertaking phase 2 of an action research study implementing and evaluating GSF within the care home setting. within 12 care homes nationally in 2004, evaluating the process and making recommendations for future development of GSF in care homes. Phase 2 began in June 2005 with approximately 100 care - homes (nursing) nationally implementing GSF through an action research and evaluation process with the national GSF team and the University of Birmingham. The plan was to develop a good practice guide at the end of phase 2 (June 2006)
http://www.goldstandardsframework.nhs.uk/care_homes.php

A briefing paper with guidelines for implementation is available at: http://www.endoflifecareforadults.nhs.uk/eolc/eolc/current/files/F2090-GSFCH-gold_standards_framework_Mar2007.pdf

Improving palliative care provision for older people in care homes

National Council for Palliative Care (2005), *Focus on Care Homes*. London, NCOP
Focus on Care Homes examines the learning from the 2004 NCPC discussion document 'Palliative care in care homes for older people' and the subsequent conference and multi-agency discussions which followed. It identifies present and potential challenges for the provision of palliative care in care homes and suggests actions to address these challenges. Orders: http://www.ncpc.org.uk/publications/pubs_list2.html

Joined-up Thinking, Joined-up Care (see above)

National Council for Hospice and Specialist Palliative Care Services

Organisation that promotes the provision of palliative care for all who need it by:

- identifying and developing policy proposals which enable improved palliative care and wider access to this
 - influencing the policies of the governments of England, Wales and Northern Ireland to this end
 - identifying good clinical and management practice and disseminating this widely.
- Further information: <http://www.ncpc.org.uk/index.html>

Collaborative working and networking

Care Provided by Generalists at the End of Life

This research summary presents an overview of a literature review and consultation exercise carried out to identify the current evidence base and priorities for further research to improve understanding of generalist care at the end of life (Higginson et al, 2007). Download summary at: <http://www.sdo.lshtm.ac.uk/files/adhoc/143-research-summary.pdf>

National Council for Hospice and Specialist Palliative Care Services

Organisation that promotes the provision of palliative care for all who need it by:

- identifying and developing policy proposals which enable improved palliative care and wider access to this
- influencing the policies of the Governments of England, Wales and Northern Ireland to this end
- identifying good clinical and management practice and disseminating this widely.

Further information: <http://www.ncpc.org.uk/index.html>

The Nursing Home Palliative Care Link Group

Run by Cheshire Hospices Education, the group provides educative seminars, online support and a place to link with other care home staff.

<http://www.che.org.uk/>

Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care is the national umbrella and representative body for palliative care in Scotland. Its charitable objectives are 'to promote, enhance, improve and extend the provision of palliative care services to patients suffering from life-threatening progressive conditions, for the benefit of such people and their families throughout Scotland'. It contributes to national thinking and policy in relation to palliative care, and promotes improvements in service delivery at local level.

Website: <http://www.palliativecarescotland.org.uk/>

St Columba's Hospice Bridges Initiative Project: Phase III Executive Summary

This project aimed to develop quality end-of-life care in eight independent nursing homes through the implementation of an integrated care pathway for the last days of life. Further information: <http://www.stcolumbushospice.org.uk/professional/research/bridges.shtml>

Care pathways

The Liverpool Care Pathway (LCP) for the dying patient

This tool was developed 'to take the best of hospice care into care for people in hospital and other settings including care homes.' It is used to care for patients in the last days or hours of life once it is known that they are dying. The LCP involves promoting good communication with the patient and family, anticipatory planning (including psychosocial and spiritual needs, symptom control and care after death). There are accompanying symptom control guidelines and information leaflets. Further information: www.mcpcil.org.uk/liverpool_care_pathway

Appendix II Notes on method

Introduction

The review of the literature for *My Home Life* was undertaken collaboratively by the National Care Homes R&D Forum (NCHR&D), led by Julienne Meyer (City University, London) and Belinda Dewar (Queen Margaret's University College, Edinburgh). It updates a previous review by Davies (2001) on the care needs of older people and family caregivers in continuing care settings, following the same methods, with one or two exceptions. Sue Davies (University of Sheffield) kindly shared her original database of references on quality of life/care in care homes (pre-2000), which was then updated (post-2000) by Belinda Dewar and Fiona O'May (Queen Margaret's University College, Edinburgh) and Jenny Dudman (freelance researcher), drawing in part on the AgeInfo database. The project team is most grateful to the Centre for Policy on Ageing for agreeing to give access to the AgeInfo database to NCHR&D Forum members for the purposes of this project.

Items for the review were identified from the fields of nursing, health, medicine, allied health, social gerontology, social work and psychology. Synthesis of this diverse literature focused upon the experiences of residents, family care-givers and staff in order to identify strategies which practitioners could use to enhance the quality of life of residents of care-homes, while also supporting care-givers in the most appropriate way. An appreciative inquiry approach was taken (Cooperrider et al, 2003) to focus on positive messages, rather than poor practice. Where possible, reviewers were asked to word their messages positively, identify examples of good practice and ensure the older person's voice remained central to the work.

Databases used

AgeInfo – covers old age and ageing

AMED – covers complementary ('alternative') medicine, palliative care, and several professions allied to medicine

BIDS – serves the academic community

BNI – covers UK nursing and midwifery

CINAHL – covers nursing and allied health

Cochrane Register – covers systematic reviews of evidence in health care

EMBASE – covers biomedical and pharmacological issues

Health Promis – covers health promotion

HMIC – covers health management and policy

HTA – covers effects of interventions used in health and social care

IBSS – covers social science and interdisciplinary research

Medline – covers life sciences and biomedical bibliographic information

NLH – covers evidence and best practice to support health care in the NHS

NRR – covers NHS research

PsycInfo – covers psychological literature

PHeL – covers public health

REFER – covers findings of research funded by Department of Health

Dates searched

Focus was on 2000–5 as researchers already had access to literature prior to 2000.

Search terms used

quality of life

older people

long-term care

care homes

nursing homes and residential homes

dementia

end of life

Approach taken

All items retrieved were entered on to a database, Reference Manager. The abstract for each item was scrutinised and key themes and concepts identified, in the context of Davies' earlier (2001) review. Material that was obviously not relevant to the focus of the review was eliminated at this stage. The following themes emerged:

- quality of life
- quality of care
- transition into a care home
- working to help residents maintain their identity
- creating community within care homes
- shared decision-making
- health and care responses
- end-of-life care
- keeping the workforce fit for purpose
- promoting positive culture.

Cross-cutting these themes were the notions of impairment (physical and mental) and the older person's 'voice'.

The identified themes were circulated to the NCHR&D Forum and members volunteered to review the articles in relation to a particular theme, the result appearing as a chapter in the final report. An additional chapter on the background context for care homes was written by Hazel Heath and Jenny Dudman. A draft of the final report was circulated to NCHR&D Forum for critical comment. In addition, contributors were asked to highlight examples of best practice and to identify any related education and training material, linked to the themes. Finally, to ensure consistency across the final report, Hazel Heath (freelance researcher) was employed to edit the document as a whole. In total, 57 different academic experts contributed to the final document, which was then circulated to a wider range of stakeholders (My Home Life steering group) for further comment.

References

Davies, S (2001) The care needs of older people and family caregivers in continuing care settings, chapter 5, In M Nolan, S Davies and G Grant (eds) *Working with older people and their families*. Milton Keynes: Open University Press

Cooperrider, D L, Whitney, D L, Stavros, J (2003) *Appreciative Inquiry Handbook: the first in a series of AI workbooks for leaders of change*. Lakeshore Communications

Prepared by the National Care Homes Research and Development Forum, this review of the available literature on care homes collates research and experiential evidence from many stakeholders on practice and other factors that impact upon the quality of life of older people living in care homes. It offers a wealth of information, analysis, comparison and valuable insights on best practice to all those involved with the residential care of older people.

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