

My Home Life

Quality of life in care homes

Introduction

The *My Home Life* report has been produced as part of an exciting new programme of the same name. Both are part of a concerted drive to improve the quality of life of older people in care homes, by creating support for practitioners and accessible tools and information resources for care-home managers, staff and commissioners which can be used in their daily work.

This report is a result of a partnership between Help the Aged, the National Care Forum and the National Care Homes Research and Development Forum in collaboration with older people and representatives from the care-home sector. Based on both research and the testimonies of service users, the *My Home Life* report provides a vision for improving the quality of life of care-home residents and highlights the specific practices, behaviour and attitudes which impact on their quality of life.

This report is a starting point for a movement among all those who believe that people's value and individuality should not diminish as a result of their need for care and support. The vision is about ensuring that people's higher human needs for enrichment, fulfilment and recognition are met in care homes. It is also about offering care-home residents the opportunity to live a life that has



meaning and purpose. This is the antithesis of the kind of process-driven care which pays no attention to individuals' needs, wants, tastes and preferences.

Equally, it is important to recognise and value those that work most closely with older people. Help the Aged believes that the only way to realise the vision is through positive action, involvement and partnership, and by regarding care homes as a positive choice for many older people. Crucial to this is our belief that the care home needs to become a community of those who live there, those who work in it and those whose relatives or friends are residents. Care homes also need to be recognised as being a part of the wider community and valued for the vital role that they play.

Key points from the *My Home Life* report

What does quality of life mean to residents in care homes?

- Quality of life is complex and depends a great deal on how individuals view what makes life enjoyable, meaningful and worth living for them. This means that staff have to ignore stereotypes and disregard assumptions about what older people want and listen to what they say they want – a preferences perspective rather than a needs-based view.

Moving into a care home

'I have lived in this residential home for two years . . . I have now rebuilt my life, thanks to the proprietor and staff. I now want to put the past behind me and live in the present and live as active a life as possible'

- Moving to a care home is a major, often final, transition in life and may involve considerable losses. While such a move often has negative connotations, if properly planned and managed it may bring benefits and a better quality of life.
- A positive change can be enabled in various ways: avoidance of pressure being brought to bear on the older person; ensuring that the decision about where to live is a joint one between the older person and his or her relatives; providing relatives and the prospective resident with adequate information; and allowing the older person to retain control over decision-making.
- Moving to a care home should be considered as much an opportunity to realise new opportunities and challenges as the result of some sort of loss of independence or declining health.



Retaining a sense of identity

'It is important for people to realise that what may seem a small matter to the management of the organisation is of great importance to some of the people's experience of living in a place. Everyone has different standards and tastes, but knowing the individual and their ways is helpful'

- Maintaining a sense of identity is linked with self-esteem and perceptions about the quality of life. Living in a care home can undermine that sense. Person-centred care is essential to helping residents retain a sense of identity.
- Many practices can be adopted to assist maintaining a sense of identity. They include reminiscence work; finding out what older people want from their lives and helping them achieve it; ensuring that staff rotas do not militate against staff and residents making personal relationships; ensuring residents exercise their preferences about how they dress, what they bring into the home, and the small things that make life worth living; letting residents take on some of the tasks of the home or showing around visitors; seeing that residents take part in activities which are tailored to their needs and preferences and offer a link back to their past lives. Spiritual needs should be recognised, as should ethnic and cultural needs. Space should be provided for intimacy and privacy for couples.

From 'home' to 'community'

'When I was not well one day, a lot of residents came up to see me as they missed me and visited me. It has helped. It is the other residents and staff together – everybody. I have more friends here'

- Rather than trying to make care homes more home-like, care homes can be created as communities. This allows reciprocity of relationships and the opportunity for those residents who are able to (and choose to) to contribute to the care home.
- Evidence shows that relationships between staff, residents, family, friends and the wider community are the most important factor in determining the quality of life of residents. Continuity of staff, good communication, staff responsiveness, dependability, trust and a degree of personal control by the resident will all help improve the quality of life of residents.
- Staff can help residents who want to have relationships with fellow residents but who find it difficult – perhaps as a result of sensory impairment, for instance.
- Most family members are keen, often desperate, to maintain their relationship with a relative in a care home. They can make a vital contribution to humanising and personalising residents' lives.
- Families who feel secure in their relationships with staff are more likely to be involved in the home.



Creating opportunities for meaningful activity

'You get everything done for you here, but I think it is inclined to make you lazy. I would love to be working. I would rather cook for myself but you are not allowed in the kitchen, and you are not allowed in the laundry either'

- Recreation, social and community activities and personal development are key factors for everyone and contribute to health and well-being among older people even where there is advanced frailty.
- Activities must be tailored to suit individual needs and preferences.
- Increased frailty should not mean that residents cannot participate in activities if they wish to do so. However, one-to-one rather than group or structured activity is likely to be more suitable for some.
- Residents often feel that they wish to 'feel useful' and should be encouraged to make use of the skills and experiences that they bring to the care home. Opportunities for residents to learn new skills should be encouraged.
- The world outside – NHS, social services, community groups, schools – needs to engage with care homes and offer support in the provision of activity.

All in it together: shared decision-making in care homes

'There is a lot of expertise among us [residents] but the skills that we have developed in our lives are completely wasted . . . There are a lot of things that residents could share if given an opportunity'

- The wish to be involved in decision-making is likely to vary from one individual to another but where it is desired residents should be encouraged to participate in all aspects of decision-making in the care home.
- The fact that a resident has severe cognitive impairment does not mean that his or her views should not be sought, although it can be challenging to know how to do so.
- Staff and relatives need to appreciate the fine balance between rights and risks that will have to be borne in mind in any decision-making process. However, there is evidence that doing everything possible to eliminate risk can act against quality of life

A healthy outlook: the place of health and social care

'It was useful to have access to a physiotherapist or occupational therapist when I needed it to help me with my mobility to enable me to be independent and to keep my confidence'

- Health is an essential ingredient of quality of life.



- Doctors, other professionals and specialists who work with older people are often not providing sufficient support to care homes.
- There is evidence that some care homes pay for services provided free by the NHS to other individuals who receive care in other sectors.
- Care-home staff, GPs and GP practices should work in partnership to ensure that residents' health is viewed holistically.

Last rights: care at the end of life

'Death is such a taboo subject. It's a big problem because all of us are so near to death. By 90 you can't get much nearer without knowing that it is around the corner, and we need to be able to express that sometimes if we want to.'

- The nature of ill-health in older age can make it difficult to define at what point someone is dying.
- Standards for those who are dying in care homes are vague and reflect society's reluctance to face mortality.
- A culture needs to be developed that gives value to a person's dying as well as to their living.
- There needs to be much more openness and awareness about end-of-life care. Death and dying should not be denied or hidden in a care home.



- Staff need to be aware of what they can do. This includes being aware of their own attitudes; recognising the values of palliative care; being open in communication; supporting families who have a dying relative; ensuring that the dying person is not left alone; supporting other residents at this time; supporting fellow staff.
- Annual services of remembrance for those who have died in the past year can be held and relatives invited. Homes could be made available to host receptions after funerals, which would allow other residents to attend.

Accentuating the positive: toward a new culture

'Several staff have been here for a very long time, even past retiring age. They're incredible. They are rare people who see it as a life job really worth doing. It's extraordinary to be able to do it for as long as that'

- The culture of a home directly affects the quality of life of its residents.
- A positive culture is one where the ethos of care is built around the resident and is based on evidence. Effective leadership and management and the availability of expert advice is paramount in the creation and maintenance of a positive culture.
- The emotional health and well-being of staff has a direct impact on both team performance and the quality of life of residents.

- The prevalent model in care emphasises the debilitating effects of old age where staff take on the role of custodians who 'do things to' residents. This devalues staff as much as residents. A more positive model is one which emphasises personal growth for residents and staff with a shared commitment to ideas, values, goals and management practices by residents, staff and relatives.
- Training and practice development are important in improving the culture of a home and have a positive impact on matters such as staff absenteeism, sickness, injury, morale, job satisfaction and teamwork.
- Training should be provided for the whole workforce rather than individuals being sent on specialist courses leading to qualification.
- Care homes and local institutions of higher and further education need to work together and recognise that care homes can be learning environments for staff and students.
- Moving away from a task-based care system allows the development of emotional care, which is especially important for those working with people who have dementia.
- Staff need space for reflection, as well as recognition for what they do from other staff, residents and relatives.

To obtain a copy of the report *My Home Life: quality of life in care homes*, please contact Jo Edler at joanna.edler@helptheaged.org.uk or 020 7239 1881.



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Help the Aged, an international charity fighting to free disadvantaged older people from poverty, isolation and neglect. Help the Aged campaigns for change in government policy, undertakes research into the needs of older people and provides local services in communities across the UK and overseas.

National Care Forum, established in 2003 to represent the interests of not-for-profit health and social care providers in the UK. The organisation, building on ten years' experience as the Care Forum, is a leading voice in its sector, representing the views and concerns both of carers and cared-for. It promotes the benefits of the not-for-profit model of care services provision to local and national government, as well as to consumers and other healthcare bodies.

The National Care Homes Research and Development Forum, established in 2003 to facilitate contact between researchers and practitioners involved in care-home work. It focuses on a common theme in members' individual work: the desire to make a difference to experiences of those who are living and working in care homes, to which end its 59 members have voluntarily shared their knowledge and expertise to inform this report. These contributions include articles, reports and databases of reference material, authorship of sections and critical reading of draft material by an expert panel.

WE WILL fight to free disadvantaged older people in the UK and overseas from **poverty, isolation and neglect**

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