

# MY HOME LIFE: PROMOTING QUALITY OF LIFE IN CARE HOMES

My Home Life is a collaborative initiative between Age UK, City University, Joseph Rowntree Foundation and Dementia UK. It promotes quality of life in care homes.

## What's the issue?

The care home sector will play an ever-increasing role in supporting older people with complex health and social care needs. Policy across all four UK nations has emphasised the need for older people to have voice, choice and control over their lives. Yet there remains a lack of real understanding as to how to make this happen in care homes.

## Ways forward

- Positive relationships in care homes enable staff to listen to older people, gain insights into individual needs and facilitate greater voice, choice and control. Relationship-centred care is at the heart of many examples of best practice.
- Care home managers play a pivotal role in promoting relationships between older people, staff and relatives. With ongoing professional development and backing from colleagues across health and social care, managers can create a culture of greater spontaneity and responsiveness where positive, informed risks can be taken within a structure of safety and accountability.
- Care home providers and statutory agencies should consider how their attitudes, practices and policies can create pressure and unnecessary paperwork which ultimately reduce the capacity of care homes to respond to the needs of older people.
- Achieving quality in care homes requires a partnership approach. Statutory bodies should work with care homes to agree a vision and identify supportive ways of working based upon mutual trust. Involvement from the local community, including advocacy projects and volunteering, can enhance voice, choice and control for older people.
- Negative stereotypes of care homes have an impact on the confidence of staff and managers. My Home Life partner organisations should consider how they can encourage more fair and balanced press coverage.

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# BACKGROUND

Care homes across the UK face the challenges of rising demand and increasingly complex needs amongst older people, against a backdrop of changes and cuts in the health and social care system. Policy and regulatory standards have emphasised the importance of involvement and choice for service users.

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This three-year action research study, led by My Home Life (MHL), draws lessons from best practice in care homes, particularly in promoting voice, choice and control for older people and developing leadership in the care home sector.

## Social and political context

There are over 18,000 care homes across the UK, supporting approximately 400,000 older people. While the majority are privately owned, care homes vary significantly in terms of size, specialism, structure and funding. Demand for places is predicted to increase in coming years, with a growing number of older people experiencing multiple co-existing conditions.

Care homes are subject to continual changes within the policy environment. Since the new millennium, there have been at least ten new UK public general acts relating to health and social care. Care homes have also had to cope with significant cutbacks in public spending.

Over the past decade, policy and regulatory standards in England, Wales, Scotland and Northern Ireland have all made some reference to user involvement and choice for service users. The general policy stance appears to infer that real choice and control is best delivered by supporting people to remain independently in their own homes for as long as possible, with care homes often being perceived as a 'last resort'. This stance, coupled with news coverage of poor practice in care homes, has impacted on the status and confidence of the care home sector.

## What is 'voice, choice and control'?

Exploring voice, choice and control in an abstract way is potentially problematic, as everyone has their own wants and needs. National Development Team for Inclusion (NDTi) and the Centre for Policy on Ageing has identified key domains over which older people value having choice and control: personal identity, relationships with others, meaningful daily life, home and personal surroundings, transport and mobility, support and care, and income and finances. Older people need to have their views and experiences taken into account on an ongoing basis to have real choice and control in decisions that affect them.

The research team for this study propose that the principles of voice, choice and control align well with the three MHL personalisation themes, developed to encourage a more relationship-centred approach in care homes:

- Maintaining identity: 'See who I am!'
- Sharing decision-making: 'Involve me!'
- Creating community: 'Connect with me!'

Older people need to be seen as individuals and given a 'voice' to express who they are and what they want (maintaining identity). Equally, there needs to be more than one way of doing things (choice), especially in situations of collective living, and older people need to have 'control' over what is the right option for them (sharing decision-making). To enable older people in care homes to have voice, choice and control, interpersonal relationships need to be good between older people, their relatives and staff in the care home, and between the care home and the local community and wider health and social care system (creating community).

## Good practice in care homes

The MHL project team gathered hundreds of positive examples of practice from care home practitioners across the UK. Some of these are presented on the MHL website: [www.myhomelife.org.uk](http://www.myhomelife.org.uk). It should be noted that the MHL team do not make any comment on how prevalent or not good practice is in care homes.

### **Maintaining identity: 'See who I am!'**

Care homes are uniquely placed to help older people maintain their personal identity because staff have the opportunity for regular interaction and engagement with the older people they are supporting over a sustained period of time. This is particularly relevant where older people struggle to articulate their views and needs due to mental and physical frailty or low self-esteem.

The examples gathered showed how older people have been supported to regain a sense of identity which may have been lost when they were living in isolation, with profound frailty, at home. Contrary to the assumption that care homes restrict the choices of older people, examples indicate that many care home staff are making significant efforts to ensure they understand what is important to older people and explore how they can accommodate individual needs.

### **Sharing decision-making: 'Involve me!'**

Different approaches exist to involving older people in decision-making, both in relation to their own care and the running of the home. Creative and informal approaches, such as shared meal times between residents and staff, were seen to have particular value in engaging older people. Though widely used, it is questionable to what extent consumer surveys offer older people any real control over the running of the home, particularly given that the surveys may be problematic to complete.

A long list of day-to-day jobs in care homes can result in a focus on tasks and not on the individual older people themselves. That said, managers can be effective in supporting staff to ensure that routine tasks revolve around the choices of older people, rather than the other way round.

Exercising voice, choice and control typically involves older people considering the inherent risks involved in any activity. Where older people are unable to make an informed judgement, staff have to balance the self-determination of individuals against the potential risks involved.

Examples show staff striving to work in the best interests of the older person, even where family members or external professionals may disagree with decisions. Staff need to feel confident in standing up for the wishes of the older person. Where care homes adopt a philosophy that 'anything is possible', they are more likely to identify practical strategies for supporting older people to make choices.

### **Creating community: 'Connect with me!'**

The MHL evidence base demonstrates the importance of relationships both within the care home and between the care home, the local community and the wider health and social care system in enabling older people to gain choice and control. Plenty of examples exist where older people are supported to engage in external community activities and where others are encouraged to come into the care home to engage in meaningful activities.

Volunteering in care homes is in many ways a 'forgotten' area. Sufficient time to recruit and support volunteers, having an external co-ordinator and simpler, speedier Criminal Records Bureau checking were all seen as valuable.

Community advocacy and befriending projects can also play a positive role in supporting older people's voice, choice and control. However, this depends on there being good relationships with care homes in place. If advocacy and befriending services are offered in a short-term and piecemeal way, then they have limited impact on the older person's sense of self-determination.

## **Areas where voice, choice and control is particularly important**

### **Managing transitions**

For some older people, the move to a care home may be associated with a loss of control and restriction of life choices. Yet the evidence suggests that life in a care home can actually open up more choices, perhaps because living in one's own home has become more and more restrictive due to physical or mental deterioration. The MHL study received many examples where older people appear to have regained purpose and confidence by moving into a care home and overcoming the social isolation that they had experienced at home.

### **Improving health and healthcare**

The good practice examples demonstrated how some care homes are actively advocating for older people when negotiating with health professionals about how and where care will be delivered. There is evidence that care home staff do challenge nurses, GPs and social workers where a decision may not be in the best interests of the older person. There is also evidence of how care homes can work with health practitioners to reduce the use of sedatives and in so doing, enable older people to be more capable of expressing their views and their choices.

## Supporting good end-of-life

Ensuring that older people are in control of the last days, weeks and months of their lives is vital. That said, opening up conversations with older people and their families about the end of life can be very challenging. A number of managers recognised the importance of identifying points in time when an older person appears to want to talk about dying, rather than simply approaching people with a checklist.

## Challenges of supporting voice, choice and control in care homes

### Unwillingness of older people to 'speak out'

Bowers *et al.* (2009) argue that, following a move into care, older people will encounter a power imbalance which means they are seldom in control of their decisions, personal arrangements or finances. Testimony from Advocacy Plus, an independent advocacy organisation for older people operating in Westminster, Kensington and Chelsea, suggests that older people (particularly those living in care homes) are often unwilling to speak out or 'make a fuss' about issues that concern them.

This notion of acquiescence amongst older people is neither a new nor uncommon phenomenon. A tendency not to speak out may be attributed to a number of factors: an unwillingness to complain, fear of repercussions, the idea that service providers are 'experts,' and a belief that no one will listen or that the situation cannot be changed (Hollingbery, 1999).

### The burden of paperwork

The various bodies and agencies involved in the care sector appear to require an enormous amount of paperwork, with care homes expected to respond to the needs of many agencies including: NHS and local authority commissioning, regulation, social work assessment and reviews, health and safety assessment, coroners' investigations, fire service requirements and agencies' safeguarding protocols, training requirement and continuing care assessments.

Managers have argued strongly for a reduction in the sheer volume of paperwork that they need to read or complete on a daily basis. This would give them more resilience and time to work directly with their staff to support the development of practice.

### Lack of trust and support for managers

Negative portrayal of care homes in the media has an impact on daily work, reducing staff morale and making managers feel mistrusted. Managers worry about the potential repercussions of making decisions that may not be viewed as appropriate by the outside world, even if these decisions are in response to the interests and needs of older people.

Constant bombardment from external bodies, lack of trust and support from both within and outside of the care home, and the fear that they might make a mistake, can all result in managers leading care homes from a position of defensiveness, stress and anxiety. Trying to control everything that is going on in a care home goes against the evidence of what constitutes good leadership, often resulting in staff simply taking orders from managers and a focus on getting tasks done.

A study undertaken for Social Care Institute for Excellence (SCIE) on 'Managing risk and minimising restraint' notes how decisions made in the best interests of the older person require negotiation skills, creativity and resilience (Owen and Meyer, 2009). Care home managers argue they need to feel less threatened and blamed by external agencies when considered risk is taken and things go wrong.

### Staff motivation

Given the limited status and pay of staff working in care homes, and the physically and emotionally exhausting nature of the work, it is perhaps no surprise that staff problems have been identified as a key obstacle to delivering a positive, enabling culture. Managers often expressed distress and frustration in relation to a lack of initiative amongst staff, or a failure to listen. In extreme circumstances, a culture of rules and inflexibility can be manifested as bullying in the workforce.

## Enhancing voice, choice and control in care homes

### Relationship-centred care

Recognising the challenges involved, the good practice observed in this study indicates that care homes can create a culture of practice where older people, their families and staff are supported to develop positive relationships with one another (relationship-centred care), to interact and explore ideas together in an informal way. Through this culture, staff are more able to connect with older people, to engage with them as individuals, to understand and respond to their interests, opinions, aspirations and needs.

Relationship-centred care is different to person-centred care, which focuses on individual service users, promoting their independence and consumer choice. MHL argue that, in long-term care settings, positive relationships between older people, relatives and staff and interdependence matter more.

Positive relationships were found to underpin much of the good practice observed in the MHL study. Where these relationships are absent, residents are at risk of being unseen, unheard and treated as 'objects of care', rather than active participants in decisions that affect them. Where there is a community that supports older people, relatives and staff, a greater connection is developed through which choice and control can be realised. This finding is not new; it reflects a strong body of knowledge surrounding relationship-centred care (Nolan *et al.*, 2006).

### Leadership in care homes

The literature on leadership in care homes also highlights the importance of positive relationships, valuing different perspectives and fostering creativity, learning and innovation. There has been increasing emphasis within policy on better leadership in social care, to deliver more personalised services. In reality, the proportion of care homes that actively engage in programmes and courses to support leadership appears to be limited.

The MHL study identified key outcomes of good leadership in the care home sector. These included a confident and stable workforce and an environment of spontaneity and responsiveness in which positive, informed risks could be taken within a structure of safety and accountability. Good leadership was also seen to support greater community involvement (family, friends, the public, etc.) and a more vibrant community of older people who felt valued. Study participants were asked to identify crucial factors that led to these positive outcomes. The following themes emerged:

- **Leadership starts at the top:** If senior managers feel empowered, safe and supported from the top, they are more likely to mirror this and communicate their confidence at a lower level with staff – who are then likely to mirror this with older people living in the home and their relatives.
- **The importance of transformational leadership:** Transformational leadership involves valuing individuals, networking, enabling, acting with integrity and being accessible and decisive. This model embraces concepts of 'dispersed leadership', in which leadership is spread throughout an organisation, and 'servant leadership', where the role of the leader is to understand what staff need to be successful and do everything possible to enable this (Buchanan *et al.*, 2007; Blanchard, 1999).
- **Getting the right staff:** Recruitment of the right staff is critical in care homes, though not easy given the complexity of the roles and minimum wages being offered.
- **Helping staff to engage with their work:** Giving staff regular opportunities to reflect on their work individually or as a team helps them remain engaged, valued and listened to.
- **Supporting staff and role modelling:** Managers can model the type of behaviour they expect from staff and support them to actively listen to what older people are saying and take the initiative in responding to their wishes and aspirations.
- **Making the environment more conducive to relationship-centred care:** Creative thinking about physical space – the configuration of armchairs in a lounge or layout of the manager's office, for example – can support relationships in a care home.

MHL has supported over 250 care home managers through its Leadership Support Programme. This programme was developed to support groups of between 12 and 15 care home managers in a 'journey' of positive culture change, through leadership skills training and 'action learning sets'. Feedback from participants mentioned the value of having a safe place to learn and reflect, increased resilience at work, changes in leadership style and better relationships across staff and residents.

### Partnership working

Quality of life and care for older people in care homes requires the support of external community, health and social care agencies. In the MHL study, managers described how difficult it was to transform the culture of a care home when owners, providers and the wider system were not supporting them to deliver relationship-centred care.

A major strand of activity within the MHL Leadership Support and Community Development Programme was to support better partnership working between care homes, the health and social care sector and the wider community to work on issues of mutual concern and help reduce some of the obstacles that care home managers face. The approach adopted varied according to the issue being tackled. In some instances, MHL shared particular concerns raised by care home managers informally with officers who held some level of responsibility within the relevant local authority or primary care trust. In other areas, MHL held discussions with groups of stakeholders (commissioners, contract officers, quality monitoring officers) to help them reflect on how their practices and attitudes could result in high levels of stress for care home managers. There was recognition that 'monitoring' in itself does not necessarily improve the quality of care.

MHL also brought together care homes with practitioners from the wider health system to explore better ways of working in improving the transition between hospitals and care homes. Such events provided an opportunity for these participants to begin to build trusting relationships with one another to support future partnership working.

MHL community development work also aimed to strengthen relationships between care homes and the wider community, for example: a joint project between schools, care homes and a local radio station; music and art workshops bringing children and local choirs into care homes; plans to involve sixth-form students and university students in specific projects; and awards for members of the community who have undertaken significant work supporting older people.

## Recommendations

Recommendations from the MHL study prioritise nurturing positive relationships in care homes, supporting transformational leadership, supporting voice, choice and control, strengthening partnerships and challenging negative stereotypes of care homes.

Care home owners and providers should:

- give care home managers regular opportunities for professional development and support, allocating specific time and budgets for training, mentoring and practice development;
- reflect on how their actions, policies and behaviours can impact on the manager's wellbeing and ability to deliver improvements within the home;
- plan changes to the organisational culture to enable relationship-centred care to flourish;
- give staff 'protected time' to foster positive relationships with, and greater knowledge about, residents and family members;
- ensure that internal paperwork is proportionate, relevant, streamlined, user-friendly and non-intrusive.

Care home managers should:

- take responsibility for their own ongoing practice support and professional development, recognising the value of regular, facilitated learning to help them cope with the pressures of the job and make improvements;
- learn about and share best practice on transformational leadership and relationship-centred care;
- consider what measures may be necessary to afford real power and control of decision-making to older people, their families and those who work closest with them;
- pilot more creative approaches to engaging the views of older people, including informal opportunities for older people to engage in dialogue with staff.

Commissioners and regulators should:

- consider introducing mechanisms to encourage or require providers to give managers regular access to external sources of support and practice development (e.g Quality Assurance Frameworks currently being developed by many local authorities);
- consider the value of partnership programmes such as MHL in offering an affordable approach to reflective learning and professional development for care homes;
- recognise the importance of providing more individual tailored support to older people and their families to cope with the practical and emotional upheaval of moving into a care home;
- consider developing a specific post to help older people within hospital and community settings make decisions about their futures;
- assess the resource implications for care homes of introducing any new requirements in terms of additional paperwork or changes in requirements.

The Government should:

- invest in helping care homes to develop new approaches so that older people can influence strategic and operational decisions within care homes;
- commission schemes aimed at delivering long-term community or volunteer advocacy for older people in care homes, so they can feel more confident in sharing their views and concerns without fear of reprisal (in line with recommendation 43 of the Commission on Dignity in Care for Older People report [2012]);

- consider the costs and benefits of reducing the duplication of paper-driven systems used by agencies that work with care homes;
- review how sharing information across agencies could release resources back into the services and reduce the time that care home managers spend on paperwork.

Statutory agencies (including Health and Wellbeing Boards) should:

- work in partnership with care homes to develop a shared understanding of what is and is not acceptable in relation to positive risk-taking for older people;
- support care homes to develop stronger links with the community by brokering Criminal Records Bureau clearance and providing advice on supporting volunteers;
- work in partnership with care homes to agree on a shared evidence-based, relationship-centred vision for quality in care homes and use this to identify collaborative ways of working;
- create regular practice forums to enable communities of practice across health and social care to develop partnerships based upon mutual trust and collaboration;
- actively encourage and support care home managers and operators to participate in local structures and processes for dialogue between care homes and across health and social care;
- oversee commissioning arrangements to ensure that care homes are actively engaged as equal partners in exploring ways to meet the needs of older people.

Agencies responsible for local safeguarding should:

- review their processes and practices to minimise the anxieties and stresses experienced by the community of the care home, and improve their capacity for relationship-centred care;
- agree safeguarding processes which are proportionate to the issue being raised, within a no-blame culture;
- make decisions as quickly as possible;
- value care home managers as colleagues who are making complex professional judgements that need support rather than investigation.

MHL partner organisations should:

- promote care homes as a positive option for older people by supporting ongoing work to identify and share good practice through bulletins, videos, website and other communication vehicles;
- counterbalance some of the negative stories within the press which reduce the value, status and, ultimately the capacity, of care homes to deliver voice, choice and control;
- develop a strategy for encouraging more fair and balanced reporting of care homes in the media.

## Conclusion

MHL has worked at a national and local authority level with care homes, statutory bodies and community organisations to identify what works well in relation to leadership and supporting voice, choice and control in care homes. The main message from this work is that good practice in care homes recognises the importance of relationship-centred care and transformational leadership.

Care home managers need ongoing professional support to help them promote positive relationships between older people, staff and relatives. When managers have the backing of practitioners and professionals from across health and social care, they feel more confident, more resilient and more able to create an enabling and supportive culture of practice for their staff, older people and their family members. The current reality for many care home managers is that this trust and support is often absent.

Achieving voice, choice and control is more complex in a setting of collective living, where the needs and aspirations of individuals have to be negotiated in the context of the needs and aspirations of the wider community within the care home. Staff levels cannot typically offer one-to-one support to older people. However, the evidence from this study questions the assertion that care homes, as a model, cannot offer the sort of opportunities that older people need to have a voice, and real choice and control, in relation to the things that are important to them. With greater levels of staffing and investment, care homes will be better placed to understand and act upon the wishes and aspirations of older people.

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## About the project

This report provides an account of a three-year action research study (2009–2012) to explore the lessons learnt from implementing best practice in care homes for older people and, in particular, in taking forward work to support the promotion of 'voice, choice and control' and 'the development of leadership' within the sector.

The work was carried out by the My Home Life programme; a UK-wide collaborative initiative led by Age UK, in partnership with City University, Joseph Rowntree Foundation and, more recently, Dementia UK.

A range of resources can be found at: [www.myhomelife.org.uk](http://www.myhomelife.org.uk)

## FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF.

The main report, My Home Life: promoting quality of life in care homes by Tom Owen and Julianne Meyer, is available as a free download at [www.jrf.org.uk](http://www.jrf.org.uk)

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