

# Finding out what determines 'a good life' for older people in care homes

Findings  
Informing change

November 2009

This study examined the experiences and aspirations of older people living in residential and nursing care homes. It highlights their ambition to increasingly influence decisions about care, support and wider issues such as whether or not to move to a care home, what helps to enhance their quality of life, and what is needed to promote their inclusion in care home, family and wider community life.

## Key points

- The voices of older people who need a lot of support are largely absent; other people (professionals, families) speak for them.
- Older people most often move to a care home as a result of crisis, with no preparation and little or no planning. Most do not choose to be there.
- The circumstances that prompt a move into a care home are often not addressed in the home. People (older people and family members) are left to make the best of their new situation.
- Older people are perceived as commodities, not as consumers or citizens with rights, entitlements or purchasing power.
- Older people who need a lot of support are seen as a burden, with little or no expectation of a fulfilling life. Care homes focus on physical support through decline.
- Within the present system, some care homes are introducing small quality improvements. There is also evidence of a focus on structural change. Neither approach is sufficient to properly support the huge life changes involved, nor to promote positive life chances for older disabled people.
- When older people need a lot of support, organisational, policy and social responses remain deeply problematic. Substantial cultural and value changes are required to improve their quality of life.

## The research

By researchers at the National Development Team for Inclusion

# Background

Approximately half a million people live in care homes (the vast majority of whom are older people) but users are reputed to have little choice and control. The Joseph Rowntree Foundation (within its Independent Living Programme) is looking at key areas in the social care system to see if barriers to 'person-centred' support can be challenged and overcome.

This study specifically sets out to describe good practice that exists or could be put into practice to build a positive and aspirational vision of 'a good life' for older people with high support needs living in care homes. At the same time it recognises the reality of most people's lives, and the capacity of the care home sector to deliver this vision.

The research team met with over 200 people including 84 older people living in care homes, extra care housing and supported family placements – quotes in this paper are all from older people living in care homes. Researchers and older people worked side by side, which allowed very different conversations to be held covering a range of experiences and support needs, including dementias. Commissioners and providers of local services, user and carer organisations, policy makers, academics and others with an interest in this area were also consulted.

## Lack of a voice for older people with high support needs

There are assumptions (after decades of research and practice knowledge) that professionals know what older people need if they require a lot of support in their daily lives.

However, in the course of this study it became clear that the voices of these older people are so quiet as to be practically absent from discussions about their requirements and importantly their preferences and priorities. Professionals, relatives, commissioners, policy makers and politicians are those who most often speak on behalf of older people, and it is their voices that dominate in these debates. The evidence from this study is that:

- Many older people in residential, nursing care and extra care housing are living in situations that are not easy to talk about.

- Some have experienced frightening and difficult times: moving into residential care as the result of sudden illness or disability; being moved quickly without advance preparation; or not returning home from hospital before moving.
- A care home is an environment where, despite good intentions, there is a great imbalance of power between the residents and those providing care or support to them. This power imbalance can also arise when older people receive a lot of support at home. The central issue is the nature of the care/support: whether it is enabling or disabling; who delivers it; and their relationship with the older person.
- Low self-esteem amongst older people living in different kinds of supported accommodation (care homes, extra care, adult placement schemes) is a huge and multifaceted issue. Participants in this study had very low expectations of their quality of life, their surroundings, and themselves.
- Low expectations of a fulfilling life were also evident among those speaking about or on behalf of older people with high support needs. Their thinking is equally institutionalised. They are unable to imagine a different type of support from that currently offered.

**I wouldn't tell anyone if I was depressed – just get on with it – which happens quite a lot.**

## Reasons for moving into care

A range of situations, events and circumstances lead older people into care, including:

- bereavement;
- concerns about health;
- poor or unsuitable housing;
- inadequate or unsatisfactory care or a breakdown in care arrangements at home; and
- other people's concerns and anxieties for their relatives'/ friends'/ patients'/clients' wellbeing, safety and protection.

It is very common for decisions to be made quickly and for events to develop at high speed when options for intensive support are being discussed – especially at times of crisis. Points of no return are reached rapidly, for example properties are sold, making it impossible to provide support at home.

**I came here eight years ago. My sight was deteriorating, bad arthritis, wasn't coping – my social worker bullied me into coming here.**

Many of the older people who took part in the research did not want to end up living in a care home. Their situation had most commonly come about as “a last resort” because few options or alternatives exist, or because people didn’t find out about them before moving.

**I didn’t make a conscious decision – I think I would have said I’d go home if anyone asked. Mind you I had the stairs and the bedroom was upstairs.**

## Problematic policy and practice

A key finding when reviewing reasons for moving into care is that it is usually other people (families, GPs, social workers) who are in control of older people’s decisions, arrangements and financial transactions at this critical period in their lives – and this situation does not change once people have moved into a care home.

Many older people in the study were trying to “make the best of it” in their new circumstances and they shared their stories about what helps them to do this, and what prevents them from doing so. Only a small number of people said that the change had been positive.

This third-party decision-making on a major life change seems to be acceptable only for older people. There is no current equivalent of this fast-track path into a care home among other groups of people needing support. The world of alternative and creative support has moved ahead much further outside the sphere of older people’s long-term care services than within it, and there are increasingly many more support options available to other groups.

**A fall whilst in hospital led to my GP deciding I should not return to live alone in my house**

**I didn’t know about the home... but my daughter had enquired in other homes but found this one more acceptable for me**

## Dominance of money and market factors

It is clear from the study findings that older people with high support needs (in general) and the resident population of care homes (in particular) are regarded as and treated like commodities, not consumers with rights, entitlements or purchasing power. This became clear in discussions about money (what people are eligible to receive) and in the way that funding and market factors dominate discussions of long-term care (rather than a focus on older people’s lives).

**I had to sell my flat to pay for X care home so now I haven’t got any choice – this is my home because it’s all I’ve got left**

## No strong vision of a good life

An understanding of and focus on voice, choice and control – on self-determination and individual human requirements – is missing at all levels for older people with high support needs:

- in individual experiences of the support people receive and the options open to them;
- in wider support and commissioning decisions that affect local communities; and
- in research and policy frameworks that influence and guide practice.

There is a clear lack (particularly by comparison to other users of social care services) of a strong and unifying vision of a good life for older people with high support needs. The language of services and needs dominates. There has been an emphasis on better management, a modernisation agenda and structural change. Sympathetic and personal language is rarely used to describe older people needing a lot of support. The evidence suggests a need to refocus on a ‘rights-based’ approach – in words and experiences that make sense to and reflect the lives of older people who need a lot of support.

**I’m new to this game and haven’t forgotten the other game yet. When you let go of a lot that went before – what can you put in its place?**

## Cultural and structural change required

Evidence from the care homes, from discussions with residents, staff and others involved, and wider discussions show that current assumptions about care home practice remain ageist and problematic. Incremental quality improvements are not moving practice towards older people’s ideas of a better life.

The evidence shows that “dignity and respect” are low aspirations on which to build a challenging agenda for government policy and best practice guidance on long-term care. Whilst dignity and respect are key ingredients, a completely different approach is required, based on citizenship and beginning with an increased focus on personal identity, self-expression and individual aspirations, rights and circumstances.

Also required is a much deeper understanding from older people's perspectives of what needs to be changed in order to have a good life, rather than just relying on professionals' and others' views about high-quality services.

*It would be great if we could use some of the fee we pay for our own leisure, maybe have someone for two hours each week to do what we want with us – take me out on the bus, sort out my wardrobe.*

*I wish I had the same person so I could get them into my routine... you end up having to fit in with their routines. I pay a lot of money here... I think it should be my routine that's found out and stuck to.*

## Conclusion

The study findings point to the need for a more positive picture of what 'a good life' looks like, even when a person needs a lot of support.

The most commonly mentioned areas were:

- people knowing and caring about you;
- the importance of belonging, relationships and links with your local or chosen communities;
- being able to contribute (to family, social, community and communal life) and being valued for what you do;
- being treated as an equal and as an adult;
- respect for your routines and commitments;
- being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with;
- having and retaining your own sense of self and personal identity – including being able to express your views and feelings;
- feeling good about your surroundings, both shared and private; and
- getting out and about.

The evidence from this study is that personal identity and self-esteem (referred to over and over again in conversations and observations of care home life) – is often underplayed or not recognised in services and support arrangements. For older people, this element needs to be at the heart of future care provision.

## About the project

The study reviewed existing literature on the subject of the voice, choice and control of older people with high support needs. A research team, including older researchers, worked in four study sites (three areas in England and one in Scotland) and had discussions with older people (living in seven care homes, two extra care housing schemes and two adult/family placement schemes) and other local stakeholders (commissioners, providers, carers and third sector organisations). A number of discussion events were also held to explore initial findings from the research. A call for information and examples of best practice provided further evidence of different approaches and knowledge about 'what works' in this area.

## The Research Project Team

Cathy Smith, Meena Patel, Lorna Easterbrook, Mairi Maclean, Rosemary Macdonald, Ann Macfarlane, Dorothy Runnicles, Tim Oshinaike, Alison Macadam, Gilly Crosby, Angela Clark, Helen Bowers. Pen Mendonca and Anita Wilkins provided expert advice and assistance in analysis, graphic and group facilitation.

---

## For further information

The full report **Older people's vision for long-term care** by the above project team is available as a free download at [www.jrf.org.uk](http://www.jrf.org.uk)

Published by the Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP. This project is part of the JRF's research and development programme. These findings, however, are those of the authors and not necessarily those of the Foundation. ISSN 0958-3084

[Read more Findings at www.jrf.org.uk](http://www.jrf.org.uk)

Other formats available.

Tel: 01904 615905 email: [info@jrf.org.uk](mailto:info@jrf.org.uk)