Shared decision-making in care homes

This briefing sets out the key findings of a research review on 'creating community' undertaken by Sue Davies and Christine Brown-Wilson, in 2006, as part of the *My* Home Life programme[1]. The briefing also provides examples of promising approaches for improving practice within this area.

The full review providing further tools and examples of 'best practice' can be accessed at the *My* Home Life website (www.myhomelife.org.uk). This review is currently being updated.

Introduction

In order for care homes to function as 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 chance to be involved in the decisions that affect them. Residents and relatives should be considered as expert partners in care unless this is contrary to the relative's or older person's wishes.

There are different types of decisions made in care homes each day. Some are removed from the daily experience of residents, relatives and staff as they are influenced by factors outside of the home. However, many decisions take place on a daily basis within the care home and the extent to which these decisions are negotiated between residents, relatives and staff is likely to create the culture of the home and may determine each resident's lifestyle and quality of life.

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.

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. This group of residents is particularly at risk if care routines become inflexible and fail to respond to individual needs and preferences. To create opportunities for shared decision-making, staff need to make this a priority and regard it as a positive component of their work. 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.

Ongoing shared decision-making through negotiation

Gathering the views of cognitively frail older people is a special challenge that requires time and skilled communication.

Extra communication methods, such as a regular newsletter to all members of the care home community, can allow everyone to be involved and to feel they have a responsibility to find solutions to problems, though for some, more creative ways to engage and disseminate information may be required.

In one care home, residents are encouraged to show staff applicants around the home, or even take part in the recruitment process, which both allows residents to contribute and shows prospective staff that the home has a culture of reciprocity.

[1]NCHR&D Forum (2007) 'My Home Life: Quality of life in care homes. A review of the literature', Help the Aged, London, available at: www.myhomelife.org.uk.

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Involving residents

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 and their families are enabled and empowered to exercise choice is increasingly accepted as essential for quality of life. The wish to be involved in making decisions 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 extent to which residents are able to exercise choice and control has been shown to have a direct influence on the relationships they develop within the home, with staff and each other. Maintaining personal control in day-to-day activities as far as possible has also been shown to be of continuing importance. For example, some studies have shown that older people would like more choice in their daily routines but care staff feel this is not always possible due to the routines within the home.

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.

Understanding 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. In a 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.

Studies have shown that many staff within care homes feel inadequately prepared to care for residents with communication difficulties. However, a number of studies have demonstrated improvements following structured intervention programmes. For example, using talking mats may help older people with communication difficulties to express their thoughts and feelings.

Some forms of interaction between staff and residents also encourage or inhibit resident involvement in decision-making. Although well-intentioned, studies caution against the use of 'elderspeak', a style of speech often indistinguishable from baby talk, which many residents find demeaning.

There may be a number of reasons why residents are not always involved in decisions that affect them. Stepping back from being in a 'controlling role' may not always be comfortable for staff, who feel a need to balance the 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. Thirdly, professionals may need to spend additional time with service users discussing and exploring their options. In the time-starved environments of many care homes, it is easier and faster to assume what an older person would like. It is suggested that nurses and carers need to possess the relevant knowledge to be able to give service users adequate information and the skills to explore sensitive and serious issues.

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.'

Involving relatives

A growing body of evidence suggests that family caregivers appreciate attempts by formal caregivers to create partnerships and to recognise their knowledge and experience.

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, some family members regard care plans as a nursing issue. This highlights the scope for educating relatives and staff about the potential value of involving relatives in care planning.

A growing sub-group of older carers are supporting a relative in long-term care. These are mostly spouses. Support for these relatives from care homes varies. Some do not recognise the contribution the former carer could make to the ongoing care of their relative. However, some homes provide support groups and encourage relatives to become involved in life within the home. This might include fundraising, helping with gardening, outings and projects. Homes that recognise the needs of a former carer tend to treat them as a partner. Recognising and using carers' knowledge of their relative's needs and preferences is very important in care planning, particularly when the resident has dementia.

Rigid policies and inflexible rules are likely to affect partnership working and shared decision-making. Indeed, a study suggests that most complaints in nursing homes result from the bureaucratisation of care and a clash of value systems.

While staff might welcome relatives' contributions, they may also feel a need to retain a position as 'clinical experts'. This needs careful facilitation, so that relatives' involvement in decision-making does not threaten staff members' sense of significance. Responding to the family's need to be educated about the changing health needs of the resident may provide a particular role for staff in this regard.

Enabling residents to make active choices is likely to involve some risk-taking by staff and family. For some family members, a safe environment for their relative is one without risk; regular communication between all parties is essential to ensure that risk-taking becomes an accepted part of caregiving.Furthermore, staff must feel supported by their managers to adopt a risk-taking approach.

Involving staff

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 that affect them. For example, involving care staff in identifying priorities and enabling them to negotiate with others in the delivery of care shows how responsive care can meet the needs of residents, relatives and staff.

Studies have shown that the participation and empowerment of staff are essential elements of a positive working environment. Furthermore, studies of staff job satisfaction in care homes suggest a relationship between job satisfaction and a sense of being involved.

Decisions to influence change

Developing relationships over a period of time seems to be key in achieving change. Feeding the views of residents and relatives into a change process should be a priority. Staff need to feel supported to enable them to involve residents and relatives in decision-making. One way of involving residents, relative and staff in decision-making could be to establish an action group where everyone is involved.

This summary was written by Christine Moss in partnership with Sue Davies and Christine Brown-Wilson for ***My* Home Life**.

The ***My* Home Life programme** is a UK-wide programme of work aimed at promoting the quality of life for those who are living, dying, visiting or working in care homes for older people.

More information can be found on www.myhomelife.org.uk

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