Our aims are:

- Supporting residents and relatives to be involved in decisions affecting their care and well-being
- Negotiating individual rights and risks to optimise quality of life

‘There is a lot of experience among the residents but the skills we have developed in our lives are completely wasted. There are a lot of things that residents could share if given an opportunity.’

www.myhomelife.org.uk

Free POSTER see inside

May 2008

ISSUE 4: Sharing Decision-making

Free

Tips for involving residents in decision-making

My life, my choice: supporting residents to maintain control of their lives
My Home Life

My Home Life is a UK initiative aimed at improving the quality of life of those who are living, dying, visiting and working in care homes for older people. My Home Life celebrates existing best practice in care homes and promotes care homes as a positive option for older people. My Home Life, led by Help the Aged, the National Care Forum and City University, is a collaborative programme bringing together organisations that reflect the interests of care home providers, health and social care commissioners, regulators, care home residents and relatives and those interested in education, research and practice development.

My Home Life, a bulletin for care home staff, is distributed to 18,000 care home contacts through Care Management Matters. Additional copies can be provided at a cost of £1 per issue (+ 50p towards p&p) from Help the Aged Publishing (tel. 020 7239 1946).

The next issue will be sent out in July 2008 with Care Management Matters.

The opinions expressed in this magazine are those of the authors and do not necessarily reflect the views of Help the Aged or its affiliates.

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Supporting older people to stay in control

Lynda Bellingham, supporter of My Home Life

All of us make decisions every day on all sorts of issues – on what we want to do and, perhaps as importantly, what we don’t want to do. We all need some level of control over our lives – it’s a basic human need. Yet for many older people who come into a care home the chance to make even the most basic choices can get lost.

Care homes can be busy places. Sometimes those who work there feel it’s easier to do things on behalf of residents rather than spending time finding out what they really want. Staff might feel that they know the routines of the residents so well that they forget they need to involve them in decisions affecting them.

With just a little thought, it’s possible to find a wide range of opportunities for residents to exercise their preferences and bring their talents and interests into play. However frail, older people have a wealth of life experience to offer and engaging them in decisions about the home, supporting them to take on roles in the home and share their skills and ideas will make them feel valued and in control. It will also create a better atmosphere in the home.

Getting residents involved in making choices can be challenging, particularly if the resident has dementia. But many care homes have found creative ways to help residents to consider what they want to wear and to eat, what time they want to go to bed, and to engage them in the bigger questions about how the home is run and organised. Some staff are highly skilled at enabling residents to retain as much control as possible. There is no doubt it can take time, but when it works, it can make a big difference to the residents’ quality of life.

Need more copies? Download at www.myhomelife.org.uk or call Help the Aged on 020 7239 1946
Residents at Milford Care Homes make a point of being involved in decisions about everything that happens in their home.

Bill Saxelby: I have been involved in both the residents’ committee meetings and the social activities meetings. We discuss what singers and entertainers we want and plan our summer outings. It gives us a chance to air our views and make choices about our lives.

Zena Steeples: We get involved in menu-planning in the home. All the residents meet the cook monthly. At the last meeting I suggested bubble-and-squeak, and told the cook how to cook it and what to have with it – hot dogs! A resident who has a birthday chooses the tea for the day. For mine, I wanted tripe. I fancied it, asked for it and got it. All this makes me feel worthy, that I matter and I’m not just a spare part.

Terry Wells: I helped interview staff for the first time in my life. I asked questions like ‘How would you help residents to be fed or dressed? What is important about looking after older people?’ Muriel and I then discussed the people and decided together who to offer the job to. I enjoyed it. It is important that I have a right to have a say.

Frank Palethorpe: I am involved in decision-making at Ernehale Lodge. I went to the local surgery at Christmas and gave them presents from the home. I feel like a staff member and am glad to help them.

Kara Gratton and her team describe how they involve residents in decisions about their care and about the home where they work.

The ethos of the home is that residents must be at the heart of everything that we do. We must continually strive to be proactive in improving the ways that they are involved in decision-making and offering choices that affect their lives. It is early days and we have a long way to go to truly change the culture. This is about educating the managers and staff and it can be hard. It’s easy just to give up when it doesn’t seem to be working, but you have to be at it all the time, questioning your practice. You should never say to residents, ‘You can’t do this’. It’s our job to say how we can make it happen.

Some residents ‘don’t like to make a fuss’, and convincing them they have a right to make decisions can be difficult. It can be frightening to join in. Sometimes it’s about starting with simple decisions – choosing a menu, when to have a bath or shower – which helps people to move on to bigger decisions.
our lives

‘Our flowers will fade if I don’t water’

We now have residents who have their own patch of the garden, choose seeds and are supported to look after it. One lady liked nothing better than to clean – she’d done it all her life, and she’s now equipped with a duster and helps the domestic staff.

For those with communication difficulties, more time and support are needed. Sometimes you just need to observe the reactions of residents with dementia to activities or ideas to get a picture of what they enjoy or dislike. We knew very little about one gentleman who joined the home. He had communication problems, but using pictures and symbols we found out about his history, who he married and his birthday. One lady who had had a stroke and could not speak became very introverted. With support she finally agreed to help us interview staff, communicating by giving a thumbs-up or a thumbs-down – that’s how we got her views when we were recruiting. Since then, she has been a bit more engaged in the home.

When you hear residents saying ‘Yes, we decided on that’ and ‘This makes me feel that I am still worthwhile’, it’s wonderful – to know you have been part of bringing about choice, and confidence that their voice is heard and that they are in control.

How well are you doing? Rate your practice

What different methods do you use to listen to and engage with residents and relatives?

How well do you listen to those residents who are less articulate?

To what extent are residents given complete choice on going to bed, getting out of the home, their meals, and who helps to take them to the toilet?

Do residents and their families have access to a responsive and effective complaints procedure?

For more ideas, tips, resources and opportunities to talk to other care homes, check out the ‘shared space’ at our website: www.myhomelife.org.uk
How can I start listening to residents’ views?

Care homes in the West Midlands offer the following tips

• Start with the assumption that every decision taken in the home should be shared with residents. This may require a new culture. It can even feel threatening, but when it works it’s great.

• Focus on what residents can rather than cannot do. Think about the skills, strengths that residents bring to the home. One resident, a keen gardener, was helped to plan the budget for the garden.

• Residents’ groups are difficult to run and don’t always work. Start by working with smaller groups or pairs, and aim to build a trusting relationship. In time residents will gradually feel more comfortable making decisions about the bigger issues too.

• Listen to staff and families: small pieces of information that might not seem important can mean a lot – a comment like ‘My mother would never wear red’ is something that you need to communicate to staff.

• Ensure that residents have proper control over their care plan. Turn it into a positive plan that explores quality of living as well as ‘care’.

• If residents complain, see this as a positive example of a resident feeling comfortable in expressing what they want.

• Allow residents to take the initiative. One resident set up a poetry group and then several others joined in.

Let’s take risks!

Mr Winters was a long-standing care home resident with Parkinson’s disease. He loved his scooter and went out regularly. One day he had a really bad accident – he came off his scooter over a high pavement, broke his hip and spent a few weeks in hospital.

Mr Winters insisted that he should get back on his scooter as soon as possible. But the inspectors and relatives were worried about the risks that Mr Winters was taking. Staff were also concerned about potential repercussions on them, particularly as his fall had made the headlines in the local newspaper.

On the other hand, they recognised that the scooter was central to Mr Winters’ quality of life. After much discussion, negotiation and a positive risk assessment process, they agreed to assess his capability to avoid accident and his confidence level. Mr Winters suggested that for the future he would feel much better if he had a walkie-talkie to contact the home in case of emergencies. Mr Winters is now back on his scooter. There have been no more accidents to date and everyone’s happy.

Thanks to Orders of St John Care Trust for this story.

Here are some thoughts on managing risk from the MHL network.

• Assess risk in a positive way. Assessment should never be about why a resident can’t do something but rather how they could be enabled to.

• Listen to the resident and help them identify what risks they are prepared to take.

• Acknowledge the risk and then work creatively to find solutions which minimise unnecessary risk.

• Keep records of accidents and incidents in order that you have firm evidence from which to assess the level of risk involved.

• Support staff to be less risk-averse. Help them to see themselves as enabling residents to play a full and meaningful life. Staff should also be involved in decisions about the organisation of the home.

• Be collaborative – involve relatives, and even inspectors, where appropriate, in the assessment and management of risks.

NEXT ISSUE: Improving health and healthcare within a care home – send us your tips and stories on responding to the health needs of your residents and working in partnership with the local NHS.
1. Decision-making
Numerous opportunities for negotiation and shared decision-making arise in every aspect of daily life. Many residents desperately want to be involved in decisions that affect them. Exercising choice is essential to quality of life.

2. Residents and relatives as expert partners
Recognise that your residents and relatives are best placed to help you deliver quality of life. Relatives need to have the opportunity to be fully involved in all aspects of care, including assessment, planning, implementation and evaluation of care, if this is what the resident wishes.

3. Taking positive risks
Enabling residents to make active choices can involve risk. It is important for staff to recognise that risk-taking is a normal part of life, so long as it is an informed and positive.

4. Working with frail older people with communication difficulties
It can be difficult, especially for residents with any degree of cognitive impairment, to express their wishes, but these are the ones who are particularly at risk if care routines become inflexible and fail to respond to individual needs and preferences.

5. Routine and order
While routine and order can help people predict events and help them feel more control over their lives, they can also act against individuals’ choice and control if they rigid and inflexible. Regimented routines restrict scope for decision-making and remove any sense of freedom.

6. Staff training
Without training, staff can find it difficult to step back from the care that they provide and re-consider how they interact with residents in a manner that respects choice and control.

7. Elderspeak
Be aware of how certain language, tones of voice or even behaviour can be perceived as demeaning or patronising by residents, which will in turn discourage them from expressing their views and opinions.

8. Time and commitment
Staff need to have the time, skills and access to information to support residents to make informed choices about their lives.

9. Staff decision-making
To truly shift the balance in allowing residents to have real decision-making power in a care home, staff also need to able to contribute to decisions that affect them.

10. A resident’s prerogative
Don’t forget that residents can always change their minds.