

My Home Life

The bulletin for care home staff

ISSUE 6: Supporting a Good End of Life

October 2008 **Free**

Dying – the last taboo

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POSTER**
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PLUS

The tale of twin sisters at Hall Grange



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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 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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Improving end-of-life care

Doreen Mantle, actress and supporter of *My Home Life*

Death and dying are taboo subjects in our society, and because of this we tend not to be very good at talking about them. Yet many older people feel a need to share their thoughts and wishes about dying and death with those close to them. This is not always easy. Relatives might wish to avoid 'difficult' conversations and staff may not wish to broach the subject in case it causes upset or distress.

So how can we best support older people who want to talk about the end of life? In the care home, perhaps the most important thing is to be more open about death and dying – to acknowledge when someone is dying, feel confident enough to discuss it openly with colleagues and residents alike, and to take time to develop close relationships with our residents so that they feel comfortable about mentioning this sensitive issue.

Caring for someone at the end of life can be a real challenge. Responding to the emotional needs of a resident, ensuring they are in comfort, without pain and have their loved ones close is the ideal that we are all working towards. Perhaps we



shouldn't expect that we can do it all without the support of others – relatives, friends and the specialist nurses and palliative care teams. I also believe that the warmth and comfort of faith can be a great help to many people.

For many older people who wish to die at home the care home is the only home they have, and the people within it their only 'family'. As older people, we need to know that when our time comes we will be cared for with love, dignity, respect and sensitivity, where there are people who will recognise the significance of our living and our dying.

Doreen Mantle

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It's the little touches that make such a difference...

Residents and staff talk openly about what helps them through the end of life



Tim O'Donovan, resident, St Michael's Care Home, Essex: 'We must remember that many of our residents are looked after well in most homes, but there is another side of our being – our spiritual side, our soul, our mind – which needs looking after. End of life is often foremost in the mind of people of my generation. It's a matter not discussed very much and is often left to individuals to cope with alone but residents, whatever their beliefs, should have the opportunity to talk about dying before it's all up in the air and too late.'

Miss Alex Thompson, care home resident, Greater London: Communication about death and dying is a problem. Residents need very badly to express sorrow and grief when somebody dies. 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.



Sam Bradshaw, Manager, Northhill, Sheffield: I was frightened to death when I first cared for a resident who was dying, but an older care assistant who mentored me said, 'Look, it's still Nelly, she's still exactly the same as she was yesterday when you washed and dressed her. She's just one step nearer to death. She still likes all the same things. Just because she's dying it doesn't mean she's suddenly stopped taking an interest in the world.'

Of course, the needs of someone who is dying can change – we should not ignore that. But we do have this strange way of treating people who are dying. For instance, why do we sometimes feel the need to close the curtains in the bedroom where someone is dying? Somebody laid in bed dying could be there for days in a dark room. Unless that resident's said to you, 'Can you close the curtains?', we should keep them open, let them see what time of day it is and that there's still stuff going on. But that's like a cultural thing, isn't it? Shutting everything out and shutting this person in – it's part of the fear that we have.

'Just because she's dying it doesn't mean she's suddenly stopped taking an interest in the world.'



The tale of twin sisters at Hall Grange

A beautiful farewell

In April of this year, residents and twin sisters Barbara and Mary turned 95. We had booked the newspaper, entertainer and cake decorator. However, the day before their birthday, Barbara became unwell and took to her chair. We celebrated for them in their absence because they were 'not in the mood'.

A week later, Mary became sad, off her food and began to refuse her medication. Barbara was still unwell in her chair. We prepared Mary and their family for the worst as we knew that Barbara was passing on. On 2 May Mary and Barbara were in Barbara's room. We had set up Barbara's room with furniture and personal items so they could spend their last days and nights together. The staff

contacted everyone Barbara and Mary had cared about, all of whom visited. They held their hands, prayed and told them they cared about them. I made a low-key announcement to other residents,



some of whom also said their farewells in person. Mary passed away peacefully that evening in Barbara's chair with Barbara sleeping comfortably in bed. They were just inches away from each other. Only two hours later, Barbara also passed away, with Mary still sitting with her.

The staff team had supported Barbara and Mary to be together in their last hours. This is part of our normal practice. Residents are helped to talk about dying. They get emotional support from me, as the manager, or from the chaplain. Staff also get supported through a counselling service run by the organisation. For all

'My wife Ann and I were contacted the day before my aunt Barbara and mother Mary passed away. We spent the afternoon of 2 May with both of them and that evening, after my mother had died, we were contacted again and were privileged to be present at the time of Barbara's passing. It felt very much as if Mary, as the older twin, led the way into this world and then led the way to the next. The sensitivity with which the staff at Hall Grange supported Barbara and Mary during their final days impressed all of our family. The arrangements they made for Mary and Barbara to spend their final hours together in Barbara's room were inspiring.'

David Chamberlayne, Mary's son

of us, this was a very special, touching occasion. Barbara and Mary knew they were loved and cared for and they had the comfort of knowing that they were together right until the end.

Emily Sullivan, Manager, Hall Grange Care Home

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

National end-of-life initiatives

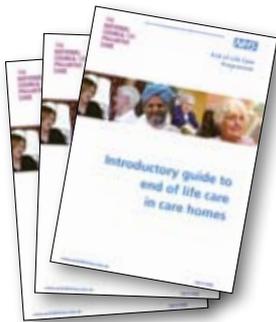
A number of national initiatives have been established to improve the experience of dying in care homes: the Gold Standard Framework, the Integrated Care Pathway for the Dying, and the Preferred Priorities for Care Initiative have received clinical and government support and their effectiveness in care homes is currently being evaluated. Various other resources and training materials are being developed specifically for care homes. The aim is to acknowledge that a person-centred approach, based on individual need, is required to support a positive end of life.

www.ncpc.org.uk/publications/freedownloads.html

www.endoflifecare.nhs.uk/eolc

www.goldstandardsframework.nhs.uk

www.mcpcil.org.uk/liverpool_care_pathway



In addition, the National Council for Palliative Care has produced a report called *Building on Firm Foundations: improving end-of-life care in care homes*, which provides some examples of good practice in care homes.

100,000

THE NUMBER OF OLDER PEOPLE WHO DIE IN CARE HOMES EVERY YEAR

Respecting and remembering

The respect paid to dying individuals, their bereaved family and friends and to fellow staff and residents helps facilitate an open culture in relation to death and dying. Here are some practical ideas that might help:

- Place a favourite possession of the deceased on the trolley and allow the body to be removed through the front door of the home
- Ensure that the news of the resident's death is communicated sensitively to staff and residents. Some homes pin a photograph on the notice-board, place a flower in a vase or light a candle
- Provide opportunities for the home to stop for a moment of quiet to respect the significance of the resident's life and death
- Provide a place for staff to talk with relatives and residents about their feelings and to exchange thoughts about the person who has died
- Facilitate the sharing of memories of the deceased: for example, by providing a book of remembrance
- Allow residents and staff personal acts of commemoration, such as attending the funeral or planting a flower in the care home garden
- Hold annual services of remembrance, to which relatives are invited, for those who have died in the past year
- Offer to host receptions after funerals, which would allow more of the other residents to attend.

Overall we need to recognise that relatives, staff and residents will have different reactions to the death of someone close. We need to acknowledge that many of us will have seen many deaths and lost many people close to us. Respecting our own emotional and psychological needs is essential.

NEXT ISSUE:

Keeping the workforce fit for purpose within a care home – send us your tips on how to support your staff to deliver quality of life for your residents.

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My Home Life

TIPS

for supporting a good end of life



1. Fostering a culture of openness

Death and dying should not be denied or hidden in a care home. Building trusting relationships among residents, relatives and staff will help facilitate conversations about the person's future, including the end of their life.

2. Sensitive communication

Some residents and family members may not find it easy to talk openly about the end of life and may need additional support to do so. As caregivers, we must recognise how our own attitude to death and dying may influence the care we provide and our ability to talk openly.

3. Supporting residents to feel in control

Residents need to be supported to consider any final actions they wish to take before dying, along with any spiritual or cultural needs that should be acted upon.

4. Dying with dementia

Recognise that certain residents may struggle to communicate their needs or the pain they are experiencing at the end of life, because of dementia or other health problems. Particular attention and support may be required for these residents.

5. Planning in advance

Where it is possible to plan, having someone – a staff member or volunteer – available to sit with them at all times can be hugely reassuring for the dying resident.

6. The last few days

Consider ways to help those relatives and friends who your resident wishes to see, with regard to transport, accommodation, refreshments and the emotional support that they may require.

7. Palliative care education

Staff need education and training in palliative care, which focuses not only on relief from pain and other distressing symptoms but also includes the psychological and spiritual aspects of care.

8. Engaging outside expertise

Support services from GPs, palliative care and hospice nurses could help you provide comfort to your dying residents and offer psychological support. Building relationships with these teams is therefore crucial.

9. Respecting and remembering

Residents, relatives and staff all need to be given the opportunity to acknowledge that a resident has died and to remember and pay their respects.

10. Supporting the community in the care home

Staff and residents will have seen many residents die. It is crucial to recognise the significance and consequences of each loss for each of us, and to get the support we need.