

## ***Supporting a good end of life***

*Good practice guide no. 6*



# My Home Life Cymru

My Home Life aims to promote quality of life for those who are living, dying, visiting or working in care homes for older people through relationship-centred practice.

My Home Life Cymru celebrates and shares existing best practice in care homes and promotes care homes as a positive option for older people. This is one of a series of eight good practice guides that follow the evidence-based My Home Life themes.

## There are eight evidence-based themes for My Home Life:

- Maintaining identity
- Sharing decision making
- Creating community
- Managing transitions
- Improving health and healthcare
- **Supporting good end of life**
- Promoting a positive culture
- Keeping workforce fit for purpose

These themes provide a framework that care homes can use to develop their services and help staff focus on quality of life issues rather than being led by the care tasks that are needed to care for the residents.



## Good practice guides

This guide will hopefully inspire discussion about how to best support residents and their families cope with death and dying.

In particular we would like you to ask yourself:

**How do you support residents who want to talk about end of life issues and worries?**

**How can you be more open about death and dying?**

As care home staff, your skills and expertise in engaging with and supporting residents can make all the difference. This guide includes some ideas, tips and practice examples to help all those involved in the care and support of residents.



# Opening the door to discuss death and dying



Enabling residents to die in comfort and with dignity is a core function of care homes. One of the key challenges for managers and staff is knowing how and when to open up a discussion with individual residents (and relatives) about what they would wish for as they near the end of life. Agreement needs to be reached on when discussions should occur, who should initiate them and what skills and competences staff require to take on this role.

Even in our modern society, death and dying are subjects that most do not feel comfortable in discussing openly. Family members may find these conversations difficult and uncomfortable. Within a care home environment, residents and their families need to be able to discuss their wishes and feelings. What can you do to make these discussions happen when they need to? What is the role of the staff in a care home when it comes to supporting residents and their families at this sensitive time?

‘When a resident moves in, we don’t know how long they are going to be with us. It’s important we get a good relationship with them and their family as soon as we can. Hopefully, they will be with us for a long time, but you never know.’

Some people are so frail when they move in; it may be that the subject of death and dying needs to be discussed sooner rather than later. We can’t think, ‘oh I don’t need to worry about that now’.

If we think about it that way, we might lose the only opportunity we are going to get.’

Sue Mason, Manager, Pencoed Residential Home, Saundersfoot



# How well are you doing? Rating your practice:

Make time to stop and think about what you do as part of your role in the care home. Here are some ideas to think about.

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:



- Get to know the residents and their family. Open discussions about death and dying will only happen between parties who have built a good relationship with each other.
- You need to recognise and respond to the emotional needs of those involved. The key to this is really getting to know your residents and their families well.
- Remember to take into account any recent changes in circumstances. This could be the death of a spouse, increased hospital admissions or a change in care setting e.g. a move from residential to a nursing home.
- When nearing the end of their life, older people in a care home need to know that they will be cared for with love, dignity, respect and sensitivity, where there are people who will recognise the significance of their living and dying.
- Provide any relevant information which may be required by the resident or their family.
- Are you making use of Age Cymru tools such as 'My Future' and 'Life Book'? These guides can help the resident 'get their affairs into order'.
- Are you making the family aware of what procedures and guidance you may be following e.g. the All Wales Integrated Care Pathway, Liverpool End of Life Pathway.
- Are you aware of the resident's wishes on issues such as resuscitation and organ donations?
- Recognise that greater attention and support may be required for those residents who struggle to communicate their needs because of dementia or other health problems. How can these needs be met?
- Ensure local healthcare professionals are aware of those residents who are approaching end of life. Some GP practices may be implementing an end of life care register.
- Make sure good communication systems are in place with all relevant services.
- Ensure you know who your key contacts are across the provider services, voluntary bodies and social care sectors.
- Ensure timely access to relevant equipment and drugs which may be required if possible.
- Inform Out of Hours Services of anticipated care needs.
- Don't forget the role that other residents, particularly those who have developed a close relationship with the person who is dying, may be able to play in the planning and delivery of care.



- Have open discussions with relatives, friends and other members of staff to ensure everyone knows what to expect during the last days of life, and offer support where needed.
- Following the death of a resident when appropriate place a favourite possession of the deceased with them 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.
- Don't forget the impact that the death of a resident may have on the other residents of the home. Some of these may have become close to the deceased, and may need support during this difficult time.
- 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.
- As an open society, we need to respect and consider the cultural issues that may arise at this time. Do you support the resident and their family appropriately in accordance with their cultural needs and wishes? You may also have a culturally diverse workforce. Are you aware of their views on death and dying, and do you provide appropriate support when needed?
- At this time, many residents and their families appreciate the support of their local place of worship. Not only from a religious leader, but possibly others from their faith community too. Their support can be of great comfort not only to the individual and their family and friends, but also to staff members who may be finding things difficult during this time.
- After a resident has passed away, can you keep an 'open door' for family and friends to continue visiting the home? They may take great comfort in being able to visit the home, and by so doing, continue the friendships and relationships that they built with other residents and staff during their visits.

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

After the resident's death and funeral, reflect on relative, staff, or advocate experiences to help provide constructive feedback to support continuous practice improvement.

### How does your practice rate?

Sometimes there are no easy answers to these questions. So much depends on individual circumstances. Try asking your colleagues what they think and share what you find.

# Top Tips for supporting a good end of life

- 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 resident's future, including the end of their life.
- 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, you must recognise how your own attitude to death and dying may influence the care you provide and your ability to talk openly.
- 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 responded to.
- Recognise that certain residents may struggle to communicate their needs or any pain they are experiencing at the end of life. Particular attention and support may be required for these residents.
- When at all possible, can you have a staff member or volunteer to sit with a dying resident at all times? This can provide needed reassurance and comfort.
- Consider ways to help those relatives and friends who the resident wishes to see, with regard to transport, accommodation, refreshments and the emotional support that they may require.
- 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.
- 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.
- 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.
- Staff and residents will have seen many residents die. It is crucial to recognise the significance and consequences of each loss for each of them, and to get the support they need.

Please visit [agecymru.org.uk/mhlc](http://agecymru.org.uk/mhlc) to view other resources to help in developing the eight My Home Life best practice themes. Presentations from previous My Home Life Cymru events are also available to download.

In addition to this, the other My Home Life web sites – [myhomelifemovement.org](http://myhomelifemovement.org) and [myhomelifedvd.org.uk](http://myhomelifedvd.org.uk) give detailed information on the work of My Home Life and are full of case studies and examples of good practice in action.

***If you would like to support our vital work and make a difference to the lives of older people in Wales please contact the fundraising team at Age Cymru on 029 2043 1555 or donate at [www.agecymru.org.uk/donate](http://www.agecymru.org.uk/donate)***



Tŷ John Pathy, 13/14 Neptune Court  
Vanguard Way, Cardiff CF24 5PJ  
Tel: 029 2043 1555  
[www.agecymru.org.uk](http://www.agecymru.org.uk)

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