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# End of Life Care



It is not surprising that many residents want to stay in the care home as they approach the end of life. It is their home. They have the reassurance of 24 hour care and support with staff they know and trust. Your role is vital in responding to their needs and wishes, making sure that they receive the sensitive care, medical attention, and family and spiritual support they want. This matters to the dying and can help you, their families and friends in the home with their loss.

## SUPPORTING END OF LIFE IS A LEGAL REQUIREMENT

Care homes must ensure that they meet the care needs of residents including their emotional, mental and physical wellbeing. *The Health & Social Care Act 2008 (Regulated Activities) Regulations 2014: No 9 Person Centred Care, No 10 Dignity and respect, No 12 Safe Care and treatment.*



### LET'S TALK ABOUT IT

Tim was so grateful to Danuta for talking to him about his wife, Julie's end of life care. Julie has advanced dementia and she had been so distressed at her last visit to hospital he wanted her to remain at the home, but hadn't known how to start the conversation. Danuta's knowledge and sensitivity reassured Tim that he could speak to her about his wishes and concerns.

### Preparation and planning

Opening discussion about end of life care planning may be triggered by the resident's own questions, by noticeable deterioration in the person's health or feedback from a doctor's visit. Whatever the prompts, now is the time for the care team to agree a plan with the person and those closest to them. Explaining what end of life care involves and how the home can provide support can calm people's fears.

**Advance care planning** covers all aspects of personal care and support including the person's comfort and well-being, medication, the management of pain and other distressing symptoms, communication, mental capacity, breathing and resuscitation, pressure area care, mouth care, nutrition, fluid balance, and continence and bowel care. As importantly, it should focus on helping the person continue to take part in the things they enjoy for as long as possible.

**Advance statements** This confirms the person's wishes and preferences for example for spiritual, religious or secular support, or to have the people closest to them to stay in the home with them during their last days. Advance statements should always be recorded in the person's care plan, but people can change their minds so they should be reviewed and updated regularly.

**Advance decisions** A person may have made an advance decision about medical interventions. These are legally binding and make sure you understand what your role is in complying with them.

**Powers of Attorney** Team members also need to be aware that the dying person may have appointed individuals as their welfare or financial attorneys to speak for them.

Preparing and agreeing these plans and decisions helps the dying person to experience a dignified and respectful death.

## Keynotes

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### BEING THERE

**“They were brilliant. When I couldn’t be there, a member of staff stayed with mum, they made sure she was comfortable and free of pain. I could ring day or night and they were always able to tell me exactly what was going on. I couldn’t be there for her final hours, but I don’t worry about it because I know a member of staff was always with her, looking after her.”**  
*(Helpline caller to R&RA)*

## Wider Teamwork and Training

Specialist end of life care may be needed from visiting professionals. Make sure you know who to contact, how and when, particularly out of hours, and understand the role of the GP, nurse/district nurse or specialist end of life care team.

Good end of life care training is essential for every team member to recognise and respond to the person’s changing condition with the most effective support for them and their families – see the Gold Standards Framework ([www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)).

## Family and Friends

Family and friends may want to help so, where you can, offer to show them how. But also be aware that people will react differently and remember to be sensitive to conflicts and emotions that bereavement may stir up. Your first responsibility is to protect the wishes and needs of the person you are caring for.

## Being there

For some residents, you may be their main form of support. Your care will mean a lot to the dying person. Equally other residents may want to visit and may need your help to do this. Those with advanced dementia will still have some emotional

awareness and respond to soothing touch. Consider giving a hand or foot massage with a moisturiser to let them know you are there. Many people retain their hearing till the last and will be comforted by your presence.

## It’s not the end

The death of a resident can affect a lot of people. Encourage family members to still feel welcome; they may wish to volunteer or stay in touch with other residents. You may yourself have found the loss of a resident painful, as may others who were close to them. Celebrating people’s lives, talking about them, can be comforting. It can help people talk about their own or a loved one’s death and make that conversation so much easier for everyone.

### GOOD PRACTICE

**A Jewish Care study found that specific end of life training for staff led to increasing confidence to discuss end of life with residents and families and 100% observance of advance wishes** The percentage of residents ending their lives in the home rather than being sent to hospital increased from 47% to 76%.

<http://www.ncpc.org.uk/sites/default/files/Gaby%20Wills.pdf>



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