Ensuring people die with dignity

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Reader Responses

Seeing a painful death made Carys Evans determined to change end-of-life care in the nursing home where she worked. Anne Gulland describes how she did this and how other care homes can improve practice in this area.

It was the distressing death of a resident in 2004 that prompted Carys Evans (pictured), then a staff nurse, to revolutionise end-of-life care at her workplace. She started her shift at the Cartref Bryn Yr Eglwys nursing home in Snowdonia on a Sunday morning to find an 88-year-old patient in a lot of discomfort.

Nursing staff and the family had agreed that the patient was dying and that she should no longer receive any active treatment. However, Ms Evans phoned the out-of-hours GP and asked him to come to give pain relief. To her shock, the GP – who was not the patient's own doctor and was 20 miles from the home – refused to attend.

'I had to beg for someone to come out. In the end, he did come and give her pain relief but, because of the delay, it was incredibly distressing for all concerned.

'The only way I could help with her symptoms was gentle repositioning and I gave her oral hygiene. She was a lovely lady and it was so distressing to go off at the end of that shift having witnessed quite an undignified end of life.

'I was determined to find something that would help us provide the type of end-of-life care that the people here deserve.'

Ms Evans, now deputy nurse manager at the home, obtained a copy of the Liverpool Care Pathway, a framework for patients who are dying that was developed by Marie Curie Hospice in Liverpool and the Royal Liverpool and Broadgreen University Hospitals NHS Trust. She also got in touch with her community Macmillan nurse and, with the agreement of local GPs – crucial in setting up the regime – the pathway was implemented in 2005.

In advance of the pathway's introduction, nurses received training from the Macmillan nurse on the use of syringe drivers and symptom control. The home now has palliative care medication in stock, which can be administered by all registered nurses. It says that 90% of patients now end their life with good symptom control.

Ms Evans admits that nurses have not always found the new approach easy. 'It can be hard to switch off from trying to keep someone alive to totally changing your way of thinking to accept that end of life is on its way and to adapt your nursing care,' she says.

'The pathway gives you prompts and questions to ask the family. It prompts you to discuss symptoms and what's going to happen. The families are more relaxed and less anxious about what's happening. And it helps us to give better care.'

According to a 2007 report from the National Council for Palliative Care – which highlighted this work as an example of good practice – this Snowdonia nursing home is one of just 5% of care homes that have implemented end-of-life tools or models. The Department of Health's End of Life Care Strategy gives evidence – albeit not quantified – that many residents are transferred to hospital at the end of life when this is neither in their best interests nor what they want.

According to Lucy Sutton, palliative care nurse and director of policy development at the National Council for Palliative Care, there are several reasons why standards of end-of-life care may fall short in care homes. Residents may arrive with more complex needs and stay for a shorter time than in the past, so there is less time to build up a relationship with them or their family. Lack of training is also a factor – tools like the Liverpool Care Pathway are only as good as the staff using them, and training and support can make all the difference.

'Care homes should look at what their particular issues are and what's going on in their local area,' says Ms Sutton. 'They need to think about things like staff support groups and linking up with local hospices.'

Hospices can be an invaluable source of expertise. Take St Christopher's Hospice in south

London, which has been supporting local care homes for many years. For the past 18 months, it has been implementing the Gold Standard Framework, an NHS end-of-life care programme, with local care homes. It is a nurse-led programme whose colour-coded register helps to identify and plan care needs for residents and families. It also aims to improve coordination and collaboration between health professionals, patients and families. Each home working with St Christopher's employs two end-of-life care coordinators and receives support from the hospice.

Deborah Holman, end-of-life care specialist nurse at St Christopher's, says: 'The Gold Standard Framework is looking at the last year or years of a resident's life. It's about providing anticipatory care and trying to plan ahead for that last year of life.'
One of the homes the hospice has worked with, Fairlie House nursing home in Lambeth, is among the first 34 care homes in the UK to be accredited to the framework. Deputy manager Phil Moon says the framework has meant that advanced care planning is in place right from admission: 'It gives you the opportunity to discuss end-of-life issues while people aren't in a traumatised state. It's also been very useful for staff who don't address [end-of-life] issues very easily.'

The home has the support of GPs as well as the hospice, and regular input from a multidisciplinary team has given nurses confidence. Its care of those who are dying is such that it was commended by the Commission for Social Care Inspection in September.

Mr Moon says: 'Nurses have found it very useful – it's made us think about our practice and reflect on what we can do better in the future. We monitor people at regular intervals and, as nurses, we feel that we are in control.'
