

# Give those in your care the best ending to a life well lived

End-of-life care may be difficult for some to talk about, but it is essential that we do so in order to offer the highest quality end-of-life care possible. In this article, Sue Austin describes how we can improve palliative care provision for older people in the UK

**A** good life needs a good ending. The responsibility for providing this often falls to those working in the care sector. Unfortunately, this is something that can be quite challenging, given the societal taboos surrounding the topic.

In the very early stages of life, there are numerous services available for pregnant women, from prenatal classes to support groups and forums, which only extend further when a baby is born. This support continues through childhood and adult life in a myriad of different ways. So why is this level of support not always given at the end of someone's life?

## Dealing with dying

Different cultures across the world deal with the end of life in very different ways. In Canada, for example, there is debate over how death and the end of life should be discussed in school as a natural part of the life process and how to prepare for it (Tremonti, 2017). While some cultures avoid openly talking about death, there are national holidays celebrating the memory of loved ones in others: we only need to look to Mexico and its infamous *Día de los Muertos* (Day of the Dead) celebrations to see how this culture remembers their dead.

In the UK, our approach has historically been much more reticent and stoic. But with a rapidly ageing population and growing concerns over social care in the future, it is perhaps time for us to adopt death, or at least discussion about it, as part of our natural conversation.

## Talking about dying

We need to take cues from our friends around the world by acknowledging that death, like taxes, is inevitable. We need to adopt a first-rate end-of-life care programme which is as compelling and noteworthy as giving someone the best start in life. How we treat our dying is a true reflection of who we are as a society. Quite simply everyone deserves the right to high-quality end-of-life care.

To do this, the care sector has to ensure that it gets this level of care right, as there are no second chances. It is a great responsibility and indeed a privilege to care for someone in the final stages of life.

I have never forgotten witnessing poor practice at the end of someone's life, as a young junior nurse, and feeling so strongly that it should not be this way. While I challenged this at the time, I was not in a position to make a difference. Instead I promised myself that throughout my nursing career I would do all that I possibly could to influence excellence in end-of-life care—something I am able to do in my role.

With many years of experience and a senior role at Morris Care, I can shape how end-of-life care is delivered, ensuring that a person lives as well as possible until they die. This means that the care provided should respect the resident's dignity and wishes, understand their needs, and keep them and their relatives informed. It means working collaboratively with other professionals with a well-rounded and holistic approach.

## The right qualities

Caring for people at the end of their life requires specialist skills and compassion; it is not for everyone. From understanding the person's wishes and providing the practical care and emotional support they require, through to helping their loved ones and friends at this challenging time, it truly is a demanding role.

To do this, we must all focus on recruiting staff with the right qualities, and give them appropriate training and skills and put clear procedures in place to deliver quality, person-centred end-of-life care. These can be monitored and evaluated through the Gold Standards Framework



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Care Homes Accreditation Quality Hallmark, ensuring that the right standards are rigorously implemented.

### A wheel of provision

Providers should have tailored plans for each individual receiving end-of-life care, incorporating a care outline where the levels of eating and drinking, symptom control, psychological, social and spiritual support are agreed. This care should be coordinated and delivered with genuine compassion. If it is not, it cannot be said to be helping the person to die well. Person-centred care is a term that is often heard in this industry. We believe that it is made up of three components: the individual, their family and the staff caring for them. Person-centred care cannot truly exist if only one or two of these are in place.

As part of our end-of-life programme we map the care plan through a 'wheel of provision'. This expresses our areas of clinical and social competence from the moment the resident arrives in our home. It encapsulates our full offer as a social care provider, but also outlines how we work holistically with professionals, the family and the individual to reassure and build trust at this difficult time. This trust is an essential part of providing high-quality end-of-life care.

### Care compass

The wheel of provision is then overlaid with our resident 'care compass', which details what we do to provide the

best possible care to our residents, whether they come for a little extra support or ultimately choosing to spend their last days with us.

This compass is about allowing and encouraging the person to continue being who they are. This can be done through providing them with the right environment to encouraging social interaction with others if they would like to do so. Whatever happens, it is important to make the resident feel like they truly count.

### Talking about death

A survey by ComRes (2013) suggested that 67% of people fear dying alone more than losing their job at 38%. Dying in pain was the biggest fear noted in the survey, by 84% of the 2028 respondents. These statistics clearly show that people are thinking about their death, and are concerned with how it will happen. This is why we need to adopt a more open approach to death and dying, and encourage people to have conversations about the inevitable. In nursing homes we need to give people the reassurance that they will not be alone at the time of their death, and that any pain will be managed where possible. It is important to include family members in these discussions too, so that they can help to dispel any worries that the resident may have.

We need to ensure that the needs and wishes of our residents are respected at the end of their lives. If a resident would like their cat to sit on the bed near them, their wish



## Key points

- The care sector needs to rise to the challenge of helping residents live as well as they possibly can until they die, starting with encouraging a more open approach to discussing death and end of life
- Collaborative working with other professionals and relatives should be part of the care package offered at the end of a person's life to ensure wishes and needs are all respected
- Tailored end-of-life care plans should include all levels of support, from the physical and psychological to the social and spiritual
- Caring should not end when a person dies—we must ensure that their relatives are given the compassion and time they need, and help them remember and celebrate a person's life after it ends

should be granted. If they want to sit in the garden to see the flowers or listen to birdsong, this should be facilitated; caring for the smallest needs is just as important as the biggest needs. Sometimes the smallest wish can make the world of difference to how that individual feels. We must listen and put the person first.

Tailoring care to the person is one of the most important things we can do in the sector, and moving towards providing first-rate end-of-life care provision should be a national priority. By listening to a person and finding out about their life, we can take the first step in creating care plans that cater to exactly what they want.

This follows by simply following the adage that you should treat others as you would wish to be treated. By ensuring that our staff are providing person-centred care in this way while offering support to the resident's loved ones, we can be confident that we are providing the level of care that we would want our own family members to receive, when they require end-of-life care.

## Remembering life after death

Our caring role should not end when the person dies. If we are to truly offer the best end-of-life care, we must honour the person's wishes that their family and loved ones will receive the same high-quality emotional care and support that they received. It is important to give family and friends as much time as they need with their loved one after death, whether it be to talk to them, sit quietly or even just hold their hand. Similarly, it is important to offer guidance on the practicalities required once a person has died, such as funerary arrangements and any coroner's enquiries that must be carried out under UK law.

Remembering the person is a large part of the grieving process, not just for friends and family, but also for those who cared for the person. At Morris Care we have a process of inviting relatives to a remembrance toast 3 weeks after a person's death, where stories are shared by all and the individual is truly remembered as the individual they were.

## Conclusion

Death is a taboo subject for many around the world, and the Great British stoicism does little to help this. However, given the importance of being able to die well, we must all do our part to encourage those in care, and those around them, to talk more openly about dying, death, bereavement and the grieving process.

Here in the care sector we can make a true difference. We can lead those conversations with fellow care providers and health professionals, and our residents and their families, to help deliver the best quality end-of-life care for everyone, without fail. The mission is simple—the challenge is that we have one opportunity to get it right. **NRC**

ComRes (2013) Death and dying survey: online fieldwork: 28th April—1st May 2011. <http://bit.ly/2svCRt4> (accessed 20 June 2017)

Tremonti AM (2017) Why an ICU doctor says death ed is as essential as sex ed in high school. <http://bit.ly/2ooii1h> (accessed 21 June 2017)