# Translating the literacy of death

Navigating the care, rituals and processes of dying can be a difficult and life-changing experience, explains School of Education and Communication Programme Leader Joss Winn.

My dad, Nigel Winn, died of cancer in 2006 aged 56. He was a bricklayer and carpenter most of his life but always dreamed of being a writer. When he was 50, he enrolled on a BA in English Literature at the University of Lincoln and gained a First-Class degree. He went on to teach at the university and following his death, colleagues established the annual Nigel Winn Memorial Prize for Creative Writing.

In the few weeks that we understood my dad was terminally ill, my family and I had to quickly learn how to navigate the 'death system', a concept that refers to the people, places, objects and symbols that are called on in the prevention of death, the care of the dying, disposal of the dead, bereavement and meaning making.

As dad was dying, I looked for a book to help us navigate the death system. Reading The Natural Death Handbook guided us in what we could do before and immediately after his death. We learned to look for the signs of a life ending, how to care for the body, and found the details of a good undertaker who allowed us to create the funeral dad wanted. Without that book, I would have been lost amidst a precious life-changing experience I could never re-create.

After dad's last breath that Spring evening, we removed the medical equipment and laid him out peacefully. Neighbours came to visit him and say goodbye. His body remained with us overnight and the undertaker came the next day. We carried him out of the house together, into the back of the undertaker's car. A few days later, my brother Luke and I helped dig his grave. Every opportunity to take part in dad's dying and death was, in hindsight, an unexpected gift.

On the day of the funeral, dad was brought back home in the willow coffin he had asked for, and mum decorated it with flowers. Members of the family gathered at the house and then we carried his body through the village to the church which was full of his friends.

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Nigel and Jacqui Winn with son Joss, centre, pictured in 2005.

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The vicar said a few words but left the service largely to us. Afterwards, we carried dad outside to the small burial ground, lowered the coffin and shovelled soil over him. Several of us remained to fill the hole. It felt right. The least we could do.

In public health circles, it is claimed that 95% of end-of-life care is provided by family, friends and communities, not by professionals. We don't all need to be experts to care for a dying family member, friend or neighbour but it will help to be 'death literate'. This means being able to have conversations about death and dying; knowing how to care for someone who is dying; understanding what to do when someone has died; and knowing where and who to go to for support if you are caring for a dying person.

What happened near the end of my dad's life was the spontaneous creation of a 'compassionate community' of people who shared responsibility for his care and dying. Health professionals, family, friends and neighbours, each played a part in dad's dying, death, and our grief. Looking back after 20 years, I can see we were fortunate and that despite our collective suffering, it was a so-called 'good death'.

Not everyone is so fortunate. Many people, especially the very old and the disadvantaged, do not have family and neighbours who are able to shoulder some of that responsibility. They might not have someone who can advocate for their wishes or feel able to make decisions when the dying person no longer has capacity to do so for themselves. Those around the dying person may not have the experience or the confidence to talk about dying; they may not know the signs of a life that is ending, or how to feed or wash them. The partner of the dying person may themselves be too frail to take responsibility for end-of-life care.

The Lancet Commission on the Value of Death, published in 2022, argues that our approach to end-of-life has become unbalanced. Over several decades, the experience of death and dying has moved from the home into the health system, with families and communities 'pushed to the margins'; our knowledge and confidence to support those who are dying and grieving has diminished. The Commission's proposed route to rebalancing is a social one: it foregrounds relationships, networks of care, and

Nigel Winn's coffin in the garden on the day of his funeral.

normalised conversations about death, dying and grief, rather than treating death solely as a medical event managed by professionals.

Lincolnshire faces a number of challenges relating to end-of-life care. Like the rest of the UK, the population of older people is rising: around 25% of Lincolnshire's residents are aged 65 and over, and this number is predicted to rise to 41% by 2043. The issue is not that there is a growing number of old people, but that the last years of life are characterised by prolonged periods of frailty, dementia and multiple long-term conditions which exceeds the capacity of the health care system and requires co-ordinated community care.

More than half of Lincolnshire's residents are classified as having high-need or long-term conditions that require comprehensive support. For people with age-related disabilities, chronic disease and pain, the 'terminal' phase of their life is not always easy to identify and plan for. Other challenges that Lincolnshire faces often relate to the specific distribution of need and access to care. Residents of rural and coastal communities, some among the most disadvantaged, have further to travel to hospital for acute care and there are difficulties recruiting and retaining skilled health and social care workers.

There are several things we can do to address these challenges: first, we can acknowledge our individual and collective mortality. We can do this by talking about it, asking those close to us what their preferences are for end-of-life care and providing information when they are not sure; learning about the health and social care services that might be co-ordinated to care for someone who is terminally ill; identifying people in our communities who would be prepared to help you care for someone, or care for you. Schools, workplaces like the university, and voluntary organisations could help normalise conversations and planning around death, dying and grief through the curriculum, our pastoral care services and 'death cafes' where people meet to chat about death in a relaxed setting.

We must remember, too, that community action is easier for some people than others and needs to be equity-driven, recognising that the most vulnerable people and deprived communities are more likely to have the greatest need for co-ordinated end-of-life support yet have less capacity to support each other and more day-to-day challenges to overcome.

Care at the end-of-life needs to be led by the dying person and those close to them in an informed way, where their preferences are understood. To be in such a position, requires death literacy, an understanding of the death system, and a compassionate community around us.

**If you want to talk about this, feel free to contact me. jwinn@lincoln.ac.uk.**