

What happens when we die?

A thoughtful perspective on dying by a doctor who has cared for thousands of patients at the end of life



By Dr Kathryn Mannix

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THE CHANGING FACE OF DYING

Each year in England and Wales, half a million people die: half die suddenly while around 250,000 have an 'end stage illness'. Where once they would have died at home, supported by family and the local community, now they are often in hospital having treatment focused on winning a few more months, weeks or even days. Death is seen, by the public and by some healthcare staff, as a failure of medical treatment instead of the inevitable consequence of having been alive.

This move to dying in hospital is a result of life-saving medical developments during the 20th century. With the discovery of antibiotics, lives were no longer shortened by bacterial infections in infancy and childhood, and women no longer died of sepsis following childbirth. Progress in cancer research meant some cancers became treatable and even curable; vaccination prevented and even eradicated some deadly infectious diseases; better medical technology meant that failing organs could be transplanted or temporarily replaced.

These are all patently good developments, but they changed public expectations of health care: any condition that threatened mortality was met with a rush into hospital to prevent death. The traditions of supporting a family member during a terminal illness were lost as the concept of terminal illness itself was challenged by medical advances. Yet in the end, all of us will die, and most people hope to be able to die at home.

A result of the new pattern of dying in hospital is that three generations of Britons have been prevented from observing the onset and progress of dying at first hand. When dying at home was common, people understood the pattern. In the 1950s, middle-aged adults would be familiar with the slow decline of vigour and alertness in a sick relative as death approached. They would recognise the onset of weakness to the point of being bed-bound as a significant prognostic sign; they would judge life expectancy over the last few days and hours of life by the dying person's alertness, by their breathing

pattern and by their skin colour and temperature. Dying has a pattern as recognisable in its elements and sequence as pregnancy and childbirth, and yet this wisdom has become lost to public knowledge.

Likewise, when dying at home was common, people could recognise when the usually peaceful process was distorted by distress that needed treatment. Just as most births require a wise midwife but no medical attention, so it is with most deaths. Now that so few people have witnessed dying, they have neither familiarity with the process nor any measure of whether it is proceeding comfortably and predictably. Deaths on film and television become the public's references. Normal dying is rarely portrayed, so the inexperienced viewer assumes that dying in torment is usual. The majority of the bereaved, who have witnessed gentle, normal dying are not moved to tell the world of their reassuring experience, and so the balance is never redressed. Even when death would be welcomed, fear of dying badly whilst enduring physical and emotional distress may haunt the ill and the aged.

Recent reviews of care of dying people in hospitals reveal that there is often little preparation of patient or family for death; if it takes place at all, preparation is postponed until the very last hours. This apparent medical 'embarrassment' at the facts of death has caused dying to be perceived as unnatural, always distressing, and something we cannot manage.

Yet, when we turn to the experience and expertise of those who spend their lives caring for the dying in hospices and palliative care teams, we hear another story. Here, the recognition that death may be approaching is acknowledged with honesty and support for the patient (if they wish to know) and their dear ones. The pattern of decline towards the end of life is described to them; the likely experience of the last days and hours of life is described, to enable patients and their families to make realistic choices about where best to care for the dying person.

Symptoms that may be caused by a terminal illness vary according to the type of illness and the parts of the body it affects. Plans can be made in advance to deal with pain, nausea, breathlessness, seizures, bleeding and other problems. Patients can discuss what their preferences are about the balance between symptom control and alertness, if their symptoms are so severe that usual doses of distress-relieving drugs are insufficient - which is unusual in experienced hands. Families can enjoy precious time and say farewells in a timely way that enables better entry into bereavement for the survivors.

A PATIENT'S STORY

This patient's story, in which the names and some of the details have been changed to preserve anonymity, illustrates some of the experiences of palliative care experts.

Dulcie and Ira's mother Cara is dying of cancer. She is 78, a widow, and surgery was not possible because of her heart problems. After a few weeks of decline she is now too tired to get out of bed; she sleeps for long periods and occasionally awakens for a while, when she is pleased to see her son, her daughter and her grandchildren. The right dose of painkillers ensures that her pain does not disturb her sleep, yet allows her to be fully alert when she is awake. She is calm and at peace when she is awake, and she knows that she will die soon.

This is what normal dying looks like, yet few people in the developed world are aware of this fact of life.

Cara's doctors have used the pace of her decline to help predict her remaining life expectancy. Prognosis is fraught with difficulty but becomes easier towards the very end of life. Now that her family report that she is less often awake day by day, the GP estimates that her life expectancy is no more than days, perhaps enough to make a week.

The family prepares for Cara's death. They have never seen anyone die before, so a palliative care nurse tells them what to expect:

'We see people become more tired', she says. 'Cara will sleep more, to gather her energy, but like a battery that doesn't recharge properly any more, sleep only provides enough energy for a short period of being awake.'

'As time goes by, she will sleep for longer and be awake for shorter times. We will find other ways to give her medications so that her rest is not disturbed by being woken up for tablets, and this will ensure that her pain stays away.'

'As she sleeps more, a change is taking place. Sometimes, her sleep will become too deep for us to awaken her: It's not just sleep, but unconsciousness – some people use the word coma. Later, when people who have been so deeply unconscious wake up again, they tell us they had a good sleep, so we know that these periods of coma are not unpleasant. As time goes by, dying people spend more time asleep, some of it in a coma, and less time awake. This is what we expect to happen to Cara.'

As they come to understand that they will die of their illness, some frightened patients ask their doctors about hastening their deaths. In the experience of palliative care teams, this question has arisen in order to explore ways to escape terror or pain during dying, or to avoid causing distress to their family. Rarely does the fear of uncontrolled distress persist, once the process of dying has been fully explained.

Cara's breathing is changing. She no longer wakes up when her family call her name; the nurses have noticed that her hands and feet are feeling cool as her circulation begins to shut down. Sometimes she takes a deeper breath and makes a noisy exhalation, as the palliative care nurse had predicted.

Dulcie sits beside her Mum and holds her hand, talking to her gently about funny incidents from their home life together, and telling her stories about

the grandchildren. She is glad to see her Mum looking so peaceful.

Ira paces around the room, saying 'You wouldn't let a dog suffer like this!' Each time Cara takes a deep breath he says 'See! She's in pain!' Ira believes his Mum is suffering unbearably.

And yet both are witnessing the same death.

Unfamiliarity can lead to fear and distress amongst those keeping vigil round a deathbed. Without skilled help to assess the dying person, to ensure their comfort needs are met and to help the watchers interpret what they are seeing (remember the Midwife analogy), some bereaved people may well believe that the death they witnessed was traumatic. They write complaints to hospitals; they contact the media; they seek ways to make sense of their distress. In so doing, they unintentionally promote the misleading picture of dying as a process of torment. The resulting fear causes the elderly and the ill to be afraid of natural dying.

Of course, some people die less peacefully than others. Sometimes dying, like the rest of life, includes some pain, or breathlessness, or distress. A palliative care team that sees thousands of people die will see distressing symptoms on a small number of occasions. But they meet 'Ira' many times beside an apparently gentle deathbed.

ACCEPTING DYING

Dying people accept imminent death in a way that is often at odds with their previous struggle against illness. Like childbirth, where a mum-to-be fears the pain of labour and yet immerses herself in the experience once it begins, so the dying portray a tranquillity and acceptance that often surprises their loved ones. This is not to imply there is no sadness; we can accompany our loved ones as they die and offer solace, but we cannot remove the pain of loss.

Dying is part of life, and we are richer if we understand it instead of fearing it. Medical futility can be recognised and discussed; treatment plans can progress from cure to promotion of best quality of life once cure is no longer possible. People cope better knowing what to expect as their illness progresses; dying can become understood, familiar and less feared. We cannot prevent sadness at the death of a loved one, but we can challenge the conspiracy of silence that leaves many of us to live misinformed and unnecessarily fearful.

GOOD CARE FOR ALL

If we want to die at home, as most of us say we do, and if we are to receive the care we need to die in peace with our loved ones around us, we need to ensure that the expertise and experience that exists in hospices and specialist palliative care teams is cascaded into community medicine and nursing, that it is there seven days a week and that families have someone to turn to when they need it. That is the object of Baroness Finlay's Access to Palliative Care Bill and we should give it our support.

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