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Dying in the modern world

In 2013 Nelson Mandela, the South African statesman who had given so much of his life to the cause of peace, lay in a critical care unit. He was ninety-four years old and had suffered from a range of chronic and distressing medical conditions for years. I was struck by the newspaper headlines around the world: 'Fears Grow for Nelson Mandela'; 'Family Gathers as Fears Grow for "Critical" Mandela'. One newspaper article reported, 'Nelson Mandela spent a second night in [a] critical condition in hospital on Monday night, with his family members, compatriots and well-wishers worldwide fearing that the anti-apartheid icon is about to lose his final struggle.'[1]

I found myself reflecting on the strangeness of this reaction, and wondering what exactly were the 'growing fears' about? There was no doubt that there were countless millions around the world who wished Mandela well, but what were they so fearful about? Was it so fearful a prospect that a frail ninety-four-year-old with multiple chronic illnesses might actually die? Was it really terrifying that the 'final struggle' of modern technological medicine against disease and death would be

lost? Why should an extremely elderly man's dying be framed in the violent terms of 'struggle' and 'battle'?

Dying then and now

To many people today, disease and death are the enemy, and we are now part of a battle, fighting against the ancient enemy with all the powerful tools of modern technology. Death and dying used to take place in the home. At the beginning of the twentieth century, fewer than 15% of all deaths occurred in an institution, such as a hospital or nursing home. The overwhelming majority of people died in their own homes, with family, children and friends present at the bedside. Certainly, an elderly and much-revered leader like Nelson Mandela would have died at home, surrounded by his family, servants and well-wishers.[2]

Now, though, the focus has shifted to the hospital, and death has become medicalized. When we become seriously ill, we expect to be admitted to hospital. We expect treatment with the latest technology, wonder drugs and brilliant surgery. We know that modern medicine can provide wonderful, even miraculous, cures, and we expect to have access to the very best and most up-to-date treatments. After all, we do not go to hospital in order to die; we go there to get better.

The reality, of course, is that the battle against death is doomed to ultimate failure. Sometimes doctors, patients and relatives enter into a joint deception to avoid discussing the likelihood of death. The doctors do not want to discuss the possibility of 'failure'; the relatives do not want to destroy the patient's hope; and the patient is clinging on to the possibility of a medical miracle. Instead of open and honest discussion about the likelihood that death is approaching, there is a strange and ultimately damaging game of pretence.

Of course, I do not want to romanticize the experience of dying in the Victorian era. Medical techniques for pain relief and symptom control were rudimentary, and many people must have faced a prolonged and distressing end. I, for one, am intensely grateful for the extraordinary advances that have occurred in the medical care of the dying over the last century. (We will look briefly at those medical advances later.) But it is clear that, just one hundred years ago, dying at home was entirely normal and commonplace. Now, in the UK, only one in five will die at home. Just over half will end their lives in a hospital, about one in six will die in a care home and only one in twenty will die in a hospice.[3]

The problem is that it is the medical team who tell us what treatments are available for our condition, and the natural assumption is that we will be compliant patients in the unceasing battle against death, passive recipients of whatever therapies are available. The battle continues until the medical professionals decide that further treatment is hopeless. And then we die. Death has become defined by what doctors can and cannot do.

Dying has become a medical event.

As theologian Allen Verhey put it, 'The body of the dying person has become the battlefield where heroic doctors and nurses wage their war against death.'[4] I find this a striking and uncomfortable sentence, illustrating the passivity and depersonalization that modern medicine can foster. The unique person, with all the wonder and mystery of life history, loved ones, joys and sorrows, has become invisible. Instead there is just a body and an unceasing battle between medical technology and death. But dying in the midst of a battlefield is not a pleasant way to die.

There seems to be an epidemic of medical overtreatment spreading across the world. Sometimes it seems to be driven by medical arrogance and machismo. Sometimes there are perverse incentives for doctors or for hospitals that reward expensive but futile and burdensome treatments. Sometimes medical overtreatment is driven by doctors' inexperience or by fear of litigation. But even very experienced doctors may persist with overtreatment because of a sense that death represents a failure of medical skill and professionalism. If we buy into the modern medical narrative of an unceasing struggle against disease and death, it seems we are condemning ourselves to die as passive hostages in a battle waged by impersonal professionals.

After Mandela's death Bishop Desmond Tutu, Mandela's lifelong friend and confidant, spoke out: 'The manner of Nelson Mandela's prolonged death was an affront. I have spent my life working for dignity for the living. Now I wish to apply my mind to the issue of dignity for the dying.'[5] Ironically, Desmond Tutu then went on to argue that the only way to avoid the passivity and powerlessness of dying in a medicalized system was to legalize assisted suicide. This way all people would have the option to take control of their own destiny by killing themselves.

From the perspective of Desmond Tutu, we are confronted with a tragic and uncomfortable choice: either we die as passive hostages in an impersonal medical battlefield, or we seize control in the only way open to us, by committing suicide. But this is a strange, and frankly distorted, way of viewing the options at the end of life. Is there not a better way?

If there is to be better care of the dying, doctors and health professionals must recognize the limitations of their technology and their abilities: that there are limits to what doctors can and should do in the quest for healing and the preservation

of life. And we have to recognize that those limits are not there because of failures in medical technology or professional skill. No; those limits come from the nature of our humanity – from the fact that we are fragile, dependent beings who are subject to disease, ageing and physical decline.

In fact, it could be argued that one of the primary roles of medical professionals in our society is to teach modern people about the limits that come from our physical nature. This is what theologian Stanley Hauerwas has called 'the wisdom of the body'. Disease provides an opportunity for learning more about the given-ness and limitations of our physical nature:

> Medicine can be viewed as an educational process for both doctor and patient, in which each is both teacher and learner. It is from patients that physicians learn the wisdom of the body. Both physicians and patients must learn that each of them is subject to a prior authority – the authority of the body. . . . [M]edicine represents a way of learning to live with finitude.[6]

The effect of religious beliefs on end-of-life treatment

From the perspective of the Christian faith, I will argue that the medicalization of death should be resisted. Dying should not be a medical event. Dying is an event that encompasses every aspect of life, and because (whether we like it or not) we are spiritual beings, death is a spiritual event. Yet one of the strange paradoxes of modern healthcare is that some Christian believers, as they approach the end of their lives, seem to cling on to powerful medical technology, even when it can bring no benefit.

Several research groups based in the USA have investigated the impact of patients' religious beliefs on the medical treatment they received as death approached.[7] Surprisingly, the

researchers found that 'religious coping behaviour' was associated with a markedly *increased* preference for receiving all possible medical treatment, even when it had no chance of prolonging life. Religious patients were more likely to die in an intensive care unit, receiving full life support to the very end, than those who stated that they did not have religious beliefs.

Why was this? Some religious people said they believed that only God could decide when a patient should die, hence to refuse any possible treatment was 'tantamount to euthanasia'. Others said they believed they had to carry on with maximal treatment to the very end, in case God was going to do a miracle. Some said that accepting palliative care meant 'giving up on God'.

But can we really believe that dying in an intensive care unit, surrounded by the impersonal technology of infusion devices, monitors and life-support machinery, is the best way for a Christian believer to end his or her life on earth?

Suicide and self-determination

Like Desmond Tutu referred to above, some have argued that the answer to medicalization is to seize control. The author Terry Pratchett said, 'I believe passionately that any individual should have the right to choose, as far as it is possible, the time and the conditions of their death. I think it's time we learned to be as good at dying as we are at living.'[8] Pratchett was a high-profile campaigner for the legalization of assisted suicide, the legal right of all human beings to take their own lives with professional medical assistance.

Philosopher John Harris argues that autonomy, the ability and freedom to make choices about how we die – in his words, 'shaping our own lives for ourselves' – is what gives

value to our existence.[9] Others have argued that each individual life story should be like a beautiful novel. I tell my own story, choosing each line and each chapter as I go along. If I cannot control my own death, that might mar the whole story of my life, just as a bad ending can ruin a beautiful novel. So I must be free to end my life in my own way, in a way that fits my life story.

The current arguments about assisted suicide are complex, as discussed in more length in *Right to Die?*, my companion volume. Behind the idea of individual autonomy is a deep individualism that stems historically from the European Enlightenment. Each person is regarded as something like a nation state with a single sovereign. This can lead to a bleak and lonely perspective. Ultimately, I am alone, locked inside my own body, making my own choices. And suicide can start to seem possible, and even attractive, from this perspective of cosmic loneliness.

It is very striking that, although suicide has been celebrated and honoured in many non-Christian cultures, it has nearly always been opposed by Christian believers. It is never glorified in the Bible, but instead seen as an act of hopelessness and despair, for example, in the tragic ends of King Saul, the first king of Israel, and Judas Iscariot. Despite this, as I have written elsewhere, it is clear that suicidal thoughts are not uncommon among God's people. Elijah wanted to die, but was sent on a sabbatical instead. Jeremiah wished he had died in his mother's womb, but discovered that God had plans for good and not for evil, to give 'a future and a hope' (Jeremiah 29:11). Job also wished he had never been born, but learnt that God was infinitely greater than his own perceptions.

As we will see in chapter 4, while suicidal thoughts may represent a temptation for some Christian believers as they come to the end of their lives, it is my profound conviction

that we should resist this temptation, because it stems from despair, not from faith and hope.

The natural death movement

Elisabeth Kübler-Ross was a Swiss-born psychiatrist whose 1969 book *On Death and Dying* pioneered what came to be known as the 'natural death' or 'death awareness' movement.[10] Her book outlined five stages of grief – denial, anger, bargaining, depression and acceptance – that she argued many people experienced when faced with the reality of their impending deaths. It has to be said that there is little empirical evidence in support of the five stages described by Kübler-Ross, and most experienced doctors and counsellors do not employ this framework in a rigorous way.

In conscious opposition to the medicalization of dying, the natural death movement insisted that, since death could not be avoided, it must not be denied. Death was part of nature; it was 'natural'. Several different meanings can be detected in this slogan. One emphasized the biological cycles of nature. All living animals have a cycle of birth, life and death – spring, summer, autumn and winter. We come into the world, we develop and grow, we flourish, we age, we deteriorate and ultimately we die. This is the cycle of nature, and so death is natural, the ecology of the natural order. We have to die so that others can be born.

But the movement emphasized that there was more to death than the biological reality. In 1975 Kübler-Ross edited a book entitled *Death: The Final Stage of Growth* in which she wrote: 'Growing is the human way of living, and death is the final stage in the development of human beings. . . . We must allow death to provide a context for our lives, for in it lies the meaning of life and the key to our growth.'[11] Here

Kübler-Ross is claiming that dying is part of the process of self-realization; it provides the meaning of life and the essential key by which we can realize our inherent potential. This exalted view of the value of dying seems remarkably high-flown and very far from the unglamorous experiences of many at the end of life.

Theologian Allen Verhey argued that the death awareness movement, as started in the 1960s, was a modern retrieval of the nineteenth-century Romantic movement.[12] Romanticism was a reaction to the Enlightenment's emphasis on reason and science as a way to master nature, and in the same way the death awareness movement reacted against the medicalization and depersonalization of dying.

But, as Verhey and others have argued, the problem with the movement's mantra that 'death is natural' is its denial of the *wrongness* of death. The cycle of nature can bring comfort and consolation, but it is only so much help when I consider my own impending death, or the impending death of an infinitely precious, cherished and irreplaceable loved one. Death remains an autobiographical event, an event in someone's story, but it is a destructive event. Winter moves on to spring – but the person is gone, and the aching arms are empty. It is not enough to say that 'death is natural'. We need a more profound response that acknowledges the terrible reality, that sees the evil that death represents and looks towards the Christian hope that death will one day be destroyed.

Death cafés

A relatively recent initiative to encourage openness about death and the process of dying involves informal meetings dedicated to 'cake, tea and the discussion of death'. In 2004

the Swiss sociologist Bernard Crettaz organized the first death café in Neuchâtel, Switzerland, with the aim of breaking the 'tyrannical secrecy' surrounding the topic of death.

The death café is not a physical location, but an event involving a handful of people hosted at someone's house. The concept has spread around the world; by 2017 there were over 4,400 death café events in forty-eight countries. The official website describes the process in simple terms: 'At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death. Our objective is "to increase awareness of death with a view to helping people make the most of their (finite) lives".'[13]

Unlike the death awareness movement, death cafés claim to have no underlying agenda, objectives or themes. The popularity and level of interest in the events reflect a deep hunger to talk honestly about the topic. As Jon Underwood, a British council worker who coordinated the movement, put it,

> In my experience, when people talk about death and dying, all their pretences disappear. You see people's authenticity and honesty among strangers. Although it might sound really weird to say you attend a death cafe, it just feels very normal.[14]

As I have given talks and led discussions on the topic of death and dying, I too have sensed a deep hunger for authenticity and honest discussion. It seems sad that the Christian church or local Christian community is not generally seen as an appropriate place in which these discussions can take place. How can we help strangers to talk about dying if we cannot even talk about it among ourselves?

Christian thinking about death

There is a strange ambivalence about Christian attitudes to death. On the one hand, it is absolutely clear in the biblical narrative that death is an enemy: indeed, death is the ultimate enemy that continually threatens and besieges humankind. In biblical thought, human death is not an original part of God's creation order; in that sense, it is not 'natural'. Death is a mysterious and terrible interruption into the nature of being. The deep intuition that we share – that physical death (especially the death of a child or young person) is an outrage, an alien interruption into the goodness of reality – reflects the original creation order. Similarly, the inexpressible longing we have for eternity, for stability, for freedom from decay, reflects our created nature. We were not intended to die; we were made to live for ever. That is why Paul teaches that the risen Christ will ultimately destroy death, the 'last enemy' (1 Corinthians 15:26).

In its ceaseless struggle against death, modern medicine is bearing witness in advance to the ultimate destruction of death. The medical struggle is witnessing to the goodness of the creation and the goodness of bodily life with all its glories and its vulnerabilities. In my own medical career I remember days and nights spent in the intensive care unit, battling to hold death at bay from a single tiny precious life in an incubator. Yes, it was worth it. Death is an enemy to fight against with all our strength, perseverance and courage.

And yet . . . In the biblical narrative the human lifespan is limited, not just as a curse, but out of God's grace. Adam and Eve, in their fallen and degraded state, were driven out of the Garden of Eden to prevent them from eating the fruit of the tree of life and living for ever. And to prevent their return and capture of the fruit by force of arms, cherubim and a

flaming sword were set 'to guard the way to the tree of life' (Genesis 3:24). The biblical narrative makes plain that to live for ever in a fallen state is not a blessing, but a curse.

So, in God's mysterious providence, death may on occasion change from being an enemy. It may become a release from an existence trapped in a fallen and decaying body – in C. S. Lewis's wonderful words, 'a severe mercy'.[15] Christian attitudes to death must always reflect this strange ambivalence. Even though human death is fundamentally an evil to be fought against, a reality that must never be sought intentionally, it may also at times be accepted as a sign of God's mercy.

Like many other Christian believers, I hesitate to talk about a 'good death', but I do believe that we can learn to die well, and that is obviously what this book is all about.