

## A time to die

## Hazel McHaffie

It is a truth, universally acknowledged, that death is an inescapable part of life. And we've certainly been reminded of that fact with the toll the Covid-19 pandemic has exacted, haven't we? When the UK went into its first lockdown in March 2020, and we were told that the National Health Service could well be so overloaded doctors would be forced to decide who to treat and who to refrain from actively treating (as had happened in Italy mere weeks earlier), I sent three emails to my son and daughter.

The first one reminded them of my long-standing advance directive spelling out my end-oflife wishes.

The second one said that, if resources became overstretched, I should not be the one to get treatment, as I'd already lived a long and fulfilled life – the chance should go to someone else.

The third message asked them, in the event of my death, just to have me quietly cremated and left on a shelf meantime, without any gathering of people whose welfare might be compromised because of the risks of Covid at that time.

Back came my daughter's response, "Is that the end of the morbid messages?!"

But, to me, they weren't morbid; they were realistic and practical, intended to relieve the family of the burden of making difficult choices and moral judgements on my behalf.

The communications were also a continuation of my sustained wishes over many decades. Each time I've had an anaesthetic or a life-threatening procedure, I've clearly stated to the responsible professionals that, if anything were to go wrong, I did not want to be resuscitated where the risk of serious damage outweighed the possibility of complete recovery. I preferred death over severely compromised life.

I'm essentially very matter of fact where death is concerned – you've probably twigged that by now! And what's more – and this is an even more powerful position statement – I made that same choice when the life of my beloved firstborn baby hung in the balance at the age of three

weeks. I did not want him to suffer a life of extremely poor quality; I would choose death for him rather than that.

I think my own opinions on the subject began to form when I was 19 years old and my 25-year-old brother-in-law died in an accident at work. Nobody talked about it. For me it became the elephant in the room.

My ideas were moulded further when I became a nurse, intimately acquainted with death. Caring for patients who were dying; holding their hands as they breathed their last; comforting relatives; dealing with their beliefs and wishes.

And over the subsequent years, seeing many beloved relatives and friends grapple with horrible diseases, face living nightmares, and die – in some cases prematurely. Each left a mark and steered me in the direction of my present understanding in relation to death.

When my career path took me into the field of medical ethics – the thinky bit behind moral judgements and choices – one topic I chose to study in depth over about eight years was the moral dilemmas associated with deciding when enough is enough; when death is a kinder option than continuing treatment for very tiny or sick babies. Listening at first hand to how these choices affected hundreds of healthcare professionals and parents, again, challenged me profoundly.

So, it's fair to say, death and dying is a subject I've wrestled with for most of my life. Indeed, my family would probably tell you it's an obsession!

When I moved from empirical research to writing novels set in the world of medical ethics, you might have thought I'd take a break and go frivolous. But no! A lighter touch and a smattering of humour, yes, but essentially ethical dilemmas – even much diluted – are pretty serious business. So, for my fourth novel, Right to Die, I elected to spend a couple of years getting inside the head of a young man with a fatal neurodegenerative condition that meant his brain remained active while his body disintegrated inexorably. It was without doubt the most emotionally taxing of all the fiction I've written, exacerbated, I suspect, by the fact that in real life a relative of mine was simultaneously living with a terminal illness. I found I was stalling; delaying the time of his end, as if in some superstitious way, I was keeping her alive too.

Perhaps because of my background and experiences, many people have talked to me about their own take on death and dying. I have no intention of betraying confidences, but I can share the fact that a significant number have expressed views they wouldn't be willing to air publicly – either because they perceive the community at large would frown on their ideas, or because

they're unwilling to let their opinions be known more widely for personal reasons. But in sharing their doubts and fears, they, in turn, have made me question more deeply just how faith, conviction and practice fit together.

Why, for example, are so many so afraid of their own death, speaking with great trepidation about the judgement seat?

Why are some so insistent on relentlessly postponing the date of dying, pursuing gruelling treatments long after any realistic hope of a cure?

Why do some visitors insist on praying at hospital bedsides, pleading with the Almighty to extend his mercy to the poor unfortunate in the bed, with a distinct undertone that it's by no means a foregone conclusion?

Why do people use the language of war to describe dealing with serious illness – fighting a courageous fight; losing the battle? As if, somehow, you're weak and feeble, or maybe even deficient in faith, if you succumb.

Why is death seen as the losing ticket?

Why are some privately in favour of assisted dying, but unwilling to express that view openly?

Why don't we address these issues overtly and honestly in our community?

I have several shelves full of books about medical- and bio- and Christian-ethics in my study, and today's subject could easily fill a few hours. But this is not the forum for an exhaustive discussion of all the finer points of law and ethics, or even of religion. Nor to beat any particular drum. I'm going to do my best to avoid the jargon, and theories, and the boring stuff, and get to the kernel of what I think these dilemmas and questions mean for us today in the 21st century. And I want to leave you breathing space to ponder the consequences of your own understanding, values, and opinions, for yourself. It's not for me to tell you what to – Goodness, I've been working in this field for decades, and I've come to the conclusion that very little is black and white. Indeed, some of the issues have become as grey as my hair!

So, here goes.

It's become apparent to me that a lot of people who profess a strong faith, have a very real fear of death. I'm not talking about a dread of the indignity and suffering and pain of the dying process, nor the mental anguish of leaving loved ones behind grieving, which are very common across the board, but the actual moment of taking that last breath. The prospect of 'meeting their Maker'.

OK, I can see some foundation for a fear of judgement.

Just as people are destined to die once, and after that to face judgment ... (Hebrews 9:27)

For we must all appear before the judgment seat of Christ, so that each of us may receive what is due us for the things done while in the body, whether good or bad. (2 Corinthians 5:10)

I tell you that everyone will have to give account on the day of judgment for every empty word they have spoken. (Matthew 12:36)

Ah, but then there are also passages that tell us that we can be assured of eternal life now: Very truly I tell you, whoever hears my word and believes him who sent me has eternal life and will not be judged but has crossed over from death to life. (John 5:24) Whoever believes

in the Son has eternal life ...(John 3:36)

I write these things to you who believe in the name of the Son of God so that you may know that you have eternal life. (1 John 5:13)

Present tense – or for the purists amongst us, present continuous. You have.

It's always a bit dodgy to start selecting verses out of context, though, and to translate meaning across languages and cultures and time. It's important to keep the bigger picture in mind. That bigger picture, over-arching the detail, is of a loving God who cares for us in a way we can only dimly perceive. And that's part of the problem, I think: our limited understanding. The images used in the Bible are an attempt to make something infinite, and outside of time and space, and as yet unknown, comprehensible to our very finite minds. On a personal level, I'm left reeling ... what, me? This awesome Being who was and is and is to come, cares about the infinitesimal speck that is me? But that's what's being conveyed in the parables and explanations and imagery. And because that's so, we can surely safely commit our future to his boundless mercy and care. So, why should we be anxious about the prospect of what's to come? As the apostles said:

Cast all your anxieties on him because he cares for you. (1 Peter 5:7)

Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus. (Philippians 4:6-7)

Picking up from what Jesus himself said:

Look at the birds of the air; they do not sow or reap or store away in barns, and yet your heavenly Father feeds them. Are you not much more valuable than they? (Matthew 6:26)

Peace I leave with you; my peace I give you. I do not give to you as the world gives. Do not let your hearts be troubled and do not be afraid. (John 14:27)

So, to be fearful of what lies ahead, seems to me to diminish the power and compassion and generosity of God. To reduce him to something far smaller than he is. To doubt the awesomeness and sufficiency of his grace.

Unfortunately, I think, the community has hammered home negative messages about our unworthiness, about the fearful judgement to come, about the dangers of being cast out, and largely overlooked the utter amazingness of grace. I too, was steeped in these texts, and heard most weeks that I was unworthy, so I was completely bowled over by the notion of being saved by grace. Charles Swindoll's book, The Grace Awakening, and Philip Yancey's, What's so Amazing about Grace? started me on a very different journey. But once you're alive to the idea, the conviction in the Bible leaps out at you.

For it is by grace you have been saved, through faith – and this is not from yourselves, it is the gift of God – not by works, so that no one can boast. (Ephesians 2:8-9)

So too, at the present time there is a remnant chosen by grace. And if by grace, then it cannot be based on works; if it were, grace would no longer be grace. (Romans 11:5-6)

Too awesome to be contained in mere words, isn't it? I like the analogy of a brother in Scotland who used the image of a journey. The train is going to the kingdom. Once you step into the carriage, that's where you'll end up, just as long as you don't get off. We have simply to put our trust in the driver.

So, if we shouldn't fear death, let's look it squarely in the face.

Death today is, of course, a very different thing from even 100 years ago. Infections and illnesses which, in the past, were regarded as the 'old man's friend', because they released him naturally from a burdensome life, have become the enemy to be fought off at all costs. Medical understanding and capacity have advanced to such a level that the fatal consequences of pretty much any illness can be deferred to some degree at least, nowadays. Buying time. Ameliorating symptoms. Delaying the moment of death.

And much of the time we welcome this, don't we? We're glad a young mum was given two extra years to spend with her children, building precious memories with and for them. We're

grateful Grandpa got to see and hold his fifth grandchild before he died. We treasure the photos of the generations together. We savour those precious opportunities to tell someone what they mean to us, show our love, repair old wounds, forgive and be forgiven.

But sometimes, extending a life, aggressively and determinedly, comes with a terrible price tag. Slow deterioration, indignity, unremitting pain, mental suffering, hopelessness. Such

prospects raise questions about whether life is indeed to be preferred to death. Would you choose life if it meant unrelenting pain which no medicine can touch? Or being mentally alert, aware of your body systematically losing all its power to function? Or a slow loss of mental acuity, knowing that indignity, loss of control, await you?

Sometimes it's the case that simply stopping treatment will allow 'nature to take its course'. Withdrawing or withholding treatment is widely approved of in most religions and is perfectly legal. It's a reality that there may be rather unpleasant consequences from diseases left to run rampant, but it then becomes a matter of dealing with the symptoms whilst not delaying death. Indeed, a consequence of giving increasing doses of pain relief, for example, can be to suppress breathing and actually hasten death. But this is permissible even in religions which revere the absolute sanctity of life.

I happen to be in a position where I require medication daily to sustain my life. If I were to develop a horrible disease which I deem intolerable, it would be perfectly possible and permissible, legally, to stop taking those drugs, and allow the condition they hold at bay to end my life, and I suspect very few would have moral qualms about that.

If death is still a long time coming, and the quality of the remaining life is poor, a next step might be to withdraw food and water. This has certainly been the subject of extensive multidisciplinary wrangling, most notably in cases of persistent vegetative state or advanced dementia, where the person is unable to feed themselves and would die if sustenance is withheld, and they're incapable at this stage of deciding for themselves. The arguments hinge on whether such nourishment constitutes a medical intervention or basic human care, and to what extent the act of withdrawing it would represent the sustained wish of the person in question. It is, in essence, a further extension of the withdrawal of life-prolonging interventions, where death is thought to be a kinder option and more in keeping with the values of the person before they were reduced to this state.

But there are tragic cases where simply stopping treatment isn't an available option. Maybe there's no treatment to be withdrawn. Maybe biological life stubbornly continues even when all measures are withdrawn. Maybe the condition is such that the body is ticking over at a very low level of functioning, or the illness is a degenerative one where the different systems are failing slowly and sequentially, or injuries sustained in an accident are so overwhelming, that physical life continues, but at the expense of mental well-being. A living hell. Then the question becomes: Is it ever right to take active steps to put an end to pain and suffering and offer a humane death?

At this point I should just mention the hospice movement – an umbrella term for the growth of end-of-life and palliative care services over the past 50 years or so. Excellent holistic care, which takes account of physical, mental, emotional and spiritual well-being, has enabled many people to have a much better quality of life as they approach death. Opponents of assisted dying argue, indeed, that it has removed the need for any more aggressive action to end a life. Well, it has undoubtedly given many dying patients a quiet and dignified death. But, sadly, it's a service that is perpetually underfunded, and not available to all. And it's also a fallacy to say that no one needs to suffer a distressing death nowadays. Good as the care is, it is not always able to contain pain and suffering. And sometimes that pain and suffering is worse than death.

Assisted dying – prescribing/supplying life-ending drugs – is already legally permissible in many countries around the world: Switzerland, Belgium, the Netherlands, Luxembourg, Canada, Colombia, Victoria (Australia) and a number of states in the USA. The laws all have strict conditions attached, which vary from country to country, and in some cases have been modified over time. In some places, the person seeking death must be able to take the medication themselves; elsewhere professional staff are permitted to administer it. But in the UK, even after numerous attempts to make it legal, it remains unlawful – a criminal offence – to help someone to die. Even landmark cases, where the effects of continuing life are obviously appalling on pretty much every measure, have failed to give the movement sufficient traction to bring about change. The phrase that's often trotted out is that 'hard cases make bad laws'. Judges will not be swayed by raw emotion. Which is why so many people from this country have travelled to Switzerland to die in a manner and timing of their choosing – it's estimated at the equivalent of one a week.

It's noteworthy that religious groups have been amongst the most vocal in opposing a change to a more liberal approach. Why? And what should our Christian response be?

Well, an obvious starting point for many Christians is the fact that the Bible is clear: God is our creator. Therefore, it's argued, human life is not our property, it's designed to be used in the service of our maker; we may not just dispense with it. As Job said: The Lord gave and the Lord has taken away (Job 1:21).

Essentially, the issue is about who has responsibility/ownership over our lives. God? – in which case, to take our life is a denial of his rights; or us, because he made us stewards of our own lives and this planet? – in which case, abandoning our lives is to deny this divinely-appointed responsibility. Either way, it's not for us to take life, even our own.

... Or is it?

Then there's the commandment in Exodus 20:13. Thou shalt not kill (KJV), or more properly rendered You shall not murder (NIV). Ending a life in any circumstances, many argue, is morally wrong. Full stop. But hey, let's not lose sight of the fact that under the law of Moses, people could be killed for many reasons: assorted sins, in battle, as part of religious genocide ... Back then, it was a case of: 'Thou shalt not kill ... except for all the times you're commanded to kill.' So, in the 21st Century AD, under the law of Christ, is compassionately easing the intolerable suffering of a fellow human being, 'murder'? We'd put down a pet on the grounds of compassionate release from a miserable existence. That's not murder: it's legal; you can even be castigated for not doing so. So why not a human life? And what about the Golden Rule to do for others what we would want for ourselves? I certainly don't want to be ending my days in unremitting pain and indignity, so what gives me the right to insist on that for my neighbour? What d'you think?

Probably the second commonest argument put forward is that assisted dying is thwarting God's will; no human authority has the right to take a human life sanctified by God. I confess I struggle to understand this one. If you go down that path, then we shouldn't wear glasses — God intended us to have impaired vision. We shouldn't have vaccinations — it's God's will we should contract Covid-19 or TB or smallpox. We shouldn't take antibiotics, or go to the dentist, or have operations, or seek treatment for our ailments. It was God's will we had an infection, or toothache or a crumbling hip joint. How can it be any more 'thwarting God's will' to end a life that's being preserved simply because medicine has found ways to thwart nature, big time? At what point does intervention become unacceptable? And who says?

There are Christians who would argue that suffering is redemptive. They turn to Romans 5:3-5, 2 Corinthians 4:16-17; James 1:2-4 to demonstrate that suffering refines our characters and leads to wisdom and maturity. Well, I'd agree that people can and do grow and mature through life's hard knocks, and they're certainly better able to comfort and support others if they have some experience of suffering themselves. But hey, if that obtains across the board, why do we try to alleviate pain and distress at all? Try having an operation without an anaesthetic, or coping with a migraine headache for three weeks without analgesia, or walking on a broken leg. Does that make you a better human being? I doubt it. So, let's be realistic here. Do you really think that extending a miserable quality of life deliberately will be good for you? Or that it's a valid reason to keep someone alive way beyond their tolerance? Remember Jesus' reminder of God's teaching: I desire mercy not sacrifice. Could this be another example of where mercy and compassion trump rules and laws, as he showed us?

Some people argue that all human life is valuable because we're made in God's image, and they turn to Genesis 9:6: Whoever sheds human blood, by humans shall their blood be shed; for in the image of God has God made mankind. It should not be cut short by so much as a second, they say. Well, human life does certainly have a special kind of status; an intrinsic value. But, does it always reflect God's image? bring him glory? I've listened to healthcare professionals weep remembering babies who were kept alive artificially for weeks and months beyond any reasonable hope of recovery, when they 'smelled of death', simply because the parents' religion, and its representatives, insisted they must. In what way could such a travesty of a life be reflecting God's image? And, couldn't the same be asked of adult lives wrecked beyond endurance?

Proponents of life-at-all-costs would come back at me, here. Our significance, and so the claim to protection, derive not from our quality of life, or intelligence, or mobility, or ability to communicate, or potential to give pleasure, but from our status as being made in God's image. And of course, we would probably all agree that a person with disabilities, or dementia, or very aged, or severely handicapped, has an inalienable value and worth by virtue of their human-ness. It could be argued, to take away any such life would be to judge that individual life as not worthwhile. But, is it right to use this argument to keep a person alive who's suffering from an irreversible degenerative illness that will eventually rob them of the ability even to move or breathe or swallow, and who would prefer not to go on living such a nightmare? Is it right to force a family to spend sixty years caring for a relative who's in a persistent vegetative state who will

never again be a sentient human being, when all concerned believe this to be a fate worse than death? How does this bring honour to God's image? It could well be argued that it's better to treasure every moment of a shorter life, filling it with love and dignity, than drag out an extended one full of pain and misery and regret.

A cornerstone of Christianity is care for others, respecting them, and their opinions, and treating them as we would wish to be treated ourselves. So, if their wish is for an end to a life that for them is not worth living, are we right to deny them that possibility? If such treatment as is available, is too burdensome and futile, should they be obliged to accept it because other people's conscience tells them it's wrong to end a life, full stop? To what extent should their own right to personal autonomy be permitted to prevail?

Autonomy – the right to self-determination – of course, is not an absolute. And this is particularly the case when exercising one's personal rights does harm to others. So, it could be argued that, by opening the door to assisted dying, other vulnerable people at the end of life might be harmed. They might risk having their lives ended, when this is not their considered wish. And here we have a good example of how complex the moral arguments become with one right or interest traded against another. I'm reminded of a definition of a moral philosopher: 'a person with eight hands'– on the one hand, but on the other ... again and again! Add to this the second argument we looked at, God's will, and many Christians would maintain that none of us has the right to end a life that's God-given. That right to determine the length of our life belongs to God not us. Round and round we go!

But this also plays into a major sticking point for me. I might well be able to argue for allowing the individual to determine the manner of their dying; to make a strong case for assisted dying in rare but intractable cases. Indeed, I might well choose such a course for myself. But I know – know for sure – that I couldn't personally be on the plunger end of the syringe, the one which would be actively instrumental in taking another human life. I haven't the courage to kill an animal, or bird, or even a snail, deliberately! There's something very awe-inspiring about life itself, which I can't explain; I just feel it in my bones, in my soul. Hmmmm; maybe I'm not so prosaic after all, huh? But anyway, if I couldn't do it myself, what right have I to require others to do it? It's an unanswerable question as far as I'm concerned. So, I have every sympathy for the many doctors who are not in favour of a change in the law, because life itself is just too sacred; it

feels like a violation of their Hippocratic Oath. Intellectually it may well be possible – even desirable; emotionally it's not.

However, I also know of Christian doctors who're much more courageous than I, who do include actively easing death in their practice, and I admire them hugely. They have the ability and strength to see beyond their own personal interests, to put compassion and love into action in a very special way, in order to respect and respond to the greater need of others. The second great commandment.

This brings me to another issue where I'm personally brought up short: who decides? Can it be right that people who've never experienced horrors such as those we're considering, nor are they likely to do so, should stand in judgement on those for whom life is a living hell? We know that God is a God of love, far surpassing the love of a parent. If I can understand a person preferring death in extreme circumstances, how much more would be sympathise and understand their plight and choice?

So, where does all this leave us? Well, death is indeed a natural part of life, but modern medicine throws up many dilemmas. It has given humans more power, and thus more responsibility, over when life ends. We do need to think about these issues.

My own view is that strict criteria and measured arguments only take us so far. Jesus himself had little time for the folk who insisted on slavishly following rules and regulations. He taught that love and compassion are of paramount importance – commandments even. So, for me, the best way to determine the right course of action, is to ask: What are my motives here? Am I slavishly following instructions from a different time and a different culture, or am I modelling my thinking and actions on the moral imperative to love and care and show compassion?

How can we best prepare for that? Well, whatever we feel about actively ending a life, I think it's fair to say, we should try to face death and dying with honesty and integrity; looking squarely at those very real fears and hang-ups we talked about at the beginning, not sweeping them under the carpet. And we should have those important conversations with our loved ones so everyone is prepared. Doing so calmly and rationally, not when we're in the thick of a painful emotional experience and our eyes are full of tears. Maybe your offspring too will call you morbid (!), but they'll thank you when the time comes to choose how you'll end your days, and what memories they'll have of them.

And as far as other people's deaths and opinions are concerned, we should try to have open minds and listening ears, and a readiness to admit we don't have all the answers. We won't always know what the right thing to do is. Our personal history, beliefs, attitudes, circumstances, might well influence us. We need to have the humility to accept that others may reach a different conclusion. And that's OK.

His grace is sufficient for us.