

A time to live and a time to die – reflections on care from diagnosis to death.

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I am a haematologist – a blood doctor. There are a number of different aspects to such a job, but a significant proportion of my time is spent treating people with malignant diseases such as leukaemia, lymphoma and myeloma. I was attracted into the speciality in the 1980's because it was rapidly developing, and in particular there were new treatments including bone marrow transplantation. These held out the promise of cure for diseases which could previously only be palliated. I researched for two and a half years on ways to improve the treatment of myeloma. It is undoubtedly very rewarding to see patients cured of their illnesses, so they come back to one's clinic alive and well, years later. But many of our patients cannot be cured; some diseases are treatable but not curable – one can control the disease for a few years, but inevitably the patient will die of their disease. Some patients are not physically able to tolerate the intensive curative treatments required and so have to be offered less intensive, palliative options. In the context of being able to cure some, it is doubly sad and tragic when a patient dies. So, as a young haematologist, I found it very hard to cope with patients dying, especially young ones whom we might have hoped to cure. But over the years, I have increasingly accepted that we cannot cure everyone. I have increasingly felt that it is my privilege to care for patients from diagnosis to death, and one's objectives at each stage are different.

I am also frequently involved in discussions and decisions around end-of-life issues. Most often this takes the form of discussions with Intensive Care doctors over whether or not to admit a haematology patient to ITU. For example there are patients whose life expectancy is short, and whose chances of getting off ITU are very slim. We may come to a decision, involving the patient and family as well, that we will support the patient on the ward as far as possible, but not resuscitate in the event of a cardiac arrest or transfer the patient to ITU for artificial ventilation. I also look after patients with more indolent long term conditions, for example those who require regular blood transfusions for survival, and some of these are very elderly and frail.

I am a believer in 'death with dignity' and 'assisted dying'. As far as possible I want to assist my patients, along with those family and friends who care most for them, to experience what we might call 'good deaths'. But I am also a passionate opponent of legislation to allow patients to request a doctor or anyone else to hasten their death either by assisting suicide or direct killing. I am sure that all of us here want to see our friends, family, patients, church members or neighbours have dignified or 'good' deaths. That is our common goal, and the basis of the dialogue in which we will take part over these 3 days.

I have put some descriptions of a so-called 'good death' on the back of my handout, which might prompt questions or discussion later.

Principles of Christian patient care, especially for health professionals

1. Human beings are made in God's Image.

Genesis 2v26: Then God said, "Let us make man in our image." Or as the NRSV puts it: "Let us make humankind in our image". Of course, whole books have been written about what this means, but it surely means more than human beings having consciousness, rationality and creativity. It implies that each individual human being reflects God's nature. I agree with John Wyatt, professor of ethics and perinatology at UCLH, who wrote: 'The divine image is like a mirror reflecting God's glory.' Each person finds his or her value in the love and care that God expresses in making and sustaining that life. It means that each person, from conception to beyond the grave bears the image of God, regardless of the supposed defects in that person. A person's value is not determined by their capacities, their health and vigour, their rationality or their independence. Each flawed masterpiece, as we all are, is loved by God, and hence is worthy of our awe, respect, care and protection. I believe that each life is precious and of equal value to God, regardless of frailty, cancer, dementia or disability, and should draw out from us the same level of compassionate care and service.

But, are we now autonomous beings, with god-like independence of thought and action? No – even in the Genesis account, we are told that we are here as stewards of God's earth, and accountable to God for our actions, not least in relation to 'being our brother's keeper'. I would add that while we were given specific creation instructions to 'go forth and multiply' in a responsible way, we were not given any instructions about controlling the timing of death. Indeed, as God said to Noah in Genesis 9, "Whoever sheds the blood of a human, by a human shall that person's blood be shed; for in his own image God made humankind."

I will leave further debate about our autonomy to later speakers and discussions, but I am clear that we have limited autonomy, under God's sovereign rule. Our lives are not our own to do with as we please – we have to account to God for his precious gift.

Let me tell you about a patient of mine (I have changed names and some details of patients mentioned in this talk). Brenda developed acute leukaemia at the age of 34. She nearly died of infection after having intensive chemotherapy to induce remission. Because of the type of leukaemia, it was decided that her best chance of cure was a bone marrow transplant from a sister. She underwent this, but developed severe graft-versus-host disease – when the transplant attacks the recipient of the transplant. This was life-threatening in its acute stage; she survived, but went on to develop very severe chronic GVHD. This particularly affected her skin which became fibrotic, contracted, de-pigmented and scarred. Her appearance is now quite marred and she has limited joint mobility and breathing. The GVHD affected her genital area, so sexual intercourse became painful and virtually impossible. Her marriage relationship became very strained. She needed intense immunosuppressive therapy, frequent admissions, and trips across the country for specialised treatments. There were several times when she said to me how awful her life was, and that she wished she had been allowed to die and not survive for such a poor quality of life. She wished she had never had the transplant. She used to say how dehumanised and de-womanised she felt. But actually underneath she was a very strong and courageous person, and gradually her active problems settled and her need for treatments reduced. Slowly, she regained her cheerful and positive outlook. She actually resists me trying to help her with her multiple medical issues, saying she wants to put her illness behind her, and make a new 'normal' life.

If we think of the things that people fear about illness and disability, Brenda has certainly had severe physical, emotional and relational pain, terrible indignity and at times marked dependence on others to look after her and her family. But the image of God is still there. Although she is physically and mentally scarred, she is now more than glad that she soldiered on through those very low patches.

2. Human beings are relational beings

Another facet of us being in God's image is that we are created for relationships. As God said in Genesis; "Let us make humankind in our image." Our humanity is only fulfilled in as far as it reflects the loving, self-giving relationships that exist between the 'us' of the godhead. As John Wyatt points out in his book, *Matters of Life & Death*, it is not so much a matter of 'I think therefore I am', but 'I am loved therefore I am'. It is not consciousness and rationality that define a person and his or her value, but the fact that he or she is loved. This essential aspect of human-ness shows why human isolation and poor relationships are so damaging. But, even if someone is deprived of all human love and relationships, the high value of their life is still assured, because all are equally and profoundly loved by God.

But we are also created for human relationships and inter-dependence. This is different at different stages of our life, from total dependence as a fetus and newborn, to practical and emotional dependence on one another as adults, to increasing reliance on others as we grow older and frailer. It is part of the human condition to bear one another's burdens, giving meaning and mutual affirmation to millions of encounters between human beings every day. I'll come on to sin in a bit, but at the heart of the human rebellion against God is a spirit of independence and self-determination. As Isaiah put it: 'All we like sheep have gone astray, we have all turned to our own way' (Is 53v6). Or in the words of the psalmist, 'the wicked lay claim to heaven, and their tongues take possession of the earth.' Just as human pride has caused us to rebel against God, so it also makes us resent and reject anything that makes us dependent on others.

One of the saddest situations in which I find myself is caring for a patient who has no family or friends to share his or her burden of illness or disability. This may be the result of them being from a small family, or never having married or had children, or just 'being a very independent person' as they say. Sometimes it is the result of fractured relationships, divorce, or family dispersal. But whatever the reason, if someone has to face illness, especially one that will entail increasing frailty and dependence, then I know it is going to be difficult. It is likely that their quality of life and even the duration of their survival may be affected.

Let me tell you about Richard. He was diagnosed about some years ago with an advanced bone marrow condition which I knew would develop into leukaemia and lead to his death within a few months to a year. He was 81 years old; he had never married, nor had any children. He had one sister, but she was elderly and lived in Scotland, and his only friend was a neighbour, but "He was no help as he was an alcoholic and couldn't be relied on." Although Richard was a stalwart and independent man, the difficulties started straightaway. I like to have someone else from the patient's immediate family, or circle of supporters, present when I explain the diagnosis and its implications. It is difficult for one person to take everything in, and I want someone there who will be a second pair of ears, and a second opinion on the patient's views on whether they might want chemotherapy etc. I also want to gauge their overall strength and health, and the support network that is going to be available to the patient. But Richard never brought anyone on any of his hospital visits. He generally came up by bus or taxi; he never had anyone to turn to when he

had a complication at home. I thought, how sad that someone who was in his last few months should be shouldering it all alone. Indeed, he resisted all attempts to get him support or help, and I don't think he had anyone extra come to his home before he died suddenly of an intracranial bleed after about 8 months. Surely, a Christian response to people who seem bereft of human support as they enter their final months, is to look out for people like this and offer them love and practical help as far as we are able and they are willing to accept. I think of a wonderful Christian lady who devotedly looked after her near neighbour, who was my godmother, for the last 18 months of her life. My godmother was another person who had no siblings, never married and had only a few other very elderly friends who couldn't be relied on to help.

I found the recent Terry Pratchett documentary called 'Choosing to die' disturbing in a number of ways. One particular thing that struck me was that his wife obviously did not support his possible plan to go for assisted suicide. Pratchett admitted that she was willing to care for him if he deteriorated into frank dementia in the future, and indeed he said, "She would like to care for me to the end." But he said, "I know more about dementia than she does, and I don't want to be a burden on her." What his wife might see as the noble, right and fulfilling culmination to a lifelong loving relationship, he wants to deny her. Suicide, even when done for what appear to be noble reasons, always affects others negatively. It will tend to make those around the person who has committed suicide feel that they didn't love or care for the person enough.

3. Human beings are fallen

God made a perfect world, but with the potential for rebellion against Him. Because of our rebellion, we now live in a fallen world, with imperfection, pain, suffering, death and evil around us. Of course evil is also within us. As Jesus said: "It is what comes out of a person that defiles. For it is from within, from the human heart that evil intentions come" – including, "theft, murder, avarice, deceit, pride." (Mk 7v20-22). This has so many implications for the care of human beings, especially as they face the end of life, but here are a few:

We cannot remove suffering completely. While we see it as our divine calling to relieve suffering and pain as far as we possibly can, it will never be done away with completely this side of the recreation of the heavens and the earth. In the consumerist individualistic culture in which we live, we may think we can demand a perfect life, a healthy body, freedom from pain, and a long life, but we cannot. And even modern medicine, with all its cleverness, cannot promise that to anyone.

We cannot prognosticate perfectly. We have human knowledge not divine. Doctors are frequently asked, 'How long have I got?' I have learned never to give a precise answer to that question, because I will always be wrong: too long or too short! Even when someone appears to be nearing death, one can get it very wrong. We can misdiagnose someone as dying. There is something called the Liverpool Care Pathway, which is used when it is reckoned that someone has less than 48 hours to live. Care patterns are shifted from trying to keep alive, to keeping comfortable, reducing unnecessary interventions etc. It is surprising how often patients survive longer than predicted – indeed I have known two patients in the last year who have recovered while on the LCP and been discharged home quite well. Although statistically we may be able to suggest a median survival for a patient, that is long way from truly being able to say how long any one individual will live.

Everyone is affected by the fall. Obviously this is true in different ways, but people may be affected by personal sin, emotional deprivation as children, messed up relationships, personal demons such as alcohol or drugs, or physical or sexual abuse. Many people in our world have a very poor sense of self worth, a feeling that they are of no value to society. And then to this may be added the burden and pressure of a disabling, painful, undignified or distressing illness. My wife, Alison, is a GP and every day she meets people who have contemplated suicide. Their stories are often heartbreaking. Some have actually attempted suicide. But for >95% of them, the mention of suicidal thoughts is not a request to give them the means to commit suicide, but a request to help them sort out their life and solve their problems. Our ministry to such people, and indeed to all people suffering from any chronic disabling or depressive illness, is to help them regain a sense of self-worth. Of course, somewhere inside each person is the need for them to experience the self-affirming, unconditional love of God. God's love, in the person and work of Christ, is the only thing that can truly reverse the effects of the fall in a person's life.

The human heart is corrupt. (Jer 17v9). We know that no person is perfect, but some are frankly evil. It is not just children suffering abuse in our society; we are increasingly aware of the abuse of the elderly. A new addition to my 'mandatory training' that I have to undergo each year, is 'Awareness of the vulnerable adult', which includes the elderly, the mentally ill and disabled. There is neglect of the elderly, frank bullying, emotional abuse, physical violence and financial exploitation. Anyone involved in ministering to, or caring for, the elderly will have seen this. In this context, it is very easy for the elderly or disabled to feel a burden to society or their family. They may justify to themselves, even in a honourable and self-sacrificial way, that they would be better off dead, to 'help the next generation'. I think it is sad, and telling, that >30% of those undergoing physician-assisted suicide in Oregon mention feeling that they are a burden on family or society as one reason why they are proceeding to suicide. In this context, I feel that our overwhelming Christian responsibility and ministry should be to protect the vulnerable. God demands of us, in Ps 82v3-4; 'Defend the cause of the weak and the fatherless, maintain the rights of the poor and oppressed. Rescue the weak and needy; deliver them from the hand of the wicked.'

I would add at this point that institutions are also not free of evil. We have heard of institutional racism, but we need constantly to restrain ageism within our society and its institutions, including our medical facilities. With all the financial and bed occupancy pressures on NHS hospitals, it is very easy to see the elderly, who are frail or disabled, but not actually dying, as at best inappropriate users of expensive NHS beds, and at worst as 'that old crumble in the side room'.

There are eternal issues at stake. As Christians, we believe that this is not the only life – there is also eternal life to think of. We have the possibility of an everlasting relationship with our Creator, by faith in Jesus Christ our Saviour. This is not automatic; we cannot just say that assisting people into the next life is a good thing. With some patients, we may be able to help them have time, and the physical and emotional environment, to hear the Gospel and make their peace with God. In an American medical study in 2000, of the attributes that were ranked most highly by dying patients, number 2 was to 'be at peace with God.'

4. The doctor-patient relationship is key to the care of the chronically ill and dying.

Obviously I speak as a doctor, but for any caring, ministering person I am sure you will agree that the relationship we develop with an individual is key to the benefit we can offer them. Just as a human being's quality of life is determined to a large extent by the quality of their relationships with family and friends, so the relationship with their carers is key to their quality of life and peace of mind during times of serious illness.

As I said at the beginning, I am often privileged to know a patient and their family from diagnosis to death, sometimes extending over several years. I have found it immensely important to make the right relationship at the beginning, which can then be sustained through the ups and downs that may follow. Thus one tries to understand the patient's worldview, their key life experiences, and important family and other relationships. One commits oneself to honesty, with gentleness, in explaining the diagnosis and prognosis, and the treatments and side effects. One encourages the patient to be as active a participant in treatment decisions as he or she wants to be. I have found it very important that the patient trusts me; that I will always seek the very best for them – e.g. that the treatments offered are the best available, even if extra effort is needed to obtain the funding. Trust will be shattered if promises are broken, so one has to fulfil promises as far as possible, and of course not promise more than can be delivered. Hence the need for total honesty in terms of side effects and possible failure of treatment, and whether the disease is curable or not.

Another very important part of this relationship is to understand what the patient values most in life. In other words, would they want to live as long as possible regardless of quality of life, risks & side effects, or would they most value some quality time with family at home, even if that means a shorter life. Sometimes the approach the patient wants to take is different from the one I would take. But the relationship of trust demands that I support the patient's decision as far as possible. I involve the family in these discussions, but I have learned to let the patient speak for himself, so I am not clouded too much by what the family think the patient wants. This sort of approach continues throughout the length of the illness, which in the case of haematological malignancies may involve periods on treatment interspersed by times of remission off treatment.

But eventually one comes to the end of life. This is where I have found that the quality of relationship established over the years really counts. If the patient believes that I really have their best interests at heart; that I will stick with them through the last few weeks or months; that I will do my best to ensure that they get the best palliative care available; then they seem to trust me that their dying process will be as pain-free and as dignified as possible. In 27 years as a haematologist, I have only been asked to assist a person to die twice. In both cases, it was a myeloma patient in severe pain. Myeloma can be an extremely painful condition, but mercifully the pain is very sensitive to radiotherapy, and to opiate analgesia. In both these cases, the pain was relieved by a combination of measures, and the patients had a few more weeks of life with their families. I think both of them died at home with the support of their GP, and the district and Macmillan nurses. I am sure it was important that the patient trusted that we would ensure this package of terminal care would be in place.

The doctor-patient relationship continues after death, in the sense that one has often been involved with a whole family. It may well be that we can help the bereaved

family come to terms with their loss, as we honour and thank them for their efforts and care for their loved one. We can help them to realise the value of a life, remembering the good rather than the bad, and to see the preciousness of time with their dying relative even when he or she seemed a shadow of their former self.

Finally I want to tell you about another mode of death, which I believe was right, dignified, Christian and legal, and I feel does not conflict with my opposition to the legalisation of euthanasia. This concerns an elderly man, well into his 80s, when I first got to know him. He had been very well regarded in Coventry. He was one of a group of far-sighted intellectuals who had campaigned for the establishment of a first rank university in Coventry in the 1950s – for some reason they chose the name ‘Warwick University’ when it was finally opened! He had a bone marrow failure syndrome called myelodysplasia requiring monthly blood transfusions. He also had severe arthritis and an element of heart failure. He was very cheerful and positive, and clearly enjoyed life, family and city friends. But after about 2 years on transfusion, he began to find the transfusions very burdensome, especially the transport to & from hospital, the sitting in a chair for 6 hours or so for each transfusion, and the pain and disability he felt from his arthritis. He eventually said to me that he wanted to stop the transfusions and be allowed to die. I knew that if he did stop the transfusions he would become very severely anaemic and would almost certainly die of heart failure, perhaps over a 2-3 month period. Obviously we had extensive discussions, over a period of some months, and involved his wife and children. But in the end I didn’t have a problem with his decision to stop the transfusions. I feel that I can only treat a patient, or do procedures to a patient, with their consent. It is their absolute right to refuse any treatment, and it is for them to decide if a treatment’s burdens and side effects outweigh the benefits they enjoy from them. He did stop treatment, and he died about 2 months later at home, with palliative care services again providing treatments to relieve the distressing shortness of breath that he developed. I think I have only been involved in one other similar case. But as mentioned, I am quite regularly involved in decisions about patients not going to ITU if their underlying prognosis is very poor and artificial ventilation or cardiovascular support appears futile.