

THE
EBOR
LECTURES



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Learning to live a life, ready for death.



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This may seem a peculiar title for a lecture, but when I was first invited to give one of these Ebor lectures, I was in the middle of the review of the Liverpool Care Pathway, a set of guidelines some of you may know about because they hit the news. Let me explain. The Liverpool Care Pathway was developed by Professor John Ellershaw, a distinguished palliative care physician, at the Marie Curie research centre in Liverpool, many years ago now. It has been through various new and revised editions, it was promoted as best practice nationally, it was adopted by many hospitals and hospices, care homes and other healthcare settings. And then something began to go wrong. What in fact began to go wrong was that the eminently sensible and carefully crafted guidelines were not being used properly- and indeed they probably needed some revision anyway. Stories began to emerge from around the country about appalling treatment of people who were terminally ill. They'd been 'put on the Liverpool Care Pathway.' At worst, you heard the LCP being used as a transitive verb- they'd been LCP'd. And it emerged that in many places the guidelines for the LCP, by then considered best practice nationally, were being used without being understood. Indeed, the guideless were not really being used at all- the checklist, the aide memoire that goes with the guidelines, was being torn off from the guidance itself and being used without any thought. So if the checklist asked the nurse or whoever whether s/he had considered whether the patient needed hydration, the practitioner would tick the box- s/he had considered it. But not necessarily done anything about it. And all too many complaints emerged of people being denied water or a cup of tea in the last days or hours of life, in case they choked!

I could go on, but this is not the subject of this lecture. However, what all this demonstrated was that all too many nurses and doctors had never been given any training in looking after people who are dying. Yet, as Benjamin Franklin once said, "in this world nothing can be said to be certain, except death and taxes". And as sure as eggs is eggs, if you are a healthcare professional you'll be encountering someone who's dying at some point in your career, and probably, for most healthcare professionals who work with adults, relatively frequently. Yet many nurses and doctors and healthcare assistants get no training in working with people who are dying.

So one of our recommendations in the wake of our review, which in the end recommended that the LCP be withdrawn, was to make training in end of life care mandatory for young medical students. And we still have not achieved that in all medical schools. Yet if young doctors and nurses are not taught about death and dying, not taught to face the truth that all of us will die, and some of us sooner than others, then what hope is there for us? And so the idea for this lecture came about. How do we all, health professionals particularly for obvious reasons, but ALL of us, prepare to meet our end, and how is it possible that we can construct professional courses for healthcare professionals that leave out the whole subject of death? How can that possibly be sensible?

So let me try a couple of things on you, before I go into the meat of what I want to say. First, I believe we're only just emerging from a death denying culture. The 60s were all about sex, but



no-one talked of dying. And sex is now discussed pretty freely in the western world whilst death has remained the great unmentionable, probably since around the end of the First World War. So to start- a bit of social history. The Victorians loved all the paraphernalia of death. The new middle classes had glorious funerals. People wore purple and black in mourning, mourning stationery was dramatic and heavily embellished, architects and stonemasons contrived gorgeous tombstones, the new splendid cemeteries out of the cities that you could reach on the train, even funeral trains, gave a new glamour to death and mourning- it was all about pomp and circumstance in death and almost rejoicing in the ceremonial. But that has to be set against the fact that death was commonplace- most children would have seen a dead (or dying) sibling, a dead baby, a dead grandparent. For many, it was common to have the deceased person lying in state in the front room- though it's rare now. Sunday School prizes adulated the beautiful both in body and soul children- usually blonde and blue eyed- who were 'called to heaven' before their time. Death was discussed, it was a commonplace, and people saw dead bodies. So you didn't have the same problem about people not having encountered death. Everyone did- it was seen as 'natural', and it would have been seen in almost all families, with the proportion of children dying before the age of 5 still very high, though it reduced as the 19th century progressed.

Roll forwards to the First World War. Almost everyone lost a family member, and those they lost were young. Not children, but the young adults who had survived the diseases and risks of childhood, whose parents would have expected them to survive for many years. It was a huge national tragedy, and yet people found it almost impossible to talk about it. Add to that the Spanish flu outbreak at the very end of the last year of the First World War and the following fifteen months, that also targeted the young more than the old, and you can see how a generation became traumatised. Those whose parents had talked about death and almost celebrated it became silent and tight lipped. They invented all kinds of synonyms that meant you didn't use the words death or dying. People passed or passed 'away' or 'on'. They 'hung up their clogs' or they 'hopped the twig'. They didn't just die. And death became sanitised. The old customs of people being laid out in the front room ceased. People went to the mortuary or funeral home, if they visited the dead person at all, and by the 1930s fewer and fewer were even doing that. Add in another World War, with civilian casualties in the thousands and military deaths in the hundreds of thousands-again-, and you can understand how a great silence came about.

But understanding it only helps up to a point. The problem is that we have to learn to talk about death and dying again. We have to face up to death, because only by doing so will we be able to face ourselves and our own futures, and deal with the loss and suffering that will surely come our way, as well as the death that will ultimately overcome us all. And if we can't teach our children to think about death and understand it, if we persist in denying death to them and keeping them away from funerals, we'll simply produce another generation of people who will be hopeless at dealing with their own impending deaths, unable to grieve properly, and, should they become healthcare professionals, they in their turn won't know how to look after us, and ultimately won't be able to cope with the bereavement and loss, which come to us all.

I believe this is urgent. I think that we have allowed a situation to develop where both knowledge and sensitivity around death and dying are in short supply. As a result, I believe we are growing a generation or more of emotionally stunted individuals who do not understand about

loss, whether their own impending death or the loss of someone dear to them. And that goes for all of us, but is particularly true for those in their 60s and older, for whom talking about death has been strongly discouraged. And we need specialised bereavement services not only because so many of us live alone, but because families and friends have neither the language nor indeed the familiarity with death to offer much comfort, and, for those who are not religious, there isn't even a conventional ritual, or conventional phraseology, to express sympathy.

Most of us try and ignore death and dying. It is commonplace to find people crossing the street to avoid a recently bereaved person, because they don't know what to say. And, worse still, when people are told of their own impending death, or given the news that their condition is incurable, though some friends and family are fantastically supportive, many are not- because they have neither the words nor the understanding to deal with it. Yet those told they have a short time to live need to put their affairs in order, say their goodbyes, do the things they always wanted to do but hadn't got around to- if they can. They need to be cherished and made much of. But we don't know how to do it, because we are not taught, and we don't have national or even regional rituals with the exception of Scotland, Ireland and the western tip of Cornwall.

So I was pleasantly taken aback when an old friend in her early seventies who was dying of breast cancer told me that she was determined to plan her own funeral down to the very last detail, including exactly who should be there. I remonstrated. 'It's up to them to decide whether to come, not you.' But she was having none of it: 'I'll decide who comes and who stays away. I don't want my ex there, but I do want my children. I don't want the grandchildren to be there, but I do want my friends. I'm giving you a list and you can see to it!' I really didn't want to accept the task; after all, funerals are not for the dead but for the living. And yet she was focusing on something that so many of us fail to do: she was looking her impending death in the eye, dealing with it, planning her funeral (and her memorial service, and her tombstone consecration), and she wanted her friends to help her make sure it would all be as she desired. And in the end it was.

I believe that we need to discuss more frequently and openly with our families, our doctors and nurses, and in the public domain, just what kind of death we want, and, more particularly, what treatment we do not want if it is offered to us. And that is one part of learning to live a life preparing for our own death. Like our seventeenth and eighteenth century forebears, I believe that having some kind of memento mori in our lives is healthy- and will enable us to plan, to grieve, to comfort and ultimately to learn to live again, if we are bereaved. But we are a long way away from that now, and I know my father was considered more than a little eccentric in keeping a small plaster pile of books with a skull on top of them on his desk, as a paperweight, throughout his life!

For many of us, it's only at death that we turn to religion. Religious funerals are still more common than humanist ones, though humanists are growing apace. Yet religious ritual probably still has something to offer to the bereaved, even if they would not be seen near a church, synagogue, mosque, gurdwara or temple in any other circumstances. So can religion help? I believe it can, even though we're increasingly a nation of non-believers, or, perhaps more accurately, a nation of believers whose beliefs fit no known religion very comfortably. I think Christianity

has lessons for us all in facing death. Broadly speaking, Christians are genuinely interested in the afterlife and some Christians find planning their funerals a very good way of thinking about what comes next. Others like to focus on the actual journey to the hereafter: for the founder of the modern hospice movement, Dame Cicely Saunders (1918–2005), it was very clear that the journey to the afterlife should be a good one. If suffering and pain made that impossible, something should be done about it.

In her thinking, to journey with equanimity into the afterlife, we should have a good death. And a good death should give us the opportunity to think about this life, to come to terms with what we have and haven't done, sort out any complications or rows with family and friends – and then die at peace. But in order to do that, we need to learn about the process of dying, think about what our end means, for us and for others, and ideally be taught how to manage at least some of the practical issues that will arise.

All this is even stranger given that, despite death being the last great taboo subject in the UK, we have wonderful palliative care services and our hospices are the envy of the world. Indeed, the only connection many teenagers in our society have with death and dying is the increasing prevalence of some of them as volunteers in hospices, or going in to sing at Christmas and other times of the year. We ought to learn the lessons hospices provide. But that means being prepared to talk about dying, to think about it and study it, in the realisation that death can touch our lives at any moment through accident or illness. All of us should think now, while we can, about how we want to be treated when the time comes for us. And that needs to be structured into our education, be it in religious studies or perhaps in whatever Personal and Social education or general studies schools provide for their pupils. No-one would consider a school not providing basic sex education. To my mind, it is just as necessary for schools to provide death education- something about the actual processes of dying, seeing pictures of dead people, possibly watching one or other of the TV programmes that have actually recorded someone dying, and then some education about hospice, pain control, different causes of death and those that are most common, and something about how we might want to think, even in our teenage years, given the prevalence of teenage cancers and suicides, about how we want to leave a legacy.

Young people often do not believe that they are mortal. Indeed, if you read the Facebook messages that some teenagers leave for teenage friends who have committed suicide or been killed in some tragic accident, those messages read as if they think they are still alive. Despite an all too frequent RIP they include lines such as 'See you later' or 'You'll be back!' Really? Is that what we want our teenagers to believe? Is that a good idea? Or should they understand the finality of death, and do that by actually watching someone dying, but also by studying and familiarising themselves with the ageing process?

To some extent, thinking about our own mortality is about taking control, be it in one's younger years, when death seems far off, or when it seems imminent and when the decisions about practical aspects of how one dies seem more urgent. It is about asking and answering ordinary questions about dying, about the place of death and manner of going, about what pain control we may need and who will be present. Back in 2000, the charity Age Concern (before it merged with Help the Aged to become Age UK) published *The Millennium Debate of the Age*. In the

volume on health and social care, the working group which I chaired, we came up with a charter for what we believed everybody should know about preparing for death. It still applies, 15 years on. It is in fact a charter of rights for the dying, both in the immediacy of impending death and as we think about death dying, though it seems decades away, as it does for some many student nurses and doctors:

- To know when death is coming and to understand what can be expected.
- To be able to retain control of what happens.
- To be afforded dignity and privacy.
- To have control over pain relief and other symptoms.
- To have choice and control over where death occurs.
- To have access to any spiritual and emotional support required.
- To have access to hospice care in any location, not only in hospital.
- To have control over who's present and who shares the end.
- To be able to issue advance directives which ensure wishes are respected.
- To have time to say goodbye and control over other aspects of timing.
- To be able to leave when it's time to go and not have life prolonged pointlessly.

None of this is about assisted dying. It's about what happens to most of us if we don't die in an accident, or have a sudden debilitating stroke. Facing the fact we'll all die involves many different activities. Sometimes it is quite practical, such as checking whether there is an up-to-date will, or whether there are final conversations to be had with loved ones. People thinking about death need to question whether they would feel able to go in peace, whether all their affairs are sorted out or whether they would be leaving a big mess for their nearest and dearest. Some of this is hugely practical, yet it is still the case that some 60% of us have not written a will, as if we believe we're immortal. Yet again, this should be part of school education, but it also needs to feature as part of the 'offer' of CABs, of churches and other religious institutions, public libraries and all sorts of organisations, such as Women's Institutes and the U3A. These are relatively practical matters, but have a huge impact on how people prepare themselves for death and how they envisage a future in which they will not be present.

The reason that this is so important is that sorting out the practicalities makes it easier to face death. If we are confident we have thought about the things that are within our power to change, strengthen and deepen, we will have the confidence to face the unknown with equanimity, including death. How we die will affect the lives of those we leave behind. We all want to be remembered for good. What we most want to avoid is leaving people with a sense of agony

in their loss – of issues that have not been resolved; with no good memories, particularly of the last few weeks, months, years before our deaths. In order to die well, we prepare ourselves, and our nearest and dearest, for death, and make the subject of death and dying a commonplace, so that every medical student or nursing student has to understand that we all expect them to know how to help us with their healthcare skills, but that their professional skills and help are seen in the context of a society that has come to terms with human mortality.

Unlike the process of dying itself, our attitudes to bereavement have changed somewhat for the better in recent years, even if so many of us find it so difficult to know what to say. Nevertheless, I believe that we need to describe the mourning process more, support it more and perhaps even institutionalise it more than we do at present.

So what should we do? I had a friend, who was about to hit 100, who was busy writing her will. She had already written one that divided up her possessions amongst her family and friends. She had even written a letter of intent for her children to follow, which listed small bequests – a favourite piece of jewellery here or a treasured book there – for various friends and carers who did not get a slice of the major bequests. But then she wrote what she called her ‘moral last will and testament’.

She wanted her children to know how, over the years, she had changed her mind on issues such as homosexuality and gay marriage, the cap on immigration, on women working and looking after their children, and music. She wanted her children to know that she did not believe it is a sign of weakness to change one’s mind. Indeed, it is a sign of strength. She thought it was only the fear of being thought weak that prevented intelligent people from changing their minds more often, on the basis of evidence. And she wanted her children to read this for themselves in black and white in her last moral will. She also wanted them to use every moment of their lives to good purpose- to “live every day as if it were their last”. (Muhammad Ali)

This is something like a genre of literature that absolutely fascinated me when I was training to be a rabbi, so called ethical wills. I came across a series of documents written by rabbis in the mediaeval period and later to their children and descendants. There were similar documents amongst the Muslim and Christian communities at that time. And yet they have largely disappeared, which is why my centenarian friend’s last moral will and testament was so interesting.

These were not wills as we now know them – about money, possessions, property and dividing things up. These ethical wills make for fine, if sometimes eccentric, reading. They instruct their children on when to read particular religious books, and when to think about getting married. They tell them to look after their mothers and their sisters. They warn them to beware dishonest traders and always to give the benefit of the doubt to people who came begging. And they try to sketch out what a good life might be. They represent a lovely custom, as parents try to sum up in them all that they have learned in life, expressing what they most want for and from their children. The letters were a precious legacy, because the parents believed that the wisdom they had acquired was just as much a part of what they wanted to leave their children as any material possessions they could pass on.

Studying the ethical wills, I puzzled from time to time about whether we could turn that kind



of thinking into something more modern and applicable to people facing death today. I was talking to a friend who is a hospice nurse when I mentioned in passing that I'd been reading a particular ethical will by a seventeenth-century rabbi; she said that the idea reminded her of something that terminally-ill young women, usually dying of breast cancer, sometimes put together for their children. They create boxes filled with objects of purely sentimental value which they want to pass on to their children, who they will never see grow up. Alongside the objects, they place letters in which they describe the things that have meant so much to them – beauty, art, helping others, books – and of course how much their children mean to them and how they were the apples of their eye... In the letters they also often suggest how their children might want to live, given that they – their mothers – would not be there to guide them through life.

In my experience, once it is suggested, people usually love the challenge of writing an ethical will, which includes their practical, moral and political hopes for the future. It is a good way to sort out what matters to us personally as we write it – which in turn helps us face our own mortality peacefully. Whether we put pen to paper or not, I think we all should consider what our own ethical will might look like if we were to write it now. They are by no means easy to write. If we are to do it seriously, we have to look inside ourselves to see what essential truths we have learned in a lifetime. We have to face up to our failures and decide what really counted. And that's an education in itself.

For, as we contemplate facing our deaths, the majority of us do not want to be forgotten. We want a form of immortality- in this life. And the majority of us want to leave something behind -- to mark our lives when we go. It may be that the desire to leave a legacy stems from the fact that we cannot, in our bones, bear the idea of simply being no more – of being gone. If we are cremated, there won't even be a place that can be visited by those who wish to see where we lie. And we need to think about that when we discuss with our families whether we want burial or cremation, and what we want at our funeral.

We need education about how we die, and the practical things that follow- wills, funerals, leaving a body to medical science, the use of our organs for transplantation. But we'll only do that if we break the great silence. There are signs of a change- the Death cafés- death and cake- in the north east, and the Dying Matters Coalition. But this is slow stuff- yet we wouldn't have the scandal of what happened with the Liverpool Care Pathway if there were a national conversation about death, and if we were educated about death and dying. Or if it were a commonplace feature of our daily lives, as for instance it still is in rural Ireland where, as the funeral cortege goes by, everyone pulls down the shop shutters, and stands silent as the bell tolls. We can learn from that.

Our ancestors before the reformation saw the legend of 'The Three Living and the Three Dead' in church frescoes up and down the country. This is the story of three young gentlemen who are out enjoying a ride or hunt when they meet three cadavers who warn them: 'Quod fuimus, estis; quod sumus, vos eritis.' What we were, you are; what we are, you will be. A memento mori. Don't forget that you'll die. We don't have a modern equivalent, and that's why we need a new syllabus, a death syllabus, and a new national conversation that makes death a subject we all want to discuss over dinner, at football matches, or wherever.



We're busy discussing physician assisted suicide- the Falconer bill and now the Marris bill-, and people campaign vigorously for euthanasia, yet few of us know what it is like to die- few of us have even seen someone die, or held their hand, or thought about what we want for ourselves. I believe that this silence, this failure, has to be broken now. People have now allowed their natural deaths to be filmed 'live', as well as the few at Dignitas, assisted dying, in Zurich. I believe we need to see those films of natural deaths, and ensure our children see them. Films of people dying need to be shown in schools, in medical schools and nursing courses..... we all need to know and see and comprehend how we die. And, until we get that sorted, I believe we will still be living under the sentence of the great silence. No knowledge or thought about dying- yet we'd never allow that about sex or even childbirth. So today I am asking you all to put on your personal agendas the need for death education in our medical and nursing schools of course, but also for the rest of us, in schools, colleges and universities, formal and informal education and discussion. Until that happens, I fear our deaths will all too often be unsatisfactory, painful, hole in corner, and not the ready coming to terms with the natural end of our lives they should be. And that's a form of tragedy. But it's an avoidable one.

Thank you for listening.

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