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DYING IN TODAY'S WORLD

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I want to address how people died in recent decades, how they die today and what the future holds.

When I was a child people often died of tuberculosis. There were no anti-tuberculous drugs. Yet now drug-resistant TB is emerging only a few years after we thought that TB was a thing of the past. In the days before vaccines, poliomyelitis and other epidemics wiped out children and young people. When I went to medical school the profile of deaths and dying was very different - and we had no idea how to manage pain and distress in those who were dying.

In the same year that I started medical school, Cicely Saunders started St Christopher's Hospice and it was through research, a systematic approach to exploring better ways of managing pain and other distress, that she coined the term 'total pain'. In the many thousands of dying patients I have looked after, pain has always had an underlying physical cause, but the pain experience is made dramatically worse by emotional, social and spiritual distress. Think of a young dying mother knowing that she is leaving her children, worrying about their future and wondering 'why me?' – her distress will be overwhelming - only lessened by helping her tackle the many problems that she needs to resolve as well as adequately and carefully treating her physical pain too. Morphine, carefully titrated up to obtain pain control and given with all other aspects of care meticulously tailored to the individual patient's needs, is safe and effective. We do not kill patients by giving morphine and other medication for pain control.

In the developed world those dying from progressive disease can die gently because palliative care is the science of supporting dying patients as they die. For most people, dying is not a sudden presence of death, but a gentle absence of life. There is no sudden catastrophic event. People often become increasingly weary, sometimes having a final burst of energy or activity in the last days of life and then, drowsy and weak, quietly slipped into a coma, breathing slows and they gently slip out of this world as a heart and breathing stop.

In the Western world most people are dying of diseases such as cancers or chronic disease, but in Africa HIV remains a major killer and in many parts of the world infection, accidents, malnutrition, disasters and warfare carry off many young lives. And what of pain relief? The global availability of morphine and other pain relief is appalling; 80% of the world's dying do not have access to morphine and 6% of them are children. Billions cannot even access basic pain control.

Yet all the evidence is that good early palliative care can improve quality of life, decrease depression, ensure that unnecessary or burdensome interventions are avoided and, as a result surprisingly, patients live better and longer.

Conversations about what is happening can be difficult. In Cardiff we developed a communication skills toolkit which has stood the test of time, stressing the importance of listening with all one's senses, with undivided



attention and from the heart to what patients are saying, exploring what is happening behind expressions of despair. It was Cicely Saunders who said 'dignity is having a sense of personal worth' and since then Chochinov has shown that the way people are cared for enhances or undermines their sense of dignity.

What about the person who says they have enough, they just want to die? There is no law against stopping treatment and indeed if treatment is stopped, duty of care continues as a person dies of the underlying disease. Sometimes the intervention that is stopped has been keeping the person alive, such as being on a ventilator, and when the ventilator is stopped the person dies gently and rapidly with good care in place – in the UK we have developed the guidelines on how to manage these situations well.

This is not euthanasia or assisted suicide. In so-called 'assisted dying' lethal drugs are injected or swallowed by the patient deliberately to bring about death days, weeks, months or years sooner than the person would have otherwise died.

We may say it is a person's autonomous wish to die, but we are all interconnected with others around. Our living and outlying affect those around us and the memory lives on in those left behind. All those feelings of 'if only', 'I wonder if...' are experienced by those who grieve. How much more difficult when you wonder whether the person did have all the care and support, whether they ended their life too early through fear of being a burden or fear of something that would never have happened. Over the years I have been struck by how children see past illness and disability far better than adults, how they see through to the person who they love and how in grief they would give anything for a few more moments with their parent or sibling who has died. In Britain around 10% of schoolchildren have suffered a serious bereavement, with 1/3 of them having lost a parent or sibling, yet only recently have children's bereavement services developed and are unable to meet need.

The assisted dying debate is not about a 'right to die'; we all will die. It is about whether we licence doctors to assist suicide or injected lethal drugs in euthanasia - in other words it is whether we involve someone else in bringing about our death. Yet the decision to end your life is the biggest decision you can make and therefore you must have accurate information, the mental capacity to take the decision and it must be voluntary. But here the difficulties begin. Prognosis is notoriously inaccurate, diagnostic errors occur and the mental capacity is impaired by illness and by medication. Even here in the UK where not very good at recognising when death is imminent, in about 1/3 of patients dying. Sadly, not all families are loving – intra-family fraud and elder abuse are rife in this country.

Laws are more than regulatory instruments, they send social messages. Laws must protect everyone, particularly the vulnerable. An 'assisted dying' law conveys the message that if you are terminally ill, it is appropriate to consider ending your life. In societies that have gone down the assisted dying road, normalisation can become an expectation. Yet it is often said the hallmark of a civilised society is the way it cares for and protects its most vulnerable citizens.

The changes in society can be seen in the escalating numbers as year on year there is an inexorable rise in such deaths; On a population basis, Oregon's physician assisted suicide death rates would now translate to about 2 ½ thousand deaths annually in England and Wales. The data from the Netherlands, where euthanasia accounts for around one in 22 of all deaths, would equate to around 25,000 such deaths per annum here. Euthanasia is not restricted to those thought to be terminally ill. The criteria of distress with no prospect of improvement has resulted in euthanasia including young people with learning difficulties, patients with severe post-traumatic stress following abuse in childhood and people suffering from psychiatric conditions.



Can 'assisted dying' be a cost saving measure? There are worrying reports, such as the 64-year-old lady in Oregon who was told that her health plan would not cover her prescribed palliative chemotherapy but assisted suicide drugs would be 100% covered as a comfort care measure. Or consider the Canadian man who went to court for assistance to live; his disability support arrangements had been denied, but he was free to pursue a medically assisted death.

But what of the future. At the beginning, I pointed out that drug resistant tuberculosis is emerging as a major threat. Across all strains of micro-organisms, antibiotic resistance is gathering pace and deaths from sepsis are becoming more common. It is not the person who becomes resistant to antibiotics. It is the bugs themselves that evolve to develop resistance; this happens more and more as bacteria are exposed to antibiotics through overuse of these miracle drugs. The extending profile of antibiotic-resistant bacteria is frightening and we must recognise that it may well be within the next one to two decades that infections once again become the leading cause of death in the UK as antimicrobial resistance emerges across the world. We have no new antibiotics in the pipeline. Our overuse and abuse of medications risk destroying our future.

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