

Sure to Die

By Prof Chee Yam Cheng, Editorial Board Member



One of the more difficult tasks for a doctor is to be with their patients up to the moment of death. This takes courage and commitment, a commitment to our personal and professional growth as well as to our patients.

The cycle of life

It does not take a child long to realise that every day, some living thing is dying. Dust thou art and unto dust thou shalt return. A child has no say in his birth and the events surrounding it. Where a child is born, in which country, which strata of society, and to a single (or double) parent does make a sizable difference to life expectancy at birth. But ageing is an individual matter. Genetics is roughly 25% to blame for the heritability of lifespan. The other three quarters can be attributed to nutrition, lifestyle, environment and chance.

Dying is a certainty of life for nothing and no one lives forever. Yes, there is embalming and there are mausoleums. But life is gone forever. Science today seems able to from pieces of skin of long dead mammoths give hope that such creatures can be brought to life again. Even if that succeeds, it is not the same individual mammoth made alive, but a clone of it, developed from the DNA from the skin. Found in the cold frozen deserts of eastern Russia, these mammoths have remained relatively intact in shape and form, but are truly dead and well-preserved.

What is the uncertainty in dying is the date

and time of death. Unless life is purposely taken away, such as in a death sentence carried out, or an act of euthanasia allowed, as it is in some countries, most of us have no say in this exit from life. Some are dying to die but others never dream of dying, while some are suddenly taken.

Suffering

So what is the difference? In one way, those who die suddenly may have never thought about it because it was all so unexpected. They were taken by complete surprise... So there was an accident, and he was gone. Just like that. Yes, only one breath away is death. If you do not breathe the next breath, then death will overcome you. And left to grieve for you will be your loved ones. But you will probably know nothing about all that. But to others, and that is the majority of us, we have lived long enough to start experiencing the process of dying. Ageing is a lifelong process. Are we programmed to die? Is life one long, or for those with progeria, a short process of dying? It seems we are programmed for survival in the genes we inherit, but we are not programmed well enough to survive indefinitely.

Once we develop disease, the suffering

starts. If it is a chronic disease, then one begins to fear the consequences of the disease cutting short one's life. Mental suffering and anguish may be worse than the actual physical suffering. And the older one gets, the more prone one is to suffering. This is because the whole body is starting to break down, though at different rates.

Wish List

So what is on your wish list after knowing the above? The genes were given to you. You had no choice in the matter. But what you eat, how you live, and your lifestyle choices are within your control. You also may have no say in how the die is cast. The element of chance can play its cruel hand. Our first terrorist victim who died in Mumbai was not supposed to be there in the first place. Assuming you could make the right choices, which would you prefer? Would you opt for a well-lived, well-enjoyed life before the body starts to break down with ageing, when death comes? Or a life of hardship and struggles trying to enjoy life and when you are able to start enjoying the life you want, ageing has started to incapacitate you? Or a life where chronic illness takes its toll from a young age?

Most of us would opt for none of the above. Instead we would like a good life, pain and suffering-free, for as long as possible, then a short dying period with minimal suffering. Or the same good life but a sudden death at a ripe old age without the intervening suffering.

Which brings me to the point about when should death be discussed? If threescore years and ten is the expected life span, or by virtue of strength a little longer, when should this topic come up and be settled? Should the context for this discussion be different? Within the family? Or between a doctor and the patient? Who should broach the subject? The one preparing for death or those expected to be left behind (including the doctor)?

The last point concerns us as doctors that we too are mortal. This brings to mind the late Dr Wong Kum Hoong, an old ACS boy whom my father taught in school. He was our family doctor. He had his wish granted. He lived long, working right until the end in his Wong Clinic in Upper East Coast road. That morning he went to see his patients in the clinic. He returned home for lunch as was his routine, had a nap but never woke up thereafter.

Dying is not something we can ignore. Suffering should not become an experience about which there is increasingly nothing to say, nothing to hope for and nothing to do, just because we have been taught in a system that has as its solitary goal the need to preserve life. Dying is a significant “sure to happen” event in any person’s life.

It should not end in despair.

Long Suffering

There are many long suffering people in this world. The causes of suffering could be mental or physical. Suffering deadens the hope of living. As doctors we strive to save life, not just in the sense of resuscitation BCLS or ACLS-style but to give hope and assurance to those who seem to be bearing unbearable burdens due to disease and social circumstance. Good health is not just the absence of disease. And the social determinants of health do outweigh the medical determinants. Be that as it may, as

doctors, we try to lighten the burden due to disease, and give hope to support the flicker of life for those in suffering. Unfortunately there is no correlation between the amount of suffering and the certainty of death. So when to broach the discussion on end of life is not easy unless the patient brings up the topic.

Certain diseases have a poor prognosis. This assumes the suffering would be short. But it could be terribly intense. Yet amidst the suffering would the patient be willing to discuss impending death with the doctor?

End of Life

Death is the terminal event of life. Pre-death, there may be compromised life if death were not sudden. There is this mood that there are not many days of life left to live. Many hospices and advance care planning agencies take this period to be the last 12 months of life. This definition presupposes that the death date is known, which we all know is not. For several diseases, medicine has defined end stage disease, for example end stage renal failure. But that does not correctly predict the date of death, whether it would be more or less than 12 months away. Or for certain cancers the prognosis is poor, meaning for example that when diagnosed with small cell lung cancer,

is often camouflaged within a complex model of care that focuses on what is happening to them, rather than what is happening with them. In the long ago days, patients refrained from coming to hospitals to die. Then not so long ago, patients came to hospitals to die because the relatives at home with them felt lost as to how to manage them. So the once unambiguous and transparent death journey has become more convoluted, complicated by ongoing medical, ethical, family and social pressures.

We should try as a society and the medical profession assisting, to make it less painful and more peaceful to die. I think palliative medicine is very good at that. Dying patients

Trust

Dying people need to tell their story and to know they have been heard. In so doing they not only reveal their suffering but often transform it. Trust is an important ingredient in all of this. One of the more difficult tasks for a doctor is to be with their patients up to the moment of death. This takes courage and commitment, a commitment to our personal and professional growth as well as to our patients. Dying is not something we can ignore. Suffering should not become an experience about which there is increasingly nothing to say, nothing to hope for and nothing to do, just because we have been taught in a system that has as its solitary goal the need to preserve life. Dying is a significant

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— Minister for Health Khaw Boon Wan, at the opening of the Childrens Hospice International Congress, 7 September 2007

the patient is not expected to live beyond six months despite heroic treatment. So in such circumstances there appears to be a window of opportunity to discuss advance care plans.

Place of death for end of life is probably easiest to discuss. The choice for many would be in their own home. But if this is not expressed and made known, in time of panic, many relatives with good intentions will bring the patient to hospital.

Advance Care Planning

This is defined as a process of discussion between a patient and professional carer, which sometimes includes family and friends. This dialogue has two outcomes. The first is an advance statement, which describes the patient's positive preferences and aims for future care. The second is an advance decision, which provides informed consent for refusal of specific treatment if the patient is not competent to make such a decision in the future. This may need legal backing in writing.

Healing

Patients die but their journey towards death

need care and understanding as much as they need medical help. Dame Cicely Saunders goes further and states, “They need the friendship of the heart more than the skills of the mind.”

Suffering that accompanies dying is often hard to recognise and difficult to define. It is patient-specific, and ultimately it is the patient, given the opportunity, who heals him/herself of this pain. It is an individual journey. We need not walk alone but we often die alone. Individuals are the only ones who can identify their suffering and they alone make the transition from struggling to healing in their own way and their own time, and mostly without the need for special psychological or pharmacological interventions. So although suffering is not something that can be investigated, treated or palliated, the clinician's role in this transformative process is still significant. To create the environment for this transformation, not with technical or clinical expertise but with ordinary faculties of wisdom, intuition, empathy and compassion, raised to a higher level; that is the clinician's role.

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And the soul shall return to God who gave it.

Some three years have passed since our Minister for Health spoke on “Living the good life, dying a ‘good death’” at the opening of the Children Hospice International Congress on 7 September 2007. I quote his concluding words here. “It takes humility to acknowledge that medical science, however advanced, has its limits. For the most vulnerable group of patients at the close of their lives, for whom curable treatment is no longer an option, their last moments matter. We must use the art and science of medicine to help them and their families find comfort and meaning in the last phase of their lives.” **SMA**

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