Memento mori: death and care at the end of life

Modern medicine seems to have lost its way and to a considerable extent this is due to having lost sight of the central importance of the care of the dying.¹

The last one hundred years have seen huge advances in biotechnical knowledge and, as a direct result, much increased effectiveness of medical treatments and much relief of suffering. However, this success has tempted many doctors to turn away from their traditional role in the care of the dying. The whole discipline of medicine has colluded in the wider societal project of seeking technical solutions to the existential problems posed by distress, suffering and the finitude of life and the inevitability of ageing, loss and death. Sickness and death have gradually come to be regarded as failures of medicine, even by doctors themselves, rather than inevitable constituents of what it is to be human. We have somehow forgotten that life without death would be intolerable: just try to imagine a world in which nothing and nobody died.

Why has medicine turned away from death

Everyone, to a greater or lesser extent, is afraid of dying and too often we try to protect ourselves by putting as much distance as possible between the healthy and the dead and dying. And yet all of us, and particularly the doctors, are surrounded by the dead. By the time I had worked as a general practitioner in Kentish Town for more than 30 years, it was populated by generations of ghosts, waiting in half-remembered interiors, alongside the changed rooms and the new inhabitants. The total population of the living and the dead had become denser and denser. We don’t forget the dead, it is just that we have forgotten how to talk about them. Yet as the American poet Marianne Moore observed: ‘Omissions are not accidents’.

In Hamlet, Shakespeare provides his famous description of death as:

\[
\text{The undiscover’d country, from whose bourn}
\text{No traveller returns} \quad ²
\]

And it is perhaps this quality of completely uncompromising unknowability that makes death so terrifying. Philip Larkin’s great poem Aubade captures the dread and the horror with visceral intensity:

\[
\text{Waking at four to soundless dark, I stare.}
\]

² Shakespeare W. Hamlet, Act 3, Scene 1.
In time the curtain-edges will grow light.
Till then I see what’s really always there:
Unresting death, a whole day nearer now,
Making all thought impossible but how
And where and when I shall myself die.
Arid interrogation: yet the dread
Of dying, and being dead,
Flashes afresh to hold and horrify.³

Being human, doctors face precisely the same existential challenges of finding meaning in the face of loss, suffering and the finitude of life, and they are no less afraid of their own dying and being dead than anyone else. They have no particular existential aptitude and very little relevant education:

Physicians are thrust repeatedly into situations in which the professional tasks peculiar to their status as physicians are linked to the existential tasks they share with all persons: maintaining a sense of meaning, security, and connectedness in the face of mortality and finitude.⁴

No wonder they resort to the increasingly sophisticated biotechnical means rather than paying real attention to the care of the dying as one of the core purposes of medicine. In David Rieff’s book about the last illness of his mother, Susan Sontag, he describes her ruthless desperation to remain alive and her willingness to undergo any treatment to this end, however small the chances of success.⁵ He asks why none of her doctors were prepared to protect her through the exercise humane clinical judgment. As more and more futile treatments are applied to patients at the end of life, it is a question that should surely be asked of many more doctors and of the discipline of medicine as a whole.

Part of the problem is perhaps that the success of biotechnical medicine has almost completely displaced the humanities from medical education and so doctors now have no grounding in the philosophy that has grappled with humanity’s profoundest existential problems over millennia and no knowledge of the dignified and comforting assertions first by Epicurus (341-270 BCE) and then by Lucretius (99-55 BCE) that:

---
Death is nothing to us. When we exist death is not, and when death exists we do not.6

Michel de Montaigne (1533–1592) owned a copy of Lucretius’ verse essay On the Nature of Things and he quotes from it more than 100 times in his own Essays.7 In the margin of his 1563 edition of Lucretius’ poem, he wrote:

Fear of death is the cause of all our vices.

And this seems particularly true of the vices of modern medicine which allow doctors and other health care professionals to pretend that, to a very great extent, death is nothing to do with them. This leads directly both to the imposition of inappropriate and futile treatments at the end of life and to ignoring the predicament and the needs of the dying by failing to acknowledge or even to recognise them.

Atul Gawande, the American surgeon and New Yorker columnist writes:

In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die. People die only once. They have no experience to draw upon. They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come—and to escape a warehoused oblivion that few really want.8

In the same famous speech from Hamlet, Shakespeare writes:

... the dread of something after death
... puzzles the will,
And makes us rather bear those ills we have,
Than fly to others that we know not of?

Throughout sophisticated healthcare systems today we see both professionals and patients opting to bear those ills they have rather than fly to those they know not of. Doctors persist with treatments well after they have become obviously futile and even cruel, and patients put up with these treatments for the same reason. It is well time for us all to find the courage for the deeper and more necessary conversations so that the grounds for David Rieff’s complaint can at last become less prevalent.

---


8 Gawande A. Letting Go. New Yorker, 27 July 2010.
Deep and difficult conversations are only possible in a context of trust and become increasingly difficult as healthcare systems become ever more fragmented. There are a very few intuitively empathic doctors and nurses who can embark on such conversations at a first meeting but usually both parties need the trust that grows within a continuing relationship. General practitioners have always valued ‘continuity of care’ and we have tended to think of this in terms of accompanying the patient on a journey or witnessing a life story, both of which seem to have some validity. However continuity is also, in itself, a dimension of health and doctors can be part of, and emphasise, the continuity that runs through a life even through the dislocation of illness. In his book Another Way of Telling, the writer John Berger suggests that a photograph is a dislocation of the continuity of time just as an illness is a dislocation of the continuity of a life. And healthcare consultations are almost like photographs of the patient’s life: they enable us to draw conclusions from short, isolated moments taken from the continuum. So we have two sorts of discontinuity – the illness and the consultation – superimposed and from this we attempt to fashion meaning.

... when we give meaning to an event, that meaning is a response, not only to the known, but also to the unknown: meaning and mystery are inseparable and neither can exist without the passing of time. Certainty may be instantaneous, doubt requires duration: meaning is born of the two.9

The science on which medicine purports to be based, gives it an aura of certainty, much of which is false. Continuity of care allows the nurturing of doubt within conversations about the relevance of the generalities of medical science to the particular life and circumstances of the unique patient. Doubt and uncertainty pervade death and dying and as doctors we should perhaps learn to accommodate them better and treasure the ambiguity and therefore the hope they afford.

Futility and cruelty at the end of life
Susan Sontag was subjected to futile and distressing treatments towards the end of life and, in her particular case, this occurred with her enthusiastic consent. All practicing clinicians are aware of similar futility in the treatment of many other people often without appropriate discussion of the potential usefulness of the intervention. Each such treatment emphasises the importance of the question posed by the medical historian Charles Rosenberg:

How does one manage death - which is not precisely a disease - when demands for technological ingenuity and activism are almost synonymous with public expectations of a scientific medicine?  

Remember the profoundly disturbing finding, from a study of the care of patients with either advanced cancer or advanced dementia, dying in an acute hospital in the US, that for 24% of both groups cardiopulmonary resuscitation was attempted and 55% of those with dementia died with feeding tubes in place. Patients who have collapsed in extreme old age or who are slipping away from life with disseminated cancer continue to be subjected to futile procedures for the sake of a perverse kind of political correctness, despite a sustained critique going back at least a decade.

American intensive care doctor, Jessica Nutik Zitter describes the predicament of doctors:

I was trained to use highly sophisticated tools to rescue those even beyond the brink of death. But I was never trained how to unhook these tools. I never learned how to help my patients die. I committed the protocols of lifesaving to memory and get recertified every two years to handle a Code Blue, which alerts us to the need for immediate resuscitation. Yet a Code Blue is rarely successful. Very few patients ever leave the hospital afterward. Those that do rarely wake up again.

The American Heart Association describes the noble goals of “emergency cardiovascular care” as being “to preserve life, restore health, relieve suffering, limit disability, and reverse clinical death.” Who could argue with these aims? The problem is that, if these are the goals, cardiopulmonary resuscitation (CPR) has a tendency to fall somewhat short. The data suggests that survival to discharge following cardiac arrest in hospital is infrequent. Of 14,720 adult resuscitation attempts in 207 US hospitals between 2000 and 2002, 44% survived for 20 minutes after CPR and only 17% survived to discharge. Of these survivors, 86% had been admitted to hospital from home but only 51% were well enough to return there. So, despite the noble goals, CPR can perhaps be regarded as a medical intervention.

---


12 http://well.blogs.nytimes.com/2014/04/10/a-better-way-to-help-dying-patients/?_php=true&_type=blogs&_php=true&_type=blogs&smid=tw-share&_r=1&

13 http://circ.ahajournals.org/content/112/24_suppl/IV-6.full

which carries significant risks to the future wellbeing of the patient. Yet the tradition of implied consent for emergency treatment means that CPR will be instituted unless the patient has explicitly opted out. The American Heart Association advises that all patients in cardiac arrest should receive resuscitation unless there is a valid Do Not Attempt Resuscitation order in place, or the patient has signs of irreversible death which are unpleasantly listed as “rigor mortis, decapitation, decomposition, or dependent lividity”, or in situations where the patient’s vital functions have deteriorated despite maximal therapy as exemplified by progressive septic or cardiogenic shock.

The situation out of hospital is even more problematic. Previously healthy people collapsing in public places and promptly resuscitated may do well but the corollary is the automatic application of CPR in a whole range of much less appropriate settings. Conroy and colleagues have argued persuasively that nursing homes should be excluded from the requirement to provide resuscitation for reasons which include the baseline annual survival in UK nursing homes being less than 50%, resuscitation attempts being almost certainly futile, the possibility that CPR will distract staff from providing the highest standards of symptomatic and palliative care, and the opportunity costs in terms of the time and distress necessarily involved in discussing DNAR orders.

When patients are dying at home, an unfortunate cascade effect can come into play. Relatives and friends are coping well and managing to provide just the kind of gentle care that most of us hope for in our dying days, but for those unfamiliar with death, the last moments of life can be distressing and frightening. Consciousness fluctuates, breathing becomes laboured, the circulation falters and the skin becomes mottled. In this situation, all too often, the carers will seek support by calling an ambulance and this becomes ever more likely with the decreasing availability of a familiar primary or palliative care professional out of hours. Once the ambulance is called, the paramedics may be obliged to attempt resuscitation, however inappropriate. Guru and colleagues documented that 10% of cardiac arrest calls in Toronto were to patients with pre-existing terminal illness, and in 63% of these the relatives asked in vain for resuscitation not to be attempted. The authors conclude that the carers of terminally ill patients should be specifically advised not to call an ambulance and be given information on other sources of emergency support.

---


For the intensive care doctor Jessica Nutik Zitter:

... in this age of technological wizardry, doctors have been taught that they must do everything possible to stave off death. We refuse to wait passively for a last breath, and instead pump air into dying bodies in our own ritual of life-prolongation. Like a midwife slapping life into a newborn baby, doctors now try to punch death out of a dying patient. There is neither acknowledgement of nor preparation for this vital existential moment, which arrives, often unexpected, always unaccepted, in a flurry of panicked activity and distress.

How many of us really want to die like this? How many of the doctors delivering these futile treatments want to die like this?17

American bioethicist Daniel Callahan describes what he has termed ‘the difficult child of medical progress’:

- the 1 percent of patients who consume some 21 percent of health care costs, usually succumbing gradually from multi-organ failure, illustrate the progress problem. Fifty years ago they would have died faster and, in many cases, with less suffering. We have traded off shorter lives and faster deaths for just the opposite, longer lives and slower death.18

I remain profoundly uncertain as to how good a trade this is.

In 2012, a New York Times op ed article by journalist Bill Keller described the death of his father-in-law in an English hospital. It was entitled ‘How to Die’19.

This is an excerpt:

The surgery had been unsuccessful, the doctor informed him. There was nothing more that could be done.
“So I’m dying?” the patient asked.
The doctor hesitated. “Yes,” he said.
“You’re dying, Dad,” his daughter affirmed.
“So,” the patient mused, “no more whoop-de-doo.”
“On the other side, there’ll be loads,” his daughter — my wife — promised.
The patient laughed. “Yes,” he said. He was dead six days later, a few months shy of his 80th birthday.

Later we learn:

19 http://www.nytimes.com/2012/10/08/opinion/keller-how-to-die.html?ref=billkeller
During Anthony Gilbey’s six days of dying he floated in and out of awareness on a cloud of morphine. Unfettered by tubes and unpestered by hovering medics, he reminisced and made some amends, exchanged jokes and assurances of love with his family, received Catholic rites and managed to swallow a communion host that was probably his last meal. Then he fell into a coma. He died gently, loved and knowing it, dignified and ready. “I have fought death for so long,” he told my wife near the end. “It is such a relief to give up.”

We should all die so well.

The key to a good death was turned with this interchange -

... There was nothing more that could be done.
“So I’m dying?” the patient asked.
The doctor hesitated. “Yes,” he said.

The doctor hesitated but had the courage to understand what he knew and to be honest with his patient. It is very important never to underestimate the courage involved in telling people that there is nothing more that can be done to stop them dying and, as a direct result, it is not said often enough or soon enough in many situations. The Polish poet Czesław Miłosz understands how this happens:

To know and not to speak.
In that way one forgets.
What is pronounced strengthens itself.
What is not pronounced tends to non-existence.

If we as doctors know and don’t speak, the reality and imminence of death tends to non-existence, and patients and relatives have no opportunity to prepare themselves. Yet, given the chance, those patients and relatives can help their doctors. The US National Institutes of Health Senior Health website suggests that, towards the end of life, five questions should be asked:

1. Since the illness is worsening, what will happen next?
2. Why are you suggesting this test or treatment?
3. Will the treatment bring physical comfort?
4. Will the treatment speed up or slow down the dying process?
5. What can we expect to happen in the coming days or weeks?
6. If I or my loved one take this treatment or participate in this clinical trial, will it benefit others in the future?

The answers might help to resolve the fundamental question posed by Atul Gawande:

---


21 https://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html
... how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are?22

American physician and bio-ethicist Leon Kass writes:

How to negotiate the balance between these two perspectives on life — the
life-preserving yet life-corroding view of medicine, and the vulnerable yet
life-fulfilling view of ordinary existence — is perhaps the deepest and most
subtle ethical task we face.23

Medicine hasn’t learned when or how to stop. We seem to have completely
forgotten that death is not necessarily a medical failure and lost sight of the extent to
which the care of the dying is a core task of medicine.

Fear and greed

The 2012 World Health Organisation Global Health Expenditure Atlas reports that the
OECD countries consume more than 80% of the world’s healthcare resources but
experience less than 10% of the world’s disability adjusted life years.24 This must be
unsustainable in terms of both global justice and the world’s capacity. The problem
is that where the OECD countries lead, the rest of the world tends to try and follow.
Or is pushed to follow.

At every level this is a story of unsustainable greed – the greed of those living in the
richer countries of the world for ever greater longevity and most particularly the
greed that drives and sustains the commercial imperatives of the pharmaceutical
and medical technology industries. Yet the flip side of greed is fear – fear that we or
someone we love will be deprived of effective treatment because of issues of price or
access to care. But neither greed nor fear can really help us. The only solutions to
the profound existential challenges posed by the inevitability of death, that have
beset humanity since the beginning of time, are to be found in courage and
endurance and acceptance of the limits of life. They are to be found in thinking
differently and more deeply.

The bizarre hope of postponing death indefinitely has been suggested and
assiduously promoted by those who also hope to make a profit from its creation.
Decades ago, Ivan Illich predicted where this would lead:

24 http://www.who.int/mediacentre/factsheets/fs319/en/
The more time, toil and sacrifice spent by a population in producing medicine as a commodity, the larger will be the by product, namely the fallacy that society has a supply of health locked away which can be mined and marketed.25

The market imperative is that only a minority of most populations is acutely ill at any one time whereas the majority is healthy. The healthy are however susceptible to persuasion that it is necessary for them to optimise their prognosis by undergoing screening and/or by taking preventive medication. Those older people who are relatively well seem to be no less susceptible to this persuasion. And, in affluent countries, because there is now more money to be made from selling so-called “healthcare” interventions for the healthy minority than for the sick majority, there is more pharmaceutical research in pursuit of preventive treatments than for the treatment of those who are already sick.26

As a direct result, society spends an ever greater amount on preventive technologies, leaving less available to treat those who are actually sick. In so doing, we shift resources from the poor and the sick to the rich and the well. This is clearly good for the medical technology and pharmaceutical industries but very bad for those funding the healthcare system, particularly as preventive technologies are much more likely to prove futile and to be overtaken by other disasters or pathologies.

The 2002 PROSPER study27 provides a cogent example. It is one of the very few studies of cardiovascular prevention in older people and is a trial of the effects of pravastatin in elderly individuals assessed to be at risk of cardiovascular disease. More than 5000 participants, aged 70-82 years were followed up for an average of 3.2 years. The results of the trial showed that pravastatin did indeed reduce rates of fatal and non-fatal myocardial infarction and stroke. However, all cause mortality was unchanged and rates of cancer diagnosis and cancer death were higher in the treatment group. There is no suggestion that statins cause cancer but, by closing off one cause of death, others are inevitably opened – first cancer, then dementia.28 This exemplifies an unprecedented contemporary phenomenon. When we vaccinate

---


26 Freemantle N, Hill S. Medicalisation, limits to medicine, or never enough money to go around? BMJ 2002; 324: 864-5.


children in infancy, we are selecting out a cause of death for them, in this case justifiably, because deaths from infectious diseases tend to occur prematurely. However, when we select out causes of death for people who have already exceeded the average lifespan, the whole endeavour becomes morally questionable. How often when we as doctors offer a statin to an elderly patient do we seek genuinely informed consent? Most older people would accept such a medication if they were told that it would reduce their chances of dying of a heart attack or a stroke, but if the doctor went on to tell them that the medication would not help them to live any longer and would increase their chances of being diagnosed with cancer or dementia, how many would still want it?

As people age, it is inevitable that their expectation of life should reduce and, exactly in parallel, their possibility of benefitting from preventive technologies is necessarily diminished. A more recent study underlines the prevalence of futility within healthcare today. Researchers at the Veterans Health Administration in the US set out to measure the prevalence of statin use during the last 6 months of life and to determine if statin prescribing varied according to the presence of a recognizable, life-limiting condition. They identified 3031 patients who died during the calendar year 2004 and within that group they found that 1584 (52%) were taking statin medication during the last 6 months of life. They then identified 337 of these 1584 who had a diagnosed terminal condition and they compared this group with controls who did not have such a diagnosis but were matched for age, socioeconomic status and number of comorbidities. Shockingly, there was no significant difference in the time off statins between the cases and the controls. The authors concluded that their findings demonstrated a missed opportunity to reduce the therapeutic burden on dying patients and to limit health care spending.

**Therapeutic burden**

In the Munch Museum in Oslo, there is a painting entitled *Self Portrait: Between Clock and Bed,* which was painted between 1940-42, when Munch was in his late seventies. It shows an old man standing in a doorway with a grandfather clock to his right and a bed to his left. The elderly Munch is caught between the clock and the bed, between the vertical and the horizontal. In this situation, open, rational discussions and shared decisions about the point at which medicine becomes futile and wasteful are fundamentally important. Sadly, there seems to be huge reluctance among doctors and policy-makers to discuss any of this which is all too easy to understand because such discussions are often difficult and painful. Nonetheless the

---


reluctance is regrettable especially when accusations of ageism are used to mask increasingly futile interventions that verge on cruelty.

When the prognosis is limited by age and infirmity, time is a precious commodity that should not be wasted on the routines and rituals of modern medical care. Carl May and colleagues have proposed the concept of ‘minimally disruptive medicine’\(^\text{31}\). They conclude that the “work” of being sick is made more onerous by serial advances in diagnosis and treatment.

They illustrate their argument with several examples, one of which is:

A man being treated for heart failure in UK primary care rejected the offer to attend a specialist heart failure clinic to optimise management of his condition. He stated that in the previous two years he had made 54 visits to specialist clinics for consultant appointments, diagnostic tests, and treatment. The equivalent of one full day every two weeks was devoted to this work.

Doctors may be blighting many older people’s lives by allowing diagnostic categories to dominate, determine and standardise the ways in which we care for illness and attempt to relieve suffering.

In 1997, the health economist Alan Williams, then in his seventies and now dead, courageously proposed that healthcare should be rationed by age using what he described as the “fair innings” argument.\(^\text{32}\) His conviction was that:

This attempt to wring the last drop of medical benefit out of the system, no matter what the human and material costs, is not the hallmark of a humane society. In each of our lives there has to come a time when we accept the inevitability of death, and when we also accept that a reasonable limit has to be set on the demands we can properly make on our fellow citizens in order to keep us going a bit longer.

Williams argued that a good start to defining a fair innings would be the biblical definition of three score years and ten.

The great American writer Saul Bellow seemed always acutely aware of humanity’s profoundest existential challenges and passages in his novel \textit{Mr Sammler’s Planet}\(^\text{33}\) suggest that he would have agreed with Alan Williams. Perhaps indeed Williams had read this particular novel. Bellow records:

\(^{31}\) May C, Montori V, Mair F. We need minimally disruptive medicine. \textit{BMJ} 2009;339:b2803, doi: 10.1136/bmj.b2803  


\(^{33}\) Bellow S. \textit{Mr Sammler’s Planet}. New York: The Viking Press, 1970
Seeing the singular human creature demand more when the sum of human facts could not yield more.

This applies to both patients and their doctors: everyone seems to want to demand more than the facts will yield. He goes on:

Scarcely worth so much effort, perhaps. There are times when to quit is more reasonable and decent and hanging on is a disgrace. Not to go beyond a certain point in hanging on. Not to stretch the human material too far. The nobler choice. So Aristotle thought.

Not to be forever pushing the law of diminishing returns becomes a noble ambition. And finally Bellow asks:

Do we always, always to the point of misery, do a thing? Persist until exhausted? Perhaps.

And it seems to me that all our hope lies in that word ‘perhaps’. It is the uncertainty of that ‘perhaps’ that lies behind the medical professions growing determination to pay serious attention to the harms imposed on our patients by the medicalisation of ageing and death and, indeed, ordinary human distress that have become more and more prevalent over the past 20 years.

It can never be appropriate to treat someone in their 80s in the same way as someone in their 30s, not least because the physiology of the ageing body is different: more vulnerable, and more susceptible to the adverse effects of drugs. This is not ageism; it is person centred care. When doctors fail to recognise and acknowledge existential suffering in the dying and take refuge in excessive technological interventions, patients become frightened and, no longer able to trust their doctors, may even request assisted dying. The medicalisation of life cannot be resolved by the medicalisation of death. Two technological wrongs do not make an existential right. I don’t want assisted dying, but I also don’t want a PEG tube.

Human society has not yet realised that Aristotle’s golden mean applies to healthcare as much as to any other human endeavour or attribute. People easily understand that too little healthcare is harmful but seem to have great difficulty in grasping that too much also causes harm. I am no less fearful of pain and suffering than anyone else, but I am still inclined to agree with the character in Emmanuel Carrère’s book Other Lives but Mine: “As a rule, he thinks one must live lucidly, experiencing everything that happens, even suffering.”

Carrère E. Other lives but mine. Serpent’s Tail, 2012.