



Atul Gawande
Being Mortal

Will

An interesting read of a book with a message. Being the age I am reflecting a possible or even probable look into the near future?

The three chapters I found most interesting are entitled 'Better Life', 'Letting Go' and 'Hard Conversations'. The first chronicling the birth of the care home from its fundamental provision for the elderly to today's modern paradigms. Although the author claims that such establishments still concentrate more on the health and safety of residents than on their happiness. However such improvements as have been made are delivered at a price

'Letting Go' resonated most with me when describing individual cases in the USA where patients with terminal disease are subjected to numerous cycles of chemotherapy and radiation, even when chances of an improvement are unlikely and of horrific cases where patients with terminal cancer being permanently attached to ventilators in intensive care. Also a patient enduring the infusion of sugars, proteins, and fats that made the painful swelling of her skin even worse - and without any tangible benefit.

'Hard Conversations' reflected hospital doctors necessary conversations with patients they hardly know to discuss potentially life-changing treatments or end-of-life care must be extremely difficult.

The author came to experience this during his surgical training and practice, when he encountered patients forced to confront the realities of decline and mortality, and it did not take him long to realise how unprepared he was to help them. There is nothing more threatening to a clinician when facing a patient with a problem they cannot solve.

Here in the UK professional groups such as doctors can undergo coaching on how to improve their approach and verbal techniques when endeavouring to secure a patient's understanding of the situation and assist the decision-making process towards the potentially life-changing outcomes of proposed procedures. The problem has been made much more difficult during the Covid-19 pandemic where a ban on family visiting in hospitals and care homes has required medical staff to activate 'Do Not Resuscitate' decisions in respect of patients without the opportunity for consulting the patient's next-of-kin.

Diagnosing the problem is much easier than solving it. Conversations with persons suffering from a chronic illness or dementia is a moral conundrum. Ascertaining people's wishes on how and when they wish to depart this life and further assisting their departure are great ethical decisions that somebody is going to have to make.

What control do we have? As John Lennon said 'Life is what happens to you while you are busy making other plans for the future' so reflects this paradox in our lives.

Living longer is all very well. Looking into the future I forecast a world where half of the

population is receiving care and the other half is looking after them.

Jean

Atul Gawande's book, 'Being Mortal', is a call for a change in the philosophy of health care. He intimates that the job of surgeons and the medical profession, rather than merely ensuring health care and survival, should also be to enable well-being in the elderly.

His book includes engaging stories, so that readers are left with a good sense of what he means. He poses the big question of what happens to people when it is no longer possible to be independent.

Gawande is concerned that medics should learn about geriatrics: not a popular choice for medics. Also the pay is less than for other specialisms.

He describes different modes of senior living, from the multigenerational household, to the nursing home, to end of life medicine and the hospice model of care.

Undoubtedly, Gawande is a gifted writer and some of his stories are are tear-inducing.

He stresses the importance of seeing the world from the perspective of older people, not just that of doctors and worried families.

There isn't much reference to people with dementia. However, the idea of bringing cats, dogs and kids into care homes is interesting and can help to instil purpose into the lives of the elderly, especially those living in smaller units.

His opinion on the Dutch laws, which enable people to seek assisted suicide, is that they are, in a way, a measure of failure. The aim should be, not just to achieve a good death, but rather , a good life.

Gawande realises, however, that there are no perfect solutions to the problems inherent in bodily decline, but that it is important to create better options and to make choices with the goal of a purposeful life in mind.

I was moved by his description of his journey to the Ganges, there to deposit his father's ashes and fulfil the Buddhist belief in achieving nirvana, a transcendental state where there is neither suffering, desire, or a sense of self. The deceased person is released from the cycle of death and rebirth.

To those of us not of the Buddhist faith, the words we'd use to describe this state are 'paradise' and 'heaven'.

'Being Mortal' is, without doubt, a thought-provoking book.

Ann

I approached the March Book Club choice with apprehension. In isolation I was more interested in being mortal and reading something more cheerful. I am more inclined to bury my head in the sand and unwilling to face up to the inevitable! However I persevered and found the book easy to read as Atul and his associates struggled to find solutions to the problems of incapacity and declining health. I recognised a lot of the problems I had and a lot I didn't know I had. The facts are unpalatable and solutions were investigated to try and minimise lack of independence, anxiety about dieing, suffering, finances and loved ones who might carry the burden of mental and physical conditions in their close relatives. I applauded his attempts to alleviate these problems.

I enjoyed the light relief in the book, where an entrepreneurial colleague introduces cats, dogs, birds and children into the collective 'homes' of the elderly and helped distract their minds in the ensuing chaos. (p. 120)

I also enjoyed the end of the book where poignantly Atul has to take his father's ashes to The Ganges and as part of the ritual has to drink 3 teaspoonfuls of the very polluted river. He does take precautionary medication, but not quite enough.

This book is not for the faint hearted, I feel, and I will not be reading it again.

Sharon

I could not honestly say that I enjoyed this book, although it is probably a valuable book.

Gawande started discussing research on ageing and an interesting point was that, when life looks fragile goals and motives shift. With reference to Maslow's hierarchy of needs (which I find has so many applications in various areas of life) he pointed out that ambition goes, to be replaced with what is important in the moment and the short term.

He discussed ways of building a health system that will help people achieve a good end and I did like his family stories illustrating this need. It was a slightly shocking realization that our system of nursing/care homes stems directly from the old, dreaded workhouses.

The second half of the book dwelt more on hospice care and his points were largely illustrated by reference to his own father's final illness. I did become a bit bored with this section but liked his simple statement that the wise course is usually unclear. Then came the question "Do one's fears or hopes matter most?", which I thought was a good way of distilling the whole difficult situation of end of life care. He concludes that people need to shape their story and have priorities beyond mere safety and living longer.

A depressing read, which I was glad to finish but I cannot disagree that we should all have these difficult conversations.

Margaret

The book (written in 2015) outlined what happened in America although it is no doubt similar to what has happened here in the past and also now, with the plight of the elderly.

A most informative book but I was a bit downhearted after the first chapters as it rather put a rubber stamp on what we know is likely to happen to us as we age, such as loss of independence. Bella's predicament was absolutely dreadful as she had no quality of life. Also the same can be said with Alice and at least the decision "Do Not Resuscitate" was agreed by all when all hope was lost, this is often the correct road to take but it must be made by families.

I loved the bit about the man of 80 who wouldn't move from his home when a volcano threatened and so he chose his end for himself.

Wilson and her mother, Jessie's plight made interesting reading, Jessie wanted "a place with a little kitchen, bathroom and her own furniture and where nobody would throw away things that she treasured due to safety hazards." In 1983 the US built "a living centre with assistance" despite the concept being attacked initially. In the UK assisted living is a good way forward where elderly people can be independent with their own space but can also call on carers if necessary.

By about the fourth chapter I became more interested as it focussed on peoples' research such as Carstensen's who, at just 21 years of age, after a car accident talked to and studied what elderly people wanted.

In chapter five I loved the humour when trying to improve life for the elderly in care homes, they brought in animals and birds into the home. A good idea apart from the initial chaos.

In chapter 8 Socrates was quoted on the meaning of courage and no one could come up with an answer but in aging courage is "to confuse the reality of mortality and which matters most, fears or hopes?"

We also learned about the predicament of the author's father and decisions he had to make and the ending of the book referred back to the author's father's death,

"We were lucky to get to hear him tell us his wishes and say his goodbyes. In having a chance to do so, he let us know he was at peace."

Finally the book does express the importance of a quality of life rather than trying to prolong it with drugs that give pain and discomfort.

Alix

I found this book very informative and useful so thanks to Stephanie for this. It made me more aware of asking questions. I found it hard to read as my husband has Ca. Prostate diagnosed 3 ¼ years ago. His treatment was Hormone Therapy alone. He did well at first on this regime but then his PSA went up slightly and he was put on a daily hormone tablet to go with the injection. This worked well for a year or so but his PSA has crept up again and they have substituted a daily steroid tablet instead. They ordered a CT scan and he has an appointment with the Oncologist at end of April. **This worried me as they seemed to act quickly and also I can not accompany him. Reading the book and telling Peter about some of it has made us realise that as I can not be there Peter needs to ask to delay making a decision on any further treatment before we have both talked it over with the Oncologist so have asked him to phone me if any decisions need to be made.**

I found many quotes useful in this book. **"You live longer only when you stop trying to live longer" Zen.**

I am grateful that in this Country we are fortunate enough to have the NHS. In America where this Surgeon was working the medics are much more likely to push for more and more chemo and radiotherapy and surgery to gain more money.

The Surgeon an Indian man living in the USA talked about how his culture and many more look after their aged and dying themselves. Us Westerners as a rule do not. **To be able to make choices of assisted living if possible or having care at home** with maybe stair lifts and downstairs shower rooms would help us all.

Not many of us these days with both partners working would want to put on our children to look after us. I feel guilty that as a 40 year old working wife and mother of teenage sons I could not offer to look after my grandmother who had helped bring me up. She had to go into a home but only for a year. She was not the sort of person who would blend into the woodwork and I knew she would interfere and cause trouble with our sons upbringing and my husband would not be happy with her living with us and so that would not work. My mother developed Osteoporosis and had mental health problems so we just had to visit. As my family lived in S. Wales it was difficult as we had to do the trip there and back in a day as our teenage sons did not want to come and could not be left alone over night. Again I feel I let them down but life is so different from when they were young.

In the Epilogue page 254 he said "Doctors should be able to enable wellbeing and wellbeing is about the reasons one wants to remain alive."

Also always ask what the bad side effects are of treatment and how you would cope without it.

Anna

I really thank Stephanie for nominating this remarkable book, which addresses the problems of how people are treated toward the end of their lives when they become less able to look after themselves, and also at the very end when death approaches.

Gawande describes problems at several levels: for the individual making what choices they have; for the providers of these services such as care homes; for government or local administration who have overall responsibility, and for clinicians such as doctors or hospice nurses who deal face to face with the physical and mental health of their old patients.

The author writes with passion on a subject he plainly feels strongly about, but makes his argument rationally with clear examples taken from his clinical practice, from the experience of friends, and especially from his own family. He feels that the true needs and wishes of old people are often not properly discussed - everyone is reluctant to face uncomfortable truths - so that people often find themselves living in a situation where they have no autonomy. In many care homes, the residents have no choice about when they get up or retire to bed, nor when or what they eat. They may have no privacy and may share a small space with a stranger. It doesn't have to be like this, and Gawande finds some inspirational examples of ways in which people can be cared for, but at the same time maintain some independence.

Gawande also tackles the huge problem of how to find ways for old people, their families and health professionals to discuss death. The difficulty is how to confront the inescapable fact in the first place, and then to understand how the old person would like to approach their end.

Part of the book is a challenge to the authorities who provide services for people as they age, and at their death, to change the structure both of those services and the physical surroundings in which they are provided, so residents and patients can continue to lead independent lives within their capabilities, with their wishes answered. The other part of the book is a challenge to us, the readers, to confront the inevitable decline and death of those we love, and of ourselves. At the same time Gawande shows us that facing these facts and discussing them with our partners and family can be rewarding and comforting.

A remarkable book, not only for the subject-matter, but for the vigorous and clear prose in which it is expressed.

Angela

Beginning this book I was a little daunted as it deals with the American system of healthcare and it took me a while to get to grips with it. However, once I had settled those details, I found this book fascinating and a real wake up call for care for the elderly and those with terminal illnesses. I absolutely gobbled the book up, couldn't put it down. I found that the first section which largely covered the difficulties of a medical system in which it is possible to prolong life enormously but without adequate attention to its quality, brought home to me my own mortality and prompted me to reflect on the personal implications and decisions I might want to make in the future. I believe this is very valuable even if tough at times. The conversations on this topic that you have with yourself and your family really matter. The second half was devoted more to palliative care. I thought that Gawande's personal and sensitive case studies were really revealing and gave much food for thought. The writing throughout is clear, jargon-free and eminently readable. Lots of information too about society and care issues. A brilliant, enlightening and profound read.

Stephanie

This thought provoking and poignant book examines the ways in which different families and societies care for terminally ill family members. The care available has clearly evolved as has the scope of medical treatments so that patients can be kept alive much longer than they might have wished under conditions they might said were intolerable had they been able to express an opinion.

The author stresses the importance of communication, and early communication, so that the patient can clearly say what is most important to him/her before it is too late.

The progress of the argument is developed through a series of case studies starting with the care of the author's grandfather in his home in a small village near Mumbai. The grandfather lived to be over 100, and as an elder, was honoured, respected and obviously much loved by his extended family. His activities were not restricted at all although the family sometimes made adjustments to protect the grandfather while still enabling him to live the life he knew. An example of this was that he liked to ride around his farm in the evenings but the family was somewhat worried by this so they bought him a smaller horse and made sure that there was always a family member with him when he was out checking his farm.

Later case studies were influenced by the demise of the extended family, increasing ability of the medical profession to keep patients alive at all cost, the refusal of many patients or their families to face the inevitable death of their loved one, and the introduction of both the hospice system and care/ nursing homes.

The author takes the reader through a number of cases always illustrating the importance of the medics asking, maybe, painful questions and gently guiding families and patients to face the realities of the case. The last case is the final illness of the author's own father and describes in detail how the father is constantly consulted and makes his own decisions on his treatment and when to stop the treatment.

This book should be essential reading for all medical practitioners and non-practitioners alike especially in the current era when discussion of death tends to be avoided if at all possible and all too frequently until it is too late.