



EncourAGING & Equipping Congregations for Older Adult Ministry

Being Mortal, Medicine and What Matters in the End, by Atul Gawande **Study Guide**, by Mark Schoepp

How to use this guide:

1. Usable by an individual or couple as they explore the topic.
2. Usable by an extended family as they explore the topic; as needed, add face-to-face meetings (or Zoom/Skype conferences) to work it through.
3. Usable by a group of people in a church or community group.

I have not set any ‘session’ breaks. If you are on your own, or with a very small group you will likely just tackle it at your own pace. If you are with a formal group that meets weekly and you have to set an agenda with start and end dates, the best approach might be to tackle it with an Introductory Session and then a session for each Chapter for a total of nine weeks (If you need a shorter time frame you might explore doing some chapters together, for example Chapters 4 and 5). In my opinion, everyone has to read the book. I’ve included some lengthy quotes, but that won’t compare to your own reading of the book. You might want to also check out a [YouTube video of Atul Gawande](#) talking about the book in his own words.

4. I have mostly highlighted what I think are important pieces of the discussion he develops. You can also use the Author’s own discussion questions found at the end of the book (page 283).

Stories

We picked the five “Ministry Areas” on ALOA’s website guided by recent life stories that made the subject hit home. This book is full of stories. You’ll hear stories about the author’s father, Alice, Joseph, Felix, Sarah and more. That is partly what makes the book so helpful. It is about real people and real situations. I’m sure you’ll have your own stories to tell as well.

Our story is an example of a frustrating end. A brother-in-law died of esophagus cancer and the end came in about four months, but the frustration is about the last few weeks, and what is described in the book: “one more procedure after another” until the wife was looking at her husband in a coma and there were no last words with each other. Accidents happen, of course, and death can come unexpectedly and quickly. But when medicine and families don’t know when to say ‘enough,’ it can be a problem. Modern medicine is good at fixing ‘fixable’ medical problems, but it is not so good at handling unfixable problems. How long do we keep trying another ‘option’? And what questions should we ask to help us decide?

Bigger picture

Although this book is clearly about the end of life, it develops the case by exploring what happens all along the journey during the last years of life. There is much to learn here about the decisions that come with the ongoing move from independence to interdependence.

A. Introduction

Beginning at the end

I suggest you start at the Epilogue with this quote: *“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable ‘well-being’. And well-being is about the reasons one wants to be alive. Those reasons matter not just at the end of life, or when debility comes, but all along the way.”* (Really, from the bottom of page 259 to the top of page 260 is well said.)

→ **How would you describe “Well-being”?**

I come from a Christian faith perspective. *“O death, where is thy sting...”* (1 Corinthians 15:55-57); and funerals that speak of being a ‘celebration of death’. Yes, we can affirm that certainty and joy in Christ Jesus, and yet no one gets a practice round at dying.

→ **Briefly share your thoughts on these topics.**

An Introductory story

Joseph Lazaroff's story (page 3 to the top of page 6), sets up the main theme of the book. The author uses this story as an example of what happens much too often at the end, and he works his way through the book to find better alternatives.

→ **Share if you have had similar experiences with friends or family.**

Where do we die?

Page 6 - as recently as 1945, most deaths occurred in the home. By the 1980s, only 17% did (and many of those died at home because it was a catastrophic end due to heart attack, stroke, etc.). The experience of advanced aging and death has shifted to hospitals and nursing homes.

Fixable or not?

page 7 - in the author's early days of medicine, when people died, the shock was that medicine did NOT pull people through. *"I didn't know what game I thought this was, but in it we always won."*

Bottom of page 8 *"...If your problem is fixable, we know just what to do. But if it's not? The fact that we have had no adequate answers to this question is troubling and has caused callousness, inhumanity and extraordinary suffering."*

Page 9 - *"You don't have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit...Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology and strangers."*

→ Some discussion questions:

What questions does this section raise for you? If you are doing this with others, check how many of the group have experienced the death of someone they know (not just someone you know who died, but you were there in the last stages before they died). As you are comfortable, share what

you felt from that experience, and how that might have changed your view of your own death.

B. Chapter 1 - The Independent Self

This is the start of our journey to the end. Really it starts at birth, but little thought is given to the subject until hard decisions are in our face.

Page 14 - 17, the author cites his grandfather's experience compared to now.

The "eight activities of Daily Living:

- shop for yourself
- prepare your own food
- maintain your housekeeping
- do your laundry
- manage your medications
- make phone calls
- travel on your own
- handle your finances

His grandfather could do only a very few of these eight, but lived happily till the end in a place of honor. That was the norm.

Now: bottom of page 17 *"...old age and infirmity have gone from being a shared, multigenerational responsibility to a more or less private state - something experienced largely alone or with the aid of doctors and institutions. How did this happen? ..."*

→ Survey your group to see how many have aging parents living with the vs the aging parents living in a separate facility. Share experiences in either circumstance as you are comfortable.

Independence is key.

The author tracks the economic changes in society - page 18-22 *"... The veneration of the elders may be gone, but not because it has been replaced by veneration of youth. It's been replaced by veneration of the independent self...but if independence is what we live for, what do we do when it can no longer be sustained?"*

→ Do you agree? Talk about the difference.

Alice Hobson's story starts top of page 23-24. *"At the end Alice did not have a fixable problem and medical world didn't know what to do..."*

C. Chapter 2 - Things Fall Apart

Note the difference in the three graphs (page 25, 27 and 28) *"...we regard living in these downhill stretches with a kind of embarrassment... we need more and more help...and we are, for the most part, medically uninteresting to the medical community..."*

- The story of our Parts: Teeth, etc. - page 29 ff.
- Why we age - page 31 bottom to page 35 middle.
- Demographic shifts - page middle 35-middle 36.
- Geriatrics and the lack of Doctors - page 36ff middle.
- * - A great geriatric visit and story- page 37 middle to page 42 top. Jean Gavrilles and Dr. Juergen Bllundau.
- Back to Alice - page 42-43.
- * - More on the stunning results of good geriatrics - page 44 top to 46 middle.
- Story - Felix Silverstone page 46 middle to 52 middle.
- More on geriatrics - page 52 middle.
- Share experiences with medical doctors and aging parents, or yourself. What can patients do to improve the care that is received?

Chapter 3 - Dependence

Stories: Felix page 55 to 59 middle; Alice page 59 middle to 61 bottom.

Unhappy in a beautiful place. How did that happen? page 61 bottom to page 65 bottom, plus more stories of Truman and Alice to middle of page 68 and then an IMPORTANT: HOW THINGS CHANGED page 68 middle to 72 middle.

Alice page 72 middle ff, "Caring vs Living' page 74 middle. Page 75 middle: *"...it seems we're succumbed to a belief that, once you lose your physical independence, a life of worth and freedom is simply not possible."* page 76 *"...In the horrible places... in the nice ones in almost no place... (Does your experience support this statement?)*

Opa's fear of having to live in "one of those nursing homes".

Alice at the end. page 77-78.

→ Discuss the difference between ‘caring’ and ‘living’. What might some of the differences be between the approach of the older parent vs their adult children? How can those differences be addressed?

Chapter 4 - Assistance

There are new options and experiments.

Stories page 79 to top of 87. Lou Sanders and Shelly.

page 87 - 92 bottom. Keren Brown Wilson, Oregon, '80s - “assisted living.” She was trying to eliminate the need for nursing homes altogether.

Page 92 bottom ff - “What makes life worth living...?” Important discussion on these pages... through page 109, Safety vs Autonomy. IMPORTANT DISCUSSION.

→ Safety vs Autonomy - which would you lean towards and why?

Share your experiences with high quality care facilities, and what criteria you use to make that determination.

Chapter 5 - A Better Life

More alternatives...

Great story of Bill Thomas Berlin, NY. An experiment, page 111 up to page 128. New Bridge, page 129 – 138, Pods in Boston suburb.

Page 139, Beacon Hills Villages.

Bottom 139 wrap up - *“Lots of models, very different from one another EXCEPT that they all were committed to a singular aim: They all believed that you didn’t need to sacrifice your autonomy just because you needed help in your life.”*

Helpful stuff up to the end of the chapter.

→ (See discussion questions under Chapter 4.)

Chapter 6 - Letting Go

This is a watershed chapter.

Previous chapters force a new question: page 149, “When do we try to fix and when do we not.” Sarah’s story page 149 to 154.

Critical quote: page 155 middle - *“People with serious illness have priorities besides simply prolonging their lives. Surveys find that their top concerns include avoiding suffering, strengthening relationships with family and friends, being mentally aware, not being a burden on others, and achieving a sense that their*

life is complete. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars. The question therefore is not how we can afford this system's expense. It is how we can build a health care system that will actually help people achieve what's most important to them at the end of their lives."

The art of dying and last words before death, page 156 and now page 157.

Sarah Creed hospice nurse - patient Cox, pages 158 to 161.

Dave Galloway - pages 161 bottom to 164 top.

Sarah again, page 165 middle to 173, page 167 - an important analysis of 'what just happened here'. Page 171, "...the long tail of possibility (Some do beat the odds!) What's wrong looking for that long tail of possibility? nothing, UNLESS IT MEANS WE HAVE FAILED TO PREPARE FOR THE OUTCOME THAT IS VASTLY MORE PROBABLE.... medical lottery tickets..."

"THERE IS A MODERN TRAGEDY, REPLAYED MILLIONS OF TIMES OVER. WHEN THERE IS NO WAY OF KNOWING EXACTLY HOW LONG OUR SKEINS WILL RUN, AND WHEN WE IMAGINE OURSELVES TO HAVE MUCH MORE TIME THAT WE DO - OUR EVERY IMPULSE IS TO FIGHT, TO DIE WITH CHEMO IN OUR VEINS OR A TUBE IN OUR THROATS OR FRESH SUTURES IN OUR FLESH. THE FACT THAT WE MAY BE SHORTENING OR WORSENING THE TIME WE HAVE LEFT HARDLY SEEMS TO REGISTER. WE IMAGINE THAT WE CAN WAIT UNTIL THE DOCTORS TELL US THERE IS NOTHING MORE THEY CAN DO. BUT RARELY IS THERE NOTHING MORE THAT DOCTORS CAN DO.... WE MOST OFTEN MAKE NO CHOICE AT ALL..."

Page 174 bottom to 175, "Rationing/death panels". Story of Nelene Fox.

page 176 to 180 middle, "Somehow... TALKING was enough..."

Page 180 ff, Gawande's own struggles with actual patients.

Page 185 "...breakpoint discussions that sort out when they need to switch from fighting for time to fighting for other things that people value." followed by real examples...

→ Discussion: Where do you agree or disagree with the surveys about what people say is a priority at the end of life? Talk about the difference between 'fighting for time' and 'fighting for other things that people value'?

Share the preparations you've made regarding legal documents about medical care decisions.

Chapter 7 - Hard Conversations

Dying around the world - page 191 ff, the rest of the world is similar to US now.

Page 192 - **three stages of medical development** countries go through.

1. extreme poverty, death is at home due to little access to medical help.
2. economics improve, access to medical care improves, death in hospitals.
3. Income to highest level, people have the means to be concerned about quality of lives, even in sickness, and death at home increases.

Since the 1980s the number of in-home deaths has reversed course, increased.

Use of Hospice grown, in home deaths now increasing. 2010 - 45% died in Hospice care.

****page 193 - **“Monumental shift** - ... *people increasingly have an alternative to withering in old age homes and dying in hospitals - and millions of them are seizing the opportunity... but we’ve not yet established our new norms.... we know the old dance moves...patient and clinician... and figure out how to face mortality and preserve a fiber of a meaningful life”*

page 193 bottom to 199 bottom, the author’s dad’s story with a brain tumor.

Doctor/Patient relationship types, bottom of 199 ff

1. Paternalistic
2. Informative
3. (new) Interpretive (We want info, control, AND guidance!)

followed by many real-life examples...

ODTAA Syndrome - (*“One damn thing after another”*) page 208, no predicable path, but the overall direction is clear.

More on his father’s example, page 218 some examples of really bad Doc speak at the end.

page 220 - *“The ‘old way’ was not really about making decisions. More like dealing with a default setting.”*

Page 223 **** his own father’s - and his - hitting the unfixable end... “an education.”

His positive experience with Hospice nurse, page 225 bottom to 228.

page 229 *“We witnessed for ourselves the consequences of living for the best possible day today, instead of sacrificing time now for time later... he found that in the narrow space of possibility that his awful tumor had left for him there was still room to live!”*

→ Discussion: Talk about this last quote from page 229. What does it mean to 'live' so close to your own death?

Chapter 8 - Courage

page 231 - Plato - what is courage?

page 232 - At least **two kinds of courage** are required in aging and sickness. The **first** is the courage to confront the reality of mortality - the courage to see out the truth of what is to be feared and what is to be hoped. Such courage is difficult enough. We have many reasons to shrink from it. But even more daunting is the **second** kind of courage - the courage to act on the truth we find. The problem is that the wise course is so frequently unclear.... One has to decide whether one's fears or one's hopes are what should matter most.

→ What are your thoughts on fear and hope?

page 234 - difficult on both sides - Doctor and Patient. Gawande slides back into being "Dr. Informative."

Page 236 - the brain - a book: Thinking, Fast and Slow. An experiment - Rating pain and the surprise "Peak-End" rule, remembering self and the experiencing self, page 238ff. Which one do you listen to? Life as story. Peaks are important but so is the end. Jewell Douglas story, 239 bottom to 242 bottom.

Closure page 243 ff...(and that page brings up 'assisted suicide'. page 244 top - which mistake do we want to do) page 245 top - *"our ultimate goal is not about a 'good death' but about a good life to the very end."* *"Assisted living is far harder than assisted death, but its possibilities are far greater as well."*

Page 249 "the dying role".

The author's father's end, page 249ff

→ Discussion: How does your family handle 'confronting the reality of mortality'? Discuss your 'fears' and 'hopes' for the end of life.