

Being Mortal Discussion Guide

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www.TheConversationProjectInBoulder.org

This 6-week discussion group is based on Atul Gawande's book "Being Mortal." Discussions focus on various aspects of aging and dying, including:

- What is important to us as we age
- Understanding our choices (medical and otherwise)
- Facing our mortality

I. Overview

Week 1: *The Author of Your Life* – Chapter 1

- Introductions, plans for upcoming sessions
- Review of "Introduction" in *Being Mortal*
- Small group sharing: good deaths, difficult deaths

Week 2: *Aging* – Chapters 2 & 3

- Frailty, physiological changes
- Patterns of decline
- Geriatric medicine
- Issues of dependence

Week 3: *Dependence* – Chapters 4 & 5

- Physical and emotional changes as we grow more dependent on others
- Story of Lou and Shelley Sanders
- Differences between Assisted Living and nursing homes

Week 4: *Letting Go* – Chapters 5 & 6

- Costs of terminal care
- Hospice
- What does it mean to "let go"
- Story of Felix and Bella

Week 5: *Hard Conversations* – Chapter 7

- Hard Conversations
- The story of Atul's father
- The Conversation Project Starter Kit

Week 6: *Courage* – Chapter 8

- Courageous decisions
- Spirituality and mortality

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II. Guidelines for Weekly Sessions

Week 1 – *The Author of Your Life* (Chapter 1)

Atul Gawande says mortality has become a clinical experience that robs patients of quality of life. He argues doctors and healthcare facilities need to shift their approach to aging and dying away from a regimented safety focus to one that fully engages the human spirit. What does that mean to each of us and our loved ones?

Gawande notes that there are two kinds of autonomy (p. 140): “free action—living completely independently, free of coercion and limitation” and the freedom “to be the authors of our lives...to shape our lives in ways consistent with our character and loyalty.” (p. 141)

Small Groups: (1) What does autonomy mean to you? (2) When you think about yourself aging, what kind of autonomy do you want to preserve? (3) How might you do that?

Week 2 – *Aging* (Chapters 2 & 3)

Gawande lists 3 patterns of aging and discusses medical aspects of aging (bones weaken, muscles thin, vessels harden, joints wear out, and the brain shrinks). He challenges us to think about how we live with (and accept) chronic diseases.

Gawande states that the medical care system is poorly equipped to care for even the physical aspects of aging let alone the social and psychological aspects.

Large group discussion: Do you have any experiences you’d like to share about primary or specialty medical care, use of geriatricians, etc.?

Small groups: As we age, we are bound to develop some type of frailty and eventually we die. (1) What are your fears in this regard? (2) What would you consider a good death vs. a bad death: any experiences to share?

Gawande discusses the movement from poorhouses to the rapid growth of hospitals, and to the development of the nursing home industry. Today we have many options:

- Aging in place (story of Felix and Bella)
- Moving in with son or daughter (story of Lou Sanders)
- Senior housing
- Assisted Living and Nursing Homes

What happens to autonomy with each of these experiences?

Distribution of the Conversation Project Starter Kit

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Week 3 – Dependence (Chapters 4 & 5)

Gawande discusses the tension between increased longevity in the U.S. and the decline of the family as primary caregivers of elderly persons. Multiple factors contribute to this disconnect and “our elderly are left with a controlled and supervised superficial existence, a medically designed answer to unfixable problems, a life designed to be safe but empty of anything they care about” (p. 109).

Example: Lou Sanders

- Lou’s Story: Widower at 76, lived independently for 10 years, valued his routines, moved in with his daughter at 89
- Shelly’s Story: Married with 2 teenagers, gradually getting more involved in her father’s care, major decision about living arrangements, responsible for Lou’s physical and mental well-being

Large group discussion: challenges, trade-offs of caring for an elderly parent in your home. Personal experiences with living with an elderly parent/grandparent?

The emergence and growth of the Assisted Living industry is largely a result of this disconnect:

- Keren Brown Wilson (late 80s) – new kind of home (quote on p. 89)
- ADLs and IADLs – what are they and why are they important?
- Quality of life – “chocolate ice-cream and football” standard
- Personal experiences with AL?

Small groups: (1) Are you prepared to make major health care decisions for someone in your life? (2) Who in your life knows what makes life worth living for (and fighting for) you? (3) Thinking about yourself right now, could you imagine answering: “What are the tradeoffs you are willing to make and not willing to make?”

Nursing Homes – a better life?

- Bill Thomas & Chase Memorial Nursing Home
- “Three Plagues” of nursing homes: boredom, loneliness, helplessness
- Culture war: running an institution vs. providing a home (p. 122)
- Eden Alternative

Large group discussion: What are your thoughts on ideal nursing homes? Lou Sanders valued privacy and solitude. What are the deal-breakers for you?

The doctor learns from the patient: “We’d been talking about the story of (Lou’s) life for almost two hours when it struck me that, for the first time I can remember, I did not fear reaching his phase of life” (p. 146). Have you ever had that flash of insight?

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Week 4 – *Letting Go* (Chapter 6)

Gawande says “as people’s capacities wane, whether through age or ill health, making their lives better often requires curbing our purely medical imperatives” (p. 149). He presents an overview of terminal care in the U.S. and related expenses:

- 25% of all Medicare spending is for the 5% of patients who are in the final year of life, and most of that goes for care in their last couple of months that is of little benefit.
- Spending for a patient with breast cancer: \$28,000 the first year, then \$2,000 until the last year. Costs rise to \$94,000 the last year.

The stories of Sara Monopoli, Lee Cox and Dave Galloway each story reflect the transition from standard medical care towards hospice care. This is not always a smooth transition.

- Standard medical care – may sacrifice quality of life for a chance of gaining time later
- Hospice care – quality life now for as long as you live, which is often longer because of the quality of care and life.
- When to opt for hospice – why do we wait
- Concurrent care (combining standard medical approaches with hospice)

Small Groups: In each of the stories, the patient and/or family member had a difficult time “letting go”. (1) Do you have any experiences (personal or family) with talking to physicians about your end of life preferences? (2) What could your doctor have done or said differently?

Large group discussion: Having difficult conversations with your doctor and with your family

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Week 5 – *Hard Conversations* (Chapter 7)

Gawande discusses issues pertinent to death and dying

- Stages of medical development in societies (death at home vs. death in institutions)
- Physician communication styles & training: paternalistic, informative, interpretive, shared decision-making

Letting go requires changing one's perspective (stories of Jewel Douglass, Atul's dad), what Gawande refers to as "stepping through the looking glass" with a serious illness diagnosis (p. 194). This brings into question procedures that prolong life, such as nutrition/tube-feeding, ventilators, and CPR (cardio-pulmonary resuscitation).

Small groups: (1) Have you had the conversation with your spouse/parent/children? (2) What problems do you anticipate or did you experience?

Large group discussion: Medical forms and terminology:

- Advanced Directives
- MOST Form, Living Will
- Medical Durable Power of Attorney

Review of The Conversation Project Starter Kit (tool for getting the conversation started)

Week 6 – *Courage* (Chapter 8)

Checking in: thoughts about difficult conversations

Gawande references Plato's dialogue on courage, observing it takes two kinds of courage to face illness and sickness: "the courage to confront the reality of mortality..." and "the courage to act on the truth we find." (p. 232)

Stories from the book:

- Atul's dad (Ram)
- Jewel Douglass
- Peg Bachelder

Small groups: What part of the aging & dying process feels like it will take the most courage for you?

Large group discussion: What grounds you and supports you in being courageous in the face of difficult realities?

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Some thoughts about spiritual and religious support:

- What support do you feel you need to face your mortality with courage and hope?
 - What can a faith community do to recognize, honor and support people for these choices?
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III. Online resources:

Frontline: <http://www.pbs.org/wgbh/pages/frontline/being-mortal/>

Interview with Jon Stewart: <http://thedailyshow.cc.com/videos/hz2xb6/atul-gawande>

Charlie Rose interview: <http://www.charlierose.com/watch/60466878>

Eden Alternative – www.edenalt.org

Pioneer Network – www.pioneernetwork.net

National Greenhouse Replication Initiative – www.thegreenhouseproject.org

The Conversation Project – www.theconversationprojectinboulder.org

PREPARE: www.prepareforyourcare.org

American Bar Association Consumer Tool Kit for Advance Care Planning:

http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_consumer_tool_kit_bk.authcheckdam.pdf

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