STEP ONE: GET READY

- Start thinking about it.
- What do you need to think about or do before you feel ready to have the conversation?
- Do you have any particular concerns that you want to be sure to talk about?

Gawande excerpts:

- “The battle of being mortal is the battle to maintain the integrity of one’s life—to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be.”
- “Our ultimate goal, after all, is not a good death but a good life to the very end.”
- “You need to understand how much you’re willing to go through to have a shot at being alive and what level of being alive is tolerable to you.”
- “In the end, people don’t view their life as merely the average of all of its moments—which, after all, is mostly nothing much plus some sleep. For human beings, life is meaningful because it is a story. A story has a sense of a whole, and its arc is determined by the significant moments, the ones where something happens. Measurements of people’s minute-by-minute levels of pleasure and pain miss this fundamental aspect of human existence. A seemingly happy life may be empty. A seemingly difficult life may be devoted to a great cause. We have purposes larger than ourselves. Unlike your experiencing self—which is absorbed in the moment—your remembering self is attempting to recognize not only the peaks of joy and valleys of misery but also how the story works out as a whole. That is profoundly affected by how things ultimately turn out. Why would a football fan let a few flubbed minutes at the end of the game ruin three hours of bliss? Because a football game is a story. And in stories, endings matter. Yet we also recognize that the experiencing self should not be ignored. The peak and the ending are not the only things that count. In favoring the moment of intense joy over steady happiness, the remembering self is hardly always wise. “An
inconsistency is built into the design of our minds,” Kahneman observes. “We have strong preferences about the duration of our experiences of pain and pleasure. We want pain to be brief and pleasure to last. But our memory … has evolved to represent the most intense moment of an episode of pain or pleasure (the peak) and the feelings when the episode was at its end. A memory that neglects duration will not serve our preference for long pleasure and short pains.” When our time is limited and we are uncertain about how best to serve our priorities, we are forced to deal with the fact that both the experiencing self and the remembering self matter. We do not want to endure long pain and short pleasure. Yet certain pleasures can make enduring suffering worthwhile. The peaks are important, and so is the ending.”

- “The value of autonomy … lies in the scheme of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent such a scheme of rights can make this possible, what he has made himself.”
- “But as your horizons contract—when you see the future ahead of you as finite and uncertain—your focus shifts to the here and now, to everyday pleasures and the people closest to you.”
- “Studies find that as people grow older they interact with fewer people and concentrate more on spending time with family and established friends. They focus on being rather than doing and on the present more than the future.”

**STEP TWO: GET SET**

- **What’s most important to you as you think about how you want to live at the end of your life?**
- **What do you value most?**
- **What matters most to me at the end of life is…**

**Gawande excerpts:**

- “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.”
- “All we ask is to be allowed to remain the writers of our own story. That story is ever changing. Over the course of our lives, we may encounter unimaginable difficulties. Our concerns and desires may shift. But whatever happens, we want
to retain the freedom to shape our lives in ways consistent with our character and loyalties. This is why the betrayals of body and mind that threaten to erase our character and memory remain among our most awful tortures. The battle of being mortal is the battle to maintain the integrity of one’s life—to avoid becoming so diminished or dissipated or subjugated that who you are becomes disconnected from who you were or who you want to be.”

- “Technological society has forgotten what scholars call the “dying role” and its importance to people as life approaches its end. People want to share memories, pass on wisdoms and keepsakes, settle relationships, establish their legacies, make peace with God, and ensure that those who are left behind will be okay. They want to end their stories on their own terms.”
- “Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same: What is your understanding of the situation and its potential outcomes? What are your fears and what are your hopes? What are the trade-offs you are willing to make and not willing to make? And what is the course of action that best serves this understanding?”

**STEP THREE: GO**

- Who do you want to talk to?
- When would be a good time to talk?
- Where would you be comfortable talking?
- What do you want to be sure to say?

**Gawande excerpts:**

- “The job of doctors is to supply up-to-date knowledge and skills. The job of patients is to supply the decisions.”
- “The aging did not lose status and control so much as share it. Modernization did not demote the elderly. It demoted the family. It gave people—the young and the old--- a way of life with more liberty and control, including the liberty to be less beholden to other generations.”
- “Courage is strength in the face of knowledge of what is to be feared or hoped. Wisdom is prudent strength. 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 seek 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.”
- “As a person’s end draws near, there comes a moment when responsibility shifts to someone else to decide what to do.”
- “In other words, our decision making in medicine has failed so spectacularly that we have reached the point of actively inflicting harm on patients rather than confronting the subject of mortality. If end-of-life discussions were an experimental drug, the FDA would approve it.”