

DISCUSSION GUIDE FOR

FINISH STRONG

Putting Your Priorities First at Life's End
SECOND EDITION

Barbara Coombs Lee



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 **compassion
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Care and Choice at the End of Life

Compassion & Choices is the nation's oldest, largest and most active nonprofit working to improve care and expand options for the end of life. From our origin in 1980, we have united over 450,000 supporters nationwide to become the preeminent leader of the movement for end-of-life options.

Compassion & Choices is leading the way to transform our "conveyor belt" healthcare system, which promotes needless pain and suffering, into one where people are in charge of decisions that will affect quality of life as illnesses progress. We are working toward a system that supports decisions that reflect individual values, in candid consultation with doctors and loved ones.

Join the movement to create a society where, in Barbara Coombs Lee's words: "A good death in one that honors the life that's been lived."

Please visit CompassionAndChoices.org today to learn more.

Finish Strong Discussion Guide

Over more than five decades, Barbara Coombs Lee worked in healthcare as a clinician, policymaker and advocate. Her indelible bedside experiences forged a deep respect for individual values and beliefs, and led her to a career in law and health policy. For the last 25 years, she has advocated for initiatives that allow individuals a full range of options and much greater agency in their healthcare decisions.

Barbara's new book, *Finish Strong: Putting Your Priorities First at Life's End, Second Edition*, contains 13 chapters, each with different themes and takeaways. This book encourages readers to engage in a new way with their healthcare providers, consider their choices in terms of the priorities of their life and ultimately help improve how care is delivered in the United States. Leading a book discussion is a great way to present these important topics to your community and to encourage personal empowerment.

This guide is intended to help facilitate a discussion of each of the topics covered. However, feel free to bring your own ideas and creativity to your group meetings.

Preparing for the Discussions

- It is strongly suggested that the group has a dedicated leader for each discussion. This can be the same person for all discussions or rotate from week to week.
- The book contains 12 chapters, so an ideal schedule would be to discuss two chapters a week over a six-week period. However, feel free to use a model which best serves your group.
- The ideal group size for a book discussion ranges from 8-16 participants.
- Choose a quiet and private location for your discussion group. If you cannot hold the group in your home, public libraries often have community rooms which can be reserved at no charge.
- Arrange seats around a table or in some sort of circular pattern where participants can view one another.
- Make sure the leader has an extra "group copy" of the book in case a member forgets their copy.
- This book covers sensitive topics. Make sure you have tissues available for group members.

Tips for Facilitating a Discussion

The discussion leader will be responsible for posing discussion questions to the group, ensuring that all members feel supported in their participation and making sure the group begins and ends on time.

1. Encourage participants to avoid judgmental words such as “like” or “dislike.” Instead ask participants to talk about their experiences and the emotions they felt as they read passages of the book.
2. Participants’ engagement styles may vary along with the frequency of their verbal contributions. Work to ensure that quieter participants have opportunities to engage, but do not feel like you have to drive them to participate if they are not comfortable doing so.
3. Participants may differ in their opinions. Discussion leaders should work to mediate tension between group members and not dwell on conflict.
4. Feel free to pause discussions and allow participants to stretch, walk around or take a break if needed.

Discussion Questions

This guide contains questions to spur conversation and deep discussion.

Each chapter theme has three related conversation questions, which ask participants to apply their reading in different ways.

- **Recall:** *Recall* questions refer to specific passages of the chapter and primarily gauge comprehension.
- **Reflect:** *Reflect* questions ask participants to relate portions of the book to their own personal experiences.
- **Apply:** *Apply* questions ask participants to express how they plan to apply lessons learned in their own lives.

Chapter 1: An Invitation

Recall: Barbara shares the stories of Otto and Nate and their differing experiences at the end of life. What differences in their experiences did you find particularly striking?

Reflect: In this chapter Barbara shares several personal stories. What personal experiences do you bring to the discussion group? Were there moments in Barbara's stories that resonated with your own experiences?

Apply: Barbara ends the chapter by inviting readers to engage in their healthcare with "consciousness and candor." What are some ways you feel you can begin consciously working with your healthcare team? What are some tools or skills you hope to acquire as you continue reading?

Chapter 2: Talking About Death Won't Kill You

Recall: Barbara uses the illustration of crow behavior to speak about the difference between "patient-centered" care and "patient-driven" care. What differences did she describe between those two modes of care?

Reflect: The chapter discusses the prospect of creating a "partner doctor" relationship. Do you consider your current relationship with your physician to be a partnership? What gaps do you see in your current communication?

Apply: The chapter discusses writing a letter to your doctor explaining your end-of-life wishes (on page 32). What would you include in your letter? What portions of the sample provided would be particularly important to include?

Chapter 3: Overtreatment and Diminishing Returns

Recall: In this chapter Barbara outlines six major reasons for overtreatment: financial gain, doctors' reluctance to deliver bad news, patients' and families' expectations, technology must be utilized, fear of lawsuits, and comfort care is seen as giving up. Which reason for overtreatment did you find most surprising and why?

Reflect: This chapter shares examples of physicians proposing tests or treatments despite their ineffectiveness. Have you or a family member personally experienced overtreatment? What was the impact on your overall well-being?

Apply: Barbara outlines tips for combating each overtreatment cause in the box on page 64. Which tips do you plan to use in your own care?

Chapter 4: Let Me Die Like a Doctor

Recall: Barbara mentions how trained medical practitioners often make different choices for themselves at the end of life than those they recommend to their patients. What differences did you find particularly striking?

Reflect: Dr. Paul Kalanithi's memoir *When Breath Becomes Air* focuses on his insistence on being present for meaningful moments with his family as his life was coming to an end. What aspects of your life would you want to focus on if facing a similar fate?

Apply: At the end of the chapter Barbara emphasizes the need to be prepared for the end of life while making an effort to remain healthy. At the close of the chapter, Barbara emphasizes the need to be realistically prepared for the end of life. What is one thing you will think about or do to be realistically prepared?

Chapter 5: Hope and Heroism

Recall: Throughout this chapter Barbara highlights the option to use less "battle oriented" language when speaking about individuals facing serious illness. What are some of the examples in this chapter you found particularly poignant?

Reflect: Barbara shares several powerful examples of individuals whose insistence on "fighting" illness ultimately resulted in a diminished quality of life at the end. She also describes the heroism of an ultimate graceful surrender. Do you have personal examples of similar situations?

Apply: What are some ways that you plan to change the way you speak about friends or loved ones who are facing serious or terminal illness? What are some alternatives that acknowledge the heroic aspect of accepting imminent death, accepting the reality of a specific situation while also being sensitive to an individual's current perspective?

Chapter 6: Hospice: The Healing Option

Recall: Barbara calls hospice the “gold standard” for care at the end of life. What are some of the services hospice provides? How does hospice support a person’s wish to die in a familiar setting?

Reflect: This chapter mentions how hospice experiences vary from provider to provider. Have you experienced these disparities of care with friends or loved ones?

Apply: Do you know which hospices are active in your area? How do the options they offer differ? Feel free to research local providers as a group and compile your answers.

Chapter 7: The Secret of Slow Medicine

Recall: Barbara describes key qualities of Slow Medicine. What are some of the key tenets of the “slow medicine” movement? How does it differ from the way in which medicine is typically practiced?

Reflect: Barbara shares Rob’s stories of his parents’ deaths in this chapter. What aspects of his story were particularly striking to you? How did his mother’s experience differ from that of his father?

Apply: With a partner, practice asking some of the questions Barbara outlines in the boxes on page 110 and 113, designed to ask before consenting to a test or procedure. Which questions did you find difficult to ask? How do you plan to integrate these questions into conversations with your own physician?

Chapter 8: Escaping Dementia

Recall: This chapter begins with a number of sobering stories and statistics. Which ones surprised you?

Reflect: Barbara outlines several end-of-life options when facing advancing dementia. What was your reaction to those scenarios? Did some seem more feasible than others?

Apply: The end of the chapter contains a number of steps to take in order to increase the chance your wishes are honored when facing dementia. Which of these steps might you plan to take if facing dementia?

Chapter 9: Inside a Growing Advocacy

Recall: Barbara details the decades-long process of advocating for the authorization of end-of-life options. What events were most surprising to you? Which story did you find most moving?

Reflect: When did you first become aware of the end-of-life choice movement? How did you hear about it?

Apply: At the end of the chapter Barbara lists multiple ways to get involved with Compassion & Choices. What are some ways you might advocate in your community? Do you have a personal story you plan to formally share?

Chapter 10: Race and Culture Matter

Recall: Throughout this chapter, Barbara discusses her connection to Rev. Dr. Paul Smith and their shared understanding of how attitudes and experiences can subvert the promise of a good death. The history of racial injustice has erected barriers to fully trusting medical providers. History and experience determine how people approach the end of life. Barbara examines the history of inequity and reveals the enormity of the task of moving beyond bias and prejudice. What are some examples of racial inequities and implicit bias, and their impact on healthcare that you remember from this chapter?

Reflect: Barbara explains that, at the end of life, the pattern of underdiagnosis and undertreatment reverses itself. Currently racial and ethnic minorities receive more intensive treatments that can impose great suffering but deliver little value. These communities are less likely to receive the benefit of hospice and palliative care. Can you recall your own personal experience or those of others which might align with this pattern?

Apply: What are the benefits of acknowledging and understanding our own biases? How can tools like the Implicit Association Test be useful? If you have concerns about bias in your relationship with your medical care providers, what can you do? If you are a medical care provider and you have concerns about your own possible bias, what can you do?

Chapter 11: People Taking Control

Recall: Barbara tells the story of multiple experiences, including those of clergy, with individuals at the end of life. Which story provided you the most insight? Did one of these clergy reflect your own faith background?

Reflect: Do you belong to a religious community? If so, has your congregation or group addressed end-of-life care? Do you feel it is important for them to do so?

Apply: Which lessons from Brittany Maynard's story do you feel are important for your own personal advocacy?

Chapter 12: Space for the Sacred

Recall: Barbara shares several examples of individuals incorporating religious beliefs in their plans for intentional dying. She describes rituals at the end of life that may provide peace and closure. What were some of your favorites?

Reflect: Have you ever been a part of a rite or ceremony for an individual at the end of life (before death)? How was the experience different from those occurring after death?

Apply: What are some elements that you would include in your own end-of-life gathering? Can you identify particular readings or songs that you would want shared?

Chapter 13: It's Harder Than You Think (But We Can Do It)

Recall: In this last chapter Barbara gives examples of individuals who have worked to ensure they have planned for their end of life. What tools did they utilize? How did their family members ensure their wishes were honored?

Reflect: As you read this final chapter, how did your reaction to the scenarios presented differ from your reaction after reading the book's first chapters?

Apply: Barbara describes "healthcare consumers" as a powerful group who can create change in the medical system. What are three ways you hope to engage differently with your providers after reading this book?