

Discussion Guide

Introduction

Inspired by decades of experience caring for the dying and years teaching contemplative care around the world, Kirsten DeLeo shares down-to-earth advice and offers short, simple, on the spot tools to help you handle your emotions, deal with difficult relationships, talk about spiritual matters, listen fully, and practice self-care.

Present Through the End shows you how to be present even when we feel utterly helpless, express your love when loss is just around the corner, and be fully alive to each moment as time runs out.

We hope the following topics will further support you in being present with a dying loved one, friend, or patient. We hope they will spark much needed conversations among families, friends, and communities about acknowledging needs and caring well for those in your midst who are dying.

Use them in your book club conversation, caregiver support group meeting, death café, or curriculum.

Questions and Topics for Discussion

1. Before reading *Present Through the End*, how did you view death and dying? How did the book change your attitude and outlook?
2. In the first chapter, the author shares how her grandmother taught her the power of a loving presence.

Did you have a role model in your childhood or adult life to guide you? Tell your story.

3. We can respond in so many ways to the sad news that someone close to us is approaching death. What was your response when you learned the news?

4. In chapter 2, "Preparing to Care," the author shares many on the spot tools that can help handle feelings of helplessness, sadness, or disbelief, and shows how to find a place of calm in order to connect with the dying person.

How did you engage with the practices? Was there a particular practice that helped you?

5. "When we prepare to care, we should remember that a dying person is still a person." We can often forget a dying person is still a person, another human being just like us with hopes and dreams, concerns, and fears. DeLeo introduces two methods to help you connect with the

person you are caring for and understand their behavior and needs: “Seeing the person as another you” and “in another person’s shoes.”

Did these practices shift your perspective? What did you learn about the needs of a dying person?

6. The author shows how being present and listening are essential while accompanying a dying person.

What barriers or difficulties did you come up against around being present and listening? Recall a tool that supported you to stay present.

7. One of the biggest fears dying people have is that their life has been wasted and they will die empty-handed. In chapter 4, “Supporting Connections,” DeLeo offers suggestions for how we can help the person reconnect with their sense of meaning through showing our genuine appreciation of what they have done in their lives and who they are as a person.

How did you support the person in reclaiming their sense of meaning and purpose? What was most helpful? Was there anything that did not work?

8. The book describes denial of death as a coping strategy or a crutch to help the person through this painful time and come to terms with the fact they are dying.

What have you observed? How did the advice shared in the book help you communicate with the person?

9. A dying person’s beliefs impact how they understand what is happening to them and why. In chapter 4, “Supporting Connections,” the author offers tools to help you explore questions around spirituality (secular and religious), belief, and faith with the person.

How did they help you to approach the subject? What gave the person a sense of inner peace?

10. In the same chapter, the author offers questions to help us make a genuine connection. Did you try any of them out? Which of them did you find most helpful, and why?

11. From chapter 5: “In our society, we value autonomy, freedom, and productivity. Experiences of illness and death poignantly show us how temporary and, on a deeper level, how illusory these values are.”

Do you or do you not agree with this statement and why?

12. In chapter 5, in the “Considerations for Advance Health-Care Directives” section, the author offers suggestions on how to explore the dying person’s wishes and values.

How is this information helping you in your preparation for dying? How did it support you in talking with a loved one? Do you have an Advanced Directive or Living Will?

13. Unfinished business and forgiveness can weigh heavily on dying people's minds, but also on the minds of the people around them. In chapter 5, the author tells the stories of Joe, a veteran, and his son, and of the elderly woman and her fifteen-year-old daughter—two stories with two seemingly different outcomes.

If the dying person had regrets or unfinished business, how did the tools offered in the book help you be there for the person and their journey towards embracing forgiveness and finding a resolution?

14. The author shares many stories about being present with dying. Which of the stories do you remember the most and why? What did the book help you discover about life and death, and living and dying?

15. In the book, DeLeo shares sage advice from Buddhist teachers and other contemplative thinkers and poets. What is your favorite poem or words of wisdom in the book? Why does this particular one speak to you?

16. From chapter 5: "Death does not only touch the person who is ill. It touches everyone around that person."

How did you work with family members and friends around supporting the dying person? What was challenging and what was supportive? What advice or tools helped you be present with grieving family members, or navigate family dynamics?

17. From chapter 5: "The best advice for speaking to a child when someone is dying—a beloved grandparent, for example—is to be sensitive but tell the truth. We may think that by not talking about it, we are protecting the child from what's happening. This is not the case. The child will pick up that something is wrong, not understanding why they get shoed out of the room, or why we cry."

What did you learn about supporting children or young adults? Was there a particular piece of advice Kirsten shared that worked for your situation?

18. From chapter 6: "Taking care of ourselves is not a luxury. It is not selfish. It's a must."

What are the warning signs that you need to take a break? What nurtures and recharges you?

19. Referring to studies and research, the author explains the differing natures of empathy and compassion.

Did this understanding help you recognize where you tend to get stuck?

20. Do you have a regular meditation practice or routine that nurtures your sense of wholeness and wellbeing? How can you make meditation part of your daily life? Which of the methods are you most drawn to?

21. From chapter 6: “Grief does not only start when the dying person is gone. It begins with the terminal diagnosis. We grieve for the life that we knew and the loss of the future that will never be. We begin to imagine what life will be like without our loved one.”

DeLeo describes the signs of “anticipatory grief” How did you deal with feelings of grief? How did the advice and practices like ‘Being A Friend to Yourself’ help you create space?

22. From chapter 6: “Dying can be messy. Every so often, while trying your absolute best, you may find yourself in an absurdly ridiculous, if not funny situation in which you cannot help but laugh out loud. With humor, our shared human experience of living and dying becomes more bearable.”

Has this happened to you? Tell your story.

23. From chapter 6: “As caregivers, friends, and family, we also have our work to do. We need to forgive ourselves, and we may also need to work towards forgiveness for the person we are caring for.”

Was there a practice, story, or piece of advice shared in chapter 6 that encouraged you to be more self-forgiving and helped you in the process of forgiving another person?

24. In chapter 7, “When Death Approaches,” DeLeo describes how powerful and profound moments of being with dying can break open our protective shell that separates us from others and how these moments can offer us a glimpse of the power of our compassionate heart.

Take time to reflect on your own experiences.

25. In the same chapter, the author introduces the practice of Tonglen as a method to unblock our compassion. How did you engage in the practice?

26. Saying goodbye to a dying person is one of the hardest things to do. From chapter 7: “Some people may feel that letting go is a betrayal and a sign that they do not love the dying person enough. Invite family members to imagine they are in the place of the one who is dying and have no choice about leaving. How would they want people they love to be saying goodbye to them? What would help them most on their journey?”

Take time to reflect on these questions. What was your process of saying goodbye? How did the advice in the book support you?

27. How did the guide help you communicate and clarify with medical staff and/or family members the wishes for both the moment of death and after death had occurred? Tell your story.

28. From chapter 7: “In the days, weeks, and months that follow the death, be kind to yourself. Grief needs time to heal and much caring attention.”

What helped you to be with your feelings of sadness and grief?

29. From chapter 8: “The process of dying is more than medical events. Being with someone during their final weeks and days is an invitation to enter a sacred space and to bear witness to life’s greatest mystery.”

How did you create a peaceful or sacred environment for the dying person? Are there traditions or rituals within your family or religion that you followed? Did you encounter any barriers in trying to create a peaceful environment? If so, describe how you worked with them.

30. In the section, “Signs That Death Draws Near,” Ann, a palliative care doctor, and Beate, a social worker, discusses the common signs and symptoms of approaching death. Being at the deathbed, what signs and symptoms did you observe? How were they addressed, or not?

31. In the final chapter of her book, the author tells the reader about the gifts of accompanying a dying person. How did you relate to what she described? Can you recall a gift you have received accompanying a dying person?

What are you grateful for right now?