

Dying Well: The Prospect for Growth at the End of Life

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How to Use This Guide

This discussion guide was developed so that Dr. Byock's book, *Dying Well* could be used for study by book clubs and classes. Each session is designed for 1-1/2 hours of discussion. Participants should read the suggested chapters of Dr. Byock's book for each session prior to each session. The questions brought forth in this guide are by no means exhaustive and time should be allotted at the end of each session to discuss any other issues that caused the participants pause as they read the material for each session.

This guide is only a jumping off point for, hopefully, valuable and meaningful discussion on the subject of "Dying Well" and what that means for each individual. It has been my hope that the sharing of views and concerns each time you meet, might dispel some myths surrounding death and dying and cause the participants to open their minds to the possibilities that lie ahead for all of us. For there is one certainty that is universal for all of humanity, and all of creation. That is, that eventually we all will die. But how we go about dying and how we attend to the dying, is still an open-ended venture.

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Session One

Chapter One - "Teaching About Living, Teaching About Dying"

1. Is there anything about Dr. Byock's personal story that sounds familiar to you?
2. Take time to tell personal stories of your own that taught you about dying. What were the hard lessons that your experience taught you?
3. Did your experience change your views about living with dying?
4. If you could do things differently, what things would you have changed?
5. What did you do that you were glad that you did?

Session Two

Chapter Two - "Questioning Assumptions and Dawning Awareness: My Journey"

It might be helpful for this session to have an attorney or social worker speak briefly to the class about Living Wills, Advanced Directives and the Durable Power of Attorney for Health Care. Have copies available for anyone who would like copies.

1. In the second paragraph of this chapter, Dr. Byock states: "the time of my father's dying, especially the last months and weeks, pervaded my thoughts and permeated my dreams. The memories were full of compelling images and poignant vignettes that connected me with a deep, aching sadness. Something about that time was also undeniably precious."(p.25) Have you had an experience similar to his? Share your experiences. What makes them so poignant? What makes these images and memories precious?
2. As Dr. Byock recalled his experience with death on a hospital unit, he asked the question, "I wondered what it was permissible to die from."(p. 27) What do you think he is asking?
3. In your experience, are there more acceptable reasons for dying compared to others? Are there reasons for death that you are more comfortable with than others?
4. Have you discussed your final wishes to those who are close to you? If not, why?
5. What does the expression "dying well" mean to you? What would be a "good death" for you when that time comes?

Session Three

Chapter 3 - "Learning to Die Well: Anne-Marie Wilson"

Dr. Byock states in this chapter: "Medical training is not very helpful for understanding the personal, as opposed to the medical, nature of dying." (p. 35)

1. What do you think he means by a personal nature of dying versus a medical nature of dying?
2. Has it been your experience that his statement is true regarding medical training? Why or why not?
3. What feelings did you have as you read about Anne-Marie's approach and experience with dying?
4. How was the human dimension of dying made available to Anne-Marie?

Session Four

Chapter Four - *"Suffering and Beyond: Douglas Kennedy"*

1. Dr. Byock believes that two kinds of suffering are universally present in the dying, physical suffering and emotional/psychological suffering. Discuss your own experiences with this.
2. What are your beliefs about suffering? Where do they come from?
3. Dr. Byock states in this chapter that "Pain and privation can be endured if it is for a purpose." (p. 83) Do you agree? Why or why not?
4. What was your reaction to Dr. Byock admitting Douglas to a psychiatric unit?

Session Five

Chapter Five - *"Finding Dignity Amid Disease and Disintegration: Wallace Burke, Julia Rosauer, Hap Vischer"*

1. Discuss your views on what gives our life dignity?
2. How does Dr. Byock define dignity? Do you agree with his definition? Why or why not?
3. Talk about how do you think you would feel if you were completely dependent on the care of others.
4. Discuss your reaction to Wallace's decision to stop eating? Would you do the same thing if you were in his situation?

Session Six

Chapter Six - *"The Hardest Decision and the Greatest Opportunities: Janelle Haldeman"*

1. Have you had the experience of being able to reconcile with someone before they died? What was that like for you and how did you know the time was right to do so?
2. Have you ever been in the position of asking yourself the question "Did I do the right thing?" following the death of someone who you were involved in decisions regarding their care? What was your answer? Was there anything you regretted? What were you most at peace with?
3. Do you agree with Dr. Byock's assessment that Janelle's body was "searching for a way to die"? (p. 135) Have you seen this before in those that you cared about who were dying?
4. How did you feel when it was decided to cease all food and hydration for Janelle? Have you had to make this decision for someone that you loved? What was that like?

Sessions Seven and Eight

Chapters Seven and Eight - *"Writing a Personal Script for Dying: Steve Morris" & "Accepting the Gift of Dependence and the Burden of Care: Jake Edwards"*

Have written on newsprint or board before the session the "Five Things of Relationship Completion: "I forgive you"; "Forgive me"; "Thank you"; "I love you"; "Goodbye"

1. How difficult would it be for you to recite the "five things of relationship completion" with someone that you love who is dying? What would prevent you from doing so? (p. 140)
2. Have you had an opportunity to do this? Share your experience with the class if you feel comfortable doing so.
3. Dr. Byock states in Chapter Seven: "One key to living well lies in expressing the essence of 'the five things' in our daily interactions with those we love." (p. 158) He seems to be suggesting that we don't have to wait until someone is dying to go about the business of "relationship completion". Have the class write down on a piece of paper the following: A person or persons they need to forgive. A person or persons from which they need to ask for forgiveness. A person or persons to which they need to say

"thank you". A person or persons to which they need to say "I love you." Someone that they might know who is dying that they need to say all of the above as well as "Goodbye".

4. Why do you think it might be important to those left behind to be able to feel that their relationship to the person who has died is completed before they died?
5. Do you have a relationship that you were unable to complete before they died? What has that been like for you?
6. Talk about possible ways to complete a relationship even though the person has died.

Session Nine

Chapters Nine and Ten - "*Growing with Tragedy: Michael Merseal*" & "*Facing Unbearable Pain, Unspeakable Losses: Terry Matthews*"

1. Once again, in the story of Michael, we are faced with the decision to cease food and hydration, except this time it is with a small child. Does this fact make a difference in how you feel about the issue of withholding food and hydration from a dying person? Why or why not?
2. In both the story of Michael and the story of Terry decisions were made to administer enough sedation to bring a state of unconsciousness and possibly hasten death. How do you feel about this?
3. Have you been faced with the same or similar decisions? Share your experiences.
4. Once the IV sedation was started on Terry and her pain ceased, causing her to fall into a deep sleep, Terry's Aunt Clarise and her sister-in-law, Candy bathed and shampooed her, gave her a pedicure and dressed her in a T-shirt that they felt she'd like to be seen in. Discuss your reactions to these ministrations.
5. In describing Terry's dying, Dr. Byock stated that "In her dying, Terry served her family." (p. 213) Discuss your understanding of this statement.

Session Ten

Chapter Eleven - "*Letting Go, Growing On: Maureen Riley*"

1. In response to Dr. Byock's inquiry regarding Mo's understanding of the time she had left, Mo responded: "I'm a bit disappointed that I'm still alive or not sicker...When I found out about this astrocytoma, I was glad it was this great big tumor rather than some dinky little polyp that was going to get me." (p. 224) What was your reaction to Mo's statement? Did it make you uncomfortable or did you understand?
2. If you were Mo's friend and she made the above statement to you, what would be your response to her?
3. Discuss your reaction to Dr. Byock telling Mo that if her symptoms began to affect the quality of her life, she could choose to stop the medication that was controlling the swelling of the tumor, thereby hastening her death?
4. Mo's children seemed to be almost pragmatic in their reaction to Mo's dying and to her. How did you feel about this?
5. How do you feel about Dr. Byock's suggestion to Mo that she needed to allow her children to care for her for their own sakes? Discuss your reactions.
6. Talk with each other about your understanding of how Mo experienced "Letting go, Growing on" in her dying.

Session Eleven and Twelve

Chapter Twelve - "*Getting There From Here: Social and Cultural Dimensions*"

1. Where have your beliefs and reactions around the issue of dying come from?
2. It has been said that in this postmodern age we seem to view death as an option not a certainty. Do you think this is a true statement? Why or why not?

3. Dr. Byock writes in Chapter Twelve: "To be terminally ill or elderly in America today is to be reminded frequently that you are a drain on the nation's resources." (p. 242) In your experience, do you believe that this statement is true? Why or why not?
4. Discuss the following statement of belief by Dr. Byock: "I believe that the root cause underlying the mistreatment and needless misery of the dying is that America, as a culture, has no positive vision and no sense of direction with regard to life's end." (p. 244)
5. Do you believe as Dr. Byock that we mistreat and cause "needless misery" on the dying? Why or why not?
6. What can we do to make it better?
7. Have your views, beliefs and ideas regarding dying changed as a result of reading this book and the discussion of it? How?
8. If you were dying at this moment, how comforting would it be to hear the following words of promise as stated by Dr. Byock: "We will keep you warm and we will keep you dry. We will keep you clean. We will help you with elimination, with your bowels and your bladder function. We will always offer you food and fluid. We will be with you. We will bear witness to your pain and your sorrows, your disappointments and your triumphs; we will listen to the stories of your life and will remember the story of your passing." (p. 247)

Dying Well: Peace and Possibilities at the End of Life. ISBN. 0786211237 (ISBN13: 9780786211234). Through the stories of the patients, families and those that are dying that can learn to deal with doctors, how to talk to friends and relatives, and how to make the time towards the end of life meaningful. I chose this book because I am now in palliative care for metastatic breast cancer; I'm not at that point yet where I need hospice care, but learning as much as I can about the death and dying process helps me to fear it less. I have learned something from every family that I read about in this book. It's a comfort to know that there are things that can be done to ease suffering, Dying well: The prospect for growth at the end of life. New York, NY: Riverhead/Putnam Books, 1997. The Four Things That Matter Most: A book about living (2nd ed.). Heffner J. & I. Byock (eds). Palliative and end of life pearls. Philadelphia, PA: Hanley & Belfus, 2002. Staton J, Shuy R, Byock I. A few months to live: Different paths to life's end.