



Happy Endings: Dying with Dignity
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Writing Your Own Story

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Topics to be Covered

“To be what we are, and to become what we are capable of becoming, is the only end of life.” - Robert Louis Stevenson

“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.”

- Ira Byok, M.D.

- ⇒ **Telling Your Own Story**
- ⇒ My Story (Oral Histories)
- ⇒ My Story (Written Histories)
- ⇒ My Story (Technology)
- ⇒ My Story (Genealogy)

Beginning the Conversation

- ⇒ Barriers to Happy Endings
- ⇒ Opportunities for Exploring End of Life Discussions
- ⇒ Applications: Case Studies

Materials Needed

- ◆ PowerPoint Presentation “Writing Your Own Story” (Included)
- ◆ Computer and Projector (for *optional* PowerPoint Presentation)

Objectives

Learning Objectives

- Participants will be able to identify how to tell and write the story of their life and family history.
- Participants will be able to identify some of the potential barriers to ending life happily such as taboos, information asymmetry, illness, and support.
- Participants will be able to identify opportunities for exploring and communicating about end of life issues.

Behavioral Objectives

- Participants will begin telling and writing their own oral and family history.
- Participants will practice strategies for breaking down potential barriers to ending life happily.
- Participants will be able to communicate their desires and wishes regarding end of life issues through using effective communication strategies.

Background Information

INTRODUCTION

How will I be remembered? This question becomes most poignant when our lives begin to wind down and we approach the inevitability of death. How we choose to answer this question, and it is a choice for most of us, will boil down to our perceptions of the life we have lived and whether or not we are prepared to exit mortality on our own terms. Making intentional choices about how to write our own story is the most important way we can choose a happy ending. It is never too early to begin discussing our desires with our loved ones and to plan for the inevitable. It doesn't matter how healthy we are now or how much money we have, planning for the unexpected future is something all of us need to do. Although talking about our future may sometimes be uncomfortable, it is a conversation we need to have to make sure our wishes, or the wishes of our loved ones, are carried out. The death of a loved one can be a stressful event. Knowing what to anticipate ahead of time can better prepare us to negotiate the many decisions that will need to be made. It is important that we evaluate how we want our story to end and how we want it to be told so our memory and legacy live on. With this in mind, take a few minutes and think about the following questions:

- How do I want my story to end?
- How do I want my story to be told? Who will tell my story? How will my story live on?
- What do I want my children's children to remember about me?
- What are some of the potential barriers that could keep me from experiencing a happy ending? What can I do to overcome these barriers?
- What opportunities exist to make sure I and my loved ones die well?
- How can I ensure that my family relationships are strengthened and not harmed by my end of life decisions?
- What social, legal, and financial decisions need to be made so that I and my loved ones can experience a happy ending?

GET PREPARED

First and foremost, you will want to make sure you evaluate how you want your story to be told. You have a lot of control about how you will be remembered to family, friends, and future generations.

COMMUNICATE YOUR WISHES

Next, communicate with your loved ones and explore with them how you want your story to be told. Will your story use metaphors such as cars you have owned, trips you have taken, or foods you are famously known for preparing and serving as a way to tell your story? Will your personality traits or love for life and learning set the stage for how you will tell your story? When you decide how your story will be told, then you will need to decide how you would like your story to be recorded and distributed.

Telling Your Own Story

THE BOOK ABOUT MYSELF

You have an excellent opportunity to shape and influence how your story (and those of your loved ones) will be told—how you want to be remembered. Being proactive and intentional about how you will tell your story, in spite of some of the barriers you will face, are strategic keys to making sure your story will result in a happy ending. In this lesson we will focus on principles and practices associated with telling your social story like you want it to be told.

MY STORY (ORAL HISTORIES)

Oral histories are recorded verbal accounts of current and past events and experiences. Dr. Paul Ortiz (n.d.) has identified 8 Steps to successfully conducting and completing an oral history interview:

1. STARTING AN ORAL HISTORY

PROJECT: This step includes making decisions about the scope, goals, and themes of the interview, who will conduct the interview, and what the overall desired outcomes will be.

2. PERSONAL AND/OR INSTITUTIONAL

MOTIVATIONS: This step includes answering questions about why the interview needs to be conducted and who will ultimately benefit from the interview.

3. LAYING THE GROUNDWORK: This step includes brainstorming about contacts that need to be made, making these contacts,

and discussing the interview with the interviewee (s).

4. INTERVIEW PREPARATION AND

BACKGROUND RESEARCH: This step includes creating the actual interview questions and scheduling the interview.

5. EQUIPMENT YOU ARE GOING TO USE:

This step includes identifying the technology that will be used to record the interview (e.g., digital recording devices). Bringing a notepad to the interview is also suggested.

6. CONDUCTING THE INTERVIEW: This

step includes signing any release forms, if needed, recording the interview, listening, empathizing, being gracious, sharing memories, taking notes, and being flexible enough to let the discussion guide the introduction of further questions to be asked.

7. THINKING ABOUT THE FINAL

PRODUCT: This step includes transcribing and indexing the interview and checking with the interviewee to make sure what was recorded and transcribed is correct.

8. PERMANENT ACCESS FOR FUTURE GENERATIONS AND COMMUNITIES:

This step includes deciding who will receive copies of the oral history, where the original will be stored, and making sure notes and documentation are all in order.

(Adapted from P. Ortiz, (n.d.). Beginning an Oral History Project: Retrieved December 11, 2013 from: <http://oral.history.ufl.edu/research/tutorials/>)

Telling Your Own Story

MY STORY (WRITTEN HISTORIES)

Written histories are printed accounts of recorded events and experiences. Written histories can include journals, scrapbooks, books, articles, blogs, emails, Facebook posts, tweets, and much more. Several tips for recording written histories include: (1) recording information regularly; (2) including all dates, full names, and other contextual information; (3) sharing personal stories, insights, quotes, dreams, memories, successes, trials, and other information that show the reader what is in your mind and heart and who you are as a person; and, (4) asking yourself what your family, friends, and children's children might find interesting and helpful. Questions that can be asked to prompt memories include: "What are your fondest memories?"; "What games and activities did you and your family like to participate in?"; Who was your favorite teacher growing up and why?" (Adapted from: Family Search (n.d.). Write a personal history; Appendix A. Retrieved December 11, 2013 from: https://familysearch.org/learn/wiki/en/Write_a_Personal_History)

Complete Section 1 of the Activity Document.

MY STORY (TECHNOLOGY)

Journals, records of personal milestones (e.g., awards, recognitions), electronic recordings, oral histories, online photo books, email chains, scrapbooks, personal narratives, life

highlights and memoirs can all be created and stored in electronic devices such as a personal computer or online through a number of different hosting services. (Ibid.)

MY STORY (GENEALOGY)

There are multiple websites and other resources you can use to compile your family history. These sites allow you to add stories, pictures, and events and provide tutorials for getting started. Some genealogy sites are free (see familysearch.org) and some are available for a fee (see ancestry.com).

BEGINNING THE CONVERSATION

The key to telling your story is to begin the conversation with those who can best help you tell it in a way that you want it to be told. Developing an awareness of the potential barriers and opportunities communicating about end of life issues could create is an important first step to constructing a happy ending.

BARRIERS to HAPPY ENDINGS

THE LIFE REVIEW: It is normal and natural as we age to begin thinking about past events and experiences to seek to find peace in our successes and to ruminate about our mistakes. Shaming ourselves by questioning our core character is never constructive.

However, disappointment and guilt can lead to some constructive outcomes when we do what we can to rectify our mistakes, overcome our weaknesses, and make amends

Wealth Concerns (continued)

with those we might have neglected or offended.

OPPORTUNITIES for HAPPY ENDINGS

EXPLORE YOUR LEGACY: Your ability to communicate and to communicate your wishes will largely determine how you will be remembered.

FIVE RELATIONSHIP KEYS TO DYING WELL:

Dying involves both physical and psychological (mental and emotional) pain for most people. Seeking relief from the physical pain can often be addressed through medications and modern medicine. The psychological pain occurs out of a desire to hold on to life, a realization that loved ones will be missed, and remorse about relationships that may have been left undone or unhealed. Dr. Ira Byok M.D., has suggested five key tasks that need to be considered in order to achieve what he calls “relationship completion”: (1) A person or persons we need to forgive; (2) A person or persons we need to seek forgiveness from; (3) A person or persons we need to say “thank you” to; (4) A person or persons we need to say “I love you” to; and, (5) A person or persons we need to say “goodbye” to. Interestingly, Dr. Byok also suggests that the same five tasks also apply to those who are seeking to “live well.” (Adapted from: Byok, I. (1997). *Dying well: The prospect of growth at the end of life*. New York: Putnam/Riverhead.)

Take several minutes and complete Section 2 of the Activity Document.

OPEN COMMUNICATION CHANNELS: Seeking to live and die well through practicing “relationship completion” can be used as a way to open up communication channels and discuss end of life issues and wishes. Consider the following:

- Have you discussed your end of life desires with loved ones?
- 60% of people say that making sure their family is not burdened by tough decisions is “extremely important”
- 56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)

- Where would you prefer to die?
- 70% of people say they prefer to die at home
- 70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)

- When you become seriously/terminally ill, who would you talk to first?
- 80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care
- 7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)

- Have you communicated your end of life

Optional Activities

wishes to your loved ones?

- 82% of people say it's important to put their wishes in writing
- 23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

(Adapted from: The Conversation Project and Institute for Healthcare Improvement (n.d.).

Your conversation starter kit. Retrieved December 14, 2013 from

<http://theconversationproject.org/wp-content/uploads/2013/01/TCP-StarterKit.pdf>

- Go to the website listed above and review the Four Steps to opening the conversation. (Note: Feel free to print out the document and to include it as an alternative activity).
- Initiate the discussion (opposite page) using the Discussion Prompts.

DISCUSSION PROMPTS

- If you feel comfortable discussing with the group, has anyone ever had to make an important life decision regarding the healthcare of a terminally-ill loved one?
- If you feel comfortable discussing with the group, has anyone here faced a situation where they did not know their loved one's final wishes? If so, please explain.
- If you feel comfortable discussing with the group, has anyone here discussed these topics with their loved ones or know of someone who has?
- What do you believe would hinder this type of discussion among families? What do you believe would help facilitate it?

APPLICATION: CASE STUDIES

- Share or elicit example case studies.

Optional Activities

Writing Your Own Story Activity Document

- Section 1: How do I think I will be remembered?
How do I want to be remembered?
List some details about who you are (how you got your name, favorites: foods, activities, hobbies, books, quotes, movies, music, people, friends).
List some brief details of your favorite experiences and memories growing up (places lived, vacations, relationships with mom, dad, siblings, aunts, uncles, grandmas, grandpas, cousins, awards, successes, joys).
- Section 2: Who do I need to forgive?
Who do I need to seek forgiveness from?
Who do I need to say "thank you" to?
Who do I need to say "I love you" to?
Who do I need to say "goodbye" to?

Take Home Messages

NOTES

Writing your own story will help you tell your story the way you want it to be told.

Communicating your wishes with your loved ones will help to ensure that your wishes are carried out according to your preferences and values.

Communicating your wishes with your loved ones will help reduce stress for your loved ones at the time of your passing.

References

- Byok, I. (1997). *Dying well: The prospect of growth at the end of life*. New York: Putnam/Riverhead.
- Family Search (n.d.). Write a personal history; Appendix A. Online: https://familysearch.org/learn/wiki/en/Write_a_Personal_History
- Harris, V.W. (2012). *Nine important communication skills for every relationship*. Online: <http://edis.ifas.ufl.edu/fy1277>.
- Harris, V.W. (2012). *Ten rules for constructive conflict*. Online: <http://edis.ifas.ufl.edu/fy1276>.
- The Conversation Project and Institute for Healthcare Improvement (n.d.). Your conversation starter kit. Online: <http://theconversationproject.org/wp-content/uploads/2013/01/TCP-StarterKit.pdf>

Additional Resources (in order of mention)

Aging with Dignity: 5 Wishes Document.

Retrieved From: <http://www.agingwithdignity.org/five-wishes.php>

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