End of Life Preparation for Humanists

The role of the Celebrant is to be there for people during life's passages. Baby naming ceremonies and weddings are usually happy occasions. Dying is sometimes not a happy passage of life. For this reason, the Celebrant must be especially prepared to accompany people on this life passage.

People deal with the end of life as variously and individually as they have lived their lives. Many people are very matter of fact in the face of death, settling their accounts and getting their affairs in order. Others refuse to give up hope, even after all medical options are gone, refusing to consider death as the next step.

This course introduces Humanist Celebrants to the process of working with families as a loved one approaches the end of their life. This course discusses events leading up to the end of life, **our Humanist Memorial Service course discusses the actual planning of the service.**

by Rev. Dr. David Breeden

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Master of Divinity from Meadville Lombard Theological School. Prior to joining at First Unitarian, Breeden was the first settled minister at the Minnesota Valley Unitarian Universalist Fellowship in Bloomington, MN.

Introduction

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As a leader of a congregation, I am able to develop long-term relationships with members, so I have many of the last wishes written down and in readily accessible files. This is the ideal situation. Unfortunately, this is not always the case. Many humanists seldom–or never–join groups. Expect "cold calls" from people who have just gotten the bad news of a fatal illness or from families who have just lost a loved one and are at a loss concerning what to do next.

What to do? The humanist Celebrant's task is threefold: comfort, console, assess: Comfort the dying person. Console the loved ones. Assess the situation and see what needs to be done next.

Comfort. Console. Assess.

Assess how ready a dying person is for discussion of palliative care; hospice; the arrangements for a memorial service; and the daunting personal and business arrangements required at the time of death.

But don't forget comforting and consoling; merely being there as a non-anxious presence is often the most important work.

Assess the Distress

First, ask questions to assess the level of distress of both the dying person and loved ones. A death in old age can be very different from the death of a younger person from disease or accident. Is the family in shock?

Do all the family members have the same religious viewpoint (ideally humanist!) If not, what are the convictions of the dying person? How much anxiety is produced in the family by the differing viewpoints?

In all eventualities, your first duty is comforting the dying person. Avoid being triangulated into longstanding family debates on religion.

Assess: What does the dying person want? For example, some people "stay alive" (or hope to) for a particular life event–a graduation, a wedding, an anniversary, turning 90 or hundred. The wishes vary, but the desire informs decisions.

Also remember: there are many "hospice graduates." Medicine is an imprecise discipline and the human will is an amazing force. Staring over the precipice of death and then pulling, or being pulled back, can produce very complex and stressful emotions for both the dying person and the family.

Hospice

Hospice care is a type of care and philosophy of care that focuses on the palliation of chronically ill, terminally ill or seriously ill patient's pain and symptoms, and attending to their emotional and spiritual needs. In Western society, the concept of hospice has been evolving in Europe since the 11th century. Then, and for centuries thereafter in Roman Catholic tradition, hospices were places of hospitality for the sick, wounded, or dying, as well as those for travelers and pilgrims. The modern concept of hospice includes palliative care for the incurably ill given in such institutions as hospitals or nursing homes, but also care provided to those who would rather spend their last months and days of life in their own homes. It began to emerge in the 17th century, but many of the foundational principles by which modern hospice services operate were pioneered in the 1950s by Dame Cicely Saunders.

Wikipedia

Flashback! The Icy Hand of Death

Most people living in North American or Western Europe have seen very little of death. Perhaps you were with a loved one who died, but more likely you left the hospital and waited by the phone. We leave death to the professionals.

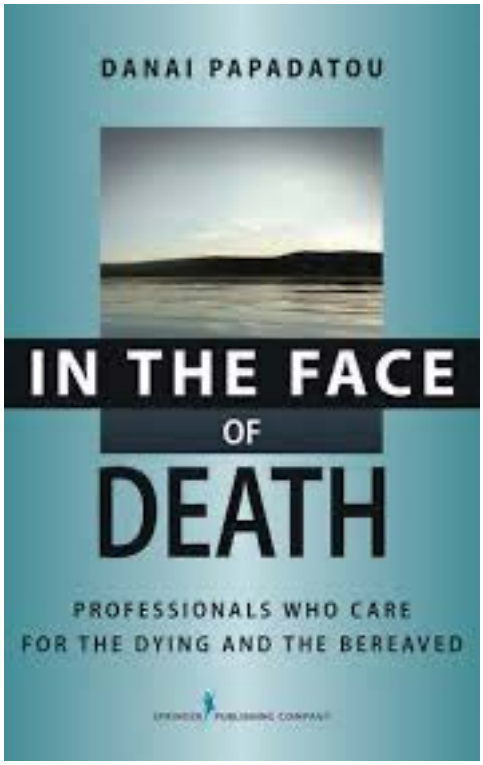
So: now you are a professional. But your heart is beating fast and your feet tell you to run…

Stop. Think: why is the situation stressful for you? Most likely it is a little bit of two emotions: fear of the unknown and a reminder of mortality, whether that be your own mortality, the mortality of those you care about, or a memory of the death of a loved one. That's natural! Take a few deep breaths. Remember that "non-anxious presence" that people need? That's you! And, yes, death comes to us all. It's a natural process, even if it isn't our favorite natural process.

What do you think of death? What do you think of your inevitable death? These are the big questions. We all do well to dwell on them and come to terms with them.

Deep breaths. Non-anxious presence.

In The Face of Death



In the Face of Death explores the experiences of health care professionals who care for the seriously ill, the dying and bereaved patients. In this book, Danai Papadatou offers a practical approach to caregiving, as well as breadth and depth of insight into both the patient's and the caregiver's responses to death.

The author discusses the issues and challenges health care professionals face when treating dying and bereaved patients. Topics include: compassion fatigue, the inevitability of suffering and the potential for growth, suffering in the workplace, team functioning in death situations, and team resilience.

Springer Publishing Company

Am I In Over My Head?

Death can bring out the worst in people. Families that have been dysfunctional for years suddenly find themselves in a tiny room. Sibling rivalries reignite. Second, third, and fourth marriages get rehashed. New spouses appear. And then there is money.

I once worked with a man whose wife was the same age as his children. The man had a lot of money. The children suspected not only that the new wife was plotting to get all the money, but that also she was trying to speed up the man's demise. Yes, death can be the stuff of TV movies. What do you do?

Find resources! Hospitals and hospices have resources. Even though a situation may be new to you, chances are the hospice and hospital staff, including physicians, nurses, therapists, and chaplains, have heard it before.

Focus on the dying person. Talk to the nurses and doctors. Talk with the family separately, if possible. If you see that you are in way over your head, recommend a professional–perhaps a psychiatrist or therapist; perhaps a mediator; perhaps a lawyer. When you are in over your head, admit it and start swimming.

Articles: Family Dynamics and the Dying Parenting

Family Feud: When Siblings Clash about a Parent's Care by Jeff Anderson

[The Impact of Late-Life Parental Death on Adult Sibling Relationships by Dmitry Khodyakov and Deborah Carr]

[Till Death (of Our Parents) Do Us Part by Avidan Milesvsky, PhD]

[How to Handle Family Dynamics Around a Dying Loved One by Judith Johnson]

[Surprising Twists In Family Dynamics As the Years Pass Along by Derek Alger]

[Family Reorganization After a Loss by Therese Rando, PhD]

Know The Ropes

As mentioned earlier, if you are just getting acquainted with the dying person or if you have few or no plans on file, the situation can be a bit tense and stressful. First, deal with any immediate trauma and assess how comfortable the dying person is in the situation. Then, discuss arrangements for the end.

Start with the immediate needs of the dying person: find out if he or she has a living will or advance directive. Often people have written these, but the family and the medical staff have no idea that they exist. Find out. Get the information to the medical staff as quickly as possible and acquaint the family with the wishes.

If need be, hospitals have these papers available and they can be filled out quickly.

Ask: does someone besides the dying person have Power of Attorney (POA)? If not, who should undertake the roll when the dying person is no longer able to fulfill that role. This is not an "if" question–it is a when question.

After ascertaining Power of Attorney, the next crucial question is how much medical intervention the dying person wishes to have. Some of this information will be in the living will. The best policy is to discuss it again anyway. Discuss intubation, often used as a last resort, and a procedure that the dying person or the person with Power of Attorney will have to sign a release form for. Be clear: intubation can be useful in getting a person through a few tough hours. It can also prolong life long after the quality of that life is gone. Intubation is a crucial discussion.

Next, discuss CPR and advanced cardiac life support (ACLS). These procedures can prolong a life but sometimes the resulting trauma is not worth it. If the person is frail, bones can be broken.

After answering the questions, the Celebrant may offer a Do Not Resuscitate (DNR) order, sometimes also call a No Code (hospital jargon that says "do not call in a Code Blue). In some states, the DNR is turned into a positive statement, AND, meaning "allow natural death."

Where are other important papers, identification cards, and credit cards? The family will need to know.

How many death certificates should the family order? It depends. If the loved one had such things as a house, a car, and the "average" number of bank accounts and certificates of deposit, fifteen to twenty death certificates should be enough. For investors or automobile collectors, the number could be far higher.

Does the dying person wish to be cremated? Know the creation options in your area. Or does the dying person wish to have his or her body donated to science (this requires paperwork that is available at the hospital). If the dying person desires a "casket funeral," know what the options are.

Does the person have a place in mind for the memorial service? Does the dying person have a burial site in mind, perhaps even purchased? How about the ashes after cremation? Spreading ashes looks dramatic in the movies, but often there are local regulations concerning where and how ashes can be spread or buried.

What might be a fitting memorial or marker for the person? The list can vary, from trees to benches to witty sayings carved in stone.

NOTE: Some humanists choose to exit life in the face of debilitating diseases. It is imperative for the Celebrant to know the laws of the state. These vary widely. For more information, the best resource is Final Exit Network.

What are Advanced Directives?

A living will allows one to document wishes concerning medical treatments at the end of life.

Before a living will can guide medical decision-making two physicians must certify:

The person is unable to make medical decisions, they are in the medical condition specified in the state's living will law (such as "terminal illness or "permanent unconsciousness"), and other requirements also may apply, depending on the state.

A medical power of attorney (or healthcare proxy) allows one to appoint a trusted person as healthcare agent (or surrogate decision maker), who is authorized to make medical decision on the persons behalf.

Before a medical power of attorney goes into effect a person's physician must conclude that they are unable to make their own medical decisions. In addition:

If a person regains the ability to make decisions, the agent cannot continue to act on the person's behalf. Many states have additional requirements that apply only to decision about life-sustaining medical treatments. For example, before your agent can refuse a life-sustaining treatment on a person's behalf, a second physician may have to confirm the doctor's assessment that they are incapable of making treatment decisions.

What Else Does One Need to Know?

Advance directives are legally valid throughout the United States. While one does not need a lawyer to fill out an advance directive, an advance directive becomes legally valid as soon as you sign it in front the required witness.

Emergency medical technicians cannot honor living wills or medical powers of attorney. Once emergency personnel have been called, they must do what is necessary to stabilize a person for transfer to a hospital.

One state's advance directive does not always work in another state. Some states do honor advance directives from another state; others will honor out-of-state advance directives as long as they are similar to the states own law; and some states do not have an answer to this question.

Advance directives do not expire.

One should review advance directive periodically to ensure that they still reflect one's wishes. *Caring Connections*

Sit Down and Breathe

After the above and important paperwork is in hand, the next thing is to return focus on the dying person and the loved ones around you. Remember: comfort and console. Does anyone look particularly agitated?

Might there be a reading that would help? I always have a book of poetry close by when I visit people who are dying.

Check out your own feeling. How stress are you? Can you articulate to yourself the reason for the stress? Sure, it's hard to deal with mortality. Yet, to repeat, it is a natural part of living. Where is the stress– or perhaps anxiety–coming from? Take a breath!

Loved ones may be experience pre-grief, also called anticipatory grief. That is, many people imagine the dying person as already dead and "try on" the feelings that they anticipate they will have. This is a natural human response, of course, but naming the phenomenon and talking about it can help people immensely. Mention the naturalness of death. Mention the naturalness of

grief. Then point out that now, in this moment, the loved one is not dead. Instead of exploring pre-grief, are there things that need to be discussed? What do you really, really want to say before you part?

Over-exercised pre-grieving can lead to the paradoxical response of "I'm so happy that's over!" after a loved one dies. This response often leads to quilt for having had the response. This cycle can be avoided or lessened by a frank discussion of what pre-grief is and the gentle suggestion that living in the moment is often our best method for keeping our psyches in healthy working order.

Again, Celebrants do well to focus on just how natural all these rampant emotions are. We hope to defuse the bad and accentuate the good.

Remember that many people have never watched a death. Loved ones may feel very awkward. Do what you can to normalize the situation. Perhaps suggest holding the dying person's hand or talking with the dying person, even if he or she is unresponsive.

Stages of Grief

Denial -As the reality of loss is hard to face, one of the first reactions to follow the loss is Denial. What this means is that the person is trying to shut out the reality or magnitude of his/her situation, and begins to develop a false, preferable reality.

Anger -"Why me? It's not fair!"; "How can this happen to me?"; "Who is to blame?" Once in the second stage, the individual recognizes that denial cannot continue. Because of anger, the person is very difficult to care for due to misplaced feels of rage and envy.

Bargaining -"I'll do anything for a few more years"; "I will give my life savings if…" The third stage involves the hope that the individual can somehow undo or avoid a cause of grief.

Depression -"I'm sad, why bother with anything?"; "I'm going to die soon so what's the point?; "I missed my loved one, why go on?" During the fourth stage, the grieving person begins to understand the certainty of death. Much like the existential concept of *The Void*, the idea of living becomes pointless.

Acceptance -"It's going to be okay"; "I can't fight it, I may as well prepare for it" In this last stage, individuals begin to come to terms with their mortality or inevitable future, or that a loved one, or other tragic event. This stage varies according to the person's situation.

Kubler-Ross model Wikipedia

Stepping Away

The fact is that death can take a very long time, even when the person is actively dying. Celebrants often must remind loved ones to take care of their own needs.

Also, those who have attended many deaths report an odd phenomenon: often a dying person will not release life while loved ones are in the room. I often invite loved ones to take a break and go get refreshments. The dying person often lets go just after loved ones have left the room.

Deathbed (and post-deathbed) Conversions

Most hospices and hospitals employ chaplains. Most of these are well-versed in religious diversity and respectful of it. However, there are some chaplains or visiting ministers who can be unscrupulous, attempting to foist a particular religious view on a person who is weakened and worried. It is good policy to pay a visit to the chaplains, tell them who you are, and who you are working with. Say it loud and proud: “We’re both humanists by the way.”

Celebrants sometimes hear “Mom was a what?” And the inevitable follow-up, “Clearly she was confused at the end, because she raised me…Methodist, Baptist, Catholic…” the list goes on.

Unfortunately, Celebrants are sometimes faced with the task of standing up for the principles of a dying or newly-departed person. In the face of hostility to humanist convictions, tact sometimes help. Sometimes a file with clearly written and signed documents concerning final wishes carry the day.

Sometimes after the death, however, Celebrants just have to walk away from the wrath of an overzealous loved one. Twice in my ministry I have had to acquiesce to the wishes of the children of departed humanists to convert mom or dad after death into the perfect Christian. In those cases I walked away and we planned our own memorial service, without the families, in our own congregation.

Unfortunately in these cases, Power of Attorney wins.

Thomas Paine's Rights of Man: A Biography

Paine's closing years, pitiful as they were, contained one closing triumph. He might have become a scarecrow-like figure. He might have been forced to subsist on the charity of friends. He might have been denied the right to vote by a bullying official, when presenting himself at the polling station, on the grounds that the author of Common Sense was not a true American. But as the buzzards began to circle, he rallied one more time. It was widely believed by the devout of those days that unbelievers would scream for a priest when their own death-beds loomed. Why this was thought to be valuable propaganda it is impossible to say. Surely the sobbing of human creature in extremis is testimony not worth having, as well as testimony extracted by the most contemptible means? Boswell had been to visit David Hume under these conditions, because he had been reluctant to believe that the stoicism of the the old philosophy would hold up, and as a result we have one excellent account of the refusal of the intelligence to yield to such moral blackmail. Our other account comes from those who attended Paine. Dying in ulcerated agony, he was imposed upon by two Presbyterian ministers who pushed past his housekeeper and urged him to avoid damnation by accepting Jesus Christ. "Let me have none of your Popish stuff," Paine responded. "Get away with you, good morning, good morning." The same demand was made of him as his eyes were closing. "Do you wish to believe that Jesus Christ is the son of God?" He answered quite distinctly: "I have no wish to believe on that subject." Thus he expired with his reason, and his rights, both still staunchly defended until the very last.

Open Culture. Christopher Hitchens: No Deathbed Conversion for Me, Thanks, But it was Good of You to Ask

Plan, Plan, Plan

Recently I got an interesting request. A man wanted me to meet with him and his two sisters in my office. He had been diagnosed with a fatal illness and was soon to go into hospice care. What he wanted from me was an open and frank discussion of his beliefs and his final wishes in the presence of his sisters. He knew they were Christian to the core and would want a Christian funeral. So, he sat down in and drew up a humanist memorial service instead.

After the man had died, the two sisters honored his wishes, despite their reservations. It was a beautiful memorial service.

That's the takeaway for Celebrants: plan if you can. Punt if you must. Comfort. Console. Assess. We humanists are a small and misunderstood group, misunderstood often even by those we love. The death process can be daunting for all involved. The humanist Celebrant can make this final journey much easier: go into the situation with compassion…and a plan.

Resources: Supportive Organizations

Final Exit Network

Guiding Principles: We hold that mentally competent adults who suffer from a fatal or irreversible physical illness, from intractable physical pain, or from a constellation of chronic, progressive physical disabilities have a basic human right to choose to end their lives when they judge the quality of their life to be unacceptable.

This right by its nature implies that the ending of one's life is one's choice, including the timing and persons present, and should be free of any restrictions by the law, clergy, medical profession, and even friends and relative no matter how well-intentioned. We do not encourage anyone to end their life, are opposed to anyone's

encouraging another to end his life, do not provide the means to do so, and do not assist in a person's death.

Mission

- *To work toward obtaining the basic human right of competent adults to choose to end lives on their own terms when they suffer from irreversible physical illness, intractable pain, or constellation of chronic, progressive physical disabilities.*
- *To raise awareness of all American concern this basic human right.*
- *To offer free service to all who quality, providing relevant information, home visits if possible an da compassionate presence for individual and family.*
- *To promote the use of advance directives an dother related legal instruments to document the intentions of any individual.*
- *To sponsor research into new peaceful and reliable methods to end life.*
- *To vigorously defend our guiding principles in a court of law when necessary.*

Grow House, Inc.

Mission: Grow House, Inc. provides education about life-threatening illness and end of life care. Our primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Our search engine gives you access to the Internet's most comprehensive collection of reviewed resources of end-of-life care.

Dying Matters

"Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

The website offers a wide range of resources to help people start conversations about dying, death and bereavement. These have been a great success: to date, we have distributed more than 750,000 different items, from DVDs, posters and leaflets

through to pens, postcards and balloons. A host of different organization including hospices, hospitals, care homes, community centers, financial advisors and funeral directors have all used them to successfully raise awareness in there are.

Caring Connections

Compassion & Choices is the leading nonprofit organization committed to helping everyone have the best death possible. We offer free consultation, planning resources, referrals and guidance, and across the nation we work to protect and expand options at the end of life.

For over thirty years we have reduced people's suffering and given them some control in their final days – even when injury or illness takes their voice. We are experts in what it takes to die well.

Compassion & Choices works with individuals and allied organizations throughout America to:

1. *Make aid in dying an open, legitimate option recognized throughout the medical field and permitted in more states.*
2. *Increase patient control and reduce unwanted interventions at the end of life.*
3. *Pass additional laws ensuring full information and access to all end-of-life care options.*
4. *Normalize accurate, unbiased language throughout the end-of-life choice discussion ("aid in dying" instead of "assisted suicide").*
5. *Establish aid in dying as a prime motivator in voter decision-making.*
6. *Support the expansion of the end-of-life choice movement and exert a leadership role in it.*

Hospice Foundation of America

National Funeral Directors Association

National Hospice and Palliative Care Organization

American Psychological Association

Prepare

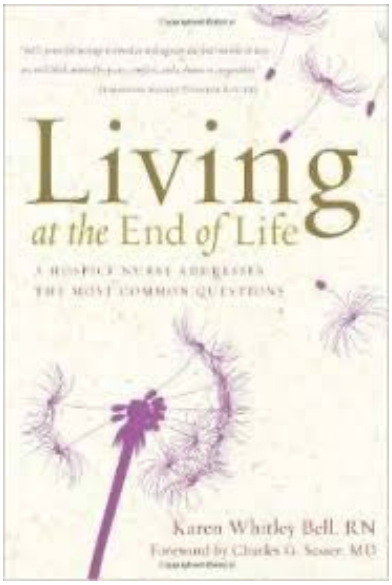
Encyclopedia of Psychology: Death and Dying

About.com: Grief Support Groups, Resources & Information

University of Minnesota Libraries: Death and Drying Resources; Concepts, attitudes, ethics, and lifestyle management related to dying, death, grief, and bereavement. Emphasizes intervention and educational aspects for community health and helping professions and for educators.

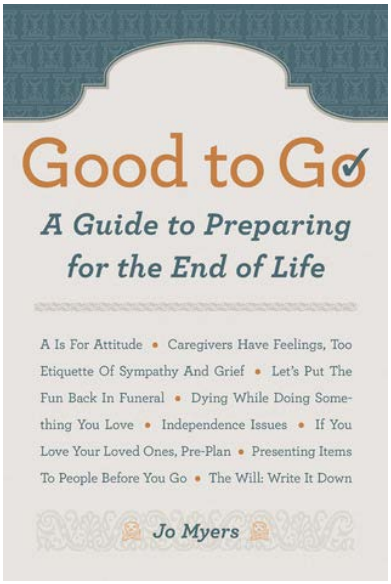
Resources: Books

Books

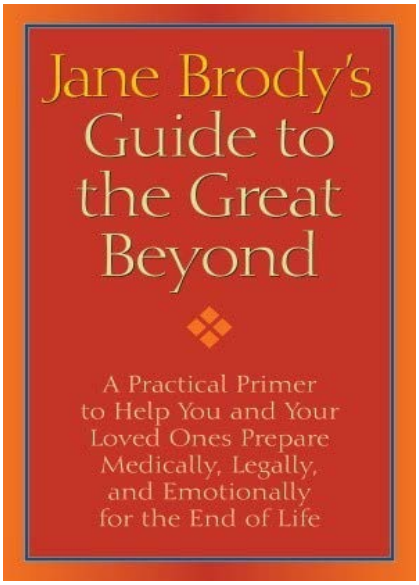


Living at the End of Life: A Hospice Nurse Addresses the Most Common Questions by Karen Whitley Bell, RN. A surprisingly warm and informative resource on hospice and other end-of-life care options–now available in paper! Individuals approaching the end of life, and their loved ones, face many challenges–but as hospice nurse Karen Whitley Bell reassures us, this difficult time also offers an opportunity to explore and rediscover a richer meaning in life. Drawing on her years of experience, Bell has created a comprehensive, insightful guide to every aspect of hospice care and the final stages of life. For people in hospice care, as well as their friends and families, this is an indispensable reference, a trustworthy source of comfort and healing.

Good to Go: A Guide to Preparing for the End of Life by Jo Myers. One of the few things in life that's certain is death—and here's a realistic, practical, and even humorous book about preparing for it. From cremation ("Making an Ash of Yourself") to funeral plans ("Plan and Plot Your Own Demise") to choosing executors and dealing with family relationships, media figure Jo Myers covers it all. It's sure to appeal to boomers caring for aging parents and anyone else who needs help approaching this not-so-easy-to-talk-about subject.



Jane Brody's Guide to the Great Beyond: A Practical Primer to Help You and Your Loved One Prepare Medically, Legally, and Emotionally for the End of Life by Jane E. Brody. From the beloved *New York Times* columnist, trusted authority on health, and bestselling author comes this complete guide to everything you need to know–emotionally, spiritually, and practically–to prepare for the end of life.



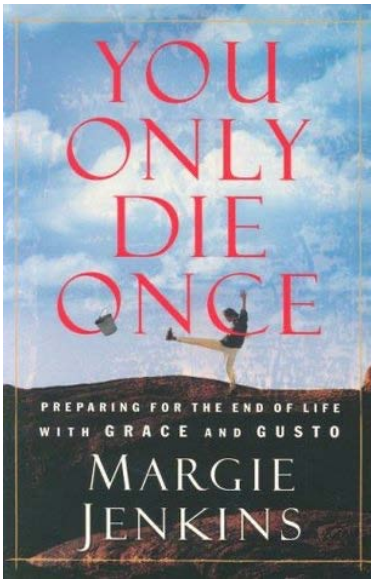
An invaluable road map to putting your affairs in order–or helping your loved ones do the same–this comprehensive book will answer every question you might have about what does and does not help smooth the transition between life and the Great Beyond. Wise, practical, and characteristically straightforward throughout, Brody advises on

• the intricacies of a well-thought-out (and fully spelled-out) living will that health care practitioners readily understand–and how to designate a health care proxy.
• planning a funeral or memorial to ensure your wishes are followed, including tips on how to reduce expenses.
• discussing prognoses and treatment options with doctors.
• your options for controlling pain, shortness of breath, bed sores, and other physical symptoms–plus the facts on feeding tubes.

• receiving the support you need through hospice care–and suggestions for loved ones and friends who want to help.
• lightening and enlightening your trials by incorporating spirituality into your life.
• understanding what happens, physically and mentally, when death is imminent, and recognizing when hand-holding and reassurance, not food or drink or an oxygen mask or CPR, is the proper course of action.
• easing your way through the journey of grief by admitting the reality of the loss, showing your emotions, and allowing yourself the time you feel you need.

No matter your age or current health, preparing for the inevitable when you are still fully in control of your faculties ensures that you'll be in a far better position to enjoy the time you have left. As Brody notes, "From the start, consider the finish."

You Only Die Once: Preparing for the End of Life with Grace and Gusto by Margie Jenkins. Death is something readers usually don't like to think about. That is understandable, but, as Margie Jenkins points out, that kind of denial misses out of life's last adventure. As practical as it is profound, this book teaches that good preparation for death is the foundation for a bold and rewarding life.



Course Complete

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Education is the most powerful weapon which you can use to change the world — Nelson Mandela