

Death with Dignity

*The Case for Legalizing Physician-Assisted Dying and
Euthanasia*

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Robert Orfali

MILL CITY PRESS



MINNEAPOLIS, MN

2011

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www.DeathWithDignityBook.com

Mill City Press, Inc.



Minneapolis, MN 55401
Tel. 612-455-2294
www.millcitypublishing.com

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Library of Congress Cataloging-in-Publication data
Orfali, Robert

Death with Dignity: The case for legalizing physician-assisted dying
and euthanasia/Robert Orfali

1. Death—End-of-life 2. Terminal illness—Psychological aspects 3.
Euthanasia —Physician-assisted suicide. I. Title

First Edition 2011
ISBN-13: 978-1-936780-18-1
LCCN: 2011923739

Cover design by Jayne Cloutier
Printed in the United States of America

In Memory of My Soulmate
Jeri Edwards Orfali
September 5, 1952 - June 19, 2009

*An extraordinary woman radiant in beauty and aloha.
I wrote this book to help pass "Jeri's Bill"*

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Introduction

“People don’t want to do this underground or covertly, with hushed tones, with great risks to themselves and their loved ones. They want to have their physician involved. They want hospice care involved. They want their family there without shame or risk.”

—Barbara Coombs, CEO, Compassion & Choices¹

As Dr. Ira Byock so eloquently reminds us, “We are, each one of us, at every moment, a heartbeat away from death.” Most of us prefer to avoid thinking about our death. If we happen to think about it, we tend to imagine a quick, painless death—a sudden heart attack, accident, or a Hollywood-style instant death: Poof! Gone! Unfortunately, the diseases that once killed us swiftly (pneumonia, influenza, cholera, infections, and massive heart attacks) have been replaced by the Big Six—heart disease, cancer, stroke, lung disease, diabetes, and Alzheimer’s. Typically, these diseases are chronic, long-term, and degenerative. Dying in the age of chronic disease is an extremely complicated process that involves a lot of anguish, pain, and suffering. The lucky few will go suddenly. But the remaining 80% will not leave life the way they would have liked to: “at home and without needless suffering.”²

Most of us will die in small steps. We’ll find ourselves navigating through a labyrinth of confusing end-of-life choices. We will spend our last days (often years) in sterilized torture chambers—hospitals, nursing homes, and even hospices. The terminally ill needlessly

¹ Robbie Brown, “Arrests Draw New Attention to Assisted Suicide,” *New York Times*, March 10, 2009.

² Stephen P. Kiernan, *Last Rights: Rescuing the End of Life System From the Medical System* (St. Martin’s Press, 2007).

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endure torture at the end of their lives. Did I say *torture*? Yes, let's call it by its name. In this case, both the torturers and the tortured are us. Our archaic laws prevent our doctors from assisting us with our death when we voluntarily request it. In most states, we haven't repealed these laws yet. Consequently, there is no one to blame but ourselves. We have put legal shackles on the people who can help us die with dignity.

We have the technology that enables us to avoid this needless suffering. We have the control switch that can end it all, on request. It's called *euthanasia*, which in Greek means "an easy and gentle death." It's the technology we use to lovingly end a pet's painful life. We make the choice of euthanasia (or painless death) for them. However, no one can, nor should, make that choice for us. It must be *voluntary euthanasia*—we would have to voluntarily request the prescription when we are terminally ill. As an added precaution, we would self-administer it. This type of euthanasia is called *assisted dying*. If we legalize it, as we have in Oregon and Washington, doctors will simply add it to their arsenal of end-of-life care. Compared to the current options, this would be, by far, the most humane, dignified, and painless final exit. As a society, we would have legalized death with dignity. It would become another end-of-life choice—another way to go. Having that choice does not necessarily mean that we would exercise it. Think of it as insurance—it buys us peace of mind. It's there if we need it. We can always choose to die the old way; most of us will.

What's Taking So Long?

So why isn't euthanasia legal? Suicide, of course, is not against the law in the United States and most advanced countries. *Assisted suicide*, however, is not legal. To do assisted dying right, it would have to be integrated into the practice of medicine. We need the help of doctors, nurses, and hospices to make it all work seamlessly. According to the U.S. Supreme Court, the decision to legalize euthanasia must be done at the state level. Every state must have this discussion and then put it

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to a vote. Some states—for example, Oregon—have had this discussion and lifted the prohibition. In the 2006 landmark case *Gonzalez v. Oregon*, the U.S. Supreme Court reaffirmed its position, by a 6-3 decision, in support of Oregon.

For most states, however, the goal remains elusive—very close, but no cigar. According to polls, the U.S. public is strongly in favor of euthanasia. For example, in a 2003 poll in Hawaii, where I live, the public was 71% in favor with 20% opposed. Yet, the *Death with Dignity* bill continues to fail year after year. The last time, our legislators failed to pass it by a two-vote margin.

So why does the majority not prevail? The answer is that the 20% opposed are strongly-motivated, well-financed, and highly-organized. On the other hand, the 71% who are pro-euthanasia are almost leaderless. Most of us prefer to avoid the topic of death: who wants to get up on a sunny Hawaiian day and go lobby the legislators for a better death? We have other things to do with our lives. There are exceptions. I was able to identify three groups who at various times have put some energy into the assisted-dying cause:

- ***Physicians, but not all.*** When it comes to assisted dying, the medical establishment is a house divided. In 2006, the *American Medical Women's Association (AMWA)* adopted a policy in support of Aid in Dying. In 2008, the *American Medical Students' Association* adopted a policy reiterating and broadening its support of Aid in Dying. However, the *AMA* hierarchy remains firmly against it, even though there is strong support among its members. Physicians are taught to fight disease till the very end. Consequently, they don't do death well. But, times are changing. The new field of palliative medicine is about end-of-life care and pain management. It has helped reduce some of the terminal torture, especially when coupled with hospice care. In addition, there is a vast underground of doctors who quietly (and illegally) help their patients die. It's all very secretive. Sometimes, they go public. The most famous example is

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Dr. Jack Kevorkian, whose flamboyant mercy killings ignited a national debate on euthanasia.

- ***People who are terminally ill.*** Some may get involved because they know death is coming. Typically, they are fighting their own disease and have little energy to give to the general cause of euthanasia. Instead, they attend self-deliverance conferences hoping to obtain information about do-it-yourself dying. What pills? How many? How do I take them? They also need names of compassionate doctors who will write prescriptions to help them die.
- ***Family members who navigated a loved one through death.*** These are typically people who witnessed the agony and suffering of the last days and feel that more could have been done for the dying. They now better understand the system and know its shortcomings. Their lives in the aftermath have taken a new direction, and they are determined to help others (and themselves) find a better way of dying. Some form or join advocacy groups for assisted dying. For example, Derek Humphry founded the *National Hemlock Society* after helping his fatally-ill wife, Jean, die. In his words, “She asked me to help her end her life.”³ In 1991, he self-published *Final Exit*, which sold over half a million copies and remained on the *New York Times* bestseller list for 18 weeks. It’s an instruction manual for do-it-yourself euthanasia. In 2005, *Hemlock* merged with another organization to become *Compassion & Choices*, which is now the largest U.S. advocacy group for patients’ rights at the end of life.

As you can see, this is a mixed bag of organizations and accidental activists. Many of the activists are not in it for the long run. They simply want to inform the public and then get on with their lives. Their opponents, however, are in it for the long run.

So, Why Did I Write This Book?

I belong to the third group. I decided to do something after I helped navigate my soulmate, Jeri, through the maze that led to her natural

³ Derek Humphry, *Final Exit* (Carol Publishing, 1991).

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death from ovarian cancer. I described the experience and process in my book *Grieving a Soulmate*. To net it out, I was traumatized by Jeri's death process and it had a big impact on my grieving. The scenes from the last days kept haunting me. Consequently, I spent a long time trying to understand what had happened. Could we have done better? Did Jeri needlessly suffer? Did I let her down? Ironically, Jeri had the perfect hospice death—she died relatively quickly from a blood clot. But I was still haunted by the 16 hours of “torture” she endured at the end of her life.

Jeri was a strong proponent of active euthanasia, but that's not how she died: it wasn't a legal option in the state of Hawaii. During my grieving, I constantly ruminated over her hospice death and tried to compare it with the assisted-dying alternative. I came to the conclusion that those 16 hours of needless torture could have been avoided had euthanasia been a choice for her. I also concluded that hospice gave Jeri the best possible death under the circumstances. And for that, I will always be grateful.

Like all terminal patients, Jeri ought to have been allowed to decide how she wanted to die. She was not given the opportunity to make that choice. Consequently, I wrote this book to help make it a choice for others. It's my tribute to Jeri. As I said, Jeri had a very soft landing. Many won't be that lucky. Their torture may extend over weeks and months. I pity them and their survivors. We must give everyone the choice to avoid this final torture if they so desire.

This book may be short, but it's packed with information. I only use Jeri's personal narrative to illustrate some of the key decision points. This book is not about Jeri. It's about euthanasia and why it must be legalized. Specifically, I advocate the legalization of physician-assisted dying modeled after Oregon's *Death with Dignity Act*. My contribution to the effort is to help inform the public by making the book freely available in all e-book forms—including Kindle, iPad, iPhone, Nook, Android, and Sony. So just tell your friends to download it into their readers. You can't beat “free.” Send them an e-mail with the links.

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Hopefully, this will make the book go viral and disseminate the information widely. Most of the proceeds from the print version will go towards advertising the book; all profits will go to charity.

Who Is This Book For?

We will all die; so this book is for everyone. We all have a vested interest in understanding our choices at the end. This book teaches you how to navigate the maze we call “end of life.” You’ll become a more informed consumer. Most importantly, it tells you how you can effect some of these choices. With a very small amount of effort, you can considerably reduce the angst, suffering and anxiety that most of us will experience at the end. A vote, a few e-mails and phone calls, can bring about change and help reduce your own suffering and that of your loved ones. Read this book, get informed, and then inform others.

Finally, I want to reiterate that supporting the right to choose does not imply that you will pick euthanasia at the end. It’s like being pro-choice on abortion without needing one. For most people, euthanasia is never a first choice. If all goes well, a natural death always seems preferable. But having that choice provides insurance for the dying. It gives them a sense of being in control of their death, which can greatly reduce their terminal anxiety. It also provides an exit option when all else fails.

How This Book Is Organized

I tried to keep the chapters focused and packed with information. Each chapter covers an issue in depth and some may be quite long. Here’s the plan:

- **Chapter 1** sets the tone. It gives you a feel for the despair, confusion, and emotional chaos that surround death. I introduce the strongest of these dilemmas: mercy killings. Then I contrast this chaotic environment with the civilized death which our pets are offered. I introduce the terminology and technology of modern-day euthanasia. I go over the different flavors of euthanasia—including active, passive, slow, voluntary, involuntary, and physician-assisted dying. I decipher the confusing terminology and discuss some of the moral

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and legal issues. Finally, I present the results of opinion polls to give you a feel for how society at large views euthanasia.

- **Chapter 2** explains the logic, as well as the lure, of euthanasia. First, I go over what it means to have that choice. Then, I explain why Jeri wanted that option. Next, I recount the dilemma she faced in a state where assisted dying is not a legal option. Again, the discussion is not about Jeri. However, she was a professional problem solver during her life and she subscribed to the principle, “My life, my death, my choice.” So, it’s enlightening to follow her decision process when she faced her terminal prognosis. She contemplated that decision with a lot of clarity and documented some of it. I use Jeri as a case study to help you understand the anguish which the terminally ill face. Their terminal anxiety is shared by their caregivers and loved ones. I will tell you how Jeri’s decision could have affected me in a very dramatic way. Yes, caregivers can turn into mercy killers out of deep love. It’s a very emotional time filled with sadness, fear, and angst. I try to deconstruct the decisions that take place during that emotional pressure cooker and present them as objectively as possible.
- **Chapter 3** is about how we die today without the assisted dying option. I explain how to navigate the end-of-life maze in hospital ICUs and hospices. I cover the advances in palliative care, hospice, and pain management. I tell you how to avoid the worst type of end-of-life torture—death in the ICU. Then, I provide the best-case scenario for hospice and palliative care, using Jeri’s death as an example. Finally, I tell you what’s missing and why the system “as is” has reached its limits. I suggest a quick fix. However, the real solution is to add physician-assisted dying to the palliative-care repertoire. I go over the advantages and synergy that this added choice provides.
- **Chapter 4** is about where we are today and how we got here. I trace the major milestones of the modern end-of-life choice movement—the court decisions, senate bills, parliamentary laws, and country and

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state battles. In the U.S., physician-assisted dying for the terminally ill is now legal in the states of Oregon, Washington, and Montana. In Europe, various forms of euthanasia are legal in Switzerland, the Netherlands, Belgium, and Luxembourg. The passive and slow versions of euthanasia are now legal and widely accepted in most advanced countries. They've become part of the standard medical practice.

- **Chapter 5** is about euthanasia as it is practiced in the real world. I cover the lessons learned from three decades of experience in the Netherlands. Then, I analyze 12 years of data from the state of Oregon's experiment with physician-assisted dying. The Oregonians have created a fine-tuned system that maximizes the dying patient's autonomy, while providing maximum safeguards with minimal bureaucracy. In many ways, Oregon may have discovered the perfect system of palliative care; it's Yankee ingenuity at its best.
- **Chapters 6 and 7** are about euthanasia's detractors and their concerns. This is not a traditional "left versus right" issue. Today, the main groups that are aligned against the passing of euthanasia bills are: the Catholic church, the pro-life movement, and *Not Dead Yet* (an advocacy group for the disabled). In 2010, they were joined by the populist *They're Trying to Kill Granny* movement. The issue is also a cause for concern for some civil libertarians, physicians, and hospice workers. The arguments against euthanasia fall into three broad categories: 1) the sanctity of life must be preserved, 2) the slippery slopes must be prevented, and 3) the medical system can alleviate end-of-life pain. I'll address each of these concerns in great detail. I'll provide points and counterpoints and let you be the final judge.
- **Chapter 8** is a call to action to make physician-assisted dying legal. I start the chapter with a review of the "euthanasia underground" and its implications for society. Baby boomers are very Internet-savvy. Consequently, when their time comes, they'll know where to find the necessary pills, exit bags, and helium tanks. Necessity is the mother

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of invention; it's just a matter of time before a budding entrepreneur starts marketing a single-pill solution—an *exit pill* that is both legal and widely available. So, we will have a free market solution to fulfill this missing option. The implications are self-evident. One way or another, the assisted-dying option will become widely available. Will it be underground? Or, will it be legally available as a palliative-care option with safeguards? We must decide. I end the chapter with an interview with the politician who is spearheading the legalization movement in Hawaii—house majority leader Blake Oshiro. We go over the bill that he is proposing and the safeguards it contains. I also quiz him on what it will take to pass this bill. Maybe, Hawaii will become the fourth state to legalize physician-assisted dying for the terminally ill.

The bottom line is that there is no real lobby for the terminally ill. Instead, there's a grass-roots movement that is both altruistic and selfish. It's altruistic because we want to help our loved ones die better. It's selfish because we are also helping ourselves die better. Let's face it—we're all going to die someday. In the words of the late Elizabeth Edwards, "The days of our lives, for all of us, are numbered." It follows that we all have a vested interest in understanding and effecting the workings of an end-of-life system that controls how we die. This book is my modest contribution towards a better understanding of that system.

***Personal note:** What qualifies me to write this book? In my previous life, I specialized in complex, distributed software systems. I learned how to deconstruct complexity and come up with better solutions. Jeri and I teamed up with Dan Harkey to coauthor books that helped a new generation of programmers understand the esoteric technology of collaborative software on large computer networks. Our books were written in an easy style to help guide these programmers and demystify the complexity of these systems. The books became bestsellers; we sold over a million copies. In this book, I use these same analytical skills to*

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unravel and demystify the most complex system I've ever encountered: our end-of-life system. I will describe how we die in America today. You'll get the good, the bad, and the ugly. I hope to make a modest contribution by explaining how to eradicate some of the "ugly" and cut down on the suffering.

I also wrote a book on grieving that deals with the same issue from a survivor's perspective. With these two contributions behind me, I now hope to get out of the death business until my time comes. There's just so much of this stuff one can take. On the other hand, this was my window to write these two books; I was writing while under the influence of the deep emotions that accompanied the death of my soulmate. I was able to look at the system from a different perspective, another angle. Hopefully, it will help guide you or your loved ones through the end-of-life maze.

Chapter 1

Father to Son: “Please, Kill Me”

“It could be that Americans struggle with death because they have made nearly everything else in their lives subject to reason, systemization, and control—from the timing of conception and manner of birth onward. Only death remains outside the corral, the wild horse that will not be tamed.”

—Stephen Kiernan¹

Dying in the modern world is hard; death itself is the easy part—it’s the release from dying. In this chapter, I first give you a feel for the profound range of emotions that the end-of-life can trigger. Often, it’s a heart-breaking tragedy of ordinary people. I explain how euthanasia could be a possible solution for these tragic end-of-life situations. For some, it can be the antidote to the dreadful suffering and isolation of a slow death. For others, it can be a form of insurance in case all else fails.

As you would expect, “euthanasia” is a loaded term. The topic is highly controversial: people have been grappling with it for ages. The current debate over euthanasia straddles multiple disciplines—including ethics, law, public policy, medicine, philosophy, and the existential meaning of life and death. Consequently, the terminology can be daunting; there is code to decipher and euphemisms to unravel. Also, there’s a lot of historical baggage to untangle.

¹ Stephen P. Kiernan, *Last Rights: Rescuing the End of Life System From the Medical System* (St. Martin’s Press, 2007).

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After clarifying the terminology, it becomes easier to introduce the technology and explain “who does what to whom.” I’ll end the chapter with the results of opinion polls. They should give you a feel for where we stand on this issue as a society, including doctors, patients, and voters.

Keith Olbermann: "My Father Asked Me to Kill Him"

My first story takes place in *New York Presbyterian*, one of the top ten medical centers in the U.S. The date is February 19, 2010. Six months earlier, Theodore Olbermann, an 80-year-old architect, was admitted to the hospital to have his colon removed. The operation was a success. However, major complications ensued after the surgery. Theodore was suffering from pneumonia, kidney failure, liver failure, and many infections. He was on feeding tubes, dialysis, respirators, and antibiotic drips.

That day, like almost every day, Theodore was visited by his son Keith (MSNBC’s well-known news anchor and political commentator). After recording his shows, Keith would head for his father’s bedside and read to him. On the evening of February 19, Keith went into his father’s hospital room and found him “thrashing his head back and forth” and mouthing the word “Help!” This is what transpired next:

Dad: Stop this. Stop, stop, stop...

Keith: Do you want me to stop all of this? Do you know what happens?

Dad: Yes.

Keith: What, you want me to smother you with a pillow?

Dad: Yes, kill me.

Keith: Obviously, I’m not going to do that...

Dad: Help, help, help...

As his father’s health-care proxy, Keith was able to request that Theodore be sedated. Luckily, the doctors agreed to do it. Theodore Olbermann died peacefully on March 13, 2010. May he rest in peace.

Chapter 1: Father to Son: “Please, Kill Me”

In the days that followed, Keith went on the air to reflect upon the end-of-life drama he had just witnessed. He explained to his viewers: “The paradoxical truth is that the people who desperately try to save your life sometimes manage to only (or also) torture you.... There was now terrifying torture. My father needed it to stop.” Then, Keith asked: “What are your options when dad says ‘Kill me’? Or, what are your options when dad is in a coma and can’t tell you a damn thing?”

Unlike the rest of us, Keith had access to a pulpit from which he was able to broadcast the end-of-life dilemma he faced. He was able to eloquently articulate a drama that millions of us silently face at the end of life—when we are slowly dying, or when we helplessly watch our loved ones die. If you get a chance, watch the entire video of the broadcast—it’s an eye-opener.²

The Unlikely Flare-Gun Killer

The next story takes place in the state of Hawaii, on the island of Oahu’s windward side. Robert Yagi and his wife Leatrice, both 71, had lived a quiet, retired life in the tiny, rain-forest community of Olomana at the base of the Koolau Mountains. By all accounts, Robert Yagi was a loving and caring husband. He was described as “pleasant and quiet.” According to neighbor Francis Calleon, the Yagis had lived in the community for more than three decades and he had never seen them argue. He added that the couple “often went places together.”³

In mid-2009, Leatrice became terminally ill and Robert took care of her. In October of that year, Leatrice was admitted to the nearby Castle Hospital Medical Center, which is about a five-minute walk from the Yagis’ home. According to a police affidavit, Robert “was seen daily in her room, tending to her needs and keeping her company.” Here’s what happened next.

² <http://www.msnbc.msn.com/id/3036677/vp/35572842#35572842>.

³ Mary Vorsino, “Motive in Shooting Not Clear,” *Honolulu Advertiser*, December 10, 2009.

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Thursday, December 10, 2009 (at 6:10 p.m.): Robert burst into Leatrice's hospital room and shot her with a plastic flare gun loaded with a shotgun shell.⁴ According to Castle officials, Leatrice suffered minor injuries in the shooting but no other patients or staff were "endangered by the perpetrator." Police believed Robert wanted to kill himself after shooting his wife. They arrested him for attempted second-degree murder. Robert had no prior criminal history. Consequently, he was released on \$150,000 bail and banned from returning to the hospital. Court documents say that Robert Yagi "may have wanted to end the life of 71-year-old Leatrice Yagi because she's suffering from a terminal illness."

Sunday, December 13, 2009: Honolulu police found Robert Yagi dead in his Olomana home. He had apparently committed suicide by hanging. Leatrice recovered from her gunshot wound. Five months later, she died from her disease after being re-admitted to the hospital.

The Yagis' tragedy resulted in an incredible outpouring of emotion in the state of Hawaii. It seemed as if the whole state was mourning with the family. Thousands of letters to the Honolulu papers were posted online. The majority were from young people who viewed Robert Yagi as a lover—not a killer. He was a compassionate hero who tried to kill his wife because he loved her. He tried to end her agony (and his) with a mercy killing, followed by suicide. The Yagis' tragedy renewed the debate over Hawaii's *Death with Dignity* bill modeled after Oregon's.

Note on how the press covered the event: *Initially, the press alluded to some crazy old man who tried to kill his wife by breaking into Castle Hospital. Later, the compassionate angle of the story began to appear. On December 10, the "Honolulu Advertiser" published an article that focused on "caregiver stress." I was a caregiver for ten years, so I understand caregiver stress. In my opinion, Robert Yagi was not driven*

⁴ Note: Press and police reports say it was a flare gun with shotgun shells. However, I heard it could have been a shotgun with flares inside. In any case, the gun malfunctioned.

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to desperation by the stress of caregiving. At the time of the shooting, Castle Hospital was providing the bulk of Leatrice’s caregiving, not her husband. What probably drove him to desperation was the unbearable agony of watching his beloved wife suffer in her hospital bed. He tried to end her agony. The day after Robert’s suicide, the story finally got the proper treatment in the press. On December 14, the “Honolulu Advertiser” ran an in-depth article that focused on the debate over physician-assisted dying in Hawaii.⁵

What Can Be Done?

Both of these stories took place in modern American hospitals. Unfortunately, even with the best of care, death remains the “wild horse that will not be tamed.” However, there is absolutely no reason for these tragedies to occur at the end of life. It’s cruel and unusual punishment for both the patients and their families.

So what happened to the ancient Greek idea of euthanasia, *the easy and gentle death*? In ancient Greece and Rome, citizens were entitled to a good death to end the suffering of a terminal illness. To that end, the city magistrates of Athens kept a supply of poison to help the dying “drink the Hemlock.”⁶ Despite the Hippocratic Oath, it was very common for physicians to end the lives of dying patients with their consent. The physicians either handed their dying patients the poison for which they asked or administered it themselves, at the patient’s request.⁷

Fast-forward to the present. This book is about restoring that ancient practice. If our dying loved ones voluntarily request it, they must be

⁵ Tim Sakahara, “Husband’s Suicide Resurrects Right to Die Debate,” *KGMB HawaiiNewsNow*, December 14, 2009.

⁶ Michael Manning, *Euthanasia and Physician-Assisted Suicide* (Paulist Press, 1998).

⁷ Ron Hamel, Editor, *Choosing Death: Active Euthanasia, Religion and the Public Debate* (Trinity Press, 1991).

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given the option of drinking “the Hemlock.” The modern-day lethal drug of choice is called *Nembutal*; it’s far gentler than what the ancient Greeks used.⁸

In the sections that follow, I will briefly introduce the terminology and technology of modern-day euthanasia. At this point, we just need a working understanding of what this is all about. We will get into the fine-print and details as the book progresses.

Passive Euthanasia: How Many of Us Die

In modern society, euthanasia has come to mean a death free of anxiety and pain, with some kind of physician assistance. It’s a deliberate act (or omission) that results in hastening a patient’s death to spare suffering. Surprise! Many of us actually die from euthanasia today in America’s hospitals. It’s called *passive euthanasia*; it does not involve lethal medication. Instead, doctors terminate a dying patient’s life by withholding or withdrawing medical treatment. For example, a feeding tube is removed, a dialysis machine is stopped, or a respirator is disconnected. Often, they let death happen by not resuscitating a patient. It’s all legal and voluntary. Doctors act according to a patient’s living will or advance directive.

What makes passive euthanasia legal? It’s legal because you never ask to have life terminated. Instead, you’re asking for the life support to be terminated. You are not asking for help to commit suicide. Instead, you are simply invoking your right to refuse treatment—including life support. You then die because nature takes its course. Of course, everyone knows that the removal of life support results in certain death. But, it’s “don’t ask, don’t tell.” Also, never call it euthanasia. It’s against the law. Instead, you must either call it “letting die” or “allowing to die.” The physicians are not helping you commit suicide. Instead, you are firing them. You no longer need their services. So they’re removing their life-support equipment and going home. And

⁸ The hemlock poison is from the plant *Conium Maculatum*—a poisonous member of the parsley family. By today’s standards, it’s not a particularly good poison.

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they’re “letting you” slowly waste away. You will then die from either the progressing disease, suffocation, or dehydration. The death will be recorded as being both legal and natural.

But, let me delve into this a little more deeply. Consider the case where the removal of a respirator is accompanied by sedation, at the request of the patient. The result is certain death. Why? Normally, you are “weaned off” the respirator a little at a time to give the body a chance to learn to breathe on its own again. However, should a patient request it, the physician is allowed to administer sedatives to relieve the terrifying panic and sense of suffocation that results from disconnecting the respirator. But, the sedatives also suppress the breathing and prevent the relearning. The result is certain death. Is this killing or letting die? I’ll let you decide. In any case, this is a perfectly legal way to die; it is humane and morally accepted by most.

Note on Terri Schiavo: In 2005, the Terri Schiavo case reinvigorated those who are opposed to the removal of any type of life support. The highly-visible protest against the removal of Terri’s feeding tube was spearheaded by the pro-life movement, previously known for its anti-abortion activism. You can protect yourself from this type of interference through a living will. Yes, there are some who are ready to turn the clock back on any advances in palliative care.⁹ I guess they want us to suffer at the end.

Slow Euthanasia: How the Lucky Ones Die

You may have heard the term *slow euthanasia*.¹⁰ Typically, it’s associated with the use of *terminal sedation*—a very common practice in hospices. The terminal patient is sedated into unconsciousness to

⁹ Lewis Cohen, *No Good Deed: A Story of Medicine, Murder Accusations, and the Debate over How We Die* (Harper, 2010).

¹⁰ Anemona Hartocollis, “Hard Choice for a Comfortable Death: Sedation,” *New York Times*, December 28, 2009.

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relieve the pain. Artificial hydration and nutrition are withheld because they may cause adverse effects, such as pulmonary edema (i.e., water in the lungs). Then death is slowly caused by whichever comes first: 1) the progressing disease taking its course, 2) respiratory failure caused by the ramping up of sedative drugs, 3) pneumonia, 4) kidney failure, or 5) starvation and dehydration.

Today, this practice is medically-accepted and legal. In the words of Supreme Court Justice Sandra Day O'Connor: "There is general agreement that a patient who is suffering from a terminal illness and who is experiencing great pain has no legal barriers to obtaining medication, from qualified physicians, to alleviate that suffering, even to the point of causing unconsciousness and hastening death."¹¹

The argument Justice O'Connor used is called the *doctrine of double effect*, which means that an action can have two effects, one intended and the other foreseen but not desired.¹² In this context, it means that hastening death is okay as long as it's not the physician's primary *intent*. The primary intent of terminal sedation is the relief of pain—death is just collateral damage. In this case, it seems we're not to be held accountable for the secondary effects of our actions. Also, you must never call this practice euthanasia or even terminal sedation. The politically correct term is *palliative sedation*.

In states that do not support voluntary euthanasia, palliative sedation is the most compassionate way to die. It's the only way to control unbearable pain. With enough sedation, the dying are finally put into a state of deep unconsciousness. We're told that they do not suffer when they're in that state. Eventually, they'll die, but "not too quickly." The process is not easy on the families. However, it's not as traumatic as watching a loved one die in an intensive care unit. I'll have a lot more to say about palliative sedation in Chapter 3.

¹¹ U.S. Supreme Court, *Washington v. Glucksberg* (1997).

¹² The doctrine has its roots in medieval Catholic theology, especially in the thought of Thomas Aquinas.

Involuntary Euthanasia: How Our Pets Die

Involuntary euthanasia is how our pets die in America today. As a society, we are incredibly compassionate when it comes to our dying pets. We will not let them suffer at the end of their lives. Period. So, how do we do it? We euthanize our pets rather than watch them slowly die in pain. Of course, our pets don’t have a say in this—it’s involuntary.

Involuntary euthanasia must *never* be legalized for humans. Why? It has too much potential for abuse. For example, shortly after they came to power, the Nazis set out to engineer a “better” race by euthanizing their “undesirables”—the handicapped, the insane, and then the elderly. Much of this happened under the supervision of German doctors. The exterminations were medicalized. Of course, we’re not Nazis. Our pets are very precious and we lovingly “put them to sleep.”

There’s much we can learn from the technology that provides this gentle death to our pets. Dr. Ronald S. Weiner (“Dr. Ron”) is a long-time veterinarian from Los Gatos, California. I’ll let him explain the process:

Robert: Thank you for taking my questions. How long have you been a vet?

Dr. Ron: A little over 35 years.

Robert: How many pets have you euthanized?

Dr. Ron: Around 4,000.

Robert: What type of pets?

Dr. Ron: Cats and dogs.

Robert: Can you briefly describe the process?

Dr. Ron: First, I place a catheter IV on the pet to insure a smooth injection. Then, I use a syringe to inject a highly-concentrated *pentobarbital* solution. Often, Valium is given before the injection.

Robert: What happens next?

Dr. Ron: The pet lapses into coma within a few seconds as the drug causes marked respiratory depression and ultimately stops the heart

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for a peaceful death. This usually occurs within one or two minutes. The heart just stops.

Robert: Do pets experience any pain?

Dr. Ron: I do not believe they feel any pain at all. It's all very humane.

Robert: How far back does this practice go?

Dr. Ron: I'd say over a century.

Yes, our pets have it good at the end—the medical technique that puts them to sleep is top-notch. Apparently, it also works well on humans. The Australian euthanasia doctor Philip Nitschke writes, “My experience in those days of legal voluntary euthanasia taught me that the drug pentobarbital (commonly known as *Nembutal*) provides the most peaceful death imaginable. And it never fails.”¹³ He is writing about his experience in 1996, when the Northern Territory of Australia led the world to become the first place where it was lawful for a terminally-ill patient to request medical assistance to die.

Voluntary Euthanasia: How Some Would Like to Die

Why can't we extend the same loving mercy to terminally-ill human beings? Why can't we grant ourselves the right to die with dignity? Unlike our pets, we have the mental capacity to *voluntarily* choose when to die and how to die. Voluntary choice, when coupled with a painless technique, gives us total control over how we die and when we die; it's the ultimate death with dignity. Yes, we can do better than our pets. Unfortunately, our pets have it better now when it comes to the technology of dying.

There are exceptions. The terminally ill in Switzerland, Belgium, the Netherlands, and the states of Oregon, Montana, and Washington have access to this technology: *Nembutal* is on the approved list of drugs that doctors can legally prescribe to the terminally ill. In these countries and U.S. states, terminally-ill humans can experience an

¹³ Philip Nitschke and Fiona Stewart, *The Peaceful Pill Handbook* (Exit International US, 2009).

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“easy and gentle” death if they request it. *Voluntary euthanasia* is an explicit request for a physician to help you die. The help can come in one of two ways:

- ***Self-administered.*** In this case, you’re asking for a prescription of Nembutal or some other barbiturate to take your own life. The physician writes you a prescription and then you’re on your own. You take your own life when you’re ready. This guarantees that it’s voluntary. In the U.S., proponents of this method call it *physician-assisted dying* or simply *assisted dying*; opponents use the terms *physician-assisted suicide* or simply *euthanasia*.
- ***Physician-administered.*** In this case, the physician will inject a lethal dose when you request it. This method requires that the physician play a more active role; it may be useful for people who can’t self-administer. This approach is called *voluntary active euthanasia (VAE)* by its proponents. Its opponents call it *euthanasia*.

The European euthanasia movement supports both methods. In contrast, the U.S. movement only supports the first method, which is now legal in the states of Oregon, Washington, and Montana.

Note on terminology: Like the rest of the U.S. movement, I am only in favor of the first method (see Chapter 2). In this book, I interchangeably call it *voluntary euthanasia*, *assisted dying*, or just “the Nembutal.” This lets me deal explicitly with the anti-euthanasia arguments in terms that can be understood. Like the ancient Greeks, I believe *euthanasia* is a noble word; it’s time to reclaim this word from those who malign it. Again, I want to make it very clear that this book only condones *voluntary euthanasia* for the terminally ill. The dying person must make the choice: no one else can. Bottom line: I am in support of a voluntary, easy, and gentle death that is assisted by a physician in the form of a legal prescription for Nembutal. My model is the state of Oregon’s “Death with Dignity” Act.

What the Polls Say

Over the years, national polls have consistently shown the U.S. public to be largely in favor of physician-assisted dying. This includes the majority of patients, physicians, and voters. Here are some examples:

- *Gallup polls* consistently indicate that Americans overwhelmingly support euthanasia. They were asked the question: “When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient’s life by some painless means if the patient and his family request it?” In the 2007 poll, 71% were in favor while 27% were opposed.
- A 2002 *Harris poll* found that 2-1 majorities continued to support rights to both euthanasia and physician-assisted suicide. 61% favored the implementation of Oregon’s *Death with Dignity Act* in their own states.¹⁴
- An April 2005 *Harris poll* found that two-thirds of the public would like their states to allow aid in dying as is currently allowed in Oregon. A 70% majority was in favor of a law that would “allow doctors to comply with the wishes of a dying patient in severe distress who asks to have his or her life ended.”
- A 2005 national survey conducted by the *Institute for Religious and Social Studies* found that 57% of the 1088 doctors polled believe it is ethical for a physician to assist a competent, dying patient to hasten death.¹⁵
- A 2010 national survey of 10,000 U.S. physicians conducted by *Medscape* found that 59.3% of respondents agreed that “physician-assisted suicide should be allowed in some cases.”¹⁶

¹⁴ Humphrey Taylor, Harris Interactive, *2-1 Majorities Continue to Support Rights to Both Euthanasia and Doctor-Assisted Suicide*, January 9, 2002.

¹⁵ Louis Finkelstein, Institute for Religious and Social Studies, *Physician-Assisted Suicide Survey* (February, 2005).

¹⁶ <http://www.medscape.com/viewarticle/731485>.

- In 2006, a California poll conducted by the *Field Research Corp.* showed that support for physician-assisted dying transcended party lines and religious affiliations. Californians were asked: “If you yourself were terminally ill and were expected to die within six months, would you want your doctor to be able to assist you in dying if you requested it?” The “yes” replies were as follows: 62% of all adults, 76% of Democrats, 51% of Republicans, 62% of Independents, 56% of Protestants, 54% of Catholics, 46% of born-again Christians, 65% of Latinos, and 70% of non-Hispanic Whites.¹⁷

These polls show that, as a society, we are ready for changes in the law to better reflect the public’s values and needs. There is no need to hide behind arcane, medieval sophistries like “the double effect.” The public seems more than ready for an open discussion about dying options.

The Bottom Line: Whose Death Is It Anyway?

For most of us, dying will not be “easy and gentle.” In ancient Greece and Rome, voluntary euthanasia was used to achieve a good death. As a society, we already practice some form of euthanasia without openly acknowledging it. Without terminal sedation (i.e., slow euthanasia), death from the chronic diseases that are now killing us would be unbearable. The cessation of life support (i.e., passive euthanasia) is another advance that makes modern dying more tolerable. There is still torture in our hospices and hospitals, but without these palliative practices it could be much worse.

Voluntary euthanasia provides another option in the continuum of palliative care choices that are becoming available to us. In later chapters, I will use empirical data to demonstrate that these approaches are complementary and synergistic. Together, they provide better end-of-life care. I will also argue that there is no moral difference between

¹⁷ Mervin Field and Mark DiCamillo, “The Field Poll: Continued Support for Doctor-Assisted Suicide,” (March, 2006).

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a physician's assistance in dying by: 1) prescribing the Nembutal, 2) removing life support, or 3) activating terminal sedation without nutrition or hydration. It's all the same.

Philosophically, this debate is about our right, when terminally ill, to choose how to die. It's about the right to control how much we have to suffer and when and how we die. It's about having some control over our dying process in a system that can aggressively prolong life with invasive technology. Luckily, we also have the technology that allows us to experience "a gentle death" on our own terms, rather than by medically set terms. In his famous essay *On Liberty*, John Stuart Mill argues strongly for our right to self-determination. He writes, "Over himself, over his own body and mind, the individual is sovereign.... He is the person most interested in his own well-being."¹⁸ These words were written over a century ago.

Opponents argue that assisted dying is not self-determination because it requires the help of a physician. Instead, it's a *joint action* by both the patient and physician. In other words, we don't have the autonomy to act on our own—we need the prescription. If you think about it, physicians are just the gatekeepers to the Nembutal—they write prescriptions for barbiturates. Our laws granted them a monopoly over controlled medications by way of these prescriptions. Hypothetically, a change in law could allow terminal patients to pick up their Nembutal directly from city hall, just like in ancient Athens. The Nembutal is a one-size-fits-all prescription; it doesn't require a physician's dosing expertise or help to administer.

In most states, a prohibition law against physician-assisted dying is restricting our right to self-determination; the prohibition prevents dying patients from doing what's best for themselves without hurting others. In this case, the prohibition is of no benefit to society at large. So, we must remove the prohibition and legalize the Nembutal for those who are dying. For each state, it comes down to a vote. For states that carry the vote, the polls seem to indicate that the majority of

¹⁸ John Stuart Mill, *Three Essays* (Oxford University Press, 1978).

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physicians are willing to prescribe the Nembutal and help us through the dying process. They will not abandon us at the end.

The twelve-year old Oregon experiment provides solid evidence that assisted dying works in the real world. Oregon supplies a proven legal framework that we can emulate throughout the United States. It also serves as our lab for the technology and the safeguards, which are both first-rate. The system in Oregon has consistently demonstrated that it is capable of providing an “easy and gentle” death without abuses. Based on opinion polls, society seems ready to have the Nembutal option added to our end-of-life choices.

I’ll close this chapter with a quote from medical ethicist Dr. Jonathan Moreno: “Euthanasia, and especially physician-assisted suicide, appears as the ultimate post-modern demand for dignity in an era of technologically-mediated death.”¹⁹

¹⁹ Jonathan D. Moreno, Editor, *Arguing Euthanasia* (Simon and Schuster, 1995).

Chapter 2

My Life, My Death, My Choice

“I don’t want to achieve immortality through my work. I want to achieve it through not dying.”

—Woody Allen

Physician-assisted dying for the terminally ill is a very simple concept. It means that at the end you should be able to ask your physician to prescribe a lethal dose of medicine, preferably in liquid form that you could easily mix with a drink when the time comes. You self-administer the medication by swallowing your drink. If you’re no longer able to swallow, you self-inject the medicine through a catheter or feeding tube. Ideally, a nurse would be present to provide advice and moral support. It’s really that simple. However, the devil is in the details—legal, moral, societal, and practical—when it comes to the issues that surround euthanasia.

In this chapter, I deal with euthanasia from a dying patient’s perspective. I try to answer the following questions: What’s the thought process at the end? How do you choose “how” to die? What’s the logic? What are the tradeoffs? Can you get around legal barriers in states that don’t support assisted dying? What are the risks? What are the implications? How much assistance will you need?

How do I answer these questions from a dying patient’s perspective? The short answer is: from the experience of my late wife, Jeri. She provides the perfect case study. In her previous life as a Silicon Valley executive with high-tech startups, Jeri was known for her laser-sharp analytical skills. She knew how to make complex decisions and deal

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with uncertainty. (Her graduate degree was in general systems theory.) Jeri left behind a trail that explains some of her thinking when she faced death. Also, she was very open with me when we broached the topic. Why? Because I was very sick at the time. So, it wasn't clear who was going to die first. Everything was on the table. It was a discussion among dying peers.

In this chapter I will focus on Jeri's decision process when it came to her choice of dying. I cover this topic for the first time here. I'll give you just a bit of narrative and then get down to the issues. You can read the details of Jeri's death in my book *Grieving a Soulmate*.

Jeri Receives Her Final Notice

Jeri was 47 when she was diagnosed with ovarian cancer in 1999. For the next nine years, she kept the cancer in check with back-to-back chemotherapy regimens. She was lucky to live in Hawaii. She became a surfer at age 50 and even won a trophy in her age group. The surfing and the ocean kept her fit during her chemo years. They helped her rebound after each chemo session. Her cancer never went into remission. However, it was microscopic and well-contained within the abdomen.

We received the first piece of bad news in late March 2008, about 15 months before Jeri's death. A routine CAT scan revealed that the cancer had spread outside the abdomen and some of it was now in her lungs. This was very bad news. The good news was that the cancer's spread did not seem to affect Jeri's quality of life. On the outside, she looked fine. She would say, "Look, I'm very healthy except for a small problem—cancer." She continued her chemo regimens, followed by good surfing days. Of course, Jeri had just received her official death sentence.

She Had a Dream: Dying, Jeri's Way

In April 2008, I became very sick. For a time, it looked like I would die first. In a reversal of roles, Jeri became my caregiver. As I lay in bed one day, I noticed that she was doing a lot of research on death and

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dying. I was not very lucid, but I felt the topic was highly relevant. So, I called her over and she sat next to me on the bed. What followed was the most extraordinary conversation. Here's my best recollection of what was said that day:

Robert: You're doing a lot of reading on dying. What are your thoughts?

Jeri: I'm not afraid of death. I'm afraid of dying in pain. I really don't want to needlessly suffer at the end.

Robert: What are you discovering? Do you have a plan?

Jeri: I don't have a plan, yet. But I have a dream...

Robert: A dream?

Jeri: Yes, a dream. It's about how I'd like to die.

Robert: I'm all ears.

Jeri: In my dream, we rent a beautiful oceanside suite at the Moana overlooking my surfing spot. We sit on the lanai and enjoy watching the surfers. There's a big swell and they're taking some great rides. Later, our closest friends join us for a nice bottle of wine. We talk story and reminisce. We laugh a lot. At sunset, I say goodbye to everyone and have one more toast to the good life. Then, I drink my final cocktail...

Robert: Your final cocktail?

Jeri: Yes. It will be mixed with something that will put me to sleep forever. I'll pour a vial into my drink. Don't wake me until I die...

The conversation ended suddenly. Jeri and I were both in tears. I hugged her tightly and wouldn't let go. It was all very emotional. I couldn't imagine life without Jeri. She had to reassure me that she wouldn't die for a while. She laughed and said, "Don't worry, Babe. I plan to catch a lot more waves before I die." Jeri wanted to savor every good moment she had left on this earth. She wanted to surf and continue to live as long as possible. In her words, "Until my life becomes more bad than good." Having seen her take chemo all those years, I knew she could absorb quite a bit of "bad." She was exceptionally brave.

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At this point, Jeri was in the planning stages. She was trying to formulate a working plan for how she wanted to die. Once she had a plan, she would shelve it until she was ready. Maybe, she wouldn't ever need it. It was just preparatory work. Jeri loved to choreograph things in advance. In this case, she wanted her forthcoming death to be a happy event which she could fully imagine. She wanted it to be a celebration of her good life. Her death would be a reflection of the way she had lived. She wanted to control the process of death as much as possible. She did not want uncontrolled suffering and pain. That was *her* dream! We all have our dreams of how we want to go. And, we all want some level of control over our death. That's why many of us have an advance directive.

Note on Jeri's dream: During my grieving, I spent a long time thinking about Jeri's dream. I came to the conclusion that it had been very therapeutic. It helped her cope with the death sentence she had just received. Her answer was to subsume her death by orchestrating it. She was going to set the narrative for her death as she had done for her life—she would provide the ending. In other words, Jeri was not going to let death define her. Instead, she was going to define death. This is the ultimate form of existential self-empowerment. It's also a very rational coping strategy. Think about it. How would you react if you were handed a death sentence? Jeri's answer was to take it on. She was a tough surfer chick who had spent years fighting ovarian cancer. She was not going to abdicate control at the very end. She would die on her own terms—Jeri's way.

Do-It-Yourself Dying With Help From the Internet

Jeri was a top-notch researcher and planner. The question was whether she could turn her dream into a working solution. She had a big obstacle to overcome: euthanasia was not a legal option in Hawaii. At first, that didn't seem to bother her. After spending a few hours on the

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Internet, she found almost everything she needed to execute her plan, including:

- ***Brand name lethal drugs and their dosages.*** She was able to locate two well-known drugs which in combination could do the job. However, the required dosages were huge. In total, she would need to swallow 180 pills. Why so many? That's what it takes to get a lethal dosage using ordinary drugs. Jeri did not like to swallow pills. With further research, she discovered how to blend them into an applesauce drink that would ease their digestion.
- ***Prescriptions from online pharmacies.*** These were easy to procure on the Internet. Her drugs could be shipped overnight by several online pharmacies.
- ***Method of administration.*** The information is all over the Internet. She had to go on a liquid diet a few days before the event. Then, she would take some anti-nausea tablets a few hours before ingesting the pills. The idea was to not throw up. Of course, the solid pills would have to be ground and dissolved in some liquid before intake. She would have under five minutes, the median time to unconsciousness, to swallow the pills.

It looked like Jeri had all the pieces. However, something appeared to be missing. She said, "It's not that easy. I'm still working on it."

Her Letter to *Compassion & Choices*

A few days later, Jeri was still searching for answers. She had made several calls to *Compassion & Choices* in Oregon, who assigned her a case worker (or counselor). Here's an unedited version of a letter Jeri sent to her case worker on May 7, 2008:

Dear Helen,

Thank you for taking the time the other day to discuss with me my situation and your services. I appreciate your help very much. As I told you, I was diagnosed with Ovarian Cancer Stage 3C in December of 1999. I have been on chemotherapy most of the time since then. I have been lucky. The chemotherapy has allowed me to

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have a high quality of life while holding the cancer at bay. My cancer has not affected me much so far (although the chemotherapy certainly has). I have been able to carve out a beautiful life around the treatments.

However, two months ago my cancer count (CA-125) began to rise sharply. And a CT-Scan showed that the cancer had spread from the lymph nodes in my abdomen to my lungs and upper lymph system. I am continuing to try different chemotherapies to stop the disease progression (and get more of those great quality days). However, I also want to begin to prepare for the case that we cannot stop it. To this end, I have completed my will, and advance directive. Given your recommendation, I have begun to look into hospice care alternatives—to be ready for the time I will need them.

My goal is to have as many quality days as possible. I have experienced days under chemotherapy when I would rather have been dead. I hung on because I knew the pain would be over within days. But there may come a time when I will see that the pain won't be over—that the pain medications won't work. I do not want to live in that state knowing that there is no chance for it to improve. I have had a great life (which I still want as much of as possible), but then I want to have a good death with dignity. Therefore, I am seeking your help in obtaining information on options to hasten my death. Can you please send me this information? Thank you again for your invaluable service.

*Sincerely,
Jeri*

This beautiful letter clearly documents Jeri's wishes for the end of her life. She wrote these words, about 13 months before she died, when she was totally lucid. However, I was totally confused. What did Jeri need from *Compassion & Choices* that she did not already have? She had the pills, the dosage, and the method. It all looked very doable. What was missing from her plan?

Help, I Need Somebody

I finally asked Jeri, “What do you need from these people? Why are you writing to them?” She was a bit teary-eyed and didn’t respond right away. There seemed to be a lot going on in her mind. Eventually, we had this very informative conversation:

Robert: What, exactly, is missing from your plan?

Jeri: I need someone on standby when I take the pills. I’m hoping that they provide that service.

Robert: Why do you need to have these people on standby? I’ll always be by your side. You just swallow that stuff and it’s over. Right?

Jeri: Wrong. The statistics I was able to find, mostly from the AIDS community, show that one out of three attempts had botched. Those who failed ended up in intensive care. I don’t want to end up there. I need someone who will assist me to finish the job in case I throw up the stuff. I don’t want to wake up in a psychiatric ward or in an intensive care unit.

Robert: What? You want someone to put a pillow over your head to finish you off?

Jeri: Yes, exactly. It’s typically a plastic bag. And, I don’t want you doing it. You’re my lover. You’ll never be able to do it. You don’t have it in you. Besides, you’re non-violent. I can’t and won’t depend on you to kill me. You absolutely don’t have my permission to do it.

Robert: Baby, these people can’t do it either. You know it’s against the law. It won’t happen. All they can do is hold your hand. No one is going to kill you.

Jeri: You’re right. I told you that I didn’t have all the answers.

Robert: What about that stuff they use in Oregon? They say it’s 100% effective.

Jeri: You mean Nembutal. I couldn’t find it on the Internet. Believe me, I searched everywhere. We’d have to go to Mexico to find it, and we wouldn’t be able to bring it back through customs. It’s illegal. The stuff I located is inferior. It requires a plastic bag to finish the

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job, but the bag may come loose. I'll need assistance if that happens. Like I said, I haven't found a clean solution yet.

Robert: Why don't you ask Dr. Terada for a prescription?

Jeri: No way! I would never put him in that situation. It would incriminate him. Do you want him to lose his license? He's a great oncologist. He's helped me fight my cancer all these years. Other women with cancer desperately need him. I'll never ask him to do anything illegal.

Robert: Sorry! I wasn't thinking. You're absolutely right. Have you considered other ways of going?

Jeri: Like shooting myself? No, I won't do anything violent. I want to die peacefully—by going into deep sleep. The pills are my only option. I just need to make it all work.

Obviously, Jeri was in a bind. She didn't have access to the best technology—meaning Nembutal. Consequently, she would need some form of assistance in dying, mostly for backup. Of course, *Compassion & Care* did not provide that service. Jeri's plan was not going to work. She needed the help of a physician who would write her a prescription for Nembutal as they do in Oregon. But this was not a legal option in Hawaii. So, for the first time in her life, “can-do Jeri” did not have a solution.

When Lovers Become Killers

Jeri's plan hit a brick wall because there was a possibility that it would have required a *mercy killing*. In contrast to legalized assisted dying, self-deliverance does not involve a physician. Typically, assistance in dying is performed, out of love and compassion, by a close family member. In the eyes of the law, mercy killing is murder. More often than not, the charge is downgraded to first-degree manslaughter which implies a lack of intent to kill. At the end of the day, most mercy killers are acquitted by sympathetic jurors and judges. The few who are found guilty receive light sentences.

So, is mercy killing a crime or a moral duty? Are the killers criminals or saints? Is the killing self-serving or altruistic? Does law of family

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trump law of state? Is there a flaw in the law or in juries' moral sense? There are many more such questions. Our society does not have the answers, which explains the ambivalence. The lenient verdicts are a moral dodge, an easy way out. Moral clarity dictates that if mercy killing goes unpunished, then it must be legalized. The law is flawed: the people's moral sense is not.

Mercy killing is precisely what legalized physician-assisted dying was designed to avoid. The orderly transaction between doctor and patient is meant to eliminate the need for desperate killing which is in clear violation of the law. Tranquil lethal dosing replaces very personal and sometimes gory methods of killing, such as strangulations, suffocations, and shootings. Instead of a non-regulated desperate act, legalized euthanasia is a well-regulated professional transaction. The idea is to prevent the tragedy of killing for love, which is an incredibly devastating, life-shattering act of desperation.

Prison is the least of their problems for family members who receive a cry for help from loved ones who want to die. This dreaded cry brings about a horrible, no-win dilemma. If they assist in their loved one's suicide or death, they will probably end up grieving forever; if they refuse, they are likely to suffer from both endless grief and guilt for not helping. To break out of this predicament, some will kill their loved ones and then take their own lives. The press calls it "murder-suicide." Jeri was seeking outside help because she did not want me to face this horrible dilemma. I was lucky that she was such a careful planner.

Killing Yourself While You Still Can

The timing of a do-it-yourself death is critical. Without access to a liquid vial of Nembutal, it becomes crucial for the terminally ill to kill themselves while they are still able to self-administer the pills and *before* they are unable to swallow. The technology dictates the timing. In this case, the underground pill technology is sub-optimal compared to the legal prescriptions of Nembutal. Consequently, many of these

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suicides are premature. People die while they still have some good life left in them.

Too-early self-deliverance can be very hard on the survivors. They may grieve for that extra time they could have had with their loved ones. During Jeri's last days, I savored every remaining microsecond I had with her on this earth; it was beyond precious. I would gladly trade the rest of my life for one more day with Jeri. I had thirty wonderful years with her, but every moment counts when you're grieving; you always want more.

You Waited Too Long

Conversely, there are those who wait too long. They want to extract every moment they can out of life. Jeri could have ended up in this category. She wanted to live as long as possible. Even at the very end, she was able to enjoy some of life's little pleasures. Typically, people will choose to live as long as they retain their dignity and the pain is still manageable. The danger is that they can hit a point of no return when self-deliverance is no longer an option. For example, this can happen when they are no longer able to swallow pills or self-administer the medication.

Not Too Early and Not Too Late

For Jeri the right time to die was not too early and not too late. She also wanted her death to be quick, peaceful, and surrounded by love. In an ultimate act of self-determination, she wanted to choose both the venue and the optimum time for her death. Finally, she wanted to die in a state of deep sleep. To paraphrase Woody Allen, "She wasn't afraid to die. She just wanted to be sound asleep when it happened."

Unfortunately, it's very difficult to achieve this ideal goal with underground euthanasia. First, you do not have access to the best technology, liquid Nembutal. Second, it's very hard to pick the optimal time without the proper support system. I'll have a lot more to say about this later.

Unnecessary Anxiety and Stress

As a terminally-ill person, Jeri ought to have been allowed to control her death. She should have had the right to choose the best way to go. Every feasible option should have been on the table. Unlike most people, Jeri had choreographed how she wanted to go, but she was never given that option. It was not legal. She also discovered that the underground approach to self-deliverance is not easy: there are too many legal blocks, too many things can go wrong, and the timing is seldom right. Even a top-notch planner like Jeri couldn't figure it out.

Without a plan, Jeri felt very exposed. She was afraid of what was to come. She was anxious about her forthcoming death at a time when she should have been enjoying every precious moment that she had left on this earth. As her caregiver, I felt the same anxiety. I was terrified that she would needlessly suffer at the end. It was all very stressful. Both of us would have felt much better had there been a legal exit path to fall back on, if all else failed. So, the lack of a fall-back plan affects more than just the aesthetics of dying. It's also a source of deep anxiety.

How Much Physician Assistance?

This question is the major dividing line between the American and European approaches to legalized physician-assisted dying. In the Netherlands, it is legal for either a physician or the dying patient to administer terminal medication. In contrast, Oregon's *Death with Dignity Act* requires that the dying self-administer the medication and no one else. Why? Because it provides the ultimate assurance that the act is voluntary.

From a dying person's perspective, there are two instances where a physician's assistance may be further required: 1) in the highly unlikely event self-administration fails (Oregon's failure rates are almost zero); 2) if the dying person chooses to live longer than he or she can self-administer and then needs assistance.

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From a moral perspective, there is no difference between a physician helping someone die by prescribing the lethal medicine versus administering it. It's all the same. We have the same kind of situation when removing life support: we rely on advance directives to ensure the will of the patient, even though someone else pulls the plug.

In this book, I advocate whatever is best for dying patients. The trade-off they face is a few more days of living versus an iron-clad guarantee that their assisted death is *voluntary*. When I first started writing this book I was in favor of a few more days. Consequently, I was leaning towards the European model. Later, I changed my mind after long discussions with the Oregon people. They convinced me that direct physician intervention was not necessary. Jeri could have had her two extra days and still terminated her own life.¹

What made me change my mind? The short answer: liquid Nembutal. Jeri would have been able to swallow it almost to the very end. If she had reached the point where she couldn't swallow it, she could have self-administered the liquid by way of a catheter. (It is perfectly legal for a nurse to insert a catheter for hydration purposes.) What if Jeri was unable to self-administer? Then, she wouldn't have been able to have the Nembutal. On the other hand, being in that bad a shape would have made her a candidate for terminal sedation—a legally available option from hospices.

It appears that the people in Oregon have the answers. Their technology provides maximum safeguards through self-administration and maximum flexibility for timing one's death. In addition, the dying can ask to have a physician present for support, advice, and standard comfort care. For example, attending physicians can clear an airway in the case of regurgitation or administer medication to relieve pain. In 2009, the state reported that a physician or health-care provider was present in 87% of the cases at the time of ingestion. In the remaining

¹ Roland Halpern of *Compassion & Choices* spent a lot of time and effort educating me. He was very patient.

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cases, the patient, for whatever reason, did not want to have a doctor or health-care provider present.²

Lessons Learned

Self-deliverance is very difficult in states where assisted dying is not a legal option. Yes, it can be done but there's also a lot that can go wrong. So reader beware. If you're in this situation, you may want to carefully consider the hospice alternative before attempting the do-it-yourself approach. Jeri's predicament clearly illustrates why assisted dying must be legalized. It's that missing insurance that she really wanted.

Here are the benefits that legalized assisted dying, Oregon style, provides in this situation:

- ***Greatly reduces terminal anxiety and angst.*** Knowing that you have access to legalized assisted dying gives you peace of mind. It's an insurance policy. You know that you can always pull the plug if things are really bad. You are able to stop worrying prematurely about the pain and agony that the disease might cause in its final stages. It helps lessen your angst during this anticipatory period.
- ***Eliminates a major source of mercy killings.*** There is no need for family members to kill their terminal loved ones who are in pain. The act is now firmly in the hands of the dying person with guidance from the medical team. The family can now breathe a sigh of relief. Family members can attend to the needs of their loved ones at the end without fear that they will be asked to commit murder.
- ***Eliminates a major source of murder-suicides.*** By eliminating the murder half, legalized assisted dying also eliminates the suicide that follows. In a strange way, assisted dying may help preserve life.
- ***Eliminates the need for clandestine pills.*** Legalized assisted dying eliminates the need for dangerous do-it-yourself solutions. Instead of

² Oregon Department of Human Services, *Twelfth Annual Report on Oregon's Death with Dignity Act* (March, 2010).

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the “not-so-lethal” underground pills, you will have access to Nembutal. This means there will be no more botched suicide attempts that require plastic bags over the head to finish the job.

- ***Eliminates the need to incriminate helpful physicians.*** Legalized assisted dying eliminates the need for a euthanasia underground. There’s no need to shop for sympathetic physicians who illegally prescribe lethal drugs. It’s now all out in the open.
- ***Lets you operate within the medical system.*** With legalized assisted dying, you’re not on your own any longer. The medical establishment can help you with all the death-related issues. Your final drugs will come from a reputable pharmacy. The dosage, determined by doctors, will be based on the best medical knowledge. Your designated caregiver can pick up the prescription. You’ll have access to nurses and doctors. In Oregon, doctors and nurses are often present at the time of death. It’s all very familiar, comforting and legitimate. You’re actively involved in all the decision-making that surrounds your death. At the very end, you can decide to die without leaving your bed.
- ***Provides death with dignity.*** Assisted dying lets you decide how much function and dignity you want left when you die. You can wait until everything shuts down, or you can go sooner. You get to determine when enough is enough.
- ***Makes the terminally ill feel they’re in control.*** At the end, you gradually start to lose control over every function. You feel totally helpless. You’re at the mercy of the disease, your caregivers, and the system. The assisted dying option puts you back in control. It would have made Jeri feel that she had total control over the most important decision—her dying. The remote control switch would have been in her hands; she could have chosen to click or not to click. Note: Research from Oregon shows that the primary motivation for physician-assisted dying is the desire for control.
- ***Provides a peaceful and restful death.*** The technology of euthanasia allows you to die painlessly, in deep sleep. It’s what most of us

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envision as an ideal death. There's no need for a violent act of self-destruction. You don't have to blow your brains out, hang yourself with a noose, jump off a cliff, or smother yourself with a plastic bag. You simply fall asleep and never wake up.

- ***Allows the terminally ill to choose the optimum time to die.*** Legalized assisted dying gives you full control over the exact timing of your death. You can decide when enough is enough. This eliminates the timing problem Jeri faced, “Not too early and not too late.” It's important that the choice of the time of death be made by the person who is dying. Typically, the family encourages their loved ones to hold on: we want to enjoy them as long as we can. However, unless you're into sadism, there's nothing enjoyable about watching a loved one being tortured by a disease in its final stages. It's important to let them know that it's okay to go. The decision of when to go is now in their hands. Note: Jeri had a vision of how she wanted to die, but she could have delayed her death as long as she wanted. There was no set date. Also, she didn't have to go that way. All the choices would be hers to make, up to the very last second. And, she could always change her mind.
- ***Makes it possible to visualize one's death.*** Imagining your death can be very empowering and highly therapeutic. For example, Jeri's dream had a very calming effect on her. She could visualize her forthcoming death and see something beautiful ahead. She imagined death as a celebration of her life. It became an event she could look forward to—like a wedding or anniversary. She imagined that her death would be peaceful, in a beautiful setting, surrounded by love and friends. It was a powerful visualization that helped her cope. She was able to look death in the face without fear. Legalized assisted dying makes it possible to envision such beautiful, calming, and self-empowering deaths.
- ***Allows the terminal to focus on the more important issues.*** During the last days of her life, Jeri should not have had to mull over the technology of dying. Instead, she should have spent every waking

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moment enjoying what was left of her life and looking back at what it was all about. Legalized assisted dying would have given her that option.

- ***Eliminates a major source of grief.*** In *Grieving a Soulmate* I explain that “the last days” have a huge impact on the grieving that follows. A “good death” leaves behind loved ones in peace. In contrast, a tortuous and painful death is the stuff of nightmares. During grieving, these final scenes are constantly being replayed and ruminated over. They are the source of lava-hot grieving pains called *grief bursts*. The survivors feel guilt for not having stopped the suffering. They feel helpless for not having been able to help their loved ones when the disease spread. The scenes from the last days can haunt them. When it comes to memories, these last few days can overshadow an entire lifetime of good living. You see your loved one through the prism of these last few days. Consequently, a good death with a proper goodbye is equally important to the survivors.
- ***Provides an iron-clad guarantee that it is voluntary.*** The Oregon model does not require a physician to administer a lethal injection. Jeri could have done it all through self-administration. This provides maximum protection against abuse.
- ***Provides safeguards that benefit the patient.*** States that support assisted dying require that physicians inform the patients about all other treatment options available to them before they prescribe the Nembutal. Mostly, they want to make sure you understand that other avenues may be available. In other words, they want you to be an informed consumer. Typically, two doctors will go over your concerns about pain management, the process of dying, and the loss of control. If you’re overly anxious or depressed, they can send you to a psychiatrist for a trial run of anti-depressants. In Oregon, they’ll point you to a hospice palliative-care specialist who can further explain your options for managing pain and dealing with disability as the disease progresses. Even if she had the Nembutal, Jeri would have used hospice as long as she could keep the pain under control.

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Disability wasn't her biggest worry. She knew that she could fully depend on me with additional help from her girlfriends and home-care assistants. She was going to postpone that final goodbye as long as she could. Jeri made informed decisions. You should note that the role of the physicians is to provide patients with information to help them make these kinds of decisions; it's informed consent. Doctors, hospices, psychiatrists, and family members may have their own biases, values, or agenda. So buyer beware! Remember, it's your life. Only you can make this final decision; no coercion is allowed.

This type of "good death" is definitely within reach in places where physician-assisted dying is legal. This option is now available in the states of Oregon, Washington, and Montana. The next chapter is about hospice and palliative care, our current best options in states where the prohibition against assisted dying is still in effect.

Chapter 3

The Way of Hospice and Palliative Care

“These days, swift catastrophic illness is the exception; for most people, death comes only after a long medical struggle with an incurable condition—advanced cancer, progressive organ failure (usually the heart, kidney, or liver), or the multiple debilities of very old age. In all such cases, death is certain, but the timing isn’t. So everyone struggles with this uncertainty—with how, and when, to accept that the battle is lost. As for last words, they hardly seem to exist anymore. Technology sustains our organs until we are well past the point of awareness and coherence.... In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die.”

—Dr. Atul Gawande¹

Nothing had prepared me for Jeri’s final days: I was completely taken by surprise. Everything happened very fast and it seemed that all I could do was react. After almost ten years of caregiving, I thought nothing could surprise me; I would just deal with each crisis as it presented itself. I was wrong. The last days are very different and extremely demanding. Why was I so unprepared after all these years? The short answer is that there is no step-by-step guide for how to deal with death by cancer—or death from any chronic disease, for that

¹ Atul Gawande, “Letting Go: What Should Medicine Do When It Can’t Save Your Life?,” *The New Yorker*, August 2, 2010.

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matter. I had to grope my way across this strange landscape we call the “end of life” while weighed down by the extreme anguish of seeing my partner go. The only real guidance I had received was from Jeri, who had given me a very clear directive: “Please, make sure I do not suffer at the end. I don’t want pain.”

In this long chapter, I will explain why modern medicine does not do end-of-life well, especially in the era of slow dying. Consequently, the majority of us will end up suffering. We will experience the “bad death.” However, there are sizable pockets within the current system where a relatively “good death” can be had. Think of it as a parallel end-of-life system. With some skillful navigation and lots of luck, you may discover the system of hospice and palliative care. Hopefully, you’ll discover it soon enough to reap the benefits. Hospice is more than just “a place to die.” It’s an end-of-life philosophy. I can tell you from first-hand experience that the end-of-life care Jeri received in that system surpassed my wildest expectations.

To help you understand the system of hospice and palliative care, I will briefly go over Jeri’s last days and the decisions that we faced along the way. The key to a “good death” is to make the transition from the medical system into the parallel end-of-life system and do it soon enough. I will cover the lessons we learned in the process of giving Jeri her good death. You’ll be getting a guided tour of America’s current end-of-life system. I’ll tell you what works, what doesn’t work, and who does what to whom and when. This is the information I wish I had when I was helping Jeri navigate through her dying process.

As good as they are, hospice and palliative care do not provide all the answers. There are many gotchas. This parallel system is not for everyone. It shouldn’t come as a surprise that I’m not particularly fond of terminal sedation; I will explain why the Nembutal does a better job and should be added to the current palliative mix. Furthermore, we need the Nembutal option when all else fails. If I was terminally ill, hospice and palliative care would be my first choice. However, I

would also want a legally-acquired vial of Nembutal in my pocket, just in case. I will end this long chapter by making the case that hospice and the Nembutal can be synergistic: we need both.

Slow Dying: Fighting Till the End

Until recently, the dying process was brief, sudden, and unexpected. Life-threatening diseases—such as infections, difficult childbirth, pneumonia, or heart attacks—would kill within days. Adults lived into their sixties. Today, we live much longer. We die from chronic diseases that progress over years. The quote from Dr. Atul Gawande describes the predicament of slow dying. Typically, it involves a long medical struggle with an incurable condition.

The trajectory of a modern death is slow decline, periodic crises, continuous medical interventions, and then death. This is complicated by the fact that modern medicine has the technology to sustain us past the point of awareness. So it's hard to know when we're actively dying. For doctors and their patients, death signifies defeat. It means losing in the war against the disease. Patients are encouraged to think positively, never lose hope, and fight to the very end. Here's a short description of how these wars play out against our most common chronic illnesses:

- **Cancer.** About one-quarter of Americans will die from cancer. Typically, the fight against cancer starts with a de-bulking operation. Next, there are the endless chemo cycles, radiations, and last-ditch clinical trials. There are visits to the emergency room to deal with chemo side effects. Later, there are hospital stays to deal with the pain caused by the cancer in its final stages. Finally, there's a period of rapid decline; death comes relatively quickly.
- **Heart disease.** This is the leading cause of deaths in the United States and is a major cause of disability. About every 25 seconds an American will have a coronary event, and about one every minute will die from one. This disease once killed people quickly. Now, most of us will live a long time with diseases of the heart and the

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circulatory system. There's a ton of technology that can be thrown into the fight against heart disease. The list includes stents, bypass surgery, defibrillators, valve replacements, transplants, medications, and so on. Each technological intervention has its side effects. Initially, people feel okay on an average day but suffer shortness of breath with physical exertion. Over time the condition worsens and reduces activity to a minimum. In the final stages of heart failure, emergency room visits grow more frequent. Life support medications temporarily improve the pumping of a failing heart. At the end, there are numerous hospital stays to relieve shortness of breath. Sometimes, weeks are spent in rehab facilities. Patients can appear to be near-death one day and then do better the next. Usually, death will be sudden when it happens.

- **Lung disease.** These are diseases like emphysema, pulmonary fibrosis, and chronic bronchitis. They are marked by intense periods of shortness of breath that require hospitalizations. As the disease progresses, the frequency of hospital visits increases. Towards the end, there could be several hospital visits a month as the lungs start to steadily decline. Treatments include the use of round-the-clock inhalers, bronchodilators, and oxygen. Various medications are administered to clear the airways, reduce anxiety, and to fight infections and inflammations. Eventually, patients are put on mechanical ventilators and kept sedated in intensive care units (ICUs). An incision may be made in the throat to insert a breathing tube. Some patients may be released to nursing homes with semi-portable ventilators.²
- **Kidney failure.** Many people have progressively diminished kidney function as they age. The two kidneys can also be damaged by diseases such as diabetes, heart complications, and severe infections. This damage results in an accumulation of toxins in the blood that would normally be cleansed by the kidneys and then eliminated

² David Feldman and Andrew Lasher, *The End-of-Life Handbook* (New Harbinger, 2007).

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through urination. A few lucky patients will receive kidney transplants. The rest will require dialysis treatment to mechanically remove the toxins from the blood. Typically, this treatment is received three times a week and keeps patients alive for years. While prolonging life, dialysis does little to halt the progression of diabetes that may have caused the kidney failure. Often the treatment causes infections in the bloodstream, which may require hospital stays. Of course, diabetes can cause other serious complications that may require amputations and other treatments. Death by withholding dialysis treatment can be relatively peaceful and quick—usually, patients die within seven to ten days. They'll require palliative treatment to ease the transition. In the United States, about 20,000 people each year choose to terminate dialysis and accept death.³

- **Brain failure.** This includes Alzheimer's, vascular dementia (small strokes), and Parkinson's disease. In 2010, 5.3 million Americans of all ages suffered from Alzheimer's.⁴ It's a very difficult disease for caregivers. As the disease progresses, patients are unable to recognize their loved ones or make decisions. In the final stages, they forget how to use their muscles and are bed-bound.⁵ They have trouble eating, swallowing, and breathing. Most end up in nursing homes. Repeated hospital stays may be needed to treat low blood pressure, infections, aspiration pneumonia, and shortness of breath. Eventually, the patient may end up in the ICU on life support attached to ventilators, antibiotic drips, heart monitors, and feeding and hydration tubes.

Modern medicine is a superb fighting machine designed to combat these chronic illnesses. The fight begins with our 911 emergency

³ Lewis Cohen, *No Good Deed: A Story of Medicine, Murder Accusations, and the Debate over How We Die* (Harper, 2010).

⁴ Alzheimer's Association, "2010 Alzheimer's Disease Facts and Figures," *Alzheimer's & Dementia* (Vol. 6, 2010).

⁵ Joanne Lynn and Joan Harrold, *Handbook for Mortals* (Oxford University Press, 1999).

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response systems, hospital emergency rooms, and ICUs. Our physicians are highly-trained specialists with access to sophisticated technology, such as CT and MRI scans, surgical robots, mechanical ventilators, dialysis machines, high-precision radiation, artificial hearts, biotech, and so on. The physicians are trained to win against the disease, and their job is to keep us alive for as long as possible. They have succeeded and we now live into our eighties.

Most of Us Die in Hospitals

The modern medical fighting machine was designed to keep us alive, not to help us die. Death is seen as an “inadequately treated disease”—a failure of modern medicine. Hospitals are not in the business of nursing the chronically ill. They’re not set up to provide end-of-life care. Typically, you are admitted for a specific condition. You are then released as soon as you get treated. In Jeri’s case, she was admitted and released several times during her last two months—mostly, to deal with her shifting pain. Patients with chronic illnesses are often rescued from the brink of death by high-tech interventions in the ICU. It’s a constant roller coaster with recovery, followed by decline, followed by slight improvement. You can never tell when the next visit to the ICU may be the final one.

Note: I believe that most insurance companies require that you be released from a hospital after treatment is completed. You just can’t say, “I think I’m going to die sometime, and I’d like to spend my remaining days in the hospital.” Of course, they’ll take you in if you need prolonged acute care. In this case, you may end up dying in the hospital’s ICU, intubated with all sorts of life-support equipment.

According to U.S. government statistics, about 50% of all patients with chronic illness die in hospitals; another 25% die in nursing homes. (Note: In 2008, 22% of patients who died in nursing homes were also enrolled in hospice.) Most of these hospital deaths are unplanned. Hospitals may provide comfort care when they think a patient has just hours or days left to live.

Nursing homes provide comfort care but very little treatment. They refuse to take responsibility for end-of-life care. Like everyone else, they dial 911 when a patient needs serious medical attention. Typically, the ICU then stabilizes the patient's condition and sends him or her back to the nursing home. This may occur several times before a fragile and exhausted patient dies.⁶ This revolving door between the nursing homes and the ICUs makes it hard to foresee where people in these situations will end up dying.

ICUs and Nursing Homes: The “Bad Deaths”

Dying in a hospital ICU is probably the most brutal type of death in America today. Why? Because ICUs are aggressive, life-saving, high-tech machines. Even for patients with less than a 5% chance of survival, the presence of the life-sustaining technology creates a moral imperative to use it for last-ditch interventions. Instead of dying gently, patients will end up going through a torture process. The torture progressively escalates as the condition worsens—first a ventilator, then feeding tubes, followed by an incision in the chest (a *thoracotomy*) to manipulate the lungs, esophagus, or heart, and the list goes on. If a heart stops beating, a surgeon may have less than a few minutes to rip through the skin, crack open the patient's chest, and then manually massage the organ to force circulation—there's no time for anesthesia. Yes, modern medicine can be aggressive. Here's a description of such a death as witnessed by ICU nurses:

“Sally was 52 years old when she was admitted to our ICU with empyema and severe congestive heart failure. We knew Sally and her family well, including her husband and two teenage children. Sally had spent two months in our unit with viral cardiomyopathy and pneumonia. During her second admission, her team of physicians, including cardiologists, pulmonologists, infectious disease specialists, and cardiothoracic surgeons, agreed that the

⁶ George D. Lundberg, *Severed Trust: Why American Medicine Hasn't Been Fixed* (Basic Books, 2000).

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chance of successfully treating the empyema without a thoracotomy was small. Furthermore, the physicians agreed that extubation after surgery would be unlikely. Unfortunately, Sally did not respond to antibiotic therapy, underwent a thoracotomy, and returned to the unit intubated....

As time went by, Sally began to write ‘let me die’ and to tug at her endotracheal tube. As they restrained and sedated Sally, the nursing staff, caught between the multiple physicians and Sally’s family members, felt increasing emotional turmoil. Although Sally’s family had witnessed her inconceivable deterioration, they were unable to initiate discussions about death and dying and saw no alternatives to her present situation. Although the nurses developed a close relationship with the family, nursing staff were uncomfortable initiating discussions about treatment options. Finally, a new consulting pulmonologist began the discussion of withdrawing life-support treatment. The family responded with relief, and Sally died several months after her admission.”⁷

Watching their loved ones die in the ICU can be very hard on families. Typically, they don’t understand all the complicating factors or the goals of the treatment. The environment is extremely high-tech and disorienting. Families just want the suffering to end. They just want to take their loved ones home like they did during previous ICU interventions. This time, it’s different. Their loved ones won’t make it.

The Modern Torture Chambers

Most patients have not had direct discussions with their loved ones about death and dying. For example, Sally did not have an advance directive. However, even if she had explicitly specified *no intubation* in a directive, it would have been a difficult decision for the family to enforce. For example, what would you do if your loved one in an ICU cried: “Help! I can’t breathe. I’m suffocating”? Many health-care

⁷ P. Miller et al., “End-of-Life Caring in Intensive Care Unit: A Challenge for Nurses,” *American Journal of Critical Care* (Vol. 10, 2001).

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proxies would probably override the directive and request that their loved one be put on a respirator. Unfortunately, it's a slippery slope from then on. One intervention leads to the next. The system has its own dynamic, which you just set in motion.

For the next days and weeks you're likely to watch your loved one being tortured in front of you. The torture chamber is postmodern with bright lights, loud noises, and high-tech equipment everywhere. You'll hardly be able to touch your loved one who is buried in tubes and surrounded by machines. The tubes in the mouth make it impossible to speak. Many will have their arms tied to the side of the bed to prevent them from pulling away the tubes to free themselves. Often, they'll be communicating through their eyes and pleading with you to let them die (or help them die).

Notice that the torture chamber at the end of life is the same facility that kept the chronically ill alive all those years—remember all those interventions. It's part of that superb system that has extended our average lifespan by twenty years. What went wrong? Unfortunately, near the end, our body starts to experience multiple failures as it starts to shut down. The ICU people will, of course, rise to the challenge, as they've always done. They have the equipment and technology to keep almost any organ going. When an organ begins to fail, they respond by attaching a new machine to keep the dying body going. Pretty soon the dying person is totally intubated. There's a machine or intervention for each failed organ. So, the person can be kept artificially alive for weeks and months. Annually, around 540,000 Americans die using ICU services.⁸ As many as 50% of those dying patients receive care that is beyond their wishes during these last days.⁹

The SUPPORT investigation of 9,000 patients dying in hospitals is the most comprehensive study of its kind ever undertaken. The findings

⁸ D. C. Angus et al., "Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study," *Critical Care Medicine* (Vol. 32, 2004).

⁹ G. M. Rocker et al., "End-of-life issues in the ICU: A Need for Acute Palliative Care," *Journal of Palliative Care Supplement* (October, 2000).

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were very disturbing. Here's some of what they revealed about dying in U.S. hospitals: 38% of patients who died spent ten or more days in an ICU; more than 50% of patients who died had moderate to severe pain during the last five days of life; more than 50% of the patients were conscious prior to death; many suffered from shortness of breath; most struggled with severe side-effects such as intense fatigue, confusion, nausea, constipation, skin sores, dry mouth, and itchy skin; only 47% of the physicians knew what their patients' desires for end-of-life care were; only 46% were aware of their patients' do-not-resuscitate (DNR) orders; and 46% of DNR orders were written within two days of death.¹⁰

If you ask me, dying in an ICU is a high-tech nightmare. Watching a loved one die there will make grieving very painful. As Virginia Morris puts it:

“The people who are dying are typically distanced, both physically and emotionally, from loved ones, who can't hurdle the physical intrusions of the hospital, and who often don't have any idea how to help or what to do. They feel powerless and frightened in the face of death. They don't know how to offer their love, to say their good-byes, or to provide solace to a loved one who is dying in such a way.”¹¹

Between hospitals and nursing homes, the situation has become so dire that in 2003 the *National Association of Attorneys General*, an organization of the fifty states' top law-enforcement officials, declared end-of-life patient care the top consumer-protection issue in the country.¹²

¹⁰ The SUPPORT principal investigators, “A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT),” *JAMA* (Vol. 274, 1995). Also check the follow-up articles.

¹¹ Virginia Morris, *Talking About Death* (Algonquin Books, 2004).

¹² Stephen P. Kiernan, *Last Rights: Rescuing the End of Life System From the Medical System* (St. Martin's Press, 2007).

Hospice: Another Way to Die

At this point, you're probably screaming, "Where's the Nembutal?" Hold on! There's another way to die in America. You may still need the Nembutal, but let's first explore the alternative. In 2008, approximately 38% of all U.S. deaths were under the care of a hospice program.¹³ Here's where these people died: 40.7% at home; 22% in a nursing home facility; 21% in a hospice in-patient facility; 6.1% in an assisted-living facility; and 10.1% in an acute-care hospital not operated by the hospice team.

The bad news is that 35.8% were in the hospice program for less than a week before they died. Typically, this means they did not get the full benefits of hospice care. For example, some could have been sent to hospice to die after a prolonged ICU stay. Also, there's another 10.1% who were sent back to the ICU to die. Consequently, only 20% of the dying in America are getting a proper hospice death. The good news is that the hospice movement is spreading out—it's now in nursing homes, prisons, and assisted-care residences. It's also good news that one in five Americans will probably experience a relatively "good death." One in ten may even die in their own home surrounded by family and friends.

So, what makes a hospice death good? The short answer: It's better than the alternative. When it comes to dying, "good" is relative. Hospice death is low-tech, holistic, and family-friendly; it's based on comfort care rather than constant medical interventions. It takes place in a residential setting instead of in a hospital. It focuses on pain management instead of treating the disease. Mostly, it's a more natural and comfortable way to die.

Origins of Hospice and Palliative Care

The modern hospice movement originated in England in 1967, when Dame Cicely Saunders founded *St. Christopher's* to provide palliative

¹³ National Hospice and Palliative Care Organization, *Facts and Figures: Hospice Care in America* (October, 2009).

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care and pain management for the dying. Her program included psychological, spiritual, social, and bereavement services for the dying and their families. Her goal was to create a future in which “no one dies alone or in pain.”¹⁴ She emphasized that family must be involved in the caregiving to ensure that the dying “live fully until they die.” The central medical philosophy of hospice is: “We do not prolong life artificially or hasten the dying process unnaturally.” Dame Saunders was actively opposed to euthanasia. However, she was a big fan of liquid morphine, which she felt the patient did not need “to earn.”

In 1974, Florence Wald, a nursing dean at Yale who worked with Dame Saunders, opened the first U.S. hospice unit in Connecticut. In 1983, Congress approved Medicare payment for hospice care, but only after curative care is stopped—you can’t have both. By 2008, the number of U.S. hospices grew to 4,850. Hospices are now located in all 50 states. According to the *National Hospice and Palliative Care Organization*, “The majority of U.S. hospices are independent, freestanding agencies. The remaining are either part of a hospital system, home-health agency, or nursing home. Hospices range in size from small all-volunteer agencies that care for fewer than 50 patients per year to large, national corporate chains that care for thousands of patients each day. In 2008, 76.7% of hospices had fewer than 500 total admissions.”

Dame Saunders’ early emphasis on “both the sophisticated science of our treatments and the art of our caring” became the basis for modern *palliative medicine*. In 1997, the World Health Organization defined palliative care as: “The active total care of patients whose disease is not responsive to curative treatment.” In September 2006, palliative medicine became a recognized medical subspecialty in the U.S. It now has its own fellowships, hospital departments, and medical school courses. Its practitioners provide pain management, symptom control, and counseling for people with advanced disease. Non-hospice palliative care is offered simultaneously with life-prolonging and

¹⁴ Constance E. Putnam, *Hospice or Hemlock?* (Praeger, 2002).

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curative therapies in hospitals. These programs are now available in more than 80% of U.S. hospitals with more than 300 beds.¹⁵ Palliative care and hospice work in tandem. You can think of hospice as intensive palliative care for people who have stopped curative treatments of their disease. There are an estimated 13,000 hospice and palliative care programs in the world.¹⁶

Hospice and palliative care have changed the paradigm on how we die. Yet, this new paradigm is not very well understood by either the public or the doctors. Some think that hospice implies “giving up.” Others have a vague idea that “it’s where you go to die and it’s a good thing.” However, we rarely understand hospice’s deep implications on how we die. Most importantly, we don’t know how or when to ask for hospice care. So, many of us end up dying in the ICU instead. Some will discover hospice—but not soon enough.

The So-Called “Death Panels”

Most of us prefer to avoid the topic of death. We live in a death-denying culture. However, denial can have some serious ramifications. Closing our eyes and letting the system follow its course could easily land us intubated in an ICU at the end of our lives. To prevent this outcome, we need to protect ourselves and understand our choices. And, we need to think about it while we still can. Typically, it means having several *conversations* about death and dying. This is especially important for the chronically ill. It could make the difference between having a relatively “good death” and a very “bad death.” It’s the difference between dying in the ICU versus dying under the care of hospice.

Ironically, some politicians called these conversations *death panels*, and they campaigned against having them funded by Medicare. It

¹⁵ Amy S. Kelley, et al., “Palliative Care—A Shifting Paradigm,” *New England Journal of Medicine* (Vol. 363, 2010).

¹⁶ William H. Colby, *Unplugged: Reclaiming Our Right to Die in America* (Amacom, 2006).

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seems that they do not want us to have any control over how we die. It seems that even discussing the topic is taboo.

Most doctors would also prefer not to discuss the topic. Why? It's very emotional and complicated. To do it justice would require hours of discussions with the patient. Doctors are trained to heal, not to discuss death. They are taught to fight the disease with everything in their arsenal. No surrender. So they would rather initiate another treatment than deal with the existential issue of dying. Continuing the treatments also protects doctors against malpractice lawsuits.

Luckily, this is an area where palliative-care specialists can be of great help.¹⁷ Even though insurance does not pay for these consultations, we must have these discussions to understand what our options are. In the next sections, I will tell you about three death-related conversations you must initiate: How do I protect myself? When do I stop fighting? Where will I die? The first conversation is straightforward and practical. The next two are blurrier; I will use Jeri's conversations to demonstrate the issues. In states where physician-assisted dying is legal, you can have one more conversation: How will I die? Sadly, it was not an option for Jeri. In Chapter 5, I cover this missing but very important conversation.

First Conversation: How Do I Protect Myself?

This is a conversation you must have immediately. Remember the family tug-of-war over poor Terri Schiavo. You can easily protect yourself from these types of situations by providing an *advance directive* consisting of two documents. You'll need a *Living Will* that specifies the type of life-support care you would want in various situations. For example, "if I become terminally ill or injured" or "if I become permanently unconscious." Because you can't anticipate every situation, you'll also need a *Durable Power of Attorney for Health Care*. This document lets you appoint your *health-care proxy*—the

¹⁷ Timothy Quill, *Caring for Patients at the End of Life* (Oxford University Press, 2001).

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person who will make health-care decisions for you.¹⁸ Be sure to pick a proxy you can trust to navigate the health-care system on your behalf.

Remember, it is a pretty complicated terrain out there: death can be quite chaotic. For example, you may have specified “no intubation,” but what if you need a ventilator for a short time? This is where your choice of proxy becomes important. It’s also a good idea to write a *goodbye letter* that provides additional guidance to your proxy. For instance, you could write, “Don’t continue treatments if there is no hope of recovery to my normal lifestyle.” You can then specify what “normal” means for you. The letter can also include your instructions on cremation or burial and the memorial service. Bottom line: Make sure your proxy knows the system well and understands your wishes.

Some states support the use of a directive known as a POLST form, short for *Physician Orders for Life-Sustaining Treatment*. A health-care professional completes the form after having a conversation with you to understand your wishes and goals of care. Both you and a doctor must sign the POLST form in order for it to be valid. The POLST complements your advance directive and is not intended to replace that document. You should insist on completing a POLST upon admission to any medical facility. It ensures that the physician has read and understood your directives and choice of health-care proxy.

At the end, your physician may issue a *Do Not Resuscitate (DNR)* order. Typically, this medical order is kept in your hospital charts. You’ll also need an *at-home DNR* to keep paramedics from resuscitating you in case someone calls 911. Yes, you must do everything you can to protect yourself from the system.

Additionally, learning more about death won’t kill you. Most of us go out of our way to avoid the topic of death and especially its details. As a result, we’re totally unprepared when end-of-life confronts us. We’re

¹⁸ Every state has its own versions. *The National Hospice and Palliative Care Organization* (www.caringinfo.org/stateaddownload) has all 50 state forms available for free download.

all going to die, so the least we can do is spend a few hours learning about death. The knowledge will make us better navigators and more informed consumers when the time arrives. I tell my friends that they should all read *Talking About Death* by Virginia Morris. Check the resources at the end of this book for additional reading.

Second Conversation: When Do I Stop Fighting?

Eventually, there comes a point where the disease has progressed and it's time to stop the fight and prepare for the next phase—dying. Yes, you must manage your death just like you managed your disease. To do this, you must step back, change course, and redirect your energy. Now is the time to deal with death.¹⁹ Of course, this is easier said than done. When is it really over? Who will make the decision? Who will initiate the discussion?

As I said earlier, each chronic disease has its own trajectory. Each patient is different. The active phase of dying, the body's shutting down, is well understood—I cover this in detail in *Grieving a Soulmate*. What we don't understand well is when to stop the treatment because it's not working any longer. Doctors want to maintain hope, and they always seem to have one more trick up their sleeves. Patients want to live, and so they side with their doctors. However, the danger is ending up dying in an ICU during one more intervention. So how do you change the course?

I will use Jeri as a case study to show what's involved in these conversations. I lifted the material from *Grieving a Soulmate*. If you're interested, you can read the details in that book. Jeri was an incredible chemo warrior. She had fought the disease nonstop for almost ten years. In the previous chapter, we went over how she handled the news that her cancer had spread—about 15 months before her death. She spent the next ten months trying out different chemos and surfing. However, the chemos seemed to be getting less and less effective. We

¹⁹ It may be a good time to read Elizabeth Kübler-Ross, *On Death and Dying* (MacMillan, 1969).

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could tell that the cancer was spreading from the rising CA-125 counts. We stopped counting when the cancer marker rose to 547—the norm is below 35. Outwardly, Jeri was still doing fine. These were very good months for her. She learned how to “walk” on her surfboard. She even managed to get me through my operation and other health-related issues. We took turns caregiving. It was a very sweet time.

No More Chemo

By February 2009, Jeri had exhausted all chemos. After more than nine years, none seemed to work. The cancer had become chemo-resistant. Dr. Terada told us, “I didn’t think I’d ever run out of chemos.” A new CAT scan revealed that the cancer had spread extensively. She had a new tumor on her bladder, and the ones in the lungs had become bigger. It looked like the end was near. Of course, no one could tell by looking at Jeri. She was beautiful and strong. Her friend Kathy would say, “She’s a force of nature.” Outwardly, Jeri looked like a surfer—an athlete. Inside, the cancer was ravaging her.

No more chemo. I was stunned. I felt that same sinking feeling I had when I first learned of Jeri’s cancer. I heard myself asking Dr. Terada, “Does this mean we should start hospice now?” He was taken aback by the question. He reflected for a second and then answered, “No, not yet. You can go talk to them if you like, but it’s not time yet. If you’re in hospice, we can’t do further treatments like radiation. We may need to radiate to manage the pain.”

In contrast to the rest of us, Jeri had a big smile on her face. On the way to the car she told me, “Now that chemo is over, I can just surf every day until I die.” It seemed like a great plan. I was all for it, but I still didn’t have a clue about what would happen next and when. I didn’t want to share my fears with Jeri. Instead, I replied, “Yes, keep surfing.” Jeri did spend the next two months surfing.

I always thought that Jeri’s death process would start with a failed organ. After the latest CAT scan, I expected either the bladder or a lung to go first. Instead, the first thing to fail was a limb. In mid-April, two months before her death, her right leg started to hurt. A week later, she

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was out swimming when the leg pain jumped through the roof. I had to rescue her out of the ocean. It was her last swim. She could hardly walk to the shore. My friend Mike helped me get her back home in a taxi. The next day, she was in a wheelchair. This was the first of a series of heartbreaks. Dr. Terada responded by prescribing Vicodin—her first narcotic painkiller. He also started Jeri on radiation. The hope was that it would shrink the tumors enough to diminish the pain. Perhaps, she would even regain the use of her leg and surf again. We had high hopes.

The Vicodin kept the pain under control for about a week. During that time, Jeri could move around in her wheelchair and go places. But it didn't last long. The pain baseline started to shift upwards again as the cancer spread. The growing tumors were pushing on nerves and causing more pain. Within three weeks she was taking the equivalent of 100 Vicodins per day in the form of Oxycontin, Fentanyl, and Methadone.

How Much Time Does She Have to Live?

Eventually, Jeri ended up in the hospital for pain management. She was treated by a world-class team of palliative-care specialists headed by Dr. Daniel Fischberg. Conveniently, Jeri's radiation treatment was also in the same hospital. So all the doctors she needed were under the same hospital roof. Again, the hope was that this dream team would find the right combination of treatments to get Jeri back in the surf lineup. This time, it didn't work.

About a month before Jeri died, I found enough courage to ask Dr. Terada the dreaded question, "How much time does Jeri have left?" He gave me the straight answer, "Well, I don't exactly know, but it's less than six months." Jeri was on the bed listening very attentively. When he left the room, she said, "Thank you for asking the question. I needed to know. It makes me feel better." In contrast, I felt like I had just been stabbed in the heart. I had to ask her, "Why does knowing this make you feel any better?" She answered, "Now I know what to expect." I was very sad.

Third Conversation: Where Do I Die?

With less than six months to live, Jeri became a candidate for hospice care. Dr. Terada signed a paper that allowed representatives from hospice to talk to us in the hospital. Because of where we lived, the choice narrowed to a single hospice, St. Francis. Tracy, the palliative-care counselor, encouraged us to take the hospice route. She wanted Jeri to be released from the hospital to the hospice. I was not convinced. Here's my best recollection of the exchange that took place that day:

Tracy: Hospices do a much better job than hospitals for end-of-life care. All the surveys show that.

Robert: I'm not convinced. I know, for a fact, that in this hospital you can keep Jeri's pain under control. We could just stay here until she dies. Her insurance covers 365 days of hospital stays. We have Dr. Terada and Dr. Fischberg here. Why would we go anywhere else?

Tracy: Hospices provide excellent pain management. Dr. Terada will still be Jeri's primary physician. In addition, they have their own doctors. Jeri will be much more comfortable there. Probably the most important thing is that they can also help you take care of her at home. She can be at home instead of in a hospital. Besides, you can always return to this hospital if things don't work out. All it takes is one signature.

Robert: But she won't have access to all the hospital equipment. What if she needs an EKG or blood transfusion?

Tracy: Yes, it's a different philosophy. Jeri can always come back to the hospital if she needs special treatment. You should talk to the hospice representatives directly and hear what they have to say. I can arrange for an interview tomorrow.

Tracy's most compelling argument was that I could have Jeri back home. The hospice people would provide round-the-clock support for pain management, which I felt we really needed to make it work from home. Later, I turned to Jeri and asked, "Where do you want to be?"

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The choices are: hospital, hospice facility, or home.” She had a very clear-headed answer, “Let’s first talk to the hospice people and see what they have to say.”

The next day we got a visit from the hospice representative. We wasted no time getting down to the issues that concerned us. Again, this is my best recollection of what was said that day:

Jeri: I don’t want to die in pain. When I need it, will you give me enough pain medicine to make me fully unconscious? How do I know that with a name like St. Francis you just won’t end up sprinkling me with holy water and giving me last rites, instead of inducing a coma?

Hospice representative: You’ll just have to trust your doctors to do what’s right for you. Dr. Terada will still be there with you. We also have our own doctors who’ll be managing your pain at all times.

Jeri: So how would we manage the pain at home? What happens if I get breakthrough pain that suddenly gets out of control in the middle of the night? How do we get the pain meds?

Hospice representative: We provide all your pain meds free of charge. Unlike regular doctors, our doctors can fax pain-medication prescriptions directly to a 24-hour pharmacy where you can pick them up. Our volunteers can also pick up the meds and bring them to you.

Robert: What happens at the brink of death when things start to break down all at once? If it really gets bad, can you guarantee her a room in the hospice facility?

Hospice representative: We’ll always guarantee her a room when she gets into the active death process. We set aside a number of rooms for these type of situations. Just don’t call 911.

Jeri: So, how will you determine that I’m actively dying?

Hospice representative: We will assign you a registered nurse (an RN) who will track your progress. Your RN will be visiting you at home on a regular basis—three times a week, or more if you need it. We also have an RN on duty at all times. Just call us when you need help.

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Jeri: What other services do you provide at home?

Hospice representative: We'll provide—free of charge—all the equipment you'll need for home care. The list includes hospital beds, bathroom chairs, oxygen tanks, commodes, bronchodilators, bedside tables, and so on. We don't provide the actual home care. Your caregiver, Robert, will take care of you. Of course, he may need to hire help. I'll provide you with a list of agencies that specialize in home care. If Robert needs relief, you can stay in our facility—provided we have space. It will cost you \$300 per day.... We're fully booked right now. Would you like me to put you on our waiting list? You can stay in the hospital until a room frees up.

Jeri: Yes, please put me on the waiting list. But Robert and I will need to research this some more before we sign up.

The meeting was very informative. Now Jeri wanted me to visit the hospice facility and report back to her. The next morning, my friend Spinner and I drove up the Pali highway to visit the hospice facility. The landscape was stunning—green forests and steep cliffs with waterfalls, as far as the eye could see. I got off at Queen Emma's summer palace. The hospice was in a beautiful mansion that stood right across from the palace gardens. Inside, the place was immaculate. There was a nice courtyard with tables and chairs. The rooms were superb and the staff seemed very friendly. It felt like we were at a bed-and-breakfast in the Napa Valley wine country. Spinner liked it, too. She said, "Jeri is going to love this place. It's so pretty."

I went back to the hospital to report to Jeri on what we had just seen. I had also talked to many people who said the hospice was really excellent. The ratings were, unequivocally, good. Here's my best recollection of the conversation I had with Jeri that day concerning hospice:

Robert: Where do we go from here? What are your thoughts?

Jeri: I like this hospice stuff. Perhaps, that's the way to go.

Robert: But I want you at home. Of course, I don't want you to suffer. Your comfort should always come first.

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Jeri: It will take a lot of effort to take care of me at home. Why do you want to put yourself through that ordeal?

Robert: Because I love you. I'm really happy to be able to do this for you. I'm glad you saved my life last year, so that I can be here for you today. Last week, you told me you wanted to die near the ocean, looking at Diamond Head. The hospice is in the mountains. Of course, it's beautiful there, too. If I could provide you with the same care, would you prefer to be at home?

Jeri: Yes, I would prefer to be at home. Listen, I have a plan that may work. What I want to do next is to get released to the hospice facility. I can spend a few days there and get to know the doctors and nurses. I also want to see if this hospice stuff works. In the meantime, you can get the apartment ready for me. I'm sure the hospice people will tell you what you'll need for home care. It's part of what they do. You can take me home when you're ready.

Robert: Yep, it's a very good plan. Let's make it happen.

The next day, Jeri was released from the hospital to the hospice. It was on May 28, three weeks before she died. There were many tears as she said goodbye to the team that had taken her this far, but she was excited about going to the hospice. I wheeled her to the car, and we took the short drive up the hill to the hospice. For the next six days, this was her new home. It certainly beat the hospital room.

Jeri really loved the hospice facility and staff. The nurses were exceptionally good. She also liked and trusted her new hospice doctor. From her bed, Jeri could see emerald-green mountains. But, most of the time, she was not in bed. Instead, she was in her wheelchair exploring the grounds and visiting with her friends. She felt very alive. Unfortunately, the people in the adjoining rooms were all in the process of dying. Sometimes, Jeri could hear sounds of death. In the mornings, she was the only patient who could enjoy breakfast on the outside patio, overlooking the mountains.

Jeri felt very alive in a facility for the dying. This turned out to be a good thing because she got to meet the people who would later help

her die. They all got to know her before she was on the brink of death. A few days later she told me, “I don’t belong here, yet. Take me home.” I was ready. With help from friends, I had turned our small apartment into a hospice suite.

Hospice: Not for Everyone

Hospice care certainly beats sudden and repeated trips to the emergency room, followed by lengthy hospital stays. However, to be eligible for hospice care, a doctor must declare that a person has no more than six months to live. Doctors can predict cancer deaths with some confidence. It’s much harder to predict deaths from other chronic diseases.

Unlike hospitals, round-the-clock home care is not covered by insurance for patients who are in the hospice system. Home care for the dying requires an enormous amount of effort and time. It takes a team effort, a village. Caregiving for the actively dying can be incredibly complicated and expensive. For example, Registered Nurses (RNs) typically charge \$50 per hour. In some cases, you may need round-the-clock RN support. Do the math to see if your finances can handle it.

***Warning:** Long-term care could easily be the wild card that wipes you out financially. You should consider buying long-term care insurance while you still can. If you don’t have a caregiver, you may consider moving into a nursing home to obtain round-the-clock care. Again, this can be very expensive without long-term care insurance. Luckily, the poor are covered through Medicaid.*

Pain Management: A Critical Issue

Pain management is a delicate and tortuous balancing act. It may take a lot of tweaking to get it right. “Enough” narcotics is whatever works to alleviate your pain. Hopefully, you’ll remain lucid to have a life. Narcotics can be safely administered for months—or even years—before death. Don’t worry: you won’t turn into a drug addict, even if

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the doses seem terrifically high. At the end of life, there should be no maximum amounts set on pain relief. It's also important to use enough medication to prevent break-through pain. The medication must always stay ahead of the pain.

***Note:** All these medications have side effects—such as constipation, nausea, delirium, somnolence, lack of awareness, and respiratory failure—which must be managed. Also, don't underestimate the effort it takes to acquire narcotic-based meds. Be sure to fill the prescriptions before you leave the hospital. Always factor in the lag time needed to contact doctors and to obtain "permissions" for pain medications. Sometimes, your proxy can also be your pain advocate. Managing pain can be grueling even in hospitals; it's much easier in a hospice setting. Hospice and palliative care departments are particularly adept at end-of-life pain management.*

Some of the extreme pain conditions—for example, nerve and neuropathic pain—may require high-tech procedures, such as the insertion of *epidural catheters* which deliver the narcotic directly to the spine. Typically, the hospice does not provide such procedures. You may want to have these done at the hospital before you sign up for hospice. In addition, *morphine pumps* are an added expense for most hospices. Consequently, they won't provide one unless you ask for it. In the final days, these pumps are needed to provide a steady supply of narcotic into the bloodstream. Make sure your proxy knows all of this.

Often, there will be unbearable suffering when the disease progresses to its terminal stages. Along with regular pain, there is a slew of "distressing symptoms." For example, the vast majority of patients with advanced cancer will have difficulty breathing.²⁰ At the end, they may appear to be gasping for air—they may feel like they're

²⁰ Suresh K. Reddy et al., "Characteristics and Correlates of Dyspnea in Patients with Advanced Cancer," *Journal of Palliative Medicine* (Vol. 12, 2009).

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suffocating. This terrifying condition, called *dyspnea*, can sometimes be alleviated with oxygen, tranquilizers, and opiates such as the ones used for pain. Opiates tend to expand the arteries in the lungs, easing the passage of air. Often terminal sedation may be required to fully alleviate the condition.

In 1990, Dr. Vittorio Ventafridda, one the world's leading pain specialists, shocked the profession when he reported that 50% of his patients with advanced cancer had to be sedated into unconsciousness to relieve their pain. He reported that half of the “unbearable suffering” was caused by pain and the other half by shortness of breath.²¹ To learn more about the experience of end-of-life pain, I recommend you read Marilyn Webb's book *The Good Death*—most of the information in it is still relevant.²²

Palliative Sedation: Can You Depend on It?

Without euthanasia, the only way to control unbearable suffering today is through sedation to the point of unconsciousness—or *terminal sedation*. Patients are given a combination of narcotics, barbiturates, and anesthetics to induce coma. Death comes slowly from either the progressing disease, pneumonia, or starvation if artificial nutrition (and hydration) is withheld.

The hospice movement can claim that all pain can be managed because hospices have access to terminal sedation, which they call *palliative sedation*. They can reassure the dying that even their most distressing physical symptoms can be relieved. Of course, the administration of palliative sedation is just a way to put you to sleep forever. Typically, artificial hydration and nutrition are also withheld to prevent edema in the lungs. When that step is combined with palliative sedation, the person is put into a deep sleep and then allowed to die slowly.

²¹ Vittorio Ventafridda et al., “Symptom Preference and Control During Cancer Patients' Last Days of Life,” *Journal of Palliative Care* (Vol. 6, 1990).

²² Marilyn Webb, *The Good Death* (Bantam Books, 1997).

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Not all hospices use palliative sedation. According to the *National Hospice and Palliative Care Organization (NHPCO)*, its use on terminally-ill patients “ranges between 1% and 52%.” This is a huge spread. It means that some hospices won’t alleviate the excruciating pain at the end, while others use the technique on 52% of their patients.

On May 5, 2010, the NHPCO Ethics Committee issued a position statement on the use of palliative sedation.²³ Their position is that palliative sedation is appropriate “for the small number of imminently dying patients whose suffering is intolerable and refractory.” They define *imminently dying* to mean “a prognosis of death within 14 days.” *Refractory suffering* is “suffering that cannot be controlled despite aggressive efforts to identify tolerable therapy that does not compromise consciousness.” As for a *small number*, it’s somewhere between 1% and 52% of dying patients, but they consider “the upper end of the range as problematic.” Finally, they want the treatment to be *titrated*, which means the level of sedation must be slowly increased to a level that is effective.

I find the NHPCO position to be extremely disturbing. If followed, it will result in a lot of unnecessary suffering. In my view, hospices must initiate palliative sedation *as soon* as the pain cannot be controlled by other means. Remember, Dame Saunders’ vision was to deal with death in the most comfortable and caring way possible—letting people die in excruciating pain is *not* comfort care.

Also, physicians have no way of determining “14 days from death”—especially in low-tech hospice settings with no access to CAT scans and other sophisticated imaging and monitoring equipment. Why 14 days? What’s so magical about that number? The NHPCO’s answer: This is how long it takes to die when hydration is withheld.

²³ Timothy W. Kirk et al., “NHPCO Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients,” *Journal of Pain and Symptom Management* (May, 2010).

Oh boy! I'll have a lot more to say about the serious ramifications of this "ethics directive." It's definitely a step in the wrong direction. Let's not give up on the Nembutal.

Hospice: Yes, There Is Unbearable Pain

Palliative medicine claims that, in theory, it should be able to control 95% of pain among those who are terminally ill. Even in this best-case scenario, more than 100,000 people will die in the U.S. each year experiencing unbearable pain. In practice, the numbers are much higher. Maybe that 95% pain-free number can be achieved, at *Memorial Sloan-Kettering's Cancer Center*, by Dr. Kathleen Foley and her team, which includes the world's leading pain specialists. Unfortunately, these numbers are not being seen at the nation's hospices which provide palliative care for the masses. Even with liquid morphine and palliative sedation, the record is dismal.

Among hospice patients who were asked about their pain level one week before death, 5% to 35% rated their pain as "severe" or "unbearable." An additional 25% reported their shortness of breath to be "unbearable."²⁴ This does not include other symptoms such as open wounds, pressure sores, confusion, vomiting, and emotional pain. The NHPCO's new conservative guidelines will only make this bad situation worse. Of course, hospice is much better than the ICU alternative, where 50% die in pain.

Jeri's Good Death, Hospice Style

Back to Jeri's story. Two weeks before she died, Jeri was back home overlooking the ocean and Diamond Head. She was so happy to be back. For the next ten days, she experienced a textbook-perfect hospice way of dying. The days were filled with fun and laughter. Her "girlfriends" turned this time into one big celebration. "We're going to bring Jeri to the ocean," became their battle cry. They were joined by

²⁴ Timothy Quill and Margaret Battin, Editors, *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (Johns Hopkins University Press, 2004).

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Nicole, our home-hospice RN. And, they enlisted the help of some very muscular Waikiki beach boys, who vowed they would carry Jeri into the ocean and then tow her to the surf lineup.

Everyone laughed and joked a lot. Jeri was slowing down, but she didn't seem to miss a beat. She was the heart of the party. She would soon tire, though, and take a short nap. This is when we planned the outing of the day. For example, we organized shopping trips to buy her new clothes. She would try them on with three of us helping her in the changing room. Several times, we took her out to dinner at some of her favorite restaurants. Jeri enjoyed her outings. She would put on makeup and get all dressed up for the occasion. Even though it made her tired, she was always ready to go.

Watching Surfers From the Moana

Eight days before Jeri died, I rented an ocean-front room at the Moana Surfrider for a 10-day stay. It was right on the beach directly overlooking her favorite surfing spot. For the next five days, the hotel room became our outing destination. We would leave home for the Moana each day at noon and return later in the evening. It was only a five-minute drive, but it took much preparation.

From the lanai of her hotel room, Jeri had a perfect view of what turned out to be the biggest swell of the year. She would wave at her surfer friends. In one gag, the girlfriends decided to bring the ocean to Jeri. So they showed up one day with a big container of ocean water with sand at the bottom. Jeri could then immerse her feet in ocean water while looking at the waves outside.

In the evenings, we would all eat dinner in the room overlooking the ocean. Jeri liked the celebration of life that these feasts represented—the sharing of good food with good friends. Even though she couldn't eat much, Jeri would sit in her wheelchair at the head of the table. Her attention would alternate between the waves outside and her friends inside. She had a say in all that was happening around her. She seemed keenly aware, but she would also withdraw inside her mind for short

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spells. Later, when I grieved, I kept asking myself: “What was she thinking then?” Now, I think I know the answer: She was starting to withdraw from life to prepare for death.

Gasping For Air

Towards the end of the tenth day of Jeri’s home-hospice stay, everything began to unravel. The day started out okay; we took Jeri for her normal outing to the Moana. The surf was up, the girlfriends showed up, and it was a good day. However, that night, Jeri began to actively die. I did everything I could to help her through the night. The next morning, Nicole called to say she was on her way. She walked into our apartment at 8 a.m., accompanied by the hospice doctor. They were followed by the girlfriends. Thirty minutes later, the medical supply people showed up with oxygen tanks. Jeri made a face when she saw them. She turned to her friend Deborah and asked, “Does this mean I’m being grounded?”

For the rest of the day, Jeri seemed to be okay as long as she inhaled her oxygen. She didn’t seem to care for the oxygen nozzle on her nose. She kept pulling it away, which sent her gasping for air. The girlfriends thought she was getting hot flashes, so they would turn up the fan.

That night was really bad. Every half hour, Jeri would sit up, pull away the oxygen nozzle, and then gasp for air. I would respond by soothing her and then gently putting the nozzle back on her nose. This went on all night long. Several times, I called the hospice for advice, but they had none. I was tempted to call 911 to have Jeri put on a respirator, but this was not what she wanted. She definitely did not want to end up on life support in a hospital. So I just held her hand and calmed her down to help her get through another night.

The next morning Nicole called to say she was on her way. But I now faced a new problem: Jeri couldn’t swallow her pain pills. Luckily, we had some liquid morphine from a previous treatment. So I gave her morphine, with Nicole’s permission. But, we had an even more serious problem. After listening to Jeri’s lungs through her stethoscope, Nicole had a very worried look. She said, “I think her lung may have

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collapsed. She's going to die today. We must take her back to the hospice facility, now." I was totally stunned. All I could mutter was, "But, she wants to die at home." Nicole just said, "Robert, she's going to be much better off in our facility. You must do what's best for Jeri. I have a room waiting for her. Our transporters are on their way." All I could say was, "OK, but if she gets better I want her back home."

"I Want to Go Home"

One hour later, Jeri was back in a hospice bed. The doctor had prescribed a heavy dose of liquid morphine. Jeri had a very hard time swallowing, so I requested that they put her on a morphine pump. Unfortunately, the pump didn't arrive until early the next morning. Jeri's girlfriend Kathy volunteered to pick it up herself. The doctor had to intervene to have the delivery of the pump expedited by courier.

Later that Tuesday, Jeri briefly came out of her semi-coma. She pointed her finger at me and then gave me a very loving smile. My heart melted. She also beamed when she recognized the girlfriends. Then she asked, "Where am I?" When she finally realized that she was back at the hospice, she pulled away her sheets and said, "I want to go home. I want to go home." I felt terrible. I had let her down. All I could say was, "Baby, please trust me. You're better off here." Luckily, the girlfriends were able to distract her and they talked about something else.

The Death Rattle

The girlfriends and I kept the vigil going around the clock. Jeri woke up once and gave me her most beautiful smile. I gave her a very wet kiss. I noticed her lips were dry, so I kept moistening them with kisses. I was holding her hands when she said, "I'm so tired. I need to rest." These would be her last words. She then fell into deep coma for the next two days. Jeri seemed to be at rest, at last. But on the evening just before she died, she began to make loud gurgling sounds as she breathed. I was terrified. I called the nurses. They tried to clear her throat, but the sounds didn't stop. The gurgling continued for the next

two hours. The nurses kept reassuring me that she was not in pain. I still wanted them to do something. Later, I was to find out that this was the infamous “death rattle.” Jeri died a few hours later. Her heart just stopped beating. Goodbye my love.

Hospice: Superb, but Suboptimal

Jeri experienced the perfect hospice death. She was not alone when she died and death came relatively quickly. Later, a nurse told me she may have died rapidly from a blood clot that penetrated the lungs. In any case, she had a very soft landing. The big surprise was how well hospice worked. Yes, it’s a radical departure from the ICU. The system focuses on total care for the dying and the people who are with them at the end. Hospice is not just “a place to go to die.” Hospice is a set of beliefs—a new philosophy for health care. It works exactly as Dame Saunders envisioned it: “As long as a person continues to live, a great deal can be done.” However, the system also has a major flaw. Here are my observations:

- ***Hospice people understand dying and are the perfect guides.*** Without a doubt, the hospice team that took care of Jeri really understood death and dying—they were pros in a death-denying society. Over the years, hospices have accumulated a tremendous knowledge-base on dying. They’ve become society’s repository of information about end-of-life—a very valuable service for those of us who have no familiarity with death. Most importantly, the hospice people also understand the emotional needs of the dying. I watched them talk softly to the dying and treat them like people till the very end. They were gentle, compassionate, and caring. They even helped me with my grief after Jeri died.
- ***Hospice helped Jeri die in a non-clinical setting.*** Jeri fully experienced the hospice way of dying. She received the best comfort care. Initially, the pain management technology was top-notch and it kept her relatively comfortable. Jeri was able to enjoy most of her remaining days at home surrounded by loved ones. She was able to visit places and say her goodbyes to the world. There was much

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attention to detail that made all this possible. For example, the hospice home nurse would tweak the pain medicines almost daily to allow Jeri to go on her outings. The nurse even tried to provide a beach wheelchair to take Jeri to the ocean. The last days are made up of many small gifts. There is a lot of life at the end—mostly in pursuit of these small gifts and joys. Hospice is about “allowing a dying person to live their last moments.”

- ***Hospice enabled Jeri’s loved ones to help her die.*** Helping Jeri die was a profound and loving experience for us. It was, by far, the most tender and loving caregiving moments I had ever experienced with Jeri. I was so much in love with her at the end. It’s impossible to imagine two people being more intimate and close. It’s incredibly sad to see your lover go, but it’s also a powerful bonding experience. It is the culmination of your love. The experience was also profound for the girlfriends and their husbands. Thanks to hospice, Jeri was back at home with us. Home and the Moana were so much better than being at the hospital. Despite her deteriorating situation, Jeri was able to enjoy life’s little pleasures and make the most of them. We knew that she would only be with us for a short time, so we wanted to savor every moment. We were able to shower Jeri with love to alleviate her angst. Hospice facilitates this type of bonding by providing a family-friendly setting. It’s a very special privilege to help a loved one die well; hospice enables us to exercise this privilege.
- ***Hospice’s weak link, palliative sedation, is suboptimal.*** It works, but it’s crude. Compared to the Nembutal alternative, it results in a lot of unnecessary suffering. In *Grieving a Soulmate* I calculated that if euthanasia had been an option, Jeri would have avoided the suffering of Monday night and Tuesday morning—a total of 16 hours. Jeri did not experience the best possible death for her situation, but she came very close. We were just 16 hours off the ideal time. When it comes to grieving, 16 hours of witnessing unnecessary suffering can haunt you for a very long time. You remember every second and replay every scene over and over again. I wrote this book because of these

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16 hours. Jeri wanted to die in her own way. She had a dream. Unfortunately, that option was not legal in Hawaii when she died. We gave her the best possible death under the circumstances. She was lucky to have palliative sedation as her second-best option.

Personal note: *Am I expecting too much? Some of you may be thinking that Jeri had a wonderful death, compared to most people. In the bigger scheme, 16 hours of pain and suffering does not appear to be much. Why make it such a big deal? The answer: It is a big deal. Here's something to chew on. Just imagine that your house is invaded by a gang of sadists. They tie you up, gag you, but leave your eyes uncovered so that you can watch. Over the next 16 hours, you helplessly watch while they torture your loved one to death. How would you feel? Yes, it's a big deal. The disease was the invader and I stood by helplessly watching Jeri suffer. Given that she was a strong proponent of euthanasia, she ended up suffering needlessly during those 16 hours. She even said, "I waited too long." To calibrate you, Jeri was incredibly tough. This opinion was shared by all her doctors, including the palliative pain specialist. Those four words meant that her pain had reached unbearable levels—a lot more than most people could stand. It was torture. Jeri was needlessly tortured because of the prohibition against the Nembutal. I wrote this book because of those four words: "I waited too long." They haunted me during my grieving.*

Hospice: The Report Card

The good news is that we have a superb end-of-life system, that almost works. The hospice system needs some serious tweaking, but we're lucky to have it. It's the polar opposite of the ICU alternative. So, in America today we can have the best of deaths or the worst of deaths. We can have hospice or we can have intubation. We can have comfort care and pain control, or we can have last-ditch heroic interventions. In the next section, I will explain how Nembutal can make hospice an even better experience. I will also present a modest proposal for improving hospice without the Nembutal.

Hospice and the Nembutal: The Case for Synergy

Here's an interesting statistic: In 2009, 91.5% of Oregon's terminally-ill patients who took the Nembutal route were also enrolled in hospice at the time of death; 98.3% died at home.²⁵ Why did these people choose the Nembutal while they were under hospice care? Clearly, something was lacking. Yes, hospice is a wonderful system. I will explain that it can be even better if the Nembutal is added to its palliative repertoire. It would be one more comfort option available to hospice patients at the very end. They could benefit from the hospice way of dying and also have the Nembutal if they request it. There's a case to be made for synergy.

Nembutal or Palliative Sedation: The Ethics

Before I start explaining what the Nembutal brings to the table, let me quickly address the ethics of Nembutal vs. palliative sedation. As you know from Chapter 1, death from palliative sedation, even when accompanied by voluntary starvation and dehydration, is totally legal in the United States. In June 2008, the *American Medical Association (AMA)* endorsed the practice at its annual meeting. Palliative sedation is morally and ethically accepted—even by the Catholic church. As the 2009 directive of the *National Conference of Catholic Bishops* explicitly states: “It is not euthanasia to give a dying person sedatives and analgesics for the alleviation of pain, even though they may deprive the patient of use of reason, or shorten his life.” This wide acceptance is based on two principles: 1) the main *intent* of terminal sedation is the relief of pain, which is a good thing (i.e., the principle of *double-effect*); and 2) the voluntary withholding of nutrition is based on the patient's right to refuse treatment (i.e., the right of *self-determination*).

Interestingly, that same reasoning can be applied to the Nembutal approach. Harvard professor of medical ethics Dr. Dan Brock makes a

²⁵ Oregon Department of Human Services, “*Twelfth Annual Report on Oregon's Death with Dignity Act*,” (March, 2010).

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very convincing case to that effect.²⁶ The Nembutal approach involves two separate acts by two parties: the physician and the patient. Dr. Brock argues that the physician can justly claim that the Nembutal prescription's main intent is to relieve the patient's *anxiety about dying*. Because of the great advances in palliative care, the physician can truthfully claim that he or she does not expect or intend that the patient use the Nembutal to die.

The patient is told that no one needs to die in pain—the system says “trust us.” Consequently, the patient can claim that the primary intention is not to use the Nembutal but just to have it as a form of backup insurance. If all else fails, the patient will take the Nembutal to relieve the pain—death is just a side effect. *Warning*: Like morphine, too much Nembutal can cause death.²⁷

According to the time-honored principle of the double effect, the Nembutal option is ethically and morally justified. As you know from Chapter 1, I am not a fan of the double effect doctrine. I only use it here to put Nembutal on par with palliative sedation from an ethics perspective. It may give ethicists something to ponder, while we move on to the more practical issues. I'll have a lot more to say about the ethics and safeguards in later chapters.

Nembutal or Palliative Sedation: Which Is Better?

By now, it should be clear that hospice provides a compassionate way to die. However, I have a lot of misgivings about palliative sedation. The biggest advantage of palliative sedation is that it is legal and available today. Another advantage is that it does not require you to take your own life, a big plus for most people. However, the method has some very serious shortcomings, when compared to the Nembutal

²⁶ Timothy Quill and Margaret Battin, Editors, *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (Johns Hopkins University Press, 2004).

²⁷ Sidney Wanzer and Joseph Glenmullen, *To Die Well* (Da Capo Press, 2007).

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alternative (i.e., the Oregon approach). Here are the advantages of Nembutal over palliative sedation:

- ***Provides optimal timing.*** You get to control the right time to go. Pain is very subjective, and only you can determine what constitutes “unbearable pain.” You take the Nembutal at the point when hospice cannot control the pain by any other means. Your pain relief is immediate. You don’t have to deal with the NHPCO’s edict of “waiting until 14 days before death.” You don’t have to deal with their “titration” or go-slow edict. Even in cases where the doctors approve the palliative sedation, you don’t have to suffer “16 hours” of torture while waiting for the morphine pumps to be connected. These long response-times translate into unnecessary torture. The torture must be made to end within minutes—not hours, days, and months. The Nembutal response-time is guaranteed to be within minutes.
- ***Guarantees relief in an unpredictable system.*** The Nembutal is your guaranteed delivery method for relieving unbearable pain. It protects you from the whims of hospices that do not provide palliative sedation. It protects you from being tortured in an ICU. You have peace of mind. You carry your delivery-from-pain mechanism with you at all times. You are not at the whim of a capricious and unpredictable system. Even with hospices, there’s no way to tell in advance whether they will use palliative sedation even if you need it. The NHPCO numbers indicate that there’s a huge disparity among hospices in the use of palliative sedation. With usage numbers ranging between 1% to 52%, obtaining palliative sedation in a hospice becomes pure luck of the draw. You’ll need the Nembutal option to protect yourself from the vagaries of the system. Hopefully, you’ll never have to use it.
- ***Guarantees that it’s voluntary.*** Palliative sedation happens as part of the treatment. The act can be carried out without an explicit discussion with an alert patient. Yes, it’s hard to think clearly when you’re in pain. There may be a consultation with the family before

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the sedation is applied, but it uses a lot of code. Why? Because it can't be explicitly said that the patient is being killed. In contrast, the Nembutal approach lets you take your own life. There is no possibility of abuse. There is no code to decipher. By taking your own life, you are ensuring that you sincerely and independently opt for death. The act is not impulsive, for you have thought about it well in advance. In Oregon, you discuss it with two physicians ahead of time; there is ample time to think about it and be evaluated for depression.

- ***Lets you self-administer.*** Unlike palliative sedation, Nembutal does not require that a physician or RN administer the medication. You, not the physician, are able to perform the final act that terminates your life. This gives you full control of the process until the very last moment of your life. And, you can always change your mind, up to the very last second.
- ***Increases your chances of dying at home.*** You can self-administer the Nembutal anywhere, including in your own home. In contrast, palliative sedation requires a morphine pump. Consequently, you must either be admitted to a hospice facility or make arrangements to have round-the-clock RN coverage at home (an out-of-pocket expense).
- ***Reduces the grieving pains of your loved ones.*** With Nembutal, death is quick and peaceful. There are no traumatic images of unbearable suffering etched in a survivor's memory. So, there is less grieving pain. In contrast, terminal sedation is a slow process. Typically, the survivors witness pain followed by a long comatose period of slow dying. During that period, the body deteriorates slowly from starvation, dehydration, or the advancing disease. The memories can be traumatic. Also, the survivors may witness some distressing scenes like the "death rattle." The dying person appears to be choking, but we are told there's no pain. Nevertheless, it's painful to watch. These final scenes can override a lifetime of good memories and have a huge impact on grieving. In my opinion, this

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dying slowly and in a coma process is not respectful, nor dignified. For the survivors, it appears cruel and inhumane; it can translate into a lot of grief.

- ***Lets you choose the level of dignity you want.*** With Nembutal you can decide how much of yourself you want left when you go. In contrast, terminal sedation will only be given if there is unbearable physical pain. The NHPCO guideline does not deal with the emotional and existential pain associated with dying. It doesn't address a dying person's need for dignity. Note: We each have our own definition of self-dignity. The dying person must be allowed to make that decision.
- ***Lets you say goodbye.*** With Nembutal the act is very specific and the intention is clear. You know when to say your goodbyes. In contrast, palliative sedation is cloaked in code. The dying part is not explicitly stated. The loved ones are often confused and then surprised by the finality of the act. Some request that the patient be revived from a coma to say their goodbyes.²⁸
- ***Provides a safer way to die.*** Nembutal is immediate and peaceful. In contrast, palliative sedation involves a long process of decay, which can sometimes last several weeks or longer. Sometimes, the decay can be quite severe. For example, there could be uncontrolled bleeding from an eroding lesion. The hope is that the dying person is actually free of suffering during the process, as opposed to being simply unable to report it. There is no published evidence that sedation relieves pain and other symptoms, even if the dying person appears calm.²⁹ This situation may be similar to surgery, where patient awareness occurs between 2% and 3% of the time without the knowledge of the anesthesiologist. It's pretty scary stuff.

²⁸ Anemona Hartocollis, "Hard Choice for a Comfortable Death: Sedation," *New York Times*, December 28, 2009.

²⁹ Mellor P. Davis, "Does Palliative Sedation Always Relieve Symptoms?," *Journal of Palliative Medicine* (October, 2009).

From the above, you can see that the Nembutal approach has many advantages. In states where it is legalized, it has been added to the repertoire of palliative choices for the dying.

Nembutal and Palliative Care: The Synergy

You may remember that Dame Saunders, the founder of the modern hospice movement, was a firm opponent of euthanasia. She felt that hospice could do the job better; euthanasia was not needed. As I explained throughout this chapter, hospices are doing a marvelous job helping us through the dying process. However, their practice of palliative sedation does not offer the kindest of deaths. I made the case that, for some, the Nembutal provides an excellent alternative at the end. It makes palliative sedation almost seem barbaric.

To recap, palliative sedation, today, is a totally discretionary practice. The doctors decide if and when to give it. The patient does not choose the timing nor provide informed consent. Also, I'm not a big fan of the comatose, slow-death vigil that accompanies palliative sedation. It's painful to watch your loved one melt away before your eyes. You don't want to remember him or her as an unconscious, living cadaver. It violates the dying person's dignity—especially if a final directive expressed an unwillingness to be maintained in a vegetative state. For all these reasons, the Nembutal must be added to the hospice palliative care continuum of choices.

Luckily, things are changing. In 2007, the *American Academy of Hospice and Palliative Medicine (AAHPM)*, the professional organization representing hospice doctors and nurses, softened its opposition to physician-assisted dying. Noting that its members were divided on the issue, the organization changed its stance from oppositional to neutral.³⁰

The experience in Oregon continues to show that legalization of physician-assisted dying leads to improved palliative care. Oregon leads all other states in several important measures of the quality of

³⁰ Source: <http://www.aahpm.org/positions/suicide.html>.

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palliative comfort care.³¹ And Oregon doctors report that, since the passage of the *Death with Dignity Act*, several important steps have been taken to improve the quality of end-of-life care—including better use of pain medications, improved ability to recognize psychiatric disorders in the dying, and an increased number of patient referrals to hospice care.³² Oregon leads the nation in terms of numbers of deaths occurring at home, the training of physicians in palliative care, and organized statewide use of POLST directives. Oregonians know that if they ever face a terminal illness, they will have control and choice over their manner of death. It appears that in states where the prohibition is lifted there is synergy between hospice and the Nembutal.

Modest Proposal for Palliative Sedation: Call 911

In the long run, the Nembutal may become a legal option everywhere. In the short run, we have palliative sedation for those who receive it. Is there a quick fix? Surprisingly, the answer is yes.

Here's my modest proposal for improving the practice of palliative sedation. I address it to the NHPCO and AAHPM:

Ladies and Gentlemen:

Thank you for all your work on behalf of the dying. Here's a modest proposal to improve your practice of palliative sedation. With these small changes, you can help millions die in less pain. My proposal is as follows:

- *Upon admission to a hospice program, patients will be provided with a bracelet identifying them as eligible for palliative sedation, should they request it. The hospice and patient must sign a legally binding agreement.*

³¹ R. Steinbrook, "Physician-Assisted Suicide in Oregon: An Uncertain Future," *New England Journal of Medicine* (Vol. 346, 2002).

³² Kathryn L. Tucker, "Choice at the End of Life: Lessons from Oregon," *American Constitution Society* (June, 2008).

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- *A patient who feels hospice pain management is not alleviating excruciating pain has the right to dial 911 and report a terminal-pain emergency.*
- *The 911 emergency response teams will respond rapidly. Their normal goal is to have a paramedic on the scene within 6 to 10 minutes. If my proposal is implemented, the team will identify the call as a request from a terminal patient for unbearable pain relief. The responding paramedic can verify that the patient is indeed terminal from the bracelet and computerized data.*
- *The paramedic will then ask the patient if palliative sedation is wanted and explain the consequences. If the answer is yes, the paramedic will hook the patient to a morphine pump and other sedation drips. The ambulances will carry the pump as standard equipment along with a standing order from hospice doctors to use it on this class of patient. Currently, ambulances carry morphine but not the pump. All paramedics are already trained to provide IV support.*
- *The patient will not be moved to a hospital facility. The administration will be performed on-location (typically, the patient's home). The hospice team will be notified, but their permission is not required. They will attend to the patient as soon as possible.*
- *The total elapsed time between the patient's call to 911 and the morphine starting to take effect must be less than one hour.*

Our taxes have financed the EMS system, which is responsible for saving millions of lives. This modest proposal says we should use this proven and familiar service to relieve the suffering of the dying. Excruciating dying pain is a reason to dial 911. The hospice movement must take advantage of 911, not avoid it.

While I have your attention, I also propose that your palliative care specialists issue bracelets to terminally-ill patients when admitted to hospitals and ICUs. This will allow any patient suffering unbearable

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pain to request immediate sedation. Hopefully, your teams will be on location to ensure it all happens.

Respectfully,

Robert Orfali

I won't hold my breath waiting for something to happen.³³ The benefit of this proposal is that it rationalizes the terminal process within the current system. No new laws are required. Under my proposal, palliative sedation becomes an explicit right for the terminally ill; it's a contract. All hospices and ICUs must provide it on demand. Bringing 911 into the process guarantees response times of less than an hour.

In addition, the proposal standardizes the process. It's not ad hoc any longer. The patients and families will be involved. Everything becomes very explicit and transparent. This eliminates the vagaries of the current system. Instead of the act being performed at the discretion of doctors, it becomes a patient's right. As part of informed consent, the patient will be able to request it. Most importantly, the practice can be expanded to the ICU. Of course, there will still be a slow-death vigil. We must keep pushing for the Nembutal option.

Bottom Line

We have two health-care systems in America today: modern medicine and hospice. (Palliative care is mostly associated with hospice, but it also has pockets within the medical system.) In the age of slow dying and chronic illnesses, we need both systems. The ICU works well for us, most of the time. It does what it was designed to do, and it does it very well. There is no need to change something that works. We have a superb illness-fighting machine. Hospice is also a superb system; it provides outstanding end-of-life care for the dying (except for terminal sedation). So, we are lucky to have two systems that work, each one superb in the function it was designed to perform.

³³ Note: I will submit the proposal after this book is published, in order to provide the necessary background.

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So what's the problem? The problem is that we live in a death-denying culture that makes it very hard to transition from one system to the next, when the right time arrives. We, and our doctors, have a very hard time accepting death. Consequently, most of us won't make the transition in time. We will end up dying in the ICU—a modern torture chamber for the dying. As Dr. George Lundberg, a former editor of the *Journal of the American Medical Association (JAMA)*, describes it: “A sophisticated hospital is the last place you want to be when terminally ill. Once you're in the hospital setting, you're trapped. The staff owns you, and they will do those terrible things they have been trained to do to prolong life, no matter how artificially or hopelessly.”³⁴

Note: Moving to hospice sooner may even prolong our lives. In a recent study, the mean survival was 29 days longer for hospice patients than similar patients who did not choose hospice.³⁵ In another study, patients with terminal lung cancer who began receiving palliative care immediately upon diagnosis not only were happier, more mobile, and in less pain as the end neared, but they also lived nearly three months longer.³⁶

The ICU was never designed to help us die; it was designed to fight disease to the end. We want our illness-fighting machine to continue doing what it does best. Instead of changing the ICU, we must change our death-denying attitude. We need to better understand the end-of-life hospice option, so that we can die in peace. In other words, we must have these open *conversations* that help us make the transition to

³⁴ George D. Lundberg, *Severed Trust: Why American Medicine Hasn't Been Fixed* (Basic Books, 2000).

³⁵ S. Connor et al., “Comparing Hospice and Non-Hospice Patient Survival,” *Journal of Pain Symptom Management* (Vol. 33, 2007).

³⁶ Jennifer S. Temel et al., “Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer,” *New England Journal of Medicine* (Vol. 363, 2010).

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hospice care at the right time (i.e., before we end up in the ICU end-of-life torture chamber).

I used Jeri's end-of-life experience to demonstrate the nature of these conversations, which happen over a period of time. I showed that there are at least three conversations on death and dying that you must have. They're not easy. Where available, the palliative care people can help you understand your options. If you're lucky, you will make the transition to hospice and won't become another ICU death statistic.

Again, I used Jeri to explain what hospice is all about. It's a wonderful, caring system for the dying. It provides top-notch pain management, most of the time. We have the best dying specialists anywhere and they're trained to be compassionate and gentle. They really understand the needs of the dying. We're lucky to have hospice as an option.

I also used Jeri's example to demonstrate the weak link in hospice today: palliative sedation. It's a slow, and often messy, way to die. It can torture the dying and leave the survivors with painful memories, which will have a big impact on their grieving. Hospice must be a torture-free zone. So, I proposed a quick fix. If the hospice people insist on terminal sedation, then they must also provide a rapid response-time system to deal with the excruciating final pain. They must connect a morphine pump in less than an hour to a patient who requests it. Yes, dying pain is an emergency. I proposed that we be able to dial 911 from within the hospice system.

Good palliative care and the availability of the Nembutal are not mutually exclusive. I made the case that no dying patient should go without good palliative care; but, currently, good palliative care does not alleviate the suffering of all dying patients. In states where it is legal, the Nembutal provides another palliative care option—an alternate way to die. It allows us to combine the beautiful hospice end-of-life experience with a "gentle and easy death." I made the case that the Nembutal is far superior to the current terminal sedation approach, with its slow and often agonizing route to death.

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Of course, we must each be allowed to decide what works best for us (i.e., how we want to die). The Nembutal is the drug of choice for those who do not want to be sedated into oblivion. For others, it serves as insurance; it's there, just in case they need it. Death remains the great "untamed." We need to keep *all* our palliative care options open. There is no right way to die. Every effort must be made to improve end-of-life palliative care. We must provide a continuum of palliative options to control pain and to prevent end-of-life suffering. To sum up, we have almost all the ingredients to make dying a gentle journey and death a dignified final exit. All we have to do now is legalize the missing ingredient, the Nembutal.