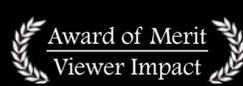


Discussion Guide

Consider the Conversation

a documentary on a taboo subject



Best Shorts International Competition

Dedication

*For Rita Bernhagen, Peter Kaldhusdal,
Dee Bennett and Martin Welsh—
four patients who taught us what matters most in life.*

*For Janet and Denise, whose sacrifice enabled their
husbands to complete this labor of love
for the benefit of others.*

Consider the Conversation™

A documentary
on a taboo subject

Produced by
Michael Bernhagen
and
Terry Kaldhusdal

Copyright 2011

Burning Hay Wagon® Productions
www.considertheconversation.org



Introduction



Dear Reader,

In the fall of 2005, Terry Kaldhusdal and I were sitting around the fire during our annual father/child camping trip in Wisconsin's beautiful Kettle Moraine State Forest.

As usual, our conversation covered many topics, but for some reason that evening, we landed on the subject of end-of-life care in America. At the time, I was two years removed from the painful loss of my mother to congestive heart failure and vascular dementia, and one year into my work as a community educator with one of the nation's largest providers of hospice care. Terry, meanwhile, was busy teaching fourth grade at Magee Elementary School in Genesee Depot, Wisconsin, and producing *The General of Progress: The Story of John S. Rockwell*, his first documentary film.

Terry listened, spellbound, as I told the story of my mother's death and lessons learned from meetings with doctors, nurses, social workers, clergy, terminally ill patients, and family members. "Someday, I'd like to make a documentary on this subject," Terry responded. "Would you be willing to help?"

Then in late April 2007, we arrived at a tipping point when Terry's brother, Pete, was diagnosed with pancreatic cancer.

Two years later, on May 7, 2009, we shot our first interview with Vermont author Stephen Kiernan. Terry was behind the camera and I conducted the interview—roles that would become the norm moving forward. Strangely enough, Stephen's answer to the last question in our 90-minute session became the film's conclusion and we worked backwards from there.

Over the course of the next 14 months, we conducted more than 100 interviews for *Consider the Conversation*—including 62 impromptu "person on the street" conversations in New York City, and over 40 in-depth interviews with patients, family members, doctors, nurses, social workers, clergy and national end-of-life-care experts from around the country. Our aim was to provide a 360-degree perspective on what it means to die in 21st-century America. What we learned is that most people find it extremely difficult to communicate about and prepare for the end of life.

It is important to understand that this project did not follow a path that is typical for most documentary films. First, *our motivation was highly personal*—we both lost loved ones to chronic disease and struggled, like most Americans do, to make sense of what was happening. Second, *there was no business plan*—we had a general vision but nothing mapped out in terms of strategies, tactics and timelines. In other words, we relied heavily on intuition and watched as the project took on a life of its own. Third, *funding the project was extremely challenging*. Not only were we unknown amateurs proposing to make a film about a difficult subject, our timing couldn't

Introduction cont.

have been worse. It was a time when the country was embroiled in debate over healthcare reform and the controversial topic of “death panels.” As a result, the grant proposals we submitted were rejected. Even those who believed strongly in the project’s worth and mission were not willing to provide financing.

Thankfully, the board of directors at Rainbow Hospice Care of Jefferson, Wisconsin (my employer) recognized the immense social value of the film, and offered, later that year, to establish a restricted fund allowing third parties to make tax-deductible contributions to the project. Ultimately, \$43,000 in private donations was raised to cover travel and other expenses. Even so, Terry and I donated more than 3,500 hours of our personal time towards the project. Without any of these factors, *Consider the Conversation* simply would not have been possible.

When filming concluded in Chicago on June 29, 2010, Terry began the laborious process of editing 70 hours of film down to one hour and I began to focus my time and energy on achieving our next priorities: 1) PBS broadcast, and 2) release of the film on DVD. What has happened following the conclusion of this work is nothing short of miraculous. First, the film was released on DVD via Amazon.com for personal and educational use on March 1, 2011. Since that time, individuals and organizations from five Canadian provinces, 49 U.S. states, and the District of Columbia have purchased the DVD and are using it to educate themselves and others. Then, on June 18, 2011, *Consider the Conversation* was released to PBS stations throughout the country, resulting in a groundswell of interest nationwide.

Our goals for *Consider the Conversation* are simple, but far from easy. First, we hope to change the

commonly held American attitude that views end-of-life as a *failed medical event* to one that sees it as a *normal process rich in opportunity for human development*. Second, we hope to inspire dialogue between patient and doctor, husband and wife, parent and child, minister and parishioner. And third, we hope to change behavior by encouraging medical professionals, healthcare organizations, and clergy to take the lead in counseling others.

Know that *Consider the Conversation* does not provide any particular answer—to do so would be to convey ignorance about the fact that the American culture is highly diverse. Instead, *it provides the questions all of us need to contemplate and answer for ourselves*. That being said, the film aligns beautifully with the concept of advance care planning which is all about talking with patients about their end-of-life wishes, documenting them and taking action to ensure they’re honored. It is our hope that hospitals, hospices, home health agencies, medical schools, nursing schools, universities, faith communities, end-of-life coalitions, etc. will use *Consider the Conversation* to educate their various constituencies and initiate dialogue in their communities while being sensitive to the unique perspective and needs of the individual. Without question, the time is now for 21st-century Americans to consider the conversation.

Sincerely,



Mike Bernhagen

Co-producer, *Consider the Conversation*

About this discussion guide



Consider the Conversation is made up of nine scenes, each with a different theme, which we refer to in this discussion guide as chapters. This discussion guide is further divided into four parts.

Part I contains a synopsis of each of the film's nine chapters; supplemental information that expands on the concepts featured in that chapter; and "questions to contemplate," pertaining to key concepts you may wish to think about and discuss.

We hope these questions spark honest, serious conversations about topics that people often want to avoid. And we encourage viewers of this film to raise their own questions as well. Each chapter ends with a behind-the-scenes look at the making of that segment of the film. Note: *To help create a more succinct yet accurate summary of each chapter, many of the synopses include words taken verbatim from filmed interviews (without giving specific credit to the person making the statements) and therefore cannot be attributed directly to the producers.*

Part II contains background information about the people involved in the project—the producers as well as those featured in the documentary. It includes our editorials that were published in the "Crossroads" section of the *Milwaukee*

Journal Sentinel and biographies of the courageous patients and professionals who share their experiences in the film. The editorials, in particular, provide the reader with key insight as to why a hospice worker and a fourth-grade teacher from the Midwest would embark upon such a journey as this.

Part III lists a wealth of additional resources the reader can access to obtain more information and support. This list is by no means comprehensive—however, it does provide myriad pathways to numerous other works, organizations, individuals, ideas, perspectives and practices related to matters concerning end of life, caregiving, grief, and other relevant topics.

Part IV acknowledges the numerous individuals and organizations whose support made this documentary a reality. Without their involvement and most generous contributions of funds, in-kind services, and encouragement, we would have never been able to move forward with our dream to produce this film.



Table of Contents

Introduction.....2

About this discussion guide.....4

Part I: The Film’s Chapters

Chapter 1: Wishes.....6

Chapter 2: History8

Chapter 3: What’s Next?11

Chapter 4: Hope.....14

Chapter 5: Magic.....17

Chapter 6: Conflict.....19

Chapter 7: 100 Things22

Chapter 8: Conversation.....27

Chapter 9: Why?.....31

Part II: The People

About the producers36

People featured in the film42

Part III: Resources.....51

Part IV: Acknowledgments56

Chapter 1: Wishes



Featuring: People on the streets of New York City and the music of Steve Price, RN

Many people are bewildered by the healthcare system. By the end of a long illness, people are commonly devastated, not only physically, but emotionally and financially as well. Most of us want to spend our final days at home, in comfort, surrounded by people we know and love, and who love us. Instead, 80 percent of Americans die in institutions, either hospitals or nursing homes. Nearly 20 percent of Americans spend their last days in an intensive care unit, often sedated or with their arms restrained so they will not pull out breathing tubes, intravenous lines, or catheters. Pain commonly remains undertreated, even in otherwise excellent medical centers and by otherwise excellent physicians. Dying is inherently hard, but it does not have to be this hard.

—Ira Byock, MD, from his testimony against House Bill 304, February 19, 2009.

Chapter Synopsis:

The film opens with a view across the skyline of New York City. The next shot looks down at the city's streets, where we see the hectic maneuverings of morning traffic. Then we settle on a busy street corner. Here, people young and old, from a wide range of backgrounds and faiths, answer

a simple question: When it is your time to die, where would you like to be, and with whom? The responses are nearly unanimous: at home with my family, with my loved ones.

The urban landscape is juxtaposed against musician Steve Price's beautiful country-folk tune. His words and voice capture the realities of nearing the end of life—when one's body is no longer able to accomplish familiar tasks, independence is lost, and there is a growing sense that the joyful things of life have passed.

Supplemental Information:

- Most Americans—upwards of 80 percent—would prefer to die at home, according to numerous polls and studies, including two sponsored by the National Hospice and Palliative Care Organization^{1,2}
- According to the “New Study of Death Patterns in the United States”, the majority of deaths (56 percent) occur in hospitals, clinics, or medical centers; 19 percent occur in nursing homes; and some 21 percent of people die at home.³ It was the first study since the 1980s to examine detailed patterns of mortality by supplementing the information provided through death certificates with interviews of next of kin.
- By contrast, 41.1 percent of all hospice patients died in their private residences in 2010, while 21.9 percent died in hospice inpatient facilities, 18.0 percent in nursing homes, 11.4 percent in acute care hospitals, and 7.3 percent in residential facilities.⁴

1 Harris Interactive. A Study about End-of-Life Care. Prepared for the National Hospice and Palliative Care Organization, January 28, 2002:2

2 The Gallup Organization. Knowledge and Attitudes Related to Hospice Care. Conducted for the National Hospice and Palliative Care Organization. September 1996:2

3 The National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention. National Mortality Followback Survey. Released: February 23, 1998.

4 National Hospice and Palliative Care Organization. NHPCO Facts and Figures: Hospice Care in America. 2011 Edition: 6.

Chapter 1: Wishes cont.

Questions to Contemplate:

- What is your answer to the question: When it is your time to die—where would you like to be, and with whom?
- Have you ever asked anyone else that question? If so, who was it and what was their answer?
- Why do you think so many people say they want to die at home?
- If your goal is to die at home, have you thought about what resources would be necessary to achieve that goal? Who would be your caregiver?
- If you want to die at home but that is not possible, or, if you would rather die in a place other than home, where would you like to be? Would you prefer an assisted living facility, a nursing home, a hospital, or some other place?
- Why do you think such a disparity exists between the way people say they want to die, and the reality of how most people actually die?
- Do you feel prepared to care for someone? What do you feel unsure about?
- How do you feel about depending on others at the end of life?
- If you had a terminally ill loved one (parent, child, grandparent, close friend), would you feel comfortable caring for him or her in your home?

Behind the Scenes:

When in New York City to film another interview, we decided to take our camera out onto the streets of Manhattan to gather responses to the question: *“When it is your time to die—where would you like to be, and with whom?”* Over the course of three days, a total of 62 randomly chosen individuals representing a wide variety of ages, races, nationalities, sexual orientations and religions, agreed to share their perspectives on camera. Amazingly, nearly everyone said the same thing: *“Hmmm, that’s a good question. I’ve never thought about that before, but now that you ask me, I’d prefer to be at home, surrounded by family, and not in a hospital or nursing home.”*

Among the many persons we filmed was a man named Steve Price, who just happens to be a registered nurse with experience in end-of-life care. Steve told us that he is also a singer-songwriter, and that his first CD, *Awake*, was a musical experiment in which he hoped to expose and maybe change attitudes about end of life. We were delighted by the coincidence and spent some time talking together. At one point, he asked us if we needed any music for the film and indicated that he’d love for us to hear his songs. Although we had no idea that we’d end up using any of his work, we exchanged information and later received a copy of his CD. It took only one listening to decide that we wanted to include his work in the film. Interestingly, before 2007, Steve had never written a song. However, when the door of inspiration opened, he soon had 12 songs about the inherent and imposed dilemmas of aging, illness, and dying.

Chapter 2: History



Featuring: Audrey R. Vizzard, RN, EdD; Loretta Downs, Rev. Dale Susan Edmonds, James Cleary, MD, Mark Thimke, JD, Kay Wipperfurth, RN, Stephen Kiernan, Gregory Gehred, MD, Bruce Wilson, MD, and Bernard “Bud” Hammes, PhD

This surprise, this unfamiliarity with death across an entire culture, is a relatively new phenomenon. A generation or two earlier, the end of a person’s days would not have been so foreign. In the early 20th century, the majority of Americans still had a connection to rural life. People witnessed death on a regular basis: the beheading of chickens and butchering of pigs, the methodical violence of hunting and trapping, the various accidents and illnesses commonplace on a farm. Urban culture, too, fostered greater awareness of mortality. ...Many urban households had multiple generations under one roof, so that from childhood forward, aging and mortality were present and even normal.

—Stephen Kiernan, from his book *Last Rights: Rescuing the End of Life from the Medical System*

Chapter Synopsis:

In this chapter of the film, several faith leaders and physicians talk about the serious problems created when people shield themselves from others who are nearing the end of life. This is in

stark contrast to earlier times when death was much more familiar and interwoven into day-to-day life.

At the turn of the 20th century, the average life expectancy was 48 years. Half of all children died before reaching the age of 12, and most people died at home where several generations lived together. Back then, it was perfectly normal for people of all ages to witness the death of family members, friends, and others around them.

Now with the intervention of advanced medical technology, most people die in hospitals or other healthcare institutions. Families are more dispersed geographically and multigenerational households are less common. As a result, death is much less familiar, and people just don’t know what to do when they are faced with their own end of life or the death of someone they care about.

What is most troubling is that it is not uncommon for people to feel shame, repulsion, uncertainty, and discomfort talking about matters related to death and dying. They feel it is something to be feared at all costs. Some operate under the illusion that it is somehow optional.

Even many doctors are reluctant to give patients a terminal prognosis because they haven’t been taught how to talk with patients about end-of-life issues, or, they equate dying as a failure. In some cases, it’s the family members who request that the doctor keep such information from the patient, thereby preventing the dying person from talking about it, too. Children especially are kept out of the loop. It’s as if everyone is afraid that by talking about it, death will come sooner; they will be perceived as silly, incompetent or stupid; or the consequences of knowing will just be too hard to bear.

Chapter 2: History cont.

Unfortunately, this discomfort with seeing, acknowledging, or talking about death can result in even greater difficulties—especially in how we relate to one another.

Acknowledging death and openly dealing with end-of-life issues, often allows for good things to happen. Fear is often alleviated, and it can be a time when people create profoundly intimate and meaningful experiences together, complete unfinished business, resolve issues, reconcile after estrangement, and experience spiritual growth.

When we talk about these kinds of things, the things that are most important to us, we become really vulnerable—it's very intimate. So just *having* the conversation conveys its importance.

Supplemental Information:

Four significant developments in the past century shed light on the present-day American struggle with end of life.

- *Where we die* has shifted dramatically. According to Stephen Kiernan's research, 75 percent of Americans died at home in 1920. By the end of the 20th century that figure had declined to 25 percent, with most people dying in healthcare institutions such as hospitals and nursing homes.⁵
- *How we die* has also changed. Until about forty years ago, most Americans died suddenly—from accidents, heart attacks and strokes; or from acute illnesses or conditions such as pneumonia, influenza, tuberculosis, and diarrhea, enteritis, and ulceration of the intestines. Now, with relatively easy access to emergency rooms, antibiotics, and more effective medical interventions and procedures, most can expect to die slowly and incrementally. Today, more than 90 million Americans live with at least one chronic illness, and 7 out of 10 Americans die from chronic disease. Among those people covered by Medicare, about 9 out of 10 deaths are associated with just nine chronic diseases: congestive heart failure, chronic lung disease, cancer, coronary artery disease, renal failure, peripheral vascular disease, diabetes, chronic liver disease, and dementia, according to the Dartmouth Atlas of Healthcare study "Tracking the Care of Patients with Severe Chronic Illness"(2008).⁶
- *The average life expectancy* in America has nearly doubled in the past 100 years, thanks to antibiotics, better sanitation, immunizations, and other medical advances. According to the National Vital Statistics Report, the estimated life expectancy at birth for all Americans in 1900 was 47.3 years;⁷ by 2008, that figure had increased to 77.8 years.⁸ In the middle of the 20th century, this increase in longevity was viewed as a great benefit. But, as Audrey Vizzard, RN, states in this chapter of the film, "We often forget that people who live into their 80s and 90s—which is quite common today—don't always live healthy and vigorous lives." For many, increased quantity of life often comes at the expense of reduced quality of life.
- *The decentralization of the American family* over the past 50 years has made the process of aging less familiar and more difficult to discuss and manage. In 1900, most elderly adults lived in multigenerational family households. But over the course of the 20th century, as a result of a range of factors, including the enactment of social safety net programs such as Social Security and Medicare, as

5 See Centers for Disease Control and Prevention website. Achievements in Public Health, 1900-1999: Control of Infectious Diseases. Figure 2: The 10 Leading Causes of Death as a Percentage of All Deaths – United States, 1900 and 1997.

6 John E. Wennberg, Elliott S. Fisher, David C. Goodman, and Jonathan S. Skinner. Tracking the Care of Patients with Severe Chronic Illness. The Dartmouth Atlas of Healthcare (2008): 1.

7 Centers for Disease Control. National Vital Statistics Report. Volume 50, No. 6: 34.

8 Centers for Disease Control. National Vital Statistics Report. Volume 59, No. 2: 27.

Chapter 2: History cont.

well as other improvements in medical care, older adults have grown healthier and more prosperous. With these changes came what amounted to a new intergenerational social contract—namely, that older adults who had the health and resources to live independently should do so. By 1980, just 17 percent of those ages 65 and older lived in a multigenerational family household. Rare is the American family with multiple generations living in the same city, let alone under the same roof.⁹

Questions to Contemplate:

- What has changed over the past few generations that make it more unlikely for people to die at home?
- Do you think it is possible or preferable to create a shift in our culture so that more people can die at home if it is their wish?
- How can decentralized 21st-century American families serve in the role of primary caregivers? What further assistance do families need to help them accomplish this goal?
- Have the changes in the predominant causes of death (chronic, incremental illness vs. sudden, acute conditions) presented us with an opportunity to learn new ways of being at the end of life so that we can remain intentionally involved in a way that is more positive physically, emotionally, socially, and spiritually?
- Have you ever personally witnessed the death of someone you know? Has that influenced you to think about how you want to die? If so, in what way?
- Have you ever talked with a terminally ill person about his or her pending death? If so, what happened; how did you experience the

conversation? Was it positive? Was it difficult? If you could change something about the conversation, would you do it differently?

- What are your greatest fears when being with or talking with someone who is terminally ill?
- What do you think a physician's role should be in discussing end-of-life issues?
- Do you think children should be allowed to know about death?
- Do you want to know if you have a terminal illness? Do you want others to know? Why or why not?

Behind the Scenes:

Interspersed with the narratives from this chapter are short clips from vintage home movies—snippets of life that capture important milestones as well as simple moments, that for us, emphasized the importance of family and the experiences we share together over time. As we viewed these images, we were reminded of similar moments in our own lives, as well as those people whom we love the most in this world.

We also couldn't help but notice that although we seem eager to document so many of the experiences that represent transitions in our lives (e.g. births, birthdays, graduations, engagements & marriages, holidays, reunions, etc.) we don't seem to acknowledge a person's death the same way. Should we not be similarly present at the end of life?

Chapter 3: What's next?



Featuring: Peter Kaldhusdal

When a person enters the final stage of the dying process, two different dynamics are at work, which are both closely interrelated and interdependent. On the physical plane, the body begins the final process of shutting down ... The other dynamic of the dying process at work is on the emotional-spiritual-mental plane, and is a different kind of process.

—Excerpted from *www.hospicenet.org*, © North Central Florida Hospice, Inc.

Chapter Synopsis:

When co-producer Terry Kaldhusdal interviewed his brother, Peter, for *Consider the Conversation*, Peter knew he was dying of pancreatic cancer. He had received the diagnosis from his physician, who then referred him to hospice.

In this segment Peter shares his personal thoughts on what lay ahead for him as he grappled with the unexpected turn of events in his life. He speaks from the perspective of a relatively young, well-educated man who grew up in a white, conservative, middle-class family, on the West Coast. He refers to how past events and experiences influenced his expectations and assumptions for

the future—and how those beliefs are holding up as he struggles to understand “What’s next?” for him after learning he was sick.

“Throughout your whole life, you always know what’s next,” said Pete. “From grammar school through junior high and high school, then on to college, you can see everybody that’s ahead of you, all those who have been doing this before you. Then you get a job, get married—you can always see what’s happening next. Then, suddenly someone tells you that you have terminal cancer. Well, there’s a ‘What’s next?’ for that, too—chemotherapy, tests, drug injections... but it’s not a guaranteed what’s next. And when none of those things are working, you’re sitting all by yourself in a ‘what’s next?’ chair, and you don’t know what’s next now. You have no idea what’s going to happen to you.”

Pete’s question, “What’s next?” can be interpreted in several ways. On one level, it is about medical prognostication and the importance of providing patients with a realistic preview of what is likely to happen as the disease progresses and the various care options that are available. On another level, it indicates the importance of addressing emotional, social and spiritual issues.

Supplemental Information:

In his 1999 book *Death Foretold: Prophecy and Prognosis in Medical Care*, Nicholas Christakis, MD, found that many physicians appeared to avoid prognostication and rarely talked explicitly with patients about their future. When he asked his colleagues about this, he learned that they avoided even thinking about prognosis explicitly, except occasionally, in the most benign and casual ways. He noticed that textbooks omitted prognosis, journals avoided it, and medical

Chapter 3: What's next? cont.

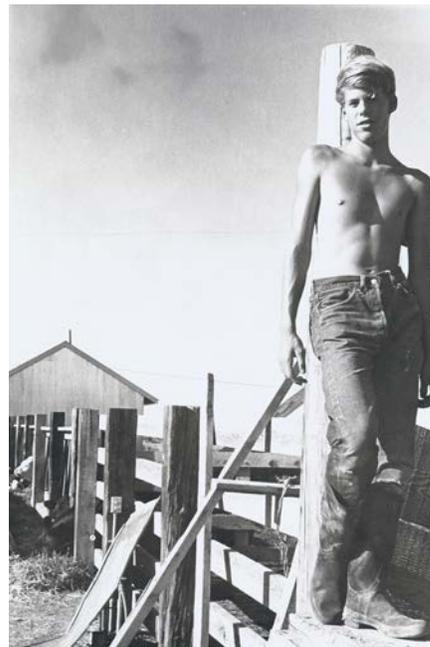
schools ignored it—concluding that the whole profession seemed to overlook prognosis. And few of his colleagues shared his conviction that this might be a problem. They even seemed bemused by his interest in this “marginal” topic, as if the proper and scientific role of medicine were only to diagnose and treat disease, not to predict its outcome.

There are those, however, that have made exploring the question of “what’s next?” their life’s work—and in the process, have increased public awareness in matters regarding the dying process significantly. For example, one of the first people who gained a high level of notoriety among mainstream audiences and medical professionals throughout the world was Elizabeth Kübler-Ross, best known for *On Death and Dying*, published in 1969. The book, based on more than 500 interviews with dying patients, identified five stages which many terminally ill patients commonly experience. The response was enormous and influenced her decision to focus her career on working with the terminally ill and their families. The intense scrutiny her work received also had an impact on her career path. Kübler-Ross stopped teaching at the university to work privately on what she called the “greatest mystery in science”—death.

Another huge element influencing exploration and understanding of these issues is the evolution of the modern hospice movement (see Chapter 9 for details), which began in the U.S. in the mid-1970s. In hospice, doctors, nurses, social workers, grief counselors, chaplains, and other therapists all help patients and family members explore these “What’s next?” issues by providing information about the natural progression of an illness and what to expect throughout the dying process.

Of course, the nature of each individual’s questions and concerns will vary greatly depending on his or her life experience—their age, culture, faith, etc. Today, the hospice philosophy and concept of care are central to models for palliative and end-of-life care and there are unlimited resources available to those who seek information—organizations, reading materials, films and videos such as ours, and much more (see Section III).

The question “What’s next?” is one of those timeless queries like “What is the meaning of life?” that philosophers, scientists, and every-day dreamers have pondered since the beginning of time. Although it’s likely that many “What’s next?” questions pertaining to death and dying will forever remain a mystery, many questions can be resolved simply by acknowledging that they exist. Our goal here is to show that questions of this nature should be expected, and un-ended suffering as a result is not the only option. What we do know, we can share.



Chapter 3: What's next? cont.

Questions to Contemplate:

- How are your expectations for the future different from or similar to Peter's?
- Can we ever know "what's next"?
- Who can help us prepare for the unknown—physically, emotionally, spiritually?
- Not every culture avoids thoughts about death like we do in the United States. Why is it that our culture seems so death phobic?
- Why is it so easy for us to act as if we will never die, ignoring the reality of our own impermanence and mortality—even though we see evidence of it every day?
- What are your greatest fears about end of life? What would help reduce those fears?
- If you or someone you loved is faced with a terminal illness, how much would you want to know about your/their condition?
- If your physician does not provide you with the information you are seeking, are you willing to ask for more information?
- How much do you think people should rely on their healthcare professionals to initiate this process? Who else might be able to help?
- Will the questions be different depending on the age of the patient? Child, young adult, middle age, elderly?
- What kind of training, tools, and support structures do you think are necessary to help medical professionals and others better prepare their patients for what lies ahead?

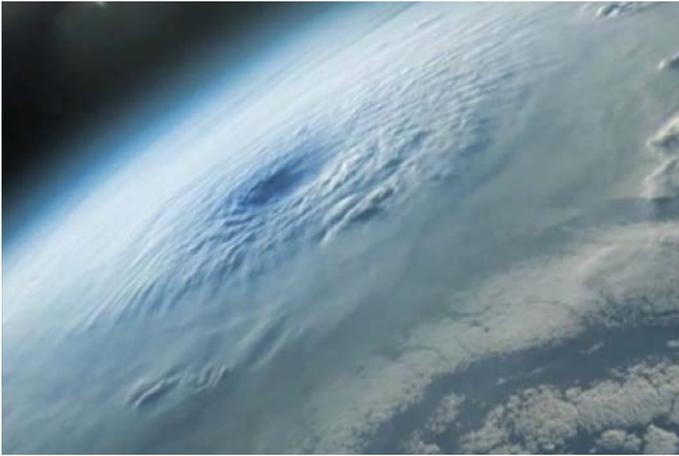
Behind the Scenes:

Despite the fact that Peter Kaldhusdal was heavily medicated to ease his physical pain, he was thinking very clearly during the first day of the shoot and talked on camera for nearly an hour. The next day, Pete climbed out of his bed and spoke from a chair. That day, his message was for doctors not to forget about their patients, even after recommending them for hospice care.

Pete also shared more information about his own personal journey into knowing what's next. "I've had a lot of time to think about this and I figured it out," said Pete. "For me, it's nothing like what I've been told. There aren't any clouds or angels with wings, but I've seen where we go. It's like being in the desert where I can see the curve in the earth. I can see the horizon. Usually, when I step toward that horizon it moves away from me, but now it's not moving. I'm walking closer to that horizon and now I can see the other side. Everyone I know and love who has died before me is there waiting for me."

Peter Kaldhusdal died 10 days after that conversation in the hospital bed set up in his family's living room, surrounded by his wife and two children.

Chapter 4: Hope



Featuring: Dee Bennett, RN; Rev. Dale Susan Edmonds; Catherine Labinski; and Bernard “Bud” Hammes, PhD

For patients and loved ones who take an optimistic attitude toward fighting a disease, the wisdom of a hospice nurse may be useful. “Hope is the last thing to go,” she said. “Almost everyone hopes for a long and healthy life. When we learn that we have a life-threatening illness, we hope that the diagnosis is wrong, or that we will recover, or that the illness will go into remission. If a condition worsens, we are likely to hope to live as long as possible. Given only a short time to live, we hope to spend quality time with those we love. When only days remain, we hope to stay free of pain and anxiety and to find the words to express affection and gratitude to loved ones. When only hours remain, we hope that death will be peaceful. Hope reaches even beyond death; most of us hope that family and friends will remember us and that we will be together again.” —Susan R. Dolan and Audrey R. Vizzard, from their book *The End of Life Advisor: Personal, Legal and Medical Considerations for a Peaceful, Dignified Death*.

Chapter Synopsis:

In this chapter, we explore the difference between hoping and planning; and how definitions and values surrounding both affect the way we make decisions and take action in our life. This section begins with the late Dee Bennett, an experienced hospice RN, who talks about how hope is helpful as we make our way through times of uncertainty. Dee is followed by Rev. Dale Susan Edmonds, a hospice chaplain, who uses the Hurricane Katrina disaster to describe how people may respond after being diagnosed with a potentially life-limiting illness or condition.

In August 2005, when the powerful storm made its way toward New Orleans, people hoped it would change direction. When it became apparent that landfall was inevitable, people hoped to get out in time. After the levees broke, people hoped to be rescued. People tend to act the same way when it comes to their health. They spend a lot of energy hoping they stay healthy, but when they do get ill they stay hopeful, although the nature of their hope may change.

For example, if a patient has a tumor, he hopes it’s benign. If he has a biopsy and finds out that it’s malignant, he hopes there’s an effective treatment. If he goes through treatment and it isn’t effective, his hope changes again: he hopes for more time—time for new treatments or therapies to become available, or for more time to make it to a specific event, such as a holiday, birth, graduation, or wedding. Then, when time seems to be running out, and he becomes weaker, less responsive, bed-bound, eating less and needing more help, his hope changes yet again—he hopes for a peaceful ending.

Chapter 4: Hope cont.

It's vitally important to recognize, however, that hope is *not* the same as a plan. If we rely solely on hope, we may be devastated if our wish does not materialize.

There is a common misperception among some medical professionals that “planning” is all about issuing do-not-resuscitate orders, not going back to a hospital, and so forth. But real planning is not about making these types of specific medical decisions (though these are decisions you may ultimately get to); it's the doctor asking the patient, “How can I care for you well at this point in your life?” and defining what good care means to the individual patient.

For example, when a physician asked one patient, a woman with advanced cancer, “How can we help you live well?” She responded that she wanted to spend as much time with her family as possible. “Concretely, what would that mean?” the doctor wanted to know. The woman questioned why she was coming in every week for blood studies. She lived 60 miles away, and coming in for the blood work took up an entire day. So she decided to stop. It wasn't that she was stopping medical care; she was stopping one part of it that was elective and not needed, because it wasn't helping her achieve what was most important to her at that point in her life.

Some people think that looking at options such as hospice for end-of-life care is the same as giving up hope. But when a doctor asks the patient the correct questions, “planning” about future medical decisions—including end-of-life care, does not need to take away hope. There are ways to have these planning conversations that are actually very positive.

Supplemental Information:

- The research of Dr. Nicholas Christakis has shown that doctors often make errors in prognosis and that such errors are not random. He found that physicians typically convey an optimistic bias when discussing prognoses with each other. As a group, doctors are likely to overestimate survival and future quality of life. Perhaps most interesting is the conclusion that many doctors believe in self-fulfilling prophecies, in other words, that predicting outcomes may actually cause those outcomes to happen.¹⁰



Chapter 4: Hope cont.

Questions to Contemplate:

- What does “hope” mean to you?
- If faced with a terminal illness, what would be most important to you? What would it mean to live well for however much time you have left?
- Have you talked with your spouse, your children, your doctor, and your clergy about your end-of-life wishes?
- What plans have you made?
- Do you have an advance directive (i.e., a living will or a power of attorney for healthcare)? Do you know how to get one? Do you know how, and when, to update your advance directives?

Behind the Scenes:

The interplay of spirituality and medicine (particularly as it relates to prognostication and advance care planning) in helping patients define hope was not immediately evident to us. Dee Bennett, a colleague of Mike Bernhagen, was interviewed in the summer of 2009 when she was dying but still fighting her cancer with chemotherapy. At the time, her comments about hope appeared to be denial. In retrospect, however, it became apparent that Dee was simply trying to make sense of what was happening by calling upon her years of experience with dying patients and their families as a hospice nurse—work that involved mind, body, spirit, soul and relationships. Looking carefully over Dee’s left shoulder, one can see a cross shining brightly on the mantle as she speaks from the heart on film about her struggle.

That same summer, we also interviewed Cathy Labinski, a hospice chaplain nearing retirement, who first introduced the idea that a patient’s perception of hope changes as his/her disease progresses. The backdrop for that important conversation was stained glass in the Chapel at AngelsGrace Hospice in Oconomowoc, Wisconsin.

The bottom line is that it wasn’t until one year later, when we interviewed the Rev. Dale Susan Edmonds on the altar at Glenview Community Church in Illinois and Bud Hammes, Ph.D. in La Crosse, Wisconsin, that we fully understood the critical role of communication at end-of-life. They helped “connect the dots”, if you will, by teaching us two things. First, that all human beings have hope, but hope by itself is not a plan. And second, that advance care planning is the means to the ends—a conversation that, if done at the right time and done well, helps prevent unnecessary suffering at end-of-life.

Chapter 5: Magic



Featuring: Doug C. Smith, MDiv, MA, MS

*When someone we love is dying... it's hard to know how to help, what to do, what to say. Yet if we know how to listen and what to look for, the dying themselves can often supply the answers, letting us know what they need to hear and express to allay their fears and face death with serenity.... —from the back cover of **Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying**, by Maggie Callanan and Patricia Kelley*

Chapter Synopsis:

This is a story about the importance of listening and being heard, as well as knowing that unexplainable experiences are not uncommon when someone is actively dying.

Doug Smith tells of an experience he had as a young priest, when a man named Jack, a former vaudeville magician, was dying in the hospital.

Jack's wife, Leona had come to Doug, concerned that Jack was hallucinating and didn't recognize her. She'd been told that Jack probably had less than 24 hours to live and asked Doug to visit Jack.

Doug agreed. When he entered Jack's room, Jack was propped up on pillows. He addressed Doug by name, saying, "Doug, we have been waiting for you." Though Doug could plainly see that he and Jack were the only people in the room, he decided to go along with what the old man was experiencing. Jack then told Doug, "We are going to initiate you into the International Brotherhood of Magicians."

Jack chanted a series of nonsensical words, then, asked Doug to come closer to him, so that he could show him "the greatest trick of all." Doug bent down toward Jack, until the two were practically nose to nose. Then, with a look that Doug described as "looking through my eyes," Jack whispered, "Watch me disappear." And then Jack died.

Doug sums up the experience with this: "The importance of that moment for me was what if I had entered the room and challenged Jack? 'Jack, there's no 'we' here. You need to talk sense.' Or if I would have said, 'Jack, this is not a time for magic. You're dying and we need to talk about that.' If I would have done either one of those things I would have ruined something that was obviously very meaningful for Jack."

Supplemental Information:

There are many resources available that can provide helpful information about what to expect as the final state of death approaches. Many address psychological, emotional, and spiritual changes as well as physical changes. One of the more popular and easily accessible references is a book titled *Final Gifts, Understanding the Special Awareness, Needs and Communications of the Dying*, authored by veteran hospice nurses Maggie Callanan and Patricia Kelley. Another

Chapter 5: Magic cont.

book, *Visions, Trips, and Crowded Rooms: Who and What You See Before You Die*, is written by David Kessler—author, public speaker, and death and grieving expert. He has published many books, including two co-written with famed psychiatrist Elisabeth Kübler-Ross.

Both books offer a wealth of insight into the way people die, including in-depth accounts that describe near-miraculous ways in which the dying communicate their needs, reveal their feelings, and even choreograph their own final moment.

Questions to Contemplate:

- Have you ever had the opportunity to be present with someone very near the end of life or actively dying?
- Have you ever heard similar stories?
- What do you know about what happens as people near death?
- How do you think you would react if you were with a dying person and they were talking about other people in the room that you couldn't see?
- If you were in Doug's place, what do you think you would have done?
- How do you think your family, friends, or physician would react if you were in Jack's place?

Behind the Scenes:

Doug Smith didn't blink when we asked him for an interview. He attended our premiere, and the day after the sold-out showing he was asked why he agreed to be part of this film, despite the fact that the two producers were unknowns. "Because

[they] had a microphone," he said. "If someone is willing to broadcast the fact that we need to improve end-of-life care, then I'm willing to talk to them."

His personal story about Jack is a beautiful way to emphasize the need to have the conversation. Not only do we need to talk about our wishes, but our loved ones and our caregivers also need to listen and follow those wishes.

It is also a reminder that to respect those wishes, it is helpful to have some understanding of the dying process—and that when someone is nearing the end of life—things can occur that would be hard to explain in a different context.

Chapter 6: Conflict



Featuring: Daniel Klein; James Cleary, MD; Susan R. Dolan, RN, JD, CHA; Rev. Jacqueline Cameron, MDiv, MD; Ira Byock, MD; James Milford, MD; Bruce Wilson, MD, FACC; Stephen Kiernan; Jung Kwak, MSW, PhD

“It is not surprising that most graduating medical students and licensed physicians have never been taught to assess and treat cancer pain, know little about hospice care, and have not been trained in ways to counsel a person with advanced illness who worries about the future or has begun to feel that life is not worth living. Today’s young doctors are bright, caring, committed, and generally well-trained professionals, but most are never taught the aforementioned skills, so it is no mystery that they don’t have them.” —Ira Byock, MD, from his testimony against House Bill 304, February 19, 2009.

Chapter Synopsis:

This chapter explores the conflicts that arise with regard to end-of-life issues from a medical standpoint. As we have seen in earlier chapters, most physicians within the U.S. healthcare system are trained to focus on treating the disease rather than on the people living with disease. The system doesn’t give them the tools to adequately deal with the “last chapter” of their patients’ lives.

Sometimes, even a patient who is obviously dying—showing all the signs of metastatic disease, experiencing decreased functional status, losing weight—has never even been told that he or she is dying, and yet the medical interventions continue. And then it becomes too late—death is imminent, and the dying person hasn’t had a chance to prepare, to place things in order, to say goodbye to family members.

At that point the physician might tell the family, “There’s nothing more I can do,” and the outcome (which was based on cure) is regarded as a failure.

Part of the cultural shift that needs to take place in our society is for physicians to acknowledge that there is so much they can do for people at the end of life. Doctor James Cleary believes that when a physician says, “There’s nothing I can do”, it is a neglect of their physician duties. Indeed, there are many things they can do. They can make sure patients are comfortable by providing pain relief and support for emotional, social, and spiritual care. They can walk the journey with their patients until the very end, and even be there for their families afterward. Most importantly, the healthcare provider can look at the individual patient, the patient’s unique circumstances, and the family’s preferences to come to a decision as to the right type of care for the patient and the family as a whole.

As a society, we need to recognize that at the two poles of life—when we’re born and when we die—we have to be fully dependent on others. We don’t consider the absolute dependence and vulnerability, even incontinence, of infants and toddlers as anything abnormal or undignified; but at the end of life, we’re supposedly undignified because we’re physically dependent on others. At both poles of life, caring for one another is what

Chapter 6: Conflict cont.

we do; it's part of our very humanity. As Dr. Ira Byock points out, "Being ill, being physically dependent on others doesn't make us undignified—it simply makes us human."

There still exists a misperception that choosing hospice and palliative care is the same as giving up. That's a perception we need to change.



Supplemental Information:

- The American Board of Internal Medicine mandated in 1997 that internal medicine residency programs include end-of-life care training. However, most medical school faculty members had little training in end-of-life care and how to teach the subject.¹¹
- Studies have shown that there is a lack of training, a lack of information in textbooks, and a lack of role models with regard to end-of-life care within the medical system.¹²
- Physicians' lack of training in end-of-life care may affect the quality and timing of end-of-life-care discussions conducted with patients and families.¹³
- During medical training, doctors are more likely to receive observation and feedback on bone marrow biopsies, which are considered straightforward procedures, than on end-of-life discussions, which are often nuanced and complicated.¹⁴
- Some studies have shown that during office visits, physicians interrupt their patients within 18 seconds of the patient beginning to speak. As a result, in 77 percent of those office visits, the patient's true reason for visiting was never obtained.¹⁵
- Those physicians who express empathy, involve patients in decision-making, ask open-ended questions, and listen attentively take no more time per average office visit than those who don't. Patients are more satisfied with their care, which leads to better and more responsible decisions, and increases the patient's willingness to carry out the prescribed treatment.¹⁶
- The most important communication skill in the nurse-patient relationship is listening.¹⁷
- Ira Byock, MD, summarizes the inadequacy of medical education in the U.S. as it pertains to end-of-life care training: "Even today, in medical schools across the country, minimal training is required in communication, pain assessment and management, ethics of decision making, and guidance for people facing life's end. And these topics are virtually absent in postgraduate training residency and

¹¹ "End-of-Life Project Trains Medical Educators to Add Palliative Care Curriculum for Medical Residents, a project with the Medical College of Wisconsin funded in part by the Robert Wood Johnson Foundation, October 1, 2006. It was part of a Program Results Report for the National Residency End-of-Life Education Project and is available online: <http://www.rwjf.org/pr/product.jsp?id=18007>.

¹² According to Dr. Kathleen M. Foley, attending neurologist in the Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center in New York City. Dr. Foley's interview was published by the Hospice Foundation of America, October 2002: www.hospicefoundation.org/pages/page.asp?page_id=49178.

¹³ Mary K. Buss, David S. Lessen, Amy M. Sullivan, Jamie Von Roenn, Robert M. Arnold, and Susan D. Block, "A Study of Oncology Fellows' Training in End-of-Life Care, *Journal of Supportive Oncology*, Vol. 5, No. 5, May 2007: <http://www.supportiveoncology.net/jso/journal/articles/0505237.pdf>.

¹⁴ Ibid.

¹⁵ J. Lee (2000), 10 Ways to Communicate Better with Patients. *Reviews of Ophthalmology*, 7 (10) 38-42.

¹⁶ A. du Pre, Accomplishing the Impossible: Talking About Body and Soul and Mind During Medical Visit. *Health Communication*, 14, No. 1 (2001), 1-21.

¹⁷ J.L. Worobey and H.W. Cummings, Communication Effectiveness of Nurses in Four Relational Settings. *Journal of Applied Communication Research*, 12, 2 (1984), 128-142.

Chapter 6: Conflict cont.

fellowship training for internists, surgeons, and other specialists.

“...Medical school deans claim that there is simply not enough time in four years to teach all that doctors need to know. That is certainly true; however, it is not a viable excuse. For instance, every medical student is still required to take nearly 200 hours of classes and clinical rotations in obstetrics as they were in the 1950s. But these days very few doctors deliver babies in their practices and every doctor who does has completed a post-graduate residency in obstetrics or family medicine.”¹⁸

- Medicare and other health insurance plans currently do not reimburse medical professionals for engaging in advance care planning discussions with patients. Perhaps this contributes to the fact that only 29 percent of Americans have a living will.¹⁹ Only two in five have any type of advance directive.²⁰ Fewer than 50 percent of seriously or terminally ill patients have advance directives in their medical records.²¹

Questions to Contemplate:

- If physicians are the product of a medical education system that views death as a failure, how can we begin the conversation with our doctors and explain our wants, needs, and fears?
- How do you think you would react if your doctor tried to discuss end-of-life care options with you? Would you feel that your doctor wasn't doing everything possible to cure your illness and save your life?
- When should physicians and other medical professionals discuss things like advance

care planning, palliative care, and hospice? Early on in the disease trajectory? Only after a terminal prognosis?

- What can be done from a medical education perspective to help the doctors of tomorrow better serve the end-of-life needs of their patients?

Behind the Scenes:

While many doctors appear in this film, we interviewed many more. The television time frame of 56 minutes forced us to leave many outstanding interviews on the cutting room floor. But every doctor we interviewed told us, “Doctors need to hear this story,” and that surprised us. We heard over and over again that doctors are really good at curing people, but they're not very good at treating people who can't be cured.

18 February 19, 2009, testimony against House Bill 304, (New Hampshire's rejected bill to legalize physician-assisted suicide), 09-0408, <http://www.gencourt.state.nh.us/legislation/2010/HB0304.html>; for analysis of the bill go to <http://www.patientsrightscouncil.org/site/new-hampshire-analysis/>.

19 2006, a Pew Research Center survey.

20 2007, a Harris Interactive Study.

21 Research conducted by the Agency for Healthcare Research and Quality (AHRQ).

Chapter 7: 100 Things



Featuring: Martin Welsh, MD

“I like to know where a road leads before I set out on a journey. Right now, one path I could take leads to a place I don’t want to go. I am determined not to start down that path, even if others think I’m being premature in my decision. In short, I may well be ready to die before my family and friends are ready to say goodbye. But they know that, as I face my diminishing list of the 100 things that make life worth living, the choice of quality over quantity has to be mine to make.”

—Martin Welsh, MD and ALS patient

Chapter Synopsis:

This chapter prompts the viewer to start digging more deeply to uncover their own personal beliefs about “quality of life” and “quantity of life”. In it, Martin Welsh, a California family practitioner, describes his journey as he progressed from being a family doctor who, for 25 years helped patients with end-of-life issues, to a terminally ill patient facing amyotrophic lateral sclerosis (ALS), the terminal condition also known as Lou Gehrig’s disease. Marty describes ALS as “a cruel neurological illness in which a normally functioning intellect becomes trapped in an increasingly weak, and then paralyzed body.” At the time of

this interview, Marty had lost his ability to speak, so his words are read by a narrator.

Marty self-diagnosed his illness five years before this interview took place. His disease was relatively slow to progress, so he was able to practice medicine for another two years. As a physician, Marty knew better than most what to expect from the disease and understood that he would eventually die from it. He would soon have to choose between depending on a feeding tube and ventilator when he could no longer eat, drink, or breathe on his own, or die a natural death. This medical technology, he felt, would only lengthen his suffering and prolong the burden on his family.

As he slowly lost the use of a hand, then an arm, then both legs, then his speech, Marty tried to stay focused on all the things he could still do. Yet it was harder to ignore all the things he *couldn’t* do. He found himself facing the same kinds of quality-of-life issues he’d discussed innumerable times with his patients. As Marty put it, “Answers vary from person to person, but the fundamental question is always this: At what point is the quality of life no longer worth the emotional and physical costs of maintaining it?”

Marty was not afraid to die. He’d seen good deaths and knew that dying could be peaceful, spiritual, and even comforting to those left behind. But how would he know when he was ready for it? Thinking about that question led him to develop a systematic exploration of quality of life vs. quantity of life—using his list of “100 Things.”

In Marty’s words, here’s how it works. “Imagine a list of 100 things you do most days. Some are routine, some are chores, and some are pleasurable. Get out of bed and walk to the bathroom.

Chapter 7: 100 Things cont.

Kiss your wife. Answer the phone. Drive your car to work. Go play golf with your friends. Brush your teeth. Write a letter, lick and seal the envelope closed, and put a stamp on it. Hug your child.

“Of course, we do many more than 100 things each day, but for now, just imagine 100 that are essential to the life you live. Now if you take away one, you can still do 99. Is life worth living without being able to smell the rose in the garden? Of course it is. How about losing 2, or 7, or 23? Is life still worth living? Of course! But suppose you get to where you’ve lost, say, 90 things... and now, with each thing taken away, a bad thing is added. You can no longer walk well, and you start falling, and it hurts. Your grip is gone, and you also suffer the ignominy of wetting your pants, because your bladder spasms. You can’t turn over in bed, and that also means you’ll get bedsores, unless someone turns you frequently. Life is still worth living, but you’re getting tired.

“At some point, no matter who you are—or how strong, you can lose enough things that matter, and acquire enough negatives, that the burdens will outweigh the joys of being alive. This is the stage when, as a doctor, I would reassure my patients and their families that they had fought the good fight, and it was now okay to accept moving to the next phase.”



Supplemental Information

How each terminally ill person defines “quality of life” and whether they pursue an increased “quantity of life” varies by individual, and depends on many different factors. Consider the following examples of three different people, all about the same age, each diagnosed with ALS.

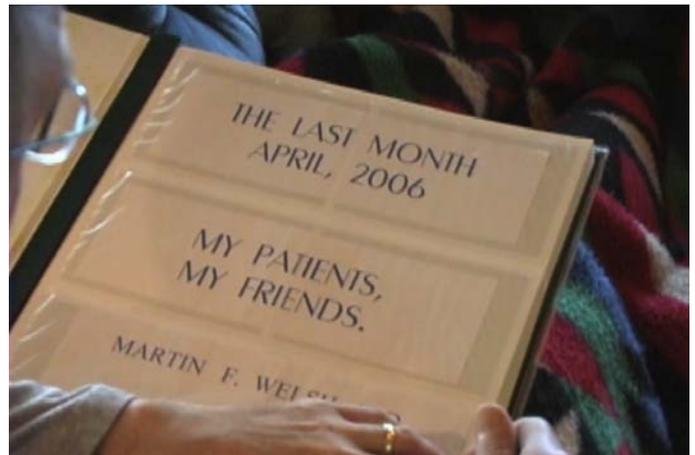
Martin Welsh decided to receive hospice care which allowed him to die naturally, yet pain-free, surrounded by his loved ones. Stephen Hawking, the world-famous theoretical physicist and cosmologist was first diagnosed with ALS in 1963, at the age of 21. Despite being completely paralyzed by his illness, his choice has been to aggressively pursue advanced treatments and procedures that have extended his life far beyond what would have been possible without them. Craig Ewert, a 59-year old retired computer science professor from Chicago, traveled to Switzerland five months after being diagnosed with ALS to arrange and carry out his physician-assisted suicide (documented in the film *The Suicide Tourist* produced by the PBS program *Frontline*).

Each of these men took very different paths while making conscious, deliberate choices about how they wanted to live and die. They also made those wishes known to their loved ones and healthcare providers. More importantly, they were supported in their decisions and had the resources available to follow through on them.

Chapter 7: 100 Things cont.

Questions to Contemplate:

- How would you define “quality of life” personally?
 - What would be on your list of “100 Things”?
 - If you were diagnosed with a terminal illness, what would be most important to you?
 - At what point do you think quality of life is not worth the emotional and physical cost of maintaining it?
 - How much medical intervention do you feel is appropriate at the end of life?
 - What might be potential consequences of “going to any length” to extend life as long as possible, unnaturally?
 - If it was determined that you were terminally ill and could no longer eat and drink on your own, would you want artificial nutrition and hydration (e.g., a feeding tube and intravenous fluids)?
 - If you could no longer breathe on your own, would you want to be hooked up to an artificial breathing device (a medical ventilator)?
 - Is it possible to actually be ready for death?
 - What do you think about Dr. Welsh’s statement that “Physicians and families sometimes feel an obligation to do all that can be done to keep someone alive”? Just because we can extend life through artificial means, should we?
 - When is enough, enough? Is more care always better care? How much care is too much care?
- In a fee-for-service reimbursement system that rewards medical professionals for providing more care to patients but does not hold them accountable for the quality of that care and currently does not pay them to have advance care planning conversations, what are the implications for end-of-life care?
 - How are we to reconcile the friction that now exists between increased quantity of life brought about by advances in medical treatment and technology and the reduced quality of life that often accompanies it?



Behind the Scenes:

- In our opinion, there is no better way to explain the “quality of life vs. quantity of life” quandary than by telling Marty’s story, “100 Things” which he wrote before his death and was first published on July 26, 2009 in the *Los Angeles Times*.

Marty’s article was brought to Terry’s attention by Alan Lawrence Sitomer, author, educator, speaker, and California’s 2007 Teacher of the Year. In July 2009, Alan brought Terry to Denver to consult on a digital storytelling project for teachers. While working together, Terry shared with Alan that he was producing a documentary on end-of-life care. Still, it was some coincidence that on July 26, the day the two wrapped up their work and headed back to their respective homes, Alan spotted the story which had been published that very morning.

Alan immediately forwarded the article to Terry who, in turn, decided to contact Marty to see if he would be interested in being part of *Consider the Conversation*. Marty quizzed Terry to see if the film reflected his values, and if we were people that he could trust to carry his message. After nearly two weeks of email correspondence, Marty asked one last question, “How do you feel about doctor assisted suicide?”

Terry understood his answer was important to Marty, but he didn’t know what Marty wanted to hear. “I don’t really understand doctor assisted suicide,” Terry wrote. “That’s not what this story is about. That’s a whole other story, and we’re not going there.” Marty wrote back immediately. “Good answer. I’d love to meet you.”

- You can learn more about Alan Sitomer’s relationship with Terry by viewing a university commencement speech he gave in April 2011, at: www.youtube.com/watch?v=itrgSB0bRoE.
- The footage we shot of Marty was done all in one day, starting at 6:30 in the morning, and concluding at 10:30 that night. The first live shot was Marty receiving a kiss from Maureen and getting out of bed. The last shot was Marty stretching before going to sleep. More than 10 hours of tape were shot for this eight-minute piece.
- The narrator of this segment is Peter Reeves, a Milwaukee actor. While Peter never heard Marty’s voice, Maureen said Peter sounded eerily similar to Marty before the disease robbed him of his natural voice.
- When developing this chapter of the film, we became aware of two other activities that can help people to identify what may be more or less important to them at the end of life.

The first activity is “**The Go Wish Game**”, created by the Coda Alliance (www.codaalliance.org). It is an easy, even entertaining way to think and talk about how you may want to be treated if you become seriously ill. The game can be used to help you and your friends understand your wishes, therefore making it easier for them to follow your wishes when the time comes.

The second is a simple “**Letting Go Exercise**” that we think is very effective in helping to clarify priorities and end-of-life goals. Step-by-step instructions for facilitating the exercise are provided on the next page.

Letting Go Exercise

Instructions: Give each participant a pencil and 12 small, separate pieces of paper. Once materials are distributed, proceed by communicating the following directions:

1. Write the following on 12 small, separate pieces of paper:

- Three people who are dear to you
- Three possessions you value
- Three activities you especially enjoy
- Three personal characteristics of which you are proud

2. Place all 12 pieces of paper face up in front of you.

You haven't been feeling well lately and after putting it off, you finally decide to visit your doctor. After having some tests, the doctor calls you in and says that she is sorry to inform you that you have cancer and that it has spread throughout your body. You can't believe what you are hearing—time seems to stop and it is as though you are watching the scene from outside your body. After a moment, you recover your senses enough to ask, "How long do I have?" She replies, "Probably about a year..."

3. Tear up three pieces of paper.

...It is three months later. You are at home and you feel OK. There have been no major symptoms yet, but your whole life has changed. Who are you? Who is with you? Does everyone in your circle know you have cancer? What is it that you want most in your life?...

4. Tear up three pieces of paper.

...It is now six months since your diagnosis. You are definitely ill. You tire easily and daily activities are difficult. Pain is becoming an issue. You need assistance with many things. Who are you? Who is with you? Who do you wish was with you? Is there anyone you still have not told about your prognosis?...

5. Tear up two pieces of paper.

...Cancer is your reality and you barely have enough energy to get through each day. You now spend most of the time in bed. You are sleeping more and need greater amounts of medication to control the pain. You need help with activities of daily living, including bathing, using the bathroom, dressing and undressing—even eating. You are becoming dependent on people and pills and have lost any sense of privacy....

6. Tear up two pieces of paper.

...You now cannot get out of bed—even to go to the bathroom. You have a catheter. Pain medication is being administered through an I.V. pump. You are awake for only brief periods each day; you have stopped eating and are not even strong enough to talk. Who are you now? What is important to you? Who is there? Who do you wish was there?...

7. Turn over the last two pieces of paper.

...Take one piece of paper from each person, leaving them with one...

8. Read the last piece of paper; tear it up.

...You have died.

At the end of the exercise, it is often helpful for participants to have the opportunity to process findings and feelings with others.

Chapter 8: Conversation



Featuring: Elliott S. Fisher, MD, MPH

Appreciate that excellence is a form of deviant behavior. You become excellent because you are doing things that “normal” people do not want to do. This represents a statistical truism. For any observation to be seen as different from others, it must exist outside of two standard deviations of the mean of the population of observations in question. Distinctively exceptional behavior, therefore, represents deviancy.—Joseph S. Bujak, MD, Inside the Physician Mind: Finding Common Ground with Doctors.

Chapter Synopsis:

In this chapter, Dr. Elliott Fisher emphasizes that there is no substitute for meaningful conversation about end-of-life wishes. He gives examples of many of the communication barriers that prevent healthcare professionals on all levels from having productive conversations about end-of-life matters with their patients.

He discusses the variations that exist across America in end-of-life medical care. In the “great” places, he says, patients are given good information and good choices about what is likely to happen, and a family practitioner helps them

make choices about exactly what kind of care they want.

In places where people spend much more time in hospitals or ICUs, it is likely that patients are not being adequately informed. The tendency in American medicine is the presumption that more care is better, and it’s going to lead to longer life expectancy. The truth is, though, that more care isn’t necessarily better care.²⁰

Overall, it seems the healthcare system is not doing a good job of informing patients, helping them understand that they’re nearing the end of life and should think about and take control of how they’ll spend their last weeks or months. Some people will want aggressive treatment; others won’t. People feel differently, and the medical profession needs to respect those different preferences.

The process of giving patients the timely, comprehensive information they need to make decisions about their treatment is referred to as advance-care-planning consultation. Conversations about end-of-life options should take place at three levels—between patient and doctor; between family members such as parent and child, husband and wife; and also within the community between minister and parishioner.

Supplemental Information:

It’s been decades since Karen Ann Quinlan, the 21-year-old woman who lapsed into a coma after ingesting a combination of drugs and alcohol, was kept alive in a “permanent vegetative state” for more than 10 years through the intervention and implementation of modern technology. In 1976, her case became national news when her parents asked the hospital to cease active care and allow

Chapter 8: Conversation cont.

her to die a natural death. The hospital refused, and a legal tug-of-war ensued. Quinlan's case became an issue because medical directives were rare in the 1970s when Quinlan was first admitted to the hospital, and she did not have one in place.

Years later, a similar battle took place between the legal guardians and the parents of Teresa Marie "Terri" Schiavo. At issue was whether the husband's granted motions and later court findings to forgo further life-prolonging procedures or life support treatment for Terri, would be carried out. The highly publicized and prolonged series of legal challenges presented by the parents and by state and federal legislative intervention resulted in a seven-year delay before life support finally was terminated.

Studies show that there is a serious disconnect between what people want and what they receive. While most people say they do not want aggressive medical treatment when faced with a dramatic decline in the quality of their lives, they have not taken steps to avoid such treatment.

Today, it is estimated that more than 30,000 Americans exist in a continually unresponsive or permanently vegetative state. Despite the sensational headlines and the tragic circumstances of the Quinlan and Schiavo cases, most Americans do not have an advance directive stipulating the amount and kind of care they wish to receive should they be unable to decide or communicate their wishes on their own.

About Advance Care Planning

Advance care planning is a process aimed at extending the rights of competent adults to legally guide their future medical care should they

become unable to make decisions on their own. Generally, the process involves three steps:

1. Proactively thinking about and talking through one's values and preferences. This may involve doing some research to learn more about the end-of-life process.
2. Documenting those values and preferences in an *advance directive* such as a living will and durable power of attorney for healthcare.
3. Distributing the information to others (family, friends, physician, etc.) who need to know your values and preferences.

Types of advance directives:

- A *living will* is a formal legal document that allows individuals to stipulate the kind of medical care you want should you become incapacitated and cannot make or communicate your own decisions. Also known as a "declaration to physicians", this directs your physician about your wishes for life-sustaining treatment such as the use of a ventilator, artificial nutrition, kidney dialysis, attempting resuscitation (CPR), organ and tissue donation, etc.
- A *durable power of attorney for healthcare*, also known as a healthcare proxy, allows the patient to designate another person, or surrogate, to make treatment decisions should the patient become unable to make such decisions themselves. The person in charge of your directive need not be your spouse or other family member; however, it *must* be someone who agrees with your wants and someone who can handle the pressures of

Chapter 8: Conversation *cont.*

making your decisions when you are physically unable to do so.

Each state has slightly different requirements and standardized forms for advance directives. Advance-directive forms and detailed instructions, including helpful suggestions to consider while creating your directives are easy to obtain through your healthcare provider or online (see references at the back of this discussion guide).

Although these are legal documents, an attorney is generally not necessary to complete them. You are encouraged to personalize your directive, adding your own language about your beliefs regarding life-support procedures, preferences for healthcare provider or facility for long term care in your home or nursing home.

Who should be aware of your advance directive? Simply having advance directives is not enough. Loved ones must understand the directives and know where to find the legal documents and your healthcare providers must have access to the information in order to carry it out.

And don't assume that your doctor will automatically follow your directives; you must have the conversation with him or her about the specific points in your directive and be confident that he or she agrees and will act accordingly should the need arise. If your doctor does not agree, then you need to find a doctor who does.

Questions to Contemplate:

- If you were faced with a possible terminal diagnosis, do you think your doctor would tell you what would be the best- and worst-case scenarios? Would he or she help you
- decide what path you should take during your remaining time in this life?
- Do you feel comfortable talking to your physician about end-of-life issues?
- Do you have an advance directive?
- Have you had the conversation about your end-of-life wishes with your family members and healthcare providers? If not, are you going to discuss these matters with them, and if so, when?
- Is simply completing an advance directive enough, or is a greater level of patient communication and advocacy necessary? Who should be responsible for advocating for the rights of patients?
- Do your loved ones understand who has "exclusive power" to follow your medical directive if you are unable to communicate?
- Do you know what would happen if you lapsed into a permanently vegetative state?
- Will there be disagreement between your loved ones if you're unable to communicate your medical needs? If so, is there anything you can do now to help resolve it?
- Do your doctor, caregiver, and spouse agree with your end-of-life plan?
- What would help you feel more comfortable about discussing your wishes and preferences with your physician?
- Do you know if your family members and doctor would honor your wishes?

Chapter 8: Conversation cont.

- How would you deal with a situation where you disagree with the wishes of a loved one? What if your loved ones disagree with your wishes?

Behind the Scenes:

At the time of our interview, Dr. Fisher was three months removed from an appearance on *60 Minutes* as part of a story titled “The Cost of Dying” and was visiting Madison, Wisconsin, to give a presentation at the state capitol on the development of accountable-care organizations (ACOs). Coined by Dr. Fisher, the term ACO refers to a group of healthcare providers that are organized to provide care to patients and then held accountable to the patients and the third-party payer for the quality, appropriateness, and efficiency of the healthcare provided. Under this model, the ACO receives reimbursement for meeting quality improvement markers and reducing costs.

During our interview, Dr. Fisher also pointed out that the state of Wisconsin is home to a region that excels at the advance-care-planning process. Based on that commentary, we later traveled to La Crosse, Wisconsin, to meet with Gundersen Lutheran Health System’s Bernard “Bud” Hammes, PhD, architect of *Respecting Choices*. It is an internationally recognized, evidence-based advance-care-planning program dramatically different from unproven advance directive programs available today (see more about this program in the *Resources* section at the end of this discussion guide).



Chapter 9: Why?



Featuring: Stephen Kiernan, investigative journalist, and author of *Last Rights: Rescuing the End of Life from the Medical System* and *Authentic Patriotism*.

Please forgive me. I forgive you. Thank you. I love you. These four simple statements are powerful tools for improving your relationships and your life. As a doctor caring for seriously ill patients for nearly 15 years of emergency medicine practice and more than 25 years in hospice and palliative care, I have taught hundreds of patients who were facing life's end, when suffering can be profound, to say the Four Things. But the Four Things apply at any time. Comprising just 11 words, these four short sentences carry the core wisdom of what people who are dying have taught me about what matters most in life. —Ira Byock, MD, from his book The Four Things That Matter Most

Chapter Synopsis:

Stephen Kiernan sums up the film by reflecting on what he has learned from his personal experiences reporting on how people die in America. He acknowledges that in spite of the fact that we all know our death is inevitable, integrating that knowledge into how we live our life is not easy. It's hard to fully accept the idea that every year, you unknowingly pass the anniversary of your

own death, a date that won't mean much to you when it happens, but one that your children will know and always remember. It's hard to think about leaving everything—work, family, home, community, this earth.

Kiernan ponders why more people don't receive hospice care, which is based on comfort rather than cure by providing a full range of physical, mental, social, and spiritual care to patients and their families at the end of life.

Perhaps more people don't go to hospice because it's easier to resist looking at the big "don't know." There are so many unknowns surrounding death; perhaps we look to all the advances in medical technology as a means to delay the "don't know" for just a little longer. Our fear may lead us to rely solely on our physicians—after all, they're the ones who have seen all this before, and we're going through it for the first (and only) time, so we depend on them to make all our decisions.

But if you have, say, a diagnosis of pancreatic cancer, and are told that you have four to six months more to live, that takes away some of the unknown. The questions now relate more to how you want to spend that time—pursuing curative treatments or life-prolonging care, or focusing on making the most of the time you have left—maybe taking a trip, connecting with certain people, having meaningful conversations with your children or other family members, mending fences if necessary...

Hospice's goal is to help patients and families make their own choices based on their personal needs and desires as they experience the natural process of dying. With hospice, the emphasis is on living life to the fullest, in comfort and with dignity—right down to the end.

Chapter 9: Why? cont.

Kiernan ends with a story about a man who was dying of leukemia. The chemotherapy hadn't worked to cure his disease, and he was receiving platelet infusions to keep his blood strong for as long as possible. He was told he probably wouldn't make it until Christmas. His daughter, who lived in Florida, had been planning to bring the grandchildren up to visit for Christmas. So, the man was able to tell her to come for Thanksgiving instead. The result, thanks to hospice, which facilitated the trip and paid for tickets for the family to travel, was that a dying man was able to hug his six- and eight-year-old grandchildren one last time. As Kiernan says, "If hospice can get us one more hug, what's better than that?"



Supplemental Information:

What is Hospice?

Since the first American hospice was started in New Haven, Connecticut in 1974, it has evolved from being a little-known medical alternative to a major option in end-of-life care. Hospice is based on comfort rather than cure—with the focus on quality of life for both the patient and his or her family members. It is holistic in nature, meaning that it addresses not only the physical needs of the patient but also his or her spiritual, social, and emotional needs. At the center of all hospice care is the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.

Hospice services are available to patients of any age, religion, race, and type of life-limiting illness such as cancer, Alzheimer's, heart, liver, and lung diseases, ALS, AIDS, and others with a probable life expectancy of six months or less. It is common for patients to receive hospice services for much longer than six months, depending when they are admitted to hospice, and the duration and progression of the terminal illness. Patients always have the right to stop receiving hospice services, for any reason. If a patient's terminal disease process enters the remission stage or improves to the point where the patient is no longer medically eligible for hospice care, he or she may be discharged from hospice for a time and readmitted again later if it becomes necessary.

Hospice services are provided using an "integrated team" which includes the patient and his or her family/caregivers, the patient's own personal physician, as well as a hospice physician (or medical director), nurses, health aides (certified

Chapter 9: Why? cont.

nursing assistants), social workers, clergy, other counselors, and trained volunteers. Speech, physical, and occupational therapists, dietitians and others are also included as needed.

Considered to be the best model for quality, the team-oriented approach provides compassionate, comprehensive expert medical care, pain management, emotional and spiritual support expressly tailored to the individual.

Family members are always considered to be part of the hospice team and provide a valuable part in making sure that the plan of care is consistent with the patient's values and wishes. Typically, family members serve as the primary caregivers for patients living at home. The primary caregiver for a hospice patient residing in an assisted-living facility, nursing home, hospital, or hospice center is the staff of that facility.

Because many hospice organizations offer care in their own facility, some people mistakenly believe that hospice is simply a place where people go to die. However, the scope of hospice extends much farther. Hospice is a philosophy of care based on the belief that everyone deserves to live out his or her life with respect and dignity, alert and free from pain, in an environment that promotes quality of life. To better understand this philosophy, it is helpful to know that the *Medicare Hospice Benefit* and many private insurance plans provide coverage for four different levels of care:

1. *Routine care* can be provided wherever the patient calls home—this can be a private residence, assisted living facility, or nursing home or other homelike setting which makes hospice accessible to all eligible patients—regardless of where they reside. Routine care is provided over the course of several weeks, months or even longer, depending on when the patient is first admitted to hospice and the duration of his or her terminal illness. Based on the unique needs and desires of each patient, hospice team members make regularly scheduled, intermittent house calls to assess the patient and provide additional care or other services. This includes providing a broad spectrum of medical, emotional, and spiritual support to the patient and his or her primary caregivers (family or facility staff). Hospice staff is also available on an on-call basis at all times.
2. *Respite care* is provided when family members acting as the patient's primary caregiver need a break. Here, the hospice team makes arrangements to have the patient transferred to a Medicare-approved facility for up to five days at a time while the family gets some much needed rest. The homelike setting found in especially dedicated facilities such as the Rainbow Hospice Care Inpatient Center in Jefferson, Wisconsin, are ideally suited for respite care—however, if the respite stay is in a hospital or nursing home, the patient's hospice team still oversees the care provided.
3. *Continuous care* may be necessary if a crisis develops. Care is still provided in the patient's home (house, apartment, assisted living facility, nursing home, etc.), with hospice staff staying for many hours at a time to manage symptoms that are out of control or to provide other more technical care than is considered routine care.
4. *General inpatient care* (GIP) may be required for patients with complex symptoms needing more intensive medical or nursing care than can be provided at home. In this scenario, the patient is transferred to a hospital, nursing

Chapter 9: Why? cont.

home, or if available—to a specially designed hospice facility. Reasons for general inpatient care may include uncontrollable pain, unremitting nausea and vomiting, severe shortness of breath, seizures, or other problems that cannot realistically be managed in the home.

Although general inpatient care is often available for patients who are expected to die within hours or a few days, the goal for most patients is to return home when their symptoms are stabilized or the care is less technical. As a result, general inpatient stays are fairly short-term. In some cases, patients may be able to remain at the inpatient hospice facility on a residential basis; however, this usually means paying out-of-pocket for services like room and board which are not covered by the *Medicare Hospice Benefit* or private insurance for routine level of care.

Hospice is typically paid for through the *Medicare Hospice Benefit*, *Medicaid Hospice Benefit*, and most private insurers. To qualify for hospice benefits, there must be documented clinical evidence of decline, two physicians must certify the patient's terminal prognosis, and the patient or his or her activated power of attorney for healthcare or legal guardian must grant consent.

The *Medicare Hospice Benefit* pays for the services of the hospice team; medications, durable medical equipment, and medical supplies related to the terminal illness; palliative therapies; and 13 months of bereavement support for surviving loved ones— all at 100 percent. It does not, however, cover room and board in a facility unless the patient is on the general inpatient level of care. Patients not eligible for Medicare or Medicaid, or who have no private insurance hospice benefit and have limited resources, are

often eligible for charitable care, funded through community donations or other sources.

In 2010, the National Hospice and Palliative Care Organization (NHPCO) reported that approximately 41.9 percent of all deaths in the United States took place under the care of a hospice program and that the median and average lengths of stay for an American hospice patient were 19.7 days and 67.4 days, respectively. Given that 90 percent of Medicare beneficiaries presently die from chronic disease and that one of the general hospice eligibility criteria is that two physicians must certify a prognosis of 180 days or less, it appears that hospice care is vastly underutilized in the United States.

Although the mission of hospice care is neither to hasten death nor prolong life—hospice patients often live longer than those who do not choose this route. Research published in a 2007 *Journal of Pain and Symptom Management* reported that hospice patients live an average 29 days longer than similar patients not receiving hospice care.

Chapter 9: Why? cont.



Questions to Contemplate:

- What is Stephen Kiernan revealing about himself when he says, “I’m now persuaded that I am indeed going to die”?
- What do you know about hospice? How did you learn about it? What experience have you had with hospice?
- Do you believe that entering hospice care means that you’re “giving up”?
- Do you know what hospice services are available to you?
- How can you learn more about the hospice care available to you?
- How will you consult with your doctor to evaluate the risks of medical procedures?
- How will you know if your illness can no longer be cured?
- When it is your time to die, where would you like to be, and with whom?

- What will you do differently today, now that you have seen this film?

Behind the Scenes:

Stephen Kiernan was the first of more than 100 people interviewed for *Consider the Conversation*. In Wisconsin for an end-of-life care conference, he gave the keynote address first thing in the morning and then an hour-long breakout presentation before lunch. Immediately following a book signing, he accompanied the producers to an off-site location where he spent 90 minutes on camera. Kiernan’s beautiful commentary in this segment of the film was his answer to the very last question in that interview: Why don’t more people receive hospice care?

It’s rare in the making of a documentary that the first shot of film ends up being the end piece in the final cut. But once this first interview was completed, the producers knew that Kiernan’s answer to the final question would be used to end the film. For the rest of the two-year shoot, the producers simply had to work their way toward those beautiful concluding comments that focus on what really matters most.

Part II: The People

About the producers



Mike Bernhagen

Mike Bernhagen is well acquainted with the American medical system. From 1994 – 2003, he worked in business development with one of the Midwest’s largest integrated healthcare delivery systems and multispecialty group practices. During this decade, his time and energy were spent focusing on things like physician incentive compensation plans, revenue growth, patient acquisition, and referral relationship development.

Those priorities changed, however, when his mother, Rita, passed away from congestive heart failure and vascular dementia. Watching her slow physical and cognitive decline, as well as, the struggle his family and her healthcare providers experienced during that process, inspired him to join the hospice movement in 2004.

Since then, Mike has been on the road working as a hospice advocate, traveling to countless destinations—clinics, churches, hospitals, nursing homes, assisted living facilities, senior citizen centers, disease specific support groups, and private residences—where he’s talked with literally thousands of people from all walks of life.

But it has been with the dying and their loved ones where his most meaningful and rewarding conversations have taken place. In fact, one of the great lessons he’s learned from terminally ill people is that

most are not afraid to die; rather they are afraid of the dying process.

Some of the common fears they have are the following:

- Am I going to suffer?
- Will I be a burden to my family?
- Will I have to leave my home?
- Will I die alone?
- Will I still get to see my doctor?
- Will I leave unfinished business?

Mike sees the potential of this documentary film to make a vast difference in people’s lives—in terms of both demystifying the dying experience and encouraging people to begin the conversation about their end-of-life wishes well before the finish line is in sight. Mike and his wife, Denise, reside in Waukesha, Wisconsin, with their two children.

Part II: The People cont.

Following is an article Mike wrote which was published September 19, 2010, in the *Milwaukee Journal Sentinel*.

A Sad Goodbye, But Life Changed

By Michael Bernhagen

Returning to healthcare was the last thing on my mind in October 2003. You see, I had just joined a small, family-owned independent insurance agency after 10 years of successful, but stressful, business development work at two local medical systems.

Here, I thought, was my best chance to finally escape the egos, hierarchy, politics and revenue growth obsession that had become characteristic of the “nonprofit” integrated healthcare delivery systems in metro Milwaukee. If this is what medicine had become, then I wanted nothing more to do with it.

Then “the call” came from my 85-year-old father late one evening. “Mike, this is Dad calling. Mom’s in the hospital again, and the doctors say there’s nothing more they can do for her. You may want to come up as soon as possible to say your final goodbye.” And so I went, first thing the next morning, along with my older brother, Phil, to the small central Wisconsin town where I grew up.

Seeing Mom in that hospital bed was hard, real hard. Although I had gotten used to the incontinence and confusion associated with the vascular dementia over the past few years, I wasn’t emotionally prepared to witness her current physical condition. Her congestive heart failure had progressed to the point where the fluid buildup in her lungs couldn’t be controlled and her breathing was extremely labored. Her kidneys were failing, and water retention had grossly swelled her legs, arms and abdomen. She was fatigued, weak and on oxygen continuously.

The strong, independent and highly intelligent woman who had survived the hunger and poverty of the Great Depression, a battle with TB in the 1950s and quadruple heart bypass surgery in 1988 was now but a shell of herself.

Upon my arrival, Dad greeted me with his customary firm handshake and a gentle hug, but the look on his face was one of physical and emotional exhaustion. I had never seen him this way.

Caring for Mom at home these past few years had clearly taken its toll on him. To his credit, he had been there for her through it all—from her repetition of stories early on, to memory loss, to inappropriate shouting at Mass, to late-night wandering at a hotel during the annual trip to Alabama, to the loss of bladder and bowel control, to bathing and feeding her, to the angina and shortness of breath, to the 911 calls.

During the past month, it had become too much for him to handle all alone. First, she was hospitalized, then she was transferred to a nursing home for rehabilitation, then she was re-hospitalized and now, apparently, the plan was to return her to the nursing home. How, I thought to myself, could anyone endure all this, let alone a frail, elderly and confused 81-year-old woman? How could Dad possibly endure the pain of losing a second wife?

Having never been in the presence of a dying person before, I wasn’t quite certain what to do. So, I simply sat on the hospital bed and held Mom’s hands in mine. We gazed deeply into each other’s eyes for several minutes saying nothing. At first, my mind questioned if she knew who I was, but something about the look in her eyes told my heart otherwise. She kissed my hands repeatedly and pulled me close as if to speak. “I’ve always loved you,” she said.

Part II: The People cont.

“I love you, too, Mom,” I replied with a smile and tears of joy welling in my eyes. I didn’t realize it at the time, but this was an intimate moment between a mother and her son that would later change the course of my life.

Not long after this visit, Mom was discharged from the hospital and returned to the nursing home, where she passed away two days later. In the months that followed, I reflected upon her decline and subsequent death, its impact on Dad, our final goodbye and wondered if enough had been done to help.

When I was talking about the experience with an old nursing friend in the spring of 2004, she asked a simple question that haunts me to this day. “Didn’t anyone mention hospice as an option to your family?” she inquired with a tone of disbelief in her voice.

I said no, no one involved in Mom’s care had ever mentioned it as an option—not her family practitioner, not her cardiologist and none of the nurses or social workers in the hospital or skilled nursing facility.

After learning how hospice could have helped Mom stay comfortable, Dad keep her at home, and me deal with the grief—I was angry and embarrassed. Angry because none of the highly educated clinical professionals in my hometown had suggested it; embarrassed because I felt I should have known something about hospice after working for the state’s largest integrated health delivery system and multi-specialty group practice but didn’t.

But then again, Mom never talked with us about her end-of-life wishes and my job back then was to help healthcare organizations make money and every “seasoned” business development professional

knows you make money on curative care and rehab not palliative care, right?

More conversations, reflection and research followed until I finally found the motivation to return to the healthcare field in November 2004 but this time as a hospice worker. This time, I told myself, the emphasis would be on helping others deal with death and dying, not personal advancement.

This time, the calling would be the message contained in a mother’s final goodbye—not market share, a fancy title or the potential for significant personal income.



Part II: The People cont.



Terry Kaldhusdal

This is Terry Kaldhusdal's fifth documentary film. The *Milwaukee Journal Sentinel* has written that Kaldhusdal's work is "clear and concise" and added that he has a "passion for learning and a talent for communicating." Columnist Laurel Walker has called his work "A-plus" and stated that he has "a knack for documenting history."

In 1991, Terry, like his wife, became a classroom teacher and moved from southern California to Wisconsin. He currently teaches fourth grade at Magee Elementary School in Genesee Depot. His students have created documentaries that include the history of the Kettle Moraine School District and personal digital stories on everything from responsibility to the three branches of government. One of Terry's students was featured at the AHA Film Festival in southern Illinois, and three of his students were honored with first, second, and third place in a statewide digital storytelling competition.

Terry has traveled across his state and across the country as a speaker to improve our public educational system. He's been honored with the Kohl Fellowship Award and has been named Wisconsin State History Teacher of the Year and Wisconsin State Teacher of the Year. Terry resides in Oconomowoc, Wisconsin, with his wife, Janet, and their three children.

Film:

- 2006— *The General of Progression: The Story of John S. Rockwell*
- 2007— *Prestige and Prominence: 100 Years of the Milwaukee Auto Show*
- 2007— *Thinking Like a Historian: Rethinking History Instruction*
- 2008— *America's Kings and Queens: The Gilded Age in Middle America (winner of the Wisconsin Historical Society's Public Programs Award)*
- 2011— *Consider the Conversation: A Documentary on a Taboo Subject*

Book:

- 2008— *The Composition Jam Box: A Complete Guide to 21st Century Multimedia Projects (co-authored with Alan Sitomer and Joseph Fatheree)*

Website:

- Mysteries of Aztalan: A Historical Look at a Lost Civilization: www2.kmsd.edu/kaldhust/aztalanhome.htm*

Part II: The People cont.

Following is an article written by Terry that was featured in the *Milwaukee Journal Sentinel* on September 19, 2010.

New Perspective from Tragic News

By Terry Kaldhusdal

Death surrounded our pioneer ancestors. They could not escape it as it struck quickly and often. Death was part of their daily lives.

Today, we are sheltered from death. Despite the fact that it is a natural part of life, it has become a forbidden subject. Few of us have seen someone die, because most of us won't die at home. We will most likely die slowly in an institutional facility. In fact, many of us die alone strapped to a bed with tubes running in and out of our bodies.

How did this happen? How did death become abnormal? Why is talking about death taboo?

Education and technology have doubled our life expectancy in just a hundred years, but few of us are celebrating that fact. Instead of enjoying the moment, many of us live in fear. The people I've met over the past 18 months of working on a documentary film about the end of life are afraid. They're scared of losing control and living the last chapter of their lives alone and in pain.

It's been a difficult journey for me to reach this realization, and it all started at 1600 Pennsylvania Avenue.

I had just met the president of the United States in the Oval Office, an honor few get to experience, especially true for a fourth-grade teacher from a small town in Wisconsin.

After the ceremony I did what any good son would do: I called my mother. Once my wife and I were

outside the White House gates, I called my oldest brother, Pete. I was recounting the surreal details when I reached the street corner, but Pete was quiet on the other end of the line. The light turned green, my wife and I stepped off the curb and started crossing the avenue. I asked Pete if everything was okay.



"I knew this was a big day for you," he said as I reached the center of the road, "so I didn't want to say anything, but about three weeks ago, I was diagnosed with pancreatic cancer."

I knew about pancreatic cancer from reading Professor Randy Pausch's book, *The Last Lecture*. It is a death sentence. Pete had a 4.5 percent chance of surviving.

But it wasn't Pete's diagnosis that led me to co-produce a documentary about end-of-life care. It was a conversation Pete and I had two years later in April 2009. He called me from the hospital after his wife had rushed him to the emergency room when the cancerous pain became unbearable.

"My doctor met me here and just told me that there's nothing else he can do for me," Pete said, "so he's sending me to hospice care. What do you think that means? I don't know what that means."

I felt heartbroken, stunned, and angry. Here's my oldest brother, the smartest one in the family, a

Part II: The People cont.

computer scientist in the Silicon Valley, who paid more in taxes than I made in wages in one year, a guy who kept a book in every room, a guy who had a great mind, a great family, and a great life. Yet he called me to learn about hospice care.

I remember I was driving south on Highway 67 when he told me this, and I replied that I would learn everything I could. And then I remember wanting to pull over to the side of the road so I could get out of my family's van and throw up.

A local oncologist told me Pete probably had between 11 days and 11 weeks, so his chances of survival were less than slim. Yet Pete had fought the good fight against a deadly disease, and he still didn't understand what hospice care meant.

Is it possible that he ignored the conversation? Absolutely. Is it possible the conversation was never established? Very likely.

It was that moment that led me on this journey. That was my tipping point. Since then, Mike Bernhagen and I have collected 70 hours of film that includes visits to hospitals, emergency rooms, intensive care units, hospice facilities, and patients' homes. We have interviewed doctors, nurses, chaplains, social workers, national experts, and patients. Three of the patients have died.

The original target audience for this documentary was patients and their family members. The terminally ill should know the options available to them. Family members need to know all of the options, but every doctor we interviewed said the medical community needs to hear this story, too.

That stunned me. I assumed the medical community was well trained in how to care for those who are terminally ill. It is not. I assumed most doctors know

how to have the tough conversations. Many don't. I assumed most doctors know when to draw the line when it comes to medical care. Many don't.

Does all of the responsibility fall with the medical community? Of course not. The responsibility falls with each and every one of us. What has become very clear is how to change this culture. The economics and politics of our healthcare system don't matter at this point. The spiritual and emotional parts of our healthcare puzzle don't matter either. None of these issues matter until we have a conversation about how we want to live before we die.

Our president needs to talk about it, our governor needs to talk about it, our doctor needs to talk about it, our loved ones need to talk about it, and we need to talk about it. How do we want to live at the end of our life?

To begin that dialogue, we need to change our focus. This became obvious during our production. It was assumed that our focal point was death, but it's not. The heart of our film, and the heart of our national discussion, should be how each of us wants to live before we die.

Do we want to be at home surrounded by our loved ones, or do we want to be in a hospital surrounded by the latest in technology?

The answer is not an easy one and is different for everyone, but what I've learned is that the question should not be, "How do you want to die?" The question should be, "How do you want to live before you die?"

For Pete, who died on June 29, 2009, at the age of 53, the opportunity to contemplate the answer to this question nearly came too late.

Part II: The People cont.

People featured in the film



Dee Bennett, RN

On January 4, 2010, hundreds of people stopped by Trinity Lutheran Church in the small southern Wisconsin city of Fort Atkinson to pay their final respects to Dee Bennett, a veteran registered nurse case manager with Rainbow Hospice Care, one of the state's few independent and nonprofit hospice programs. Family, friends, and former co-workers were among the mourners, but so were the loved ones of countless former patients. You see, Dee had touched many lives during her 10 years of work as a hospice nurse, and her death sent a huge wave of grief across the surface of this rural Midwestern landscape. Her three-and-a-half-year experience with signet ring cell tumor, an aggressive form of cancer, taught the people of this community—and indeed the producers of this film—many lessons about the meaning of life and the definition of hope from her unique perspective of both patient and nurse.



Ira Byock, MD

Dr. Byock is director of palliative medicine at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire, and a professor of anesthesi-

ology and community and family medicine at Dartmouth Medical School.

Widely regarded as the nation's leading expert on end-of-life issues, Dr. Byock has been involved in hospice and palliative care since 1978. During his residency, he helped found a hospice home care program for the indigent population served by the university hospital and county clinics of Fresno, California. He is past president (1997) of the American Academy of Hospice and Palliative Medicine and during the 1990s was a co-founder and principal investigator for the Missoula Demonstration Project, a community-based organization in Montana dedicated to the research and transformation of end-of-life experience locally, as a demonstration of what is possible nationally. From 1996 through 2006, he served as director for Promoting Excellence in End-of-Life Care, a national grant program of the Robert Wood Johnson Foundation.

Dr. Byock has authored numerous articles on the ethics and practice of hospice, palliative, and end-of-life care. His first book, *Dying Well* (1997), has become a standard in the field. His second book, *The Four Things That Matter Most* (2004), is widely used as a counseling tool by palliative care and hospice programs, as well as within pastoral care. And, his third book, *The Best Care Possible*, is scheduled for release in 2012.

Byock has been a featured guest on numerous national television and radio programs, including NPR's *All Things Considered* and *Fresh Air*, ABC's *Nightline*, CBS's *60 Minutes*, and PBS's *The News Hour*.

Part II: The People cont.



***Reverend Jacqueline
Cameron,
MDiv, MD***

Jacqueline Cameron is an Episcopal priest and a physician specializing in hospice and palliative medicine. She is an attending physician with Horizon Hospice and Palliative Care and is based at St. Joseph's Hospital in Chicago. She is also an assistant professor in the Department of Religion, Health and Human Values at Rush University Medical Center; is a member of the Ethics Consultation Service at the hospital; and works with Bishop Anderson House, an Episcopal ministry based at Rush. In addition, Dr. Cameron is an assisting priest at Church of the Atonement in Chicago and an adjunct professor at Seabury-Western Theological Seminary in Evanston, Illinois. She serves on the board of MAP (Medical Assistance Programs) International, an ecumenical global health and development organization, and is also on the board of Doctors on Call for Service (DOCS), a group that promotes medical education in central Africa. A graduate of Northwestern University Medical School, Dr. Cameron also holds an MA in theological studies and Christian ethics from King's College London, and a MDiv from the General Theological Seminary of the Episcopal Church in New York City.



***James F. Cleary, MD,
FACHPM***

Dr. Cleary is associate professor of medicine (Division of Hematology/Oncology), University of Wisconsin School of Medicine and Public Health; and director of the Pain and Policy Studies Group, a World Health Organization Collaborating Center for Pain Policy and Palliative Care.

After receiving his medical degree from the University of Adelaide Medical School, South Australia, Dr. Cleary did his internal medicine residency and oncology fellowship at the Royal Adelaide Hospital and three years of research in opioid pharmacology at the University of Adelaide. He moved to the University of Wisconsin in 1994, where he has developed global connections in cancer pain management and palliative care. Dr. Cleary has been a master facilitator for the Education of Physicians in End-of-Life Care (EPEC) program and EPEC-Oncology and a Faculty Scholar of the OSI (Open Society Institute) project on death in America. He was the 2004 president of the American Academy of Hospice and Palliative Medicine (AAHPM). He serves as a North American editor of *Palliative Medicine*, the research journal of the European Association of Palliative Care.

He continues to direct the UW Health Palliative Care program, a long-standing consultation service that has recently expanded to include a 10-bed inpatient unit. He develops and implements educational initiatives in palliative care for faculty, residents, and medical students within

Part II: The People cont.

the UW Health System and UW Medical School partners throughout Wisconsin, particularly Agrace HospiceCare of Madison, Wisconsin. As a leader of the Wisconsin Comprehensive Cancer Control plan, he has been instrumental in the inclusion of palliative care in that statewide project.



***Susan R. Dolan, RN,
JD, CHA, and Audrey R.
Vizzard, RN, EdD***

Susan Dolan and Audrey Vizzard are co-authors of the award-winning book *The End-of-Life Advisor: Personal, Legal, and Medical Considerations for a Peaceful, Dignified Death*. Dolan, of Park Ridge, Illinois, is an attorney, registered nurse, former executive director of a national hospice organization, and current healthcare consultant. Vizzard, of Scotts Valley, California, is a registered nurse, clinical psychologist, former adjunct professor of psychology at Purdue University, and the author of many books and articles. She also served as a hospice volunteer and facilitates on ongoing Good Grief Group for seniors actively dealing with caregiving and loss. Audrey also happens to be Susan's mother.



Loretta S. Downs

Loretta Downs of Chicago is a speaker, writer, facilitator, and consultant on the subject of supporting positive experiences at the end of life. She is president of the Chicago End-of-Life Care Coalition and founder of Chrysalis End-of-Life Inspirations. In 1995, responding to the health crisis in her industry (the holiday decoration business) and the loss of dozens of friends and business associates, she became a volunteer on the AIDS ward at Illinois Masonic Hospital in Chicago. There, she began to notice the positive difference in the quality of the deaths of patients dying with hospice care.

Following her father's death in a hospital in 1991, Loretta became a caregiver to her mother, Anna. The last six years of Anna's life were spent in the Fairmont Care Center, a nursing home, during which time Loretta and her mother experienced deep, transformational personal growth that healed their lifelong emotional difficulties. Their reconciliation changed their relationship from one of animosity and shame to one of mutual respect and unconditional love. This reconciliation, and her experience in caring for hospice patients at the Fairmont, inspired Loretta to create the Chrysalis Room so that her mother and other residents who had become family, would have a dignified, peaceful, and loving passage.

Part II: The People cont.



Rev. Dale Susan Edmonds

After 26 years as an ordained minister in the United Church of Christ and currently as a hospice chaplain, Rev. Dale Susan Edmonds of Chicago has witnessed many families in crisis because they did not have prior discussions with aging parents to guide and direct critical decisions. She created a website: *www.Talk-Early-Talk-Often.com* to provide resources and information about the conversations and choices people need along their journey. Her website is emerging as a touchstone for people with aging parents, siblings of special needs adults, congregations trying to support caregivers, and baby boomers looking to plan their own futures.



Elliott S. Fisher, MD, MPH

Dr. Fisher is director of population health and policy at the Dartmouth Institute for Health Policy and Clinical Practice (TDI). He also directs TDI's Center for Population Health and is the James W. Squires Professor of Medicine and Community and Family Medicine at Dartmouth Medical School. Dr. Fisher received his undergraduate and medical degrees from Harvard University and completed his residency in internal medicine at the University of Washington, where he was

a Robert Wood Johnson Clinical Scholar and received a master's in public health.

He co-founded and serves as senior associate of the VA Outcomes Group. He is principal investigator of the Dartmouth Atlas Project, succeeding longtime colleague Dr. John Wennberg, and also serves as principal investigator of the Dartmouth Prevention Research Center, funded by the Centers for Disease Control.

Dr. Fisher's research focuses on exploring the causes of the twofold differences in spending observed across U.S. regions and healthcare systems—and the consequences of these variations for health and healthcare. His work, demonstrating that higher-spending regions and health systems do not achieve better outcomes or quality, has had a major impact on the current thinking about healthcare and healthcare reform. He is also actively engaged in developing practical approaches to healthcare reform, most recently as one of the leading developers of the concept of accountable care organizations.



Gregory Gehred, MD

Dr. Gehred is a family physician and 1967 graduate of Case Western Reserve Medical School. For 25 years, he worked in the Indian Health Service in Santa Fe, Taos, and Santa Clara Pueblo, New Mexico, followed by 11 years of group family practice with the University of Wisconsin Health system in Wisconsin. In 2003, he helped found the Rock River Free Clinic in Jefferson, Wisconsin.

Part II: The People cont.

Medical ethics issues, including the care of the dying and the seamless garment of life, have been a focus in his career. These interests led him to become ordained as a deacon for the Catholic Diocese of Madison in 2004. The parents of six children, Greg and his wife, Pat, now reside in South Bend, Indiana, where Greg is active in medical volunteering as well as parish and jail ministries.



Bernard "Bud" Hammes, PhD

Bernard "Bud" Hammes was educated at the University of Notre Dame, receiving his BA in 1972 and his PhD in philosophy in 1978. He has taught at the University of Gonzaga in Spokane, Washington, and at the University of Wisconsin–La Crosse. Since 1984, he has served as the director of Medical Humanities and Respecting Choices for the Gundersen Lutheran Medical Foundation and the Gundersen Lutheran Medical Center in La Crosse, Wisconsin. In this position he provides educational programs for house staff, medical students, nursing students, and physician assistant students. He also provides in-services and workshops for the medical and nursing staff, social workers, and the pastoral care department. Dr. Hammes chairs both the Institutional Review Board and Ethics Committee. For the Institutional Ethics Committee he serves in the role of ethics consultant.

Dr. Hammes is a professor of clinical science at the University of Wisconsin–La Crosse and an associate adjunct professor of the Institute for Health and Society at the Medical College of Wisconsin and a clinical assistant professor in

the Department of Pediatrics at the University of Wisconsin School of Medicine and Public Health.

Dr. Hammes' work has been primarily focused on improving care at the end of life. He has developed institutional policies and practices, staff education, and patient/community education with a special focus on advance care planning. This work has resulted in two nationally recognized programs on advance care planning: *If I Only Knew...* and *Respecting Choices*. He has authored or coauthored at least 40 articles and book chapters that are focused on clinical ethics, advance care planning, and end-of-life issues. Currently he serves as chair of the National POLST (Physician Orders for Life-Sustaining Treatment) Paradigm Task Force.



Peter J. Kaldhusdal

Peter Kaldhusdal of Livermore, California, was the older brother of *Consider the Conversation* co-producer Terry Kaldhusdal. His untimely death from pancreatic cancer on June 29, 2009, at the age of 53 was not without a fight. After being diagnosed in the spring of 2007, Pete did everything humanly possible to beat the disease. While most people die within six months of being diagnosed, Pete fought the disease for more than two years. He was passionate about his family, his friends, his work, his music, his politics, and life in general.

He worked in the aerospace industry in California for more than 25 years. He treasured anything

Part II: The People cont.

with wheels and wings. He loved to drive, work on antique cars, attend auto races, and build model cars and planes. His passion for books was always evident; it was common for him to have a book in progress in nearly every room in the house. He was a devoted husband and loving father who took great pride in his children's successes. He cared deeply about his community. He was a volunteer for Habitat for Humanity, a former Big Brother, a volunteer coach, a Sunday school teacher, and a school volunteer. Pete donated his body for research purposes to help find a cure for pancreatic cancer.



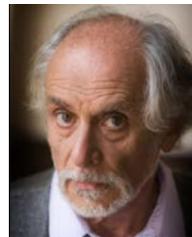
Stephen P. Kiernan

Stephen Kiernan is the author of *Last Rights: Rescuing the End of Life from the Medical System* and *Authentic Patriotism*. A graduate of Middlebury College, he received a Masters of Arts degree from Johns Hopkins University, and a Masters of Fine Arts degree from the University of Iowa Writers' Workshop. Over two-plus decades as a journalist he has won 40 awards, including the Bechner Institute's Freedom of Information Award, the Gerald Loeb Award for financial journalism (two-time commentary finalist) and the George Polk Award.

He has taught at Middlebury College and the New England Young Writers Conference and has worked on the staff of the Breadloaf School of English and the Breadloaf Writers Conference. He serves on the board of the Young Writers

Project and the advisory committee of the New Hampshire Palliative Care Initiative.

In addition, Kiernan travels the country speaking to varied audiences about healthcare, civic engagement, ethics, service learning, meaningful living, medical research, the green economy, criminal justice, race relations, the power of personal commitment, hospice, palliative care, and advance directives.



Daniel Klein

Daniel Klein, a graduate of Harvard in philosophy, is co-author (with Thomas Cathcart) of the international bestseller *Plato and a Platypus Walk into a Bar* and of *Heidegger and a Hippo Walk through those Pearly Gates*. He has written comedy material for Lily Tomlin and Flip Wilson, several mysteries and thrillers, and most recently the award-winning novel *The History of Now*.



Jung Kwak, MSW, PhD

Dr. Kwak is assistant professor of social work in the Helen Bader School of Social Welfare at the University of Wisconsin–Milwaukee. Dr. Kwak's primary research areas focus on surrogate end-of-life-care decision making and develop-

Part II: The People cont.

ing caregiver support interventions to facilitate informed decision making and improve mental health outcomes among family caregivers. She teaches undergraduate and graduate courses on research methods, statistics, and end-of-life issues.

In 2010, she was selected as a Hartford Geriatric Social Work Faculty Scholar. With grant support from the Hartford program and the Parkinson Research Institute at Aurora Sinai Medical Center, she is conducting a study to identify caregiving and decision-support needs among caregivers of people with dementia or Parkinson's disease. Dr. Kwak's scholarly work on end-of-life care and caregiving has been published in journals including *Aging and Society*, *American Journal of Nursing*, *The Gerontologist*, and *Journal of the American Geriatrics Society*.



Catherine Labinski, MTS

For 16 years, Catherine Labinski worked as a hospice chaplain with ProHealth Care Home Hospice in southeastern Wisconsin. She received a master's degree in theological studies from St. Francis Seminary in Milwaukee, Wisconsin, in 1992 and did a clinical pastoral education unit at Children's Hospital in Milwaukee in 1994. For over 30 years, Cathy has served as a facilitator for a breast cancer support group. All those educational experiences prepared her for hospice chaplaincy work. While serving, she focused her time and energy on meeting the spiritual needs of both the patient and the family. She invited patients to explore their hopes, fears, regrets, accomplish-

ments, joys in life, concerns, and needs for reconciliation with others and to look at any other unfinished tasks needing completion. In conjunction with end-of-life-review work, she facilitated prayer services, rituals, and sacraments; shared scripture/spiritual readings; and always ended her visits with a blessing.

In Cathy's encounters with patients, she believed in a mutuality of gift giving; that is, she gave to the patients but also believed that, in a deeper way, they gave to her. She valued their gifts of wisdom, their words of affirmation, their singing, their laughter, their tears, their honesty, and their words of blessing to her. She felt that they strengthened her sense of courage, hope, and faith. As Cathy met the deep spiritual hungers of the hospice patients, she radiated a deep, abundant spirit of gladness. Her future hope is to devote her time to writing a book that shares the wisdom she has gleaned from the dying.



James Milford, MD

Dr. Milford is a board-certified family practice physician with University of Wisconsin Health Partners in Lake Mills, Wisconsin, and a longtime medical director with Rainbow Hospice Care of Jefferson, Wisconsin. A native of the Midwest, he completed his undergraduate work at the University of Wisconsin-Madison before receiving his MD from Loyola Stritch School of Medicine in Chicago. Among Dr. Milford's many other professional roles have been that of emergency department staff physician (Watertown Memorial

Part II: The People cont.

Hospital and St. Michael Hospital), assistant clinical professor (UW Medical School and Marquette University), advisory faculty for the Advanced Life Support in Obstetrics course, volunteer at Rock River Free Clinic, and past chief of staff, Watertown Memorial Hospital.

Dr. Milford strongly believes that in order to be a good physician, one must advocate for patients, showing compassion and teaching along the way. His family is important to him and he enjoys spending free time backpacking with his wife, Karen, and their four children, Amanda, Jackson, Renae, and Margaret.



Douglas C. Smith,
MDiv, MA, MS

Douglas C. Smith, of Madison, Wisconsin, is a professional speaker, trainer and consultant with over 25 years' experience as a counselor, therapist and healthcare administrator. He has worked in hospitals, hospices, and social service agencies. He is the author of several books, including *"The Tao Of Dying"*, *"Caregiving: Hospice-Proven Techniques For Healing Body And Soul"*, *"Being A Wounded Healer"*, and *"The Complete Book Of Counseling The Dying And The Grieving"*. He has also published in several journals including *The American Journal of Hospice & Palliative Care*, *The Hospice Journal*, *Caring Magazine*, *Counseling and Values*, *Medical Hypno-analysis Journal*, *Journal of Pastoral Care*, and *Omega: Journal of Death and Dying*.

Doug's three master's degrees in three different healthcare disciplines give him a truly holistic

perspective that takes into consideration the physical, psychological, and spiritual dimensions of patients. He has presented workshops in all 50 states and has much experiential knowledge in the fields of terminal illness and grieving, having lost to death a brother and two daughters.



Mark Thimke, JD

Mark A. Thimke is a partner with Foley & Lardner LLP. He is a member of the firm's Environmental Regulation Practice and the Energy Industry Team. Mr. Thimke has lectured on environmental matters throughout the country and has participated in several small group workshops with personnel from the United States Environmental Protection Agency, which developed recommendations for improving the Superfund cleanup process, cost allocation, and dispute resolution methods. At the state level, he has served on the Wisconsin Department of Natural Resources NR 700 External Advisory Committee, which worked for two years on the development of a comprehensive state cleanup code. He continued his work in this area as a member of a select focus group that worked on the development of soil cleanup standards and a comprehensive remedy selection process.

Mr. Thimke is a graduate of the University of Wisconsin Green Bay (B.A., *summa cum laude*, 1976) and Duke University (J.D., 1979), where he was elected to Order of the Coif and served as a staff and editorial board member on the *Duke Law Journal*.

Part II: The People cont.



Martin Welsh, MD

Dr. Martin Welsh of Camino, California, was a family practitioner who diagnosed himself with amyotrophic lateral sclerosis (ALS), or Lou Gehrig's disease, in 2004. At the time of our filming he had lost the use of his legs, right arm and hand, and voice. Dr. Welsh shared his story in his very personal essay "100 Things, Leading to a Single Choice." First published in the *Los Angeles Times*, "100 Things" was reprinted many times in newspapers across the nation and internationally.

He opened his essay explaining he was a "retired family doctor with a large, loving family and innumerable friends and former patients whom I see often. I am an extraordinarily lucky man." The reality is that we are the ones who are lucky. Dr. Welsh's wisdom, first as a doctor and then as a patient, helps others define quality of life and sheds light on the importance of listening to a patient's end-of-life wishes.



Bruce Wilson, MD, FACC

Dr. Wilson is a cardiologist whose beautiful essay "Doing Death Better" was published in the *Milwaukee Journal Sentinel* on October 26, 2009. He is president of Wilson Heart Care Associates in Milwaukee and lectures nationally and inter-

nationally on the human stress response and its effect on health and performance. Dr. Wilson's interest in end-of-life care dates back to his first clinical rotation as a medical student. Since then, he has served as medical director of a hospice program in Milwaukee and written extensively on how the medical system poorly prepares physicians for end-of-life conversations.



Kay Wipperfurth, RN

Kay Wipperfurth received her nursing diploma from Madison General Hospital School of Nursing, her Bachelor of Science in Nursing from Mt. Senario College, and her MBA from the University of Wisconsin-Milwaukee. She was a first lieutenant in the Army Nurse Corps for two years before beginning her career at Fort HealthCare in Fort Atkinson, Wisconsin, where she is currently the vice president of ancillary and support services. Wipperfurth has been instrumental in beginning many new patient-oriented programs during her tenure in administration at Fort HealthCare. She also volunteers time in the community, serving on several nonprofit boards, including that of Rainbow Hospice Care. Kay and her husband, Will, live in rural Lake Mills, Wisconsin, and are fortunate to have their son's family (including three wonderful grandsons) living nearby.

Part III: Resources

Advance Care Planning Assistance

Advance care planning is a process aimed at extending the rights of competent adults to guide their medical care through periods of decisional incapacity. The process involves three steps:

- Thinking through one's values and preferences
- Talking about one's values and preferences with others
- Documenting those values and preferences

Aging with Dignity:

www.agingwithdignity.org (888) 5-WISHES

Aging with Dignity is a national non-profit organization with a mission to affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life. Aging with Dignity's founder Jim Towey served as Mother Teresa's friend and legal counsel for 12 years and was a full-time volunteer in her home for people with AIDS. Her tender care and concern for all a person's needs—medical, emotional, and spiritual—served as the inspiration for Aging with Dignity and for *Five Wishes*, America's most popular living will—the first living will that talks about personal, emotional, and spiritual needs as well as medical wishes.

Aging with Dignity introduced *Five Wishes* to Florida in 1997 and to the nation a year later. Dubbed “the living will with a heart and soul,” *Five Wishes* today meets the legal requirements in 42 states and has helped literally millions of people plan for and receive the kind of care they want. *Five Wishes* is unique among all other advance directives and living wills because it is

user-friendly and easy to complete. The document is available in 26 languages and in Braille.

Caring Connections:

www.caringinfo.org

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life. It provides numerous free resources and information to help people make decisions about end-of-life care and services before a crisis. And it brings together community, state, and national partners working to improve end-of-life care through a national campaign called *It's About How You LIVE*.

American Hospital Association:

www.aha.org

The American Hospital Association has published *Put It In Writing: Questions and Answers on Advance Directives*, an easy guide with basic information about advance directives.

National Healthcare Decisions Day:

www.nationalhealthcaredecisionsday.org

National Healthcare Decisions Day (NHDD) is an initiative to encourage patients to express their wishes regarding healthcare and for providers and facilities to respect those wishes, whatever they may be. The NHDD website provides information as a public benefit and lists participants in the effort to achieve a National Healthcare Decisions Day.

Part III: Resources cont.

Respecting Choices:

www.respectingchoices.org

Respecting Choices is an internationally recognized, evidence-based advance care planning program dramatically different from those that focus only on document completion. Since 2000, *Respecting Choices* has assisted other organizations in replicating the *Respecting Choices* model through the design of key elements that help busy professionals do the right thing, and the adoption of advance care planning as an ongoing process of communication that is integrated into the routine of patient—centered care and appropriately staged to the individual’s state of health.

As innovators and leaders in advance care planning education and systems development since 1991, *Respecting Choices* has provided training, consultation, and materials to organizations and communities around the world.

Hospice and Palliative Care

National Hospice and Palliative Care

Organization: *www.nhpco.org*

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

With headquarters in Alexandria, Virginia, the National Hospice and Palliative Care Organization advocates for the terminally ill and their

families. It also develops public and professional educational programs and materials to enhance understanding and availability of hospice and palliative care; convenes frequent meetings and symposia on emerging issues; provides technical informational resources to its membership, conducts research, monitors Congressional and regulatory activities, and works closely with other organizations that share an interest in end-of-life care.

American Hospice Foundation:

www.americanhospice.org

The American Hospice Foundation, a 501(c)(3) non-profit organization, supports programs that serve the needs of terminally ill and grieving individuals of all ages. The Foundation advances hospice concepts by:

- Training school professionals who work with grieving students.
- Educating employers and managers about the needs of grieving employees.
- Creating tools to help hospices reach out to their communities.
- Promoting improved hospice benefits in managed care organizations.
- Initiating research on consumer needs and preferences in end-of-life care.

By forging partnerships at local and national levels, the Foundation ensures that hospice care is available to many who might otherwise be underserved. Their current initiatives include:

Part III: Resources cont.

- Training workshops and materials on grieving children for educators.
- Employer outreach campaigns to aid bereaved employees and their co-workers.
- In-service programs for hospice and nursing home staff.
- Tools for decision-making at the end of life for caregivers of the terminally ill.

Hospice Foundation of America:

www.hospicefoundation.org

Hospice Foundation of America provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the U.S. healthcare system and the role of hospice within it.

Hospice Foundation of America meets its mission by conducting programs of professional development, public education and information, research, publications, and health policy issues. It's programs for healthcare professionals assist those who cope, either personally or professionally, with terminal illness, death, and the process of grief, and are offered on a national or regional basis. Public programs assist individual consumers of healthcare who are coping with issues of caregiving, terminal illness, and grief.

Center to Advance Palliative Care:

www.capc.org

The Center to Advance Palliative Care (CAPC) provides healthcare professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care

programs in hospitals and other healthcare settings. CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness.

As the nation's leading resource for palliative care program development, CAPC offers comprehensive training for palliative care programs at every stage - from strategic planning and funding to operations and sustainability. CAPC provides seminars, audio conferences, tools, reference materials, a robust website, and the Palliative Care Leadership Centers™ (PCLC) - a major training and mentoring initiative. It also sponsors *www.getpalliativecare.org*, a website for patients and families.

Growth House Inc.:

www.growthhouse.org

Growth House, Inc., provides education about life-threatening illness and end of life care. Its primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Its search engine provides access to the Internet's most comprehensive collection of reviewed resources for end-of-life care, including free access to over 4,000 pages of high-quality education materials about end-of-life care, palliative medicine, and hospice care. It provides education both for the general public and for healthcare professionals. Content is provided through syndication arrangements with over forty major healthcare organizations and publishing houses who are members of the Inter-Institutional Collaborating Network On End-of-life Care (IICN), a content syndication network founded in 1996.

Patient/Family Communication

CaringBridge:

www.caringbridge.org

CaringBridge provides free websites that connect people experiencing a significant health challenge to family and friends, making each health journey easier. It is a service entirely funded by generous donors. CaringBridge websites offer a personal and private space to communicate and show support, saving time and emotional energy when health matters most. The websites are easy to create and use. Authors add health updates and photos to share their story while visitors leave messages of love, hope and compassion in the guestbook.

Carepages:

www.carepages.com

CarePages.com is another online community with over a million unique visitors a month who come together to share the challenges, hopes and triumphs of anyone facing a life-changing health event. Through personalized websites, members can relate their stories, post photos and update friends and family instantly. In turn, people who care send messages of love and encouragement. CarePages.com also offers resources and support tools for living a more compassionate life.

Private-labeled CarePages websites are also offered by over 625 U.S. and Canadian health-care facilities. CarePages has a simple, singular mission: to ensure that no one faces a health challenge alone.

Research on Healthcare Utilization and Trends

The Dartmouth Atlas of Healthcare:

www.dartmouthatlas.org

For more than 20 years, the Dartmouth Atlas Project has documented glaring variations in how medical resources are distributed and used in the United States. The project uses Medicare data to provide comprehensive information and analysis about national, regional, and local markets, as well as individual hospitals and their affiliated physicians. These reports and the research upon which they are based have helped policy makers, the media, healthcare analysts, and others improve their understanding of the efficiency and effectiveness of our healthcare system. This valuable data forms the foundation for many of the ongoing efforts to improve health and health systems across America.

This website provides access to all Atlas reports and publications as well as interactive tools to allow visitors to view specific regions and perform their own comparisons and analyses.

Part III: Resources cont.

Recommended Reading

Bujak, Joseph S., *Inside the Physician Mind: Finding Common Ground with Doctors*. Chicago: Health Administration Press, 2008.

Byock, Ira. *Dying Well*. New York: Riverhead, 1997.

Byock, Ira. *The Four Things That Matter Most: A Book About Living*. New York: Simon & Schuster, 2004.

Cathcart, Thomas, and Daniel Klein. *Heidegger and a Hippo Walk Through Those Pearly Gates: Using Philosophy (and Jokes) to Explore Life, Death, The Afterlife, and Everything in Between*. New York: Viking, 2009.

Callanan, Maggie and Patricia Kelly. *Final Gifts, Understanding the Special Awareness, Needs and Communications of the Dying*, New York: Simon & Schuster, 1992.

Chen, Pauline, W., *Final Exam: A Surgeon's Reflections on Mortality*, New York: Alfred A. Knopf, 2007.

Christakis, Nicholas A. *Death Foretold: Prophecy and Prognosis in Medical Care*. Chicago: University of Chicago Press, 1999.

Dolan, Susan R., and Audrey R. Vizzard. *The End-of-Life Advisor: Personal, Legal, and Medical Considerations for a Peaceful, Dignified Death*. New York: Kaplan Publishing, 2009.

Dolan, Susan R., and Audrey R. Vizzard. *From the Start Consider the Finish: A Guide to Excellent End-of-Life Care*. Parker, CO: Outskirts Press, 2007.

Gladwell, Malcolm. *Outliers: The Story of Success*. New York: Little, Brown and Company, 2008.

Kiernan, Stephen P. *Authentic Patriotism: Restoring America's Founding Ideals Through Selfless Action*. New York: St. Martin's Press, 2010.

Kiernan, Stephen P. *Last Rights: Rescuing the End-of-Life from the Medical System*. New York: St. Martin's Press, 2006.

Kessler, David. *Visions, Trips, and Crowded Rooms: Who and What You See Before You Die*. Hay House, USA: 2010.

Smith, Douglas C. *Being a Wounded Healer: How to Heal Ourselves While We Are Healing Others*. Madison, WI: Psycho-Spiritual Publications, 1999.

Smith, Douglas C. *Caregiving: Hospice-Proven Techniques for Healing Body and Soul*. New York: Macmillan, 1997.

Smith, Douglas C. *The Tao of Grieving*. Madison, WI: Psycho-Spiritual Publications, 2007.

Part IV: Acknowledgments

Special thanks are in order for Karen Carrig, president and CEO of Rainbow Hospice Care in Jefferson, Wisconsin, as well as her board of directors. This organization immediately recognized the social value of our film, supported production, and underwrote a share of the cost.

Numerous other organizations also played a vital role by providing access to patients, facilities, and staff or otherwise assisting during production. They include:

- Alden Estates of Countryside, Jefferson, WI
- AngelsGrace Hospice, Oconomowoc, WI
- Aurora Medical Center, Summit, WI
- Dean Health System East Clinic, Madison, WI
- Fairmont HealthCare and Rehabilitation Centre, Chicago, IL
- Fort HealthCare, Fort Atkinson, WI
- Glenview Community Church, Glenview, IL
- Nashotah House, Nashotah, WI
- New York University, New York, NY
- ProHealth Care, Pewaukee, WI
- St. John's Northwestern Military Academy, Delafield, WI
- The First Presbyterian Church in the City of New York, NY
- University of Wisconsin Hospital and Clinics, Madison, WI
- University of Wisconsin School of Medicine and Public Health, Madison, WI

- UW Health Fort Atkinson Clinic, Fort Atkinson, WI
- UW Cancer Center Johnson Creek, Johnson Creek, WI
- UW Health Partners Watertown Regional Medical Center, Watertown, WI

We deeply appreciate the contributions of Rainbow Hospice Care's D.J. Scullin, who did an amazing job designing our website; Karen Reppen, who oversaw the production of this discussion guide; Barbara Walsh, for her editorial guidance; and Melanie Wallace for her design and layout of the discussion guide. We're also indebted to Carlton Mok and Lai Gay Mok, the grandson and grandmother whose beautiful picture now adorns this discussion guide, the *Consider the Conversation* website, and the cover of our DVD packaging.

It is important to understand that this project could not have been completed without the full love and support of our families. They too made serious sacrifices in the making of this film. Thank you Denise, Evan, Anna, Janet, Tazmin, Madison and Kahlil.

Of course, this film would not have been possible without the inspiration provided by four very special people in our lives—Rita Muriel Bernhagen, Peter Kaldhusdal, Dee Bennett, and Dr. Martin Welsh—as well as the amazing and courageous on-camera contributions of all those interviewed.

Finally, we wish to thank the following individuals and organizations for their financial support. Without their generosity, this documentary film project would not be possible.

Part IV: Acknowledgments cont.

Gold Sponsors (\$5,000 plus)

- Dan and Marina Harkins
in memory of Luone Harkins
- Debbink Family Foundation, Inc.
- Dr. Martin Welsh and Maureen Gill
- End-of-Life Coalition
of Southeastern Wisconsin
- Patricia and Allen Gill Family Trust
- Rainbow Hospice Care, Inc. of Jefferson, WI

Silver Sponsors (\$2,500–\$4,999)

- Larry Laux and Nina Wulff
- Susan R. Dolan and Audrey R. Vizzard in
memory of Charles V. Riker
- The Dolan Family in memory of William V.
and Frances M. Dolan

Bronze Sponsors (\$1,000–\$2,499)

- Chicago End-of-Life Care Coalition
- David and Lisa Young Family Foundation
- Kathy Ledvina and Paul Jasinski
- Kenneth P. Quade
- Tom Mack
- Thomas X. Herro Memorial Fund

Friends of Consider the Conversation (up to \$1,000)

- Anonymous in honor of Marty Welsh
- Anonymous in honor of
Marty and Carey Welsh
- Anonymous in honor of Marty Welsh and
Maureen Gill
- Anonymous in honor of the Nevada Center for
Ethics & Health Policy
- Anonymous in honor of those whom I
comforted as they died
- Anonymous in memory of Dennis Roberts
- Anonymous in memory of Charles E. Roberts
- Anthony R. Welsh in honor of Martin Welsh
- AseraCare Hospice of West Allis, WI
- Catherine Labinski
- Charles J. Herro
- Chelsea Hanson in memory of Donna Olson
- Cheryl Morris
- Craig Moore in memory of Chris Steinmeyer
- CRG Services, Inc. of Brookfield, WI
- Curtis A. and Nancy L. Waddell
- David A. Welsh in memory of
Dr. Martin Welsh
- David M. and Anne M. Domach
- David Rusch
- Hal Horneffer
- Holly Mann in memory of Bobbie Mann
- Jacqueline Cameron, MDiv, MD

Part IV: Acknowledgments cont.

- Jake's Pizza of Winneconne and Omro, WI
- James Lucas
- Jamie Welsh in honor of Carey and Jason Welsh
- Jamie Welsh in memory of Dr. Martin Welsh
- Jim and Leona Hays in honor of Martin Welsh
- Jim and Tori Stephens in memory of Helen Stephens
- Joan L. and Peter R. Kaldhusdal
- Judith Carey Maas
- Justin Minkel in memory of Pete Kaldhusdal
- Karen Kehl in memory of Laura M. Schaub
- Karen Reppen
- Katherine Jarman in memory of Walter A. Wands
- Kevin Callaghan Welsh in honor of Martin Welsh
- Kevin Welsh in honor of Dr. Martin Welsh
- Kurt Klismet in honor of John W. Klismet
- L C Guertin in memory of Dr. Martin Welsh
- Leah Turner in memory of Marty Welsh
- Lori Guyant in honor of Jimmy Johanknecht
- Madaline L. Fennell in memory of Leona Fennell
- Mark Horneffer, MD
- Mark Kal, MD, in memory of Martin F. Welsh, M.D.
- Maureen Gill in honor of David and Susan Welsh
- Melinda/Dave Welsh/Webb in honor of Tony, Jaime and Clara Welsh
- Michael L. Bennett in memory of Delores A. Bennett
- Michael T. and Tanya M. Sutton in memory of Roger Baeckmann
- Mike and Jill Huff in memory of Peter Kaldhusdal and Sue Huff
- Nancy Anderson
- Nancy Yeomans Behnke in memory of Charles and Marjorie Yeomans with whom I've had the conversation
- Peter and Earlene Ronk
- Robert Wilson in memory of Jack Wilson
- Sandi Hebley in honor of Doug McGuire
- Sandi Hebley in memory of Mabel Bowling McGuire
- Sheila Semrou in memory of Clementine Semrou
- Shreda Paire in memory of Rita Sue Paire
- Small Business Success, Inc. of Bend, OR
- Susan Ryder in memory of Mary Givens