

A 14 MINUTE VIDEO: “DEATH PANELS” AND AGGRESSIVE TREATMENT

- *At* April 25, 2019
- *By* **Mark B. Peterson**

Medicine has performed many miracles and the video link below chronicles a rather typical and understandable end of life event: a seemingly minor health issue cascades into a series of other issues which result in prolonged pain and suffering. With each succeeding medical issue, most people engage in hoping that maybe “this treatment” or procedure will get things back on track. But then it doesn’t.

Generally, older adults are more prone to these health care challenges. Our aging bodies do not respond as well or recover as quickly. All this can elevate the challenge of being a proxy who should be prepared to ask important questions to the person they represent and to the medical personnel caring for them. Those questions are articulated in my book as a template of questions to ask.

Sometimes it is only in retrospect that we see that our well-meaning responses prolonged suffering and/or reduced quality of life. See the anguish, pain and frustration of Keith Olberman as he describes being his Dad’s proxy and the excruciating dilemmas he faces. Note how he urges the viewer to “have the conversation”.

That being said, there are no simple answers to these profound life dilemmas but it is worth at least being aware that we all need to be aware of the challenge of hope versus the reality of our mortality. Being a proxy can be very difficult.

View this with your proxy and discuss how you would want your proxy to respond. It is understandable that you cannot anticipate every medical situation, but it is worth a general conversation.

- At January 16, 2019
- By **Mark B. Peterson**

I was privileged to read a galley proof of this book in January of 2019. The book will be released February 19, 2019 and is published by Scribner.

Butler has written a comprehensive guide to end of life incorporating many practical suggestions for the reader's consideration. The book may be of equal or even greater value to adult children of aging parents who often find themselves in the position of helping to make very difficult decisions.

Chapters include, among others, gently encourage slowing down, developing an acceptance of mortality, the house of cards (when we become more fragile and less resilient), accepting hospice, and active dying. She has structured the chapters to begin with invitations to reflect on oneself at the beginning of chapter as well as some practical next steps at the end to take based on the content of the chapter.

Butler does address some aspects of advanced medical directives (especially the importance of them) but does not spend as much time on the details and implications of choices as I do. But she does cover a much broader consideration of the practical issues than anything I've read. It will be a useful reference for planning.

I highly recommend this book as a useful resource for aging adults. Watch for its release!

VIDEO OF AN 82-YEAR OLD WOMAN WHO HAS DECIDED TO END HER LIFE

- *At* January 16, 2019
- *By* **Mark B. Peterson**

The video that accompanies this post is of an 82 year old woman a former nun and philosophy professor who has decided to have a medical assist in dying.

Your first response is likely to be one of shock. She has been ravaged by cancer and the treatments to stop it. She is choosing to end her life and her rationale and logic are clear. Making a choice to treat cancer has consequences which can cure you, devastate your quality of life, or even kill you.

Watch this with an eye towards what you would choose if you were impacted by cancer and had exhausted your options. In nine states in the US you can make this choice, in others it would not be permitted. There are forces actively working to make it impossible for anyone to ask for relief from their suffering. Among them is one member of the Supreme Court (Justice Gorsuch) who has written a book opposing Medical Assistance in Dying. If you believe that this is a right (as a substantial majority of those polled do, express your opinions as constituents to both local and congressional leaders. Support Compassion and Choices, a national organization which is actively advocating for the right to die.

- At December 01, 2018
- By [Mark B. Peterson](#)

Birnstengel, Web Editor “*One Doctor’s Plea: Consider Palliative Care, An Oncologist Grapples With Letting Patients Suffer When There’s An Alternative*” November 9, 2018

Most Advanced Medical Directives ask you to choose some of the most basic treatments such as CPR, breathing machines, etc. They rarely include information about the implications or consequences of your choices So you are really choosing blind... without much information as to what might be either the side effects or the outcome.

This article describes the anguish of an oncologist who would like to see more people with cancer accept palliative care: a medical response which focuses on symptom relief and is tailored to what matters most to you. (You can watch a brief Ted Talk which describes palliative care. You will see Dr. Timothy Ihrig describe how patients lived 3-6 months longer with a better quality of life including less pain and fewer hospital admissions.)

Advanced Medical Directives also fail to ask you about what kinds of responses you might want in a broader sense. For example, you might want to consider whether you would want Hospice, experimental clinical trials, no more hospitalizations, etc. These critical issues and others are addressed in chapter 4 of my book, *Your Life, Your Death, Your Choice*.

I AM AWED AND HUMBLLED BY THE WILL TO LIVE... REACTIONS TO A DEAR FRIEND

- *At* November 12, 2018
- *By* **Mark B. Peterson**

Being clear about his choices.

B died on November 1st, 2018 in the afternoon after struggling with ALS since the summer of 2017. I think that he was 81 years old. He was a quiet, caring, and shy man who had difficulty sharing his emotions. He was a dear friend and a colleague as we had both been professors at the same university in 1969 when we met.

On numerous occasions as we socialized, the idea of how we would want to die was discussed and he was consistent and resolute that he didn't want to suffer, to be a burden, or to linger. He'd seen that with both his parents and two brothers and that was not for him. His usual refrain was "just take me out in the woods and shoot me".

When B was diagnosed with ALS, we talked by phone about his options and he declared that he didn't want a feeding tube which would be necessary because his ALS made it impossible for him to manage swallowing. In September of 2017, he told me that he'd "done the research" and the feeding procedure was very susceptible to infection at the entry port. He was very clear that he didn't want a feeding tube. However, he was having a great deal of difficulty receiving nutrition and hydration because swallowing difficulties caused gagging and choking.

B had weighed about 190 pounds and by early December he weighed 145. It was then that he chose to have a feeding tube installed and began a process of 4 daily feedings of liquefied food. Almost every feeding resulted in violent stomach aches. Occasionally he would take something by mouth but the consequences of that were usually very unpleasant. When he died, he weighed 120.

The months since the feeding tube have seen him gradually deteriorate, losing some of his mental capacities and towards the end being unable to do much of anything other than sleep and receive his feedings. He was able to communicate up to a few weeks ago when the ALS took his ability to speak. He used a white board then.

Changing his mind and struggling to live

Of great interest to me is the decision that B made to reverse course when he saw that he was facing death, accept a feeding tube and all the compromises that his illness imposed, and soldier on with trying to live. It is one more lesson to me about the power of our will to live which is especially energized when we are facing a real death, not one speculated about and discussed over drinks in an intimate setting when we are healthy.

While I'm sure that there have been some good moments spent together with B during the past 13 months as his disease progressed, I have also known that his decision has had consequences for the family. These include the pain and anguish of seeing him suffer with the ghastly symptoms that ALS brings upon a person, the periodic life-threatening crisis which occurred and necessitated worrisome phone calls and quick visits to his bedside. And especially to his wife of 55 years who has been by his bed side and seen how much suffering he has experienced.

Reflecting on my choices...

I have been teaching about end of life planning and medical directives now for almost 9 years. I have read widely, heard countless stories of good and bad endings, and I have tried to imagine what I would do if I were confronted with a life-threatening illness.

I know what I think I want which is a less prolonged suffering and a more peaceful end. I do not want to linger in a diminished state, and I have often joked that when I no longer care about listening to NPR or watching PBS, then there is not much to live for.

I am even clearer and feel strongly that I don't want to be a burden to my wife or family with an extended illness. I would like time with each of them, but I don't want them to be filled with worry and concern that drags on and on.

I underlined "*think*" because I don't really know what I will feel when I am faced with a possibly fatal illness and leaving this earth. B has taught me that I can't count on my thinking when I am facing death. The power of that existential moment of facing death is enormous and mysterious to me. It is only certain that it is a matter of time until we face it.

Some who read this may be clearer but none of us know what will happen until we are faced with our mortality.

What do you think that you would do if you were B?

EVEN MEDICAL PERSONNEL HAVE DIFFICULTY TALKING ABOUT END OF LIFE AND THERE ARE CONSEQUENCES

- At October 16, 2018
- By **Mark B. Peterson**

Colleen Chierici, published an article entitled, “*The Cost of Not Talking About Death to Dying Patients*”. The Hill, October 8, 2017

The author is a nurse. Most medical personnel have substantially more insight and knowledge than most of us about medicine, hospitals, treatment, and mortality. But she had trouble talking with her dying mother.

Her article is one of the best descriptions of a particular challenge for those of us who will be confronted with an incurable illness. It’s not the only challenge because there are many different kinds of medical situations which confront us. Here are a few of the elements addressed in this article

- In retrospect, Colleen’s mother died a terrible death because no one (including the author!) talked with her about the fact that she was dying from cancer. Instead, they tried to treat her.
- Many (but not all) doctors and nurses are either ill prepared or unwilling to “have the conversation”... or both.
- She admits that it was difficult for her to raise the issue with her own mother. It’s not unusual, but it has consequences for both the patient and their family.

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There is a need to go far beyond the dying patient featured in this opinion. *Everyone* needs to make their choices known. You can do this only if you (1) inform yourself, (2) reflect on what is most important to you, and (3) have deep conversations with those who are important to you... not just once, but frequently.

WHEN TREATMENT OF A HEART PROBLEM CAN MAKE THINGS WORSE IN THE LONG RUN.

- *At* July 30, 2018
- *By* **Mark B. Peterson**

The author is a cardiologist who describes in the New York Times on 7/30/18 the complicated dilemma he faces when discussing a heart problem called fibrillation... a condition that causes the heart to beat erratically and ineffectively. In a patient with this condition, s/he can die suddenly and quickly without a “defibrillator”. Electronic ones can be implanted to shock the heart back into a regular beat. But the downside of an implanted defibrillator is that as a patient’s heart continues to decrease in effectiveness, they are likely to die a much more prolonged and unpleasant final ending. In this article, you can see that both patients and the doctor have difficulty coping with this dilemma.

It is worth it to attempt to think about what you would choose if you were confronted with this unfortunate choice. It starkly raises the question of quality of life over quantity. Have a conversation with your family and proxy about this dilemma. Maybe you can all profit from this discussion.

JESSICA ZITTER, MD SPEAKS ABOUT HER MORAL QUALMS ABOUT KEEPING PEOPLE ALIVE WITH MACHINES

- At March 03, 2018
- By [Mark B. Peterson](#)

Dr. Zitter is interviewed by Amy Tobin, CEO of an organization which focuses on new ideas in Berkeley. This podcast is about the importance of considering your choices long *before* being admitted to the hospital with a serious illness or injury. She is a specialist in intensive care, pulmonary diseases, and palliative care. The title of the episode is: **DEATH 101**.

Zitter is the author of Extreme Measures a book about her work as a physician with patients who are very sick and often dying. Her argument is that we spend too much time denying death and too little accepting the inevitability of it. The result is often catastrophic suffering caused by avoidance of important conversations which should be started when a child is 18 (or earlier) and revisited throughout life.

Zitter is also featured in a 20-minute Netflix film, **Extremis**, which was nominated for an Academy Award in 2016 for “best short documentary”. It is worth watching.

<https://www.berkeleyside.com/.../new-podcast-death-101>

or

<http://berkeleyside.libsyn.com/podcast>

Episode 27 (2/21/18) is 41 minutes long.

After listening to this podcast, share your impressions with your friends and loved ones. Tell them what you want in the way of aggressive treatment if you are not able make choices for yourself. Everyone is different and when a medical crisis occurs, they will have a better idea of what you want and can help you.

A TRUE STORY ABOUT DETAIL IN DIRECTIVES AND HOW A FAMILY COPEd

- *At* February 12, 2018
- *By* **Mark B. Peterson**

A healthy active woman in her early 70's had a massive stroke while living alone. At the point of discovery several hours later, she was placed on a ventilator and taken to a major hospital. Brain surgery was performed which enabled her to be somewhat responsive by using hand squeezes. (Having a ventilator does not allow you to speak.)

When her family located the woman's advanced medical directive, they were deemed too vague to respond to the complexities of her situation. Would she have elected to remain indefinitely on the ventilator, or would she have chosen otherwise? They didn't know.

After consultation with doctors, the family attempted communication including telling her the neurologist's opinions and the likelihood of her recovery. Through the use of hand signals, it was determined that the woman asked to be removed from the ventilator and refused further aggressive care. Her wishes were respected, and she died within 24 hours with her family present.

Unfortunately, this situation is not uncommon. Although forms were completed, they lacked specificity with the end result being to put the proxy and family in a state of uncertainty. Often forms are simply a series of check marks and thus do not take into account the complexities that can arise in a life-threatening situation. Additionally, forms are often completed with little or no conversation with proxy or family members who in a medical crisis such as this one, are often unable to act in accordance with what one may have wanted.

Here are some important positive elements.

- The family was together
- The patient was consulted throughout
- The patient was able to make her choice
- The hospital and doctors respected her choices
- The patient passed on her terms.

Here are some thoughts for reflection and some suggestions for action:

1. *Reflect on what you would choose if you were the patient.*
2. *Review your forms to see if they contain enough detail*
3. *Give thought to probabilities: what would you choose if you had 10% chance of living off a respirator? Or a 60% chance of being bedridden? Or a 40% chance of living on your own after you recovered?*
4. *Share this story with your medical proxy, family, and doctor and ask them what they would do in a similar situation and then share your choice. Have a conversation!*
5. *Write down your thoughts/decisions and put them into your Advanced Medical Directives.*

Share your own story here.

DEMENTIA IS AHEAD FOR MANY PEOPLE ARE YOU PREPARED?

- At January 28, 2018
- By [Mark B. Peterson](#)

Medical science has greatly enhanced the life span. This increased longevity means that you must carefully reflect on what how much treatment you want as you age. Research is revealing that living longer increases the chance of developing dementia, for which there is no cure. It is an illness that can strip you of your dignity, consume your family's caretaking capacity, and exhaust your financial resources. Many elements of dementia care are not covered by Medicare.

The following three articles will help you understand the complexity of the dementia issue.

In 2015 Paula Span, a well-known journalist, described a man who adapted his Advanced Medical Directives to explicitly state that he did not want to be fed if he could no longer feed himself. Span's article preceded by two years a troubling situation in Oregon that featured a woman in a nursing home with advanced dementia whom her husband claimed was being fed against her stated medical directives. When her husband filed suit against the nursing home, the court ruled that because she opened her mouth when a spoon was put up to it "she wanted to eat". It was not viewed as a purely reflexive response.

On January 19, 2018, Span published another article describing the efforts to improve the clarity of dementia directives through the use of forms designating what you would want under mild, moderate, or advanced states of dementia. You can view, download and print the five page document which includes three forms addressing each level of dementia.

This directive is limited in two respects: (1) the choices of treatment are more limited and (2) the implications of choices are not addressed. For more detail, I refer you to the Chapters 3 and 4 in my e-book *Your Life*,

Your Death, Your Choice to understand the implications of twelve choices for treatment. Chapter 5 provides information on the 3 levels of dementia with only one form to complete. You can view and compare my dementia directive, “Situation E” which includes 12 choices (including feeding) by [clicking here](#).

We are a very long way from a solution to this issue. In the meantime, it is important to take the necessary steps of deciding how much treatment you want, having important conversations about your choices with your family, doctor, and health care proxy *and* completing one of the forms to ensure that your choices are honored.

Here are a few questions for you:

Have you experienced dementia with a relative? What did you see or experience?

Are you aware of dementia as something that might be inherited in your family?

How much treatment would you want? Do you have the resources for that treatment? Have you considered whether you would try to find out if you had dementia by dna testing?

Have you completed any advanced medical directives? If not, would you consider doing it and including a dementia focused directive/

Have you had conversations with those important to you about what you would want?

DEMENTIA AND DEATH WITH DIGNITY LITTLE PROGRESS.

- *At* January 19, 2018
- *By* **Mark B. Peterson**

Paula Span is an incredible journalist who often offers observations which are cutting edge. In 2015 she wrote about the need for clear and detailed statements about your choices for end of life care if you are suffering from dementia. In particular the individual she was featuring had taken pains to detail that feeding and hydration should be terminated. He simply didn't want his life to continue in a severely compromised state with little or no dignity left.

It was prescient. In August of 2017 an article was published (not by Span) which described how the State of Oregon had ordered the feeding of a woman with advanced dementia despite what her advanced directives said. The reasoning was that she had "not provided adequate detail" in her directives and because she opened her mouth when a spoon was brought to it, she "wanted to eat and to live".

The husband (her proxy) filed suit against the nursing home and the court ruled against him. She remains in a nursing home (at \$85,000/year) being fed by hand. Keep in mind that Oregon is the State with the longest and most progressive attitude towards death with dignity.

As a good adjunct to detailed instructions in the event that someone is develops dementia, it is also worthwhile to video tape the signing of the directives and to have the person state what their wishes are if they become unable to recognize or interact with others. You can do this with your smart phone but be sure to save it to a flash drive.

As the situation above illustrates, it may make no difference.

HOSPICE IS GOOD RESOURCE, BUT IT ISN'T ALWAYS GOOD... BEWARE AND DO YOUR RESEARCH

- At January 11, 2018
- By **Mark B. Peterson**

“This Was Not the Good Death We Were Promised” NY Times, Op. Ed. January 6, 2018. This is a story about *one* hospice in *one* community at *one* particular point in time.

All Hospice organizations are different and have different cultures. While they ostensibly do the same thing; provide care for those at the end of their life, they have different cultures and go through all of the stresses and strains of any organization. For example, I recently learned of a situation where two parents went into the same Hospice within a year of each other and the first experience was very positive while the second was not. It is to the credit of the Hospice organization that they scheduled a meeting to learn how they had not met the expectations of the family and were determined to correct the problems.

One distinction that may be important to consider is whether the organization is a nonprofit entity. It is logical that a “for profit” entity has more of an eye on how to keep costs down. [Click here](#) to read the story.

Talk with your family about whether you want Hospice as a resource when your life is coming to an end. As friends who might have had a relative what their experience with Hospice was like. Did you know that Hospice patients generally live longer with less pain and discomfort than a similar group? Unfortunately, when many hear that someone has gone into Hospice, they consider it a death sentence. It is not. It is a decision to live for as long as they can with the greatest humanity and comfort that can be provided. Too many families and patients wait too long to contact Hospice. Have a conversation about hospice while you are well and let your family know whether you would want hospice.

GREAT VIDEO ABOUT AGING, MAKING ADVANCED MEDICAL DIRECTIVES, AND OVER TREATMENT

- At January 11, 2018
- By [Mark B. Peterson](#)

Video: **End of Life – Aging Matters**, NPT report.

This 59-minute video produced by Tennessee Public Television presents the issue of aging and the associated increasing need for medical services. It is a comprehensive look at the issues that are present for so many and articulates well the many “systemic problems” that plague our current health care system. It comments on the many failures of the health care system because of its orientation and its economics. It is also disturbing to see repeated statements by patients or family members who didn’t feel that they were asked what they wanted, given choices, or told what they could expect with regard to their health issues.

This is an important video for seniors *and especially for their children or other relatives* to watch and discuss so everyone can all be “on the same page” when decisions have to be made. As one physician comments, when the patient is in the Intensive Care Unit is not the time to be start having important conversations. The same statement has been made by Emergency Room doctors. [Click here](#) to watch.

If you have children or relatives who you would like to start conversations with about your choices, send them the link and invite them to be in touch to discuss their reactions. Or better yet, watch it with them and stop and talk about things that particularly impact you during the viewing. This is how you will get to know each other’s views. Start the conversation!

WHEN THE ICU CAN LEAVE YOU WORSE OFF

- *At* September 07, 2017
- *By* Mark B. Peterson

Let's start with the obvious: the ICU saves lives that otherwise would end. But the impact of this aggressive care can compromise life after release from the ICU.

This segment broadcast in June of 2016 describes the adverse impact of the ICU and speaks of a new diagnostic term Post-Traumatic Intensive Care Syndrome (PICS) describing the lasting emotional and cognitive effects of being in the ICU.

You will be able to see efforts by Vanderbilt University Hospital to help patients who are suffering with PICS. It's clear that the ICU impacts emotional stability may also impair cognition. But there is less research about whether the impact on cognition is a lasting or a transitory effect of the very heavy medication often used in the ICU. Two very interesting elements to this video are (1) the statistic that 1/3 get better, 1/3 stay the same, and 1/3 get worse in terms of their psychological functioning and (2) that one of the patients (a physician) said he is absolutely terrified about ever going back into the ICU. Note that this patient was in the ICU longer than the three-day average.

The ICU is mentioned in Chapter 4 of my book as an important issue to think about because of the implications for your overall welfare.

There is no doubt that the ICU saves lives through the use of high-tech equipment, powerful drugs, and highly skilled physicians and nurses. I know that I am repeating myself... yes, the ICU can truly save your life! And this video says it can come with costs.

Show it to your family and proxy and think about what you want for yourself. If you have an aging relative, show it to them and ask what they would choose: comfort care or aggressive care?

There are important implications for your advanced medical directives. Serious conversations need to be initiated about how much treatment is right for you. Keep in mind that age can play a substantial role in making the best choices.

- At August 29, 2017
- By **Mark B. Peterson**

Finns, MD, Joseph “The Civil Rights We Don’t Think About.” *New York Times*, 8/24/17 Opinion page. Published also on Sunday in the *Review*, Section (8/27/17 page 10).

Most advanced medical directives do not invite input into a variety of situations where a person may not be conscious. The term “persistent vegetative state” which ordinarily suggests no brain activity is not even used in some forms. This article suggests that it is even more complicated and that there are marginal states where a person may be “minimally conscious” and able to express him/herself through a small action such as an eye blink. There are even small indications that the brain can adapt and make repairs.

The article raises many questions about the treatment of these patients and the consideration of their rights to be consulted about their treatment despite limitations in their capacity to respond.

There are many comments responding to this article which may help you think through what choices you would make and whether you would want to anticipate and express your choices in your own directives prior to a medical event. Consider doing the following.

Given the possibility that this could happen to you, what would you want for treatment? Would you want to register your choices ahead of time in your directives? How does your current age figure into your choices? Are there financial concerns? Are there concerns as to how your impairment would impact your family and those you love? Share this article with your family. Ask what they would want for themselves. Then discuss your thoughts and choices.

JESSICA ZITTER, MD IS FEATURED IN A COMPELLING OSCAR NOMINATED DOCUMENTARY ABOUT DIFFICULT DECISIONS.

- AT FEBRUARY 19, 2017
- BY **Mark B. Peterson**

Extremis, released in September 2016 is available to be streamed from Netflix.

This film is about the effort to make treatment decisions for patients who are gravely or terminally ill. Dr. Zitter and others struggle to determine what a patient wants and then help the family make their best decision. It is an elegant display of a caring physician and other health care providers attempting to do their best while knowing that providing more interventions can extend life but enhance suffering.

A review of this film in the *Journal of the American Medical Association* (Jan 17, 2017 volume 317, number 3) states the following: “... many Americans will encounter end of life decision making – not as an active choice but, passively, with little or no opportunity to influence the decision or the outcome.” (pg 241). This statement makes it clear that very sick patients can lose their voice in their health care.

Extremis is a stark and deeply moving testimony to the importance of deciding what you want and “having the conversation” with your family, doctor, and health care agent (Medical Proxy). It illustrates the difficulty of making choices when there have not been adequate conversations and when there is an urgency to make decisions.

Dr. Zitter has also written a memoir *Extreme Measures – Finding a Better Path to the End of Life* which is to be published in February of 2017. (Penguin)

Much of this film focuses on two patients who end up with different decisions with regard to breathing machines.

After viewing, try to decide what your choices would be if you were either of these patients. Then show the film to your loved ones and proxy and have a conversation. Begin by asking them what they would choose if they were one of these patients, followed by sharing your choices. Take note of the ICU setting in which this drama plays out. These units provide the most aggressive highest level of care that may: (1) save your life, (2) extend it without any improvement in the quality, (3) extend it and permanently decrease the quality of your life, or (4) possibly result in your death. What would you choose?

YOUR LIFE, YOUR DEATH, YOUR CHOICE AN E-BOOK PUBLISHED EARLY OCTOBER 2016

- At October 08, 2016
- By **Mark B. Peterson**

Your Life, Your Death, Your Choice: How to Have Your Voice to the End of Your Life is an e-book based on six years of research and teaching providing you with the necessary resources for considering your end of life options.

It is...

- Written for adults of all age
- Provides options and guidance for choosing your medical proxy and advanced medical directives
- Encourages reflection, choice making and conversation
- Gives direct information about the implications of your choices
- Uses many real examples
- Enables interaction with over 65 web sites through links to videos, pod casts and articles
- Suggests tools and strategies to “have the conversation” with family, doctor, and health care agent
- Addresses dementia and medical directives
- Includes forms to view, download, and print

If you have an older adult who is not computer literate, buy it and read the book with her/him. If you are younger, buy it for yourself. As you will see when you read some of the examples, accidents and illness can strike at any time.

The book is available in a variety of formats for different kinds of tablets and computers. [Click here](#) to buy the book.

Note:

If you choose to read on a computer, you must download e-book reader software. *Ice Cream* is an e-reader software that works well on PC computers. Search your app store for “e-book readers” to select and download the one that appeals and matches your computer operating system (Mac or PC).

GRAY AREAS AND THE EVENTUAL COST OF DEMENTIA CARE. IT'S SUBSTANTIALLY MORE THAN FOR HEART DISEASE OR CANCER.

- At November 24, 2015
- By **Mark B. Peterson**

Gray areas...

In our “Having Your Voice” class, we talk about *gray areas*... the time when we begin to lose the ability to make effective decisions.

Anyone living long enough will experience this to some degree but, for some, it is the beginning of a more serious, substantial, and accelerated decline into dementia. It is important to appreciate that Alzheimer's is not the only form of dementia... there are others that are equally devastating. Gina Kolata's article from the New York Times on October 26, 2015 states that the cost for treatment of heart disease and cancer for the last five years of life is roughly \$175,000 while the cost for dementia care is \$285,000. The cost difference is due to the hands-on care required for caring for someone with dementia.

If you want to learn more about the impact on family, read “A Life Worth Ending”, a compelling article by Michael Wolff whose mother had dementia. He beautifully describes the woman she was, the last tragic years of her life, and the impact on the family.

What are the options for someone who develops dementia?

1. Having financial means helps because there are resources to support the person.
2. Having long term care insurance is valuable in gaining assistance. However, it is expensive and usually has to be purchased when you are young and don't need it. (Wolff comments darkly about the ongoing struggles to gain payment for services for which he asserts his mother is entitled).

While I am not advocating suicide, two well written articles address the decisions that were made by two women who were diagnosed with early onset Alzheimer's disease. Both women recognized the loss of dignity and the many burdens they would place on others as their disease progressed. They made a different choice.

Gilean Bennet, a former professor and psychotherapist who lived in western Canada, wrote a farewell that described her reasoning and decision to take medicine to end her life. It includes comments about the needless expenditure of resources when there was little that would bring her a satisfying quality of life.

Robin Henig wrote about a professor of psychology who carefully researched how to take her life after she was diagnosed with early onset Alzheimer's disease. Although she didn't want to take her life, she knew that she would get to the place where she couldn't because of the impairment of her disease. Henig describes how her impairment almost defeated her intention.

In the realm of Hollywood films, "Still Alice" beautifully depicts the dilemma faced by a professor diagnosed with early onset dementia. It depicts Alice's failing in an attempt to take her life because she was too impaired to complete the act of taking pills. Clearly, in patients with dementia, the window of opportunity to take their own life closes at some point.

Questions for you:

As always, there are profound and difficult questions for you to ponder.

Here is a brief sample:

- 1. What would you do if you were diagnosed with a progressive incurable form of dementia?*
- 2. How much medical care would you want to sustain your life (such as for blood pressure, cholesterol, heart medication)?*
- 3. Are there family members you could identify who would be willing to care for you?*

4. Do you or they have the resources (financial, personal, spiritual, etc.) to care for you?

5. Would you consider taking your life if you were able to do it?

Share your responses to these questions with your family. It's an important conversation to have.

A PSYCHIATRIST’S OPINION: DYING WELL IS DYING AT HOME.

- *At* October 17, 2015
- *By* **Mark B. Peterson**

In a short article, Dr. Allen Frances, a psychiatrist, makes the case for the He states that, “...there is no worse death than a hospital death”. He emphasizes the unpleasantness of the ICU given the noise, light, strangers, unfamiliar physicians, etc. about how doctors die, has observed that they are less likely to choose to die in hospitals than the general population.

But dying at home is not always a choice. Sometimes family or care givers are not capable of providing the care needed to prevent hospitalization. Quite possibly the medical needs of the patient are too complex, or the patient doesn’t want to subject the family to the burden of care.

If you could choose where you spent your last days and hours, where would you want to be? When making your choice it is important to discuss your wishes with your proxy, doctor, and loved ones.

[Click here](#) for insights into Death with Dignity: Brittany Maynard’s choice and her husband’s experience with her choice.

- *At* October 17, 2015
- *By* **Mark B. Peterson**

On October 15, 2015, *Compassion and Choices* posted two videos to honor Brittany Maynard, a 29 year old woman diagnosed with terminal brain cancer who took her life on November 2, 2014 through the Oregon Death with Dignity law. In the first video, Maynard talks about her

decision and why she was choosing to die. Prior to her death, she tirelessly advocated for a death with dignity law for California that passed in the legislature in September 2015. Governor Brown signed the law on October 5th, 2015. The 6 minute video includes information about the efforts of Compassion and Choices in helping the passage.

In a second five minute video you can watch Oprah Winfrey interviewing Maynard's husband. He describes Maynard's last hours of life as being peaceful, loving, and filled with dignity. The video is a rare opportunity to have a window on one of the most intimate moments in life.

Given that we are all going to die, what end would you choose for yourself? Would you want to die in a hospital or medical facility or to die at home? What's most important for you? How do you feel about the growing movement of assisted suicide? If you support assisted suicide, assisted dying, or death with dignity, contact your state legislators.

A NURSE WITH FATAL BREAST CANCER OPTS FOR CARE ORIENTED TO QUALITY OF LIFE RATHER THAN QUANTITY OF LIFE.

- *At* October 17, 2015
- *By* **Mark B. Peterson**

This article in the Washington Post in September 2015 articulates a clearly chosen path for a breast cancer patient to seek comfort care through a palliative approach rather than aggressive care which was discerned to not bring much relief, extend her life, or offer a good quality of life. The patient, Amy Berman, is a nurse with a clear-eyed perspective on her cancer enabling her to choose quality of life over quantity of life. To date, she has had five reasonably good years without the debilitating effects of chemotherapy.

Note that the treatments she received to shrink tumors on her ribs involved radiation, not to kill the tumor, but to reduce it and thereby provide her with greater comfort with less pain. Palliative medicine can sometimes be aggressive in the service of creating a better quality of life. Surgery is another option, although it has not been part of Amy's treatment.

What is unfortunate is that unlike Amy, many patients are neither medically trained nor sufficiently experienced to see that there are options other than aggressive care. "Curative" (aggressive treatment approaches) treatment is often selected because of a diagnosis that naturally creates anxiety about mortality. Added to this is our faith and hope that technology and medications can solve our problems.

Further pressure comes in the form of advertisements from hospitals and treatment centers. There is an increase in advertising offering solutions to the dilemma of how to respond to a diagnosis of cancer, heart disease, etc. Some imply that you should seek out "this" or "that" treatment because "you owe it to your loved ones..." that can be seen by some as a

thinly veiled guilt trip. Given that some new treatments are showing great promise, the challenge is to sort out what is realistic from what is appealing because it eases our anxiety.

At the very least, the medical establishment needs to make these options clear to patients. It requires that doctors talk honestly with you about the treatments, probability of success, and cost in terms of side effects.

Doctors vary in their ability/willingness to engage in this conversation with their patients and their families. An “optimism bias” lurks here that naturally causes humans to embrace the positive solution that they most want. Combine this with doctors wanting to give you hopeful news and there is a potent force to ignore the down sides of aggressive treatment.

Do you think that your doctors are capable of talking honestly about your mortality?

Reflect on what you would want if you were diagnosed with a fatal cancer and what choices you would make if you had a 5% chance of recovery or a 50% chance of recovery. It's hypothetical, of course, but by sharing your thinking you can inform those you care about as to your initial thinking.

ETHAN'S BLOG: WHAT'S IT LIKE TO HAVE CANCER AND FIGHT IT WITH CHEMOTHERAPY?

- *At* October 17, 2015
- *By* **Mark B. Peterson**

Ethan Remmel, a 40 year old professor of Psychology who, when diagnosed with Stage 4 colon cancer, chooses to write a blog. In Ten Blog Entries he takes the reader from the time of diagnosis to his farewell posting. His blog is a valuable contribution from a thoughtful, articulate, and honest patient enabling us to understand his thoughts and feelings about choices he makes related to his cancer's relentless progress. Additionally, he shares his struggle with "quantity of life" versus "quality of life". He enhances our understanding of the positive and negative aspects of chemotherapy and vividly describes the complex aspects of the fatigue he experiences.

One of the surprising things that Ethan mentions is losing a sense of identity because so much of his life, energy, and passion is taken from him by the chemotherapy side effects. It left him lonely, dispirited and discouraged.

Because Ethan lived in Washington State, he was eligible for and received a prescription for medicine that would allow him to end his life. His response to filling the prescription was a common one – just knowing that he could make the choice to take the medicine gave him relief. He was in charge whether he exercised that option or not.

Note:

At this point (January 2017) seven states and the District of Columbia have provisions for taking one's life. Sixteen other states are considering some form of legislation. Public opinion polls in 2015 found that up to 68% of persons responding support "death with dignity" when a person is terminally ill and in pain.)

A posthumous family post at the end of Ethan's blog describes a peaceful and intimate end which Ethan chose to have for himself. We are the recipients of a great gift in this blog – one filled with insight and care for others. It is a moving display of honesty and courage.

Reading this blog enables you to understand more deeply what a friend or loved might go through when they have treatments with debilitating side effects, and (2) it affords you the opportunity to consider what you would do if you were in Ethan's situation.

Ask yourself how hard would you fight to “beat” a cancer diagnosed as terminal? Would you opt for experimental treatments? What about costly uncovered treatments? Do you have concerns about how your family would deal with you being ill? Would they be able to cope with the care you needed? How would you know when the rigors of chemotherapy were no longer worth the discomfort?

After you've thought about these questions, talk to someone who loves you so they will know what you want. It's all about the conversation. If you don't have it, no one will know what you want.

HOW DOCTORS DIE IS DIFFERENT. WHAT'S GOING ON HERE?

- *At* June 22, 2015
- *By* **Mark B. Peterson**

A short report on California Public Radio reviews the work of Ken Murray, MD who noticed several years ago that when his physician colleagues died, they rarely died in a hospital. He hypothesized that they had made a choice to die at home because they had seen too much unnecessary and futile aggressive treatment given to patients most likely to die.

Unfortunately, many doctors are not willing or able to talk about dying. According to some studies, only about 10% of doctors nationwide have had conversations with their patients about death and dying which means that many patients may not be told the truth about their illness. To support this asserted communication failure, the NPR reporter who produced this piece interviewed a woman whose husband died of an inoperable brain tumor. She felt that the doctors pressed her to undertake treatments that adversely impacted the quality of his life and may also have shortened his life.

In another article, Dr. Murray shares the story of an orthopedic surgeon who consulted a colleague who diagnosed him with pancreatic cancer. Despite the fact that this physician was an expert in treating pancreatic cancer, the survival rate was less than 15%. Given the odds, the orthopedic surgeon closed his practice that very day and died 9 months later having spent his remaining time with his family.

Dan Gorenstein also reported on this topic on NPR's "Market Place" commenting on the extraordinary cost of aggressive care when an older person is fighting a serious illness. About 20% of all Medicare costs are spent in the last six months of life at the cost of roughly \$300 billion dollars.

The most compelling and thorough presentation on this topic is a 20 minute Radio Lab pod cast entitled, “The Bitter End”. Sean Cole interviewed doctors at John Hopkins regarding the results of a study of physicians’ attitudes towards treatment options if they are in a coma. A graph showed that 60%-90% elected not to have any treatment for most options (90% rejected CPR). However, more than 80% would want medicine for pain management.

Listen to the interview to hear how doctors feel about extraordinary treatment and how strongly some of them express their wishes. Note the description about what being on a ventilator is like and take note of the comment by a doctor who says to a colleague while they are working on a very sick person in the ICU, “If this happens to me, kill me.” It is also fascinating to hear Cole interview his own father (a doctor) who makes his advanced directive known.

WHAT IS THE “TAKE AWAY” FROM THIS POST?

- Doctors are less likely to elect aggressive treatment when they are faced with a serious or fatal medical problem.
- Doctors know more about the consequences both of certain illnesses and of the likely treatments.
- Doctors may not share information about the impact of treatment on the quality of life.
- They may be more likely to recommend treatment different from what they would choose for themselves. You may have to push hard for this information.
- Aggressive treatment and intrusive procedures may complicate your life, degrade the quality of your time during or after the treatment.
- Aggressive treatment may permanently impact your quality of life, and/or cause your life to end sooner than with hospice and palliative care.

- Ask your doctor(s), “If you were facing my illness, what treatment would you elect to have?” Or, “If this was your mother (dad, wife, relative), what would recommend?”
- You must be alert to evaluate both the meaning and value of treatments as well as the consequences for quality of life.

Now is the time to have serious conversations about your own mortality as well as those you love, not when you are in the ER and in the midst of confronting a serious and possibly life-threatening issue.

USE OF VENTILATORS: ALIVE BUT AT WHAT COST TO QUALITY OF LIFE?

- At June 13, 2015
- By [Mark B. Peterson](#)

An article was published in the Philadelphia Inquirer on May 28th, 2013 entitled: “Alive but at what kind of quality of life?” (pg. A-3) by Stacey Burling. The article is not available unless you are a digital subscriber to the Inquirer.

The author reports on the results of two critical care physicians who have begun to research the consequences of using breathing machines for two weeks or more on seriously ill patients. Their research (often called a “meta-analysis”) involved reviewing 124 studies from 16 countries – an impressive comprehensive study. Results showed that 30% of the patients who had been on ventilators for two weeks or more died while in the hospital once the ventilator was removed. Furthermore, 60% died within the year. Information on the results for remaining 10% was not a part of the study.

Studies show that medical research seems to focus predominantly on how to keep patients alive and/or getting ahead of the life-threatening condition. Rarely is attention given to the quality of life *after* an intervention. The medical field has developed powerful technologies and medicines designed to stave off dying but one of the unintended consequences has been keeping our bodies alive when there is little apparent quality of life. This is becoming a major concern among some physicians.

While medicine rightly focuses on preventing death, the reality is that we are all going to die at some point. Because of this, the use of radical or high-tech interventions to keep us alive needs to be weighed against the impact of these interventions on the quality of life of the patient as well as their family *after the intervention*. Age will have a lot to do with

choices since interventions for a younger healthy person may have a better prospect of full recovery compared to an older person. It can be a tough judgment call. Consideration of the use of these technologies on older frail adults is especially critical. This is especially true of both CPR and ventilators.

The following applies to all who are placed on a ventilator regardless of age.

- You will have air pumped in and out of your lungs which will keep you alive.
- You will not be able to speak.
- You may be heavily medicated.
- You may be paralyzed with drugs so you won't "fight" the rhythm of the ventilator.
- You will be hydrated and fed liquid nutrition by tubes.
- You will be catheterized.
- You may have a rectal catheter because you will only be receiving liquid nutrition which means you will likely have diarrhea.
- You will lose the strength of muscles you use to breathe which will necessitate physical therapy at the end of treatment to regain your breathing capacity.
- You may never regain sufficient capacity to be free of supplementary oxygen which means carrying oxygen with you 24/7. (While there are exceptions, some physicians say that beyond 2 weeks on a ventilator may result in not being able to survive without it.)
- You may be intellectually compromised due to low oxygenation of your brain related to your condition either permanently or temporarily.
- Most physicians (85%) when polled said that they would not want to be on a ventilator if they were unconscious and needed ventilation.
- You may recover completely!

It is clear from this article that doctors don't know in the long term what will happen to the quality of your life when you are placed on a ventilator. You should consider carefully under what circumstances you would want assistance with breathing and talk it over with your proxy, your family, and your physician. Include, if you wish, a statement about how to assess (as a percentage) your likelihood for survival and recovery. For example, if your family and proxy were told that you had a 10% chance of complete recovery would you want to have this treatment?

Be aware that this statistic also indirectly states the reverse: that you have 90% chance of NOT recovering fully. Would you want to be ventilated? How long would you be willing to be on a breathing machine?

Remind your family that an effort to obtain an honest statement from the doctor can be compromised by his/her lack of knowledge about the long-term quality of life following ventilation because there is limited research on this topic. And remind your proxy and family that many doctors do not like to give bad news. They prefer instead to instill hope because it's less painful for them and for your family to hear.

CODED TALK ABOUT ASSISTED SUICIDE CAN LEAVE FAMILIES CONFUSED

- *At* June 13, 2015
- *By* **Mark B. Peterson**

In late May 2015, there was a brief four minute piece on All things Considered which is informative. It points out that doctors may speak in code to a medical proxy or family member about actions which might be taken if the patient in question is very sick and not likely to survive. The “code” in this case was related to accepting extra morphine to give to a dying patient. Whether the doctor was alluding to unanticipated pain which might occur or to the potential for aiding the dying process is not clear which testifies to the possibly coded nature of the communication.

This may be relevant to you. You need to tell your family, your proxy, and your physician what you would want if you were gravely ill and likely to die. In addition, you may need to be very clear about your wishes as well the laws about assisted suicide in your state. Currently it is a crime in most states to assist in a suicide. Penalties can be severe.

You should also be aware that once morphine is administered to someone who is likely to not live long, they may slip into a “morphine haze” and be less able to sustain a conversation. As a result, it is important for significant persons to have a chance to converse *before* the morphine has begun to have its impact.

A very prominent case in 2014 was featured on CNN and involved the accusation that a nurse and daughter had assisted in the death of her father when she gave him some morphine at his request. While she was cleared, her father died in severe pain and she spent almost a year and \$120,000 defending herself from the allegations.

The legal situation is changing rapidly: seventeen states are considering bills to make assisted dying legal and legislation in California, Colorado,

and the District of Columbia passed 2016. Until it does change, be aware that speaking in “code” may be the nature of communication from compassionate physicians when it comes to helping a seriously ill person leave this world with dignity and relative comfort.

HOW MUCH TREATMENT FOR THE OLDER CITIZEN CONFRONTED WITH A DIFFICULT ILLNESS?

- *At* May 21, 2015
- *By* **Mark B. Peterson**

Recently, a very dear 88 year old friend, whom I have known for 50 years, was diagnosed with cancer near his pancreas. One option was to do nothing that would likely result in his death. The second option was a radical invasive surgery called “the Whipple Procedure” that required an eight-hour operation. On the web I read that the survival rate for this procedure was 25% for 5 years.

My friend was a healthy, lively, and creative man whom I cared for dearly. When given the choice, he elected for surgery, in part, because he was curious to see what would happen and how he would do. Obviously, he had an adventuresome spirit and often spoke with an awe about life.

I was pleased for him and his choice and hoped he would have a good recovery. Unfortunately, it was not good, and he died 14 months later after struggling with the many side effects of the surgery and a return of the cancer.

Although I supported my friend’s choice, I’m not sure that I would have taken that 25% risk. The many side effects from surgery can be hard on our aging bodies and we don’t heal as quickly. Complications such as strokes, infections, difficulty with digesting food, multiple medications can make life pretty miserable. Instead of surgery I might choose Hospice with palliative care and make the most of the opportunity to spend time with my family and friends. My choice rests on my desire to have death with dignity on my terms.

Hospice patients tend to live 25% longer, have a more pleasant end, and cost less in every way. Families report that while there is grief (as there

should be), it is not as deep or infused with complicated feelings about treatment choices.

Examples such as my friend's help us decide what we would do in a similar situation. Making a choice is good for us to do now while we have the capacity to make decisions for ourselves. It also enables us to make our family aware of what we would want in case the decision is suddenly and unexpectedly thrust upon them to make in our behalf. It can be as simple as saying, "Remember when Uncle John had that medical problem? Here's what I would want to happen if it were me.". If you engage in this conversation repeatedly, you inform your family and loved ones as to what you would choose.

And don't forget, you can always change your mind...no one needs to hold you to what you said. Who knows – when I get to 88 maybe I'll decide that the Whipple Procedure doesn't look so bad.

DEATH WITH DIGNITY FOR THOSE WITH ALZHEIMER'S DISEASE: DIFFICULT CHOICES

- *At* May 21, 2015
- *By* [Mark B. Peterson](#)

In the May 17, 2015 NY Times Magazine, Robin Henig chronicles the experience of a 60 year old Cornell psychology professor diagnosed with Alzheimer's disease who decides to take her life rather than live on in a demented and helpless state. The most challenging aspects of the decision is *when* she will do it. How long can she wait while retaining her capacity to actually take the actions she wants? It is a provocative and compelling article which we all should consider for ourselves. This issue is well demonstrated in the movie "Still Alice" released in 2014. Alice is a professor of linguistics, who wants to take her life but loses the capacity to take her life by waiting too long.

Here are just a few questions: Would you have the courage to take your life? Are their religious or spiritual issues for you? Will your family or loved ones accept your decision? Can you really say "goodbye" to life? Is this a better end than one that drags on consuming the resources, (emotional, loving and financial) of your family? Or is it a gift to them to allow them to care for you?

You may also want to read a beautifully written essay posted in 2014 by Gillian Bennett a philosopher and psychotherapist who also was faced with increasing dementia and explained the reasons for her decision to take her life. It is based on many factors which contributed to her decision including not wanting to be a drain on both personal and governmental resources. In Bennet's case, she is clearly seeing a progression towards greater impairment. She is compelled by this awareness to act before she does not have the capacity to do so. And she does.

In Your Life, Your Death, Your Choice: Having Your Voice to The End of Your Life, dementia is understood as a series of gray areas...the time when we begin to lose our capacity to think, remember, reason, etc. The darker the gray, the more dementia is clouding our ability to think and interact. Forms have been developed which allow individuals to declare their wishes while completely capable of making decisions for themselves.

Another beautifully written essay by Michael Wolff is entitled: *“A Life Worth Ending. The era of medical miracles has created a new phase of aging, as far from living as it is from dying. A son’s plea to let his mother go”*. He describes the descent of his mother and the power of medicine to sustain the body but not the person. While this essay makes it clear that she would not want to live this way, even more poignant is the profound emotional and economic costs of her long illness on the author and his family.

Would you like the opportunity to have assistance in dying if you no longer were capable of living the kind of life that you wanted? Should the government provide avenues for doing this? Have you talked about this issue with your family? Given the state of Wolff’s mother, would you want to be kept alive if you were permanently and irrevocably in that state?

ASSISTED DYING AND DEATH WITH DIGNITY?

- *At* May 21, 2015
- *By* Mark B. Peterson

According to a recent editorial in the New York Times, 17 states and the District of Columbia are considering legislation acknowledging that gravely ill patients who have little or no chance of recovery deserve the right to die with dignity. wrote forcefully about this in an essay in which he criticized the effort to sustain the life of Nelson Mandela whose body was kept alive long after he had ceased to be conscious. Tutu flatly stated that death with dignity is a civil right.

More recently, Brittany Maynard became prominent when she declared that she intended to take her life rather than succumb to the brain cancer that was progressively causing massive seizures. Maynad feared that she would not be unable to take her life if she didn't act quickly. To accomplish her goal of a dignified death, she was forced to move to Oregon and establish residency in order to qualify for the Aid in Dying program – a program that has numerous safe guards in place to insure that a person is not simply trying to find a way to commit suicide. With the support of her family, she took her life on November 1st, 2014.

The state legislatures currently considering a Death with Dignity law will encounter stiff opposition from individuals within the medical community as well as from some organized religious groups. Detractors include physicians (Ira Byock, M.D for one) and those whose religious beliefs include the tenant that if “God gave life, only God can take it away”. But as the population ages and more individuals become afflicted with fatal illnesses, the pressure will increase for ending suffering in a way that is both humane and reasonably regulated.

An interesting aspect of the use of the law in Oregon is that only 60% of those who qualify for the program actually secure and use the physician prescribed medication. But almost all patients describe great relief at

knowing that they have the means to end their life if their suffering becomes unbearable.

If you were confronted with an incurable and progressive illness which was sure to take your life, would you want to have the option to die with dignity on your terms with the assistance of a physician? Or are you supportive of the government saying that you must live out your natural life despite, pain, discomfort, and a lack of dignity?

PRESENTATIONS

- At May 21, 2015
- By **Mark B. Peterson**

November 17, 2013

Tiburon Community Congregational Church Tiburon, CA. *The Toughest Choices You'll Ever Make.*

This talk focused on how difficult it can be to make choices when there are two “rights”: the desire to maintain the life of your gravely ill loved one at all costs and the courage to let your loved one go if there is no hope and they don't want to live. A secondary focus on advanced planning and conversation about dying – activities that provide survivors with a more comfortable road map as to how to proceed when decisions must be made.

January 26, 2014

Temple Beth David, Northern Philadelphia. *How to Have your Voice when a Serious Illness or Accident Occurs.*

A 90 minute “mini seminar” introduced participants to the complexity of decisions and the kinds of circumstances patients may encounter. The essential issue of opening up conversations with doctors, family members, and designated proxy.

February 11, 2014

The Hill at Whitmarsh, Philadelphia, Pa. *Having Your Voice to The End of Your Life.*

Presented to a retirement community that addressed the issues associated with end of life planning.

March 30, 2014

Temple University's OLLI Program (A lifelong learning center)

End of Life Planning: *Having Your Voice to The End of Your Life.*

This class has been offered since 2011. A ten hour seminar addressing obstacles and resources for having one's own voice, completion of forms

that outline one's wishes, about gray areas associated with aging, addressed issues related to conversation they must have with doctors, family members, and their medical proxy who will make medical decisions for them. Developments in new legislation to legalize assisted dying are discussed.

October 2014

A presentation to the Positive Aging group of active seniors. *End of Life Planning: What's it all About.*

March 2015

A presentation to the Transition Network introducing the concepts associated with *Having Your Voice to The End of Your Life.*

May 28, 2015

Presentation to a Men's Group of Friends in the City. *Five Short Videos That Could Change Your Life.*

September 2015

Temple University OLLI Program. *Four Short Videos that Could Change Your Life.*

February 2016

Presentation to the Einstein Circle at Sarasota, Florida. *Four Short Videos that Could Change Your Life.*

Here is a review from the producer of this program:

"I'm delighted with all the positive feedback that came from your Einstein's Circle and was glad to see the annotated bibliography, as a number of people came up to me at last week's Einstein's Circle to ask when it might be expected. I also want to let you know that as a direct result of being there for your presentation, three couples made a point of telling me they made appointments to have the

*“conversation” with their doctors and get their Florida DNR’s in order and acknowledged by their physicians. A fourth woman told me that that evening she and her husband talked about how they felt after listening to you and watching the videos and it caused them to come to a decision to leave Florida in the near future and relocate to California to be near their children and grandchildren as they grow older and face the possibility of serious health issues. Your talk was, indeed, conscious raising and begs to be repeated here in Sarasota again on another occasion.
Thank you again for the time, the effort, the dedication and the energy you put into this very worthwhile mission.”*

September 2016

Presentation to the Media OLLI program: *Your Life, Your Death, Your Choice: Having Your Voice to The End of Your Life.*

October 2016

Author Presentation to Friends in the City and the Philadelphia Public Library on *Your Life, Your Death, Your Choice: How to Have Your Voice to The End of Your Life.*

DOCUMENTARY BY KEN BURNS ON CANCER Aired March 30, 2015

- *At* March 28, 2015
- *By* **Mark B. Peterson**

Cancer: The Emperor of All Maladies

Siddhartha Mukherjee's Pulitzer Prize-winning book was published in 2010 and has been made into a 6 hour documentary produced by Ken Burns. It about the history of cancer, recent developments, and prospects for the future of one of the most complicated and vexing diseases that has confronted the human race. It aired beginning Monday night March 30th, 2015 on PBS.

A startling fact is that one in two men and one and three women will be confronted with cancer in their lives. The two reasons for this are (1) that we live longer and cancer is more likely to occur and (2) that we are impacted by environmental toxins and life style choices... such as smoking. There will be many stories included and the future does appear to be promising through highly technical and innovative targeted drugs specifically designed to respond to an identified defect within the genetics of a particular patient's cancer cells.

While the prospects for a future with many new and wonderful treatments is good, the time horizon for "cures" will be long for many kinds of cancer. "Cures" is in quotations because oncologists in many cases are not sure at this point whether a particular response is a cure or remission. It's going to take time.

We must always be vigilant as to whether hope is obscuring the greater probability that treatment will not extend life and may severely compromise the quality of our life. There is no magic formula for discerning when it is the right to switch to hospice care. Hope can be a powerful drug for good on the one hand, and on the other, an aid to

embracing denial. Hope can afflict your thinking, your family's wishes for your survival and recovery, and your doctor's thinking as well.

What's the message in all this?

Be vigilant so you don't lose your voice about your end of life care!

DEATH WITH DIGNITY ON THE MOVE?

- At February 11, 2015
- By [Mark B. Peterson](#)

In January 2015, the Canadian Supreme Court reversed a decision from 20 years ago which said that it was illegal to assist someone who was very ill from taking their life. The most recent ruling impacting the entire country now states that “death with dignity” is an inherent right of all Canadian citizens. In the USA seven states (Montana, Oregon, Washington, Vermont, New Mexico, California, and Colorado) now have either statutes of case law which mandates that patients who are ill and dying must have the right do death with dignity through assisted suicide, or specific statutes that prescribed the regulations that must be followed. There are strict guidelines that must be met to qualify for receiving the life ending medicines.

It may be of interest that Archbishop Desmond Tutu has written on this subject stating that death with dignity should be an inherent right and that Nelson Mandela was not accorded this at the end of his life. He was kept alive for about four months on machines... longer than his body would have naturally survived.

A celebrated case involves Brittany Maynard who was diagnosed with a brain tumor in February of 2014 and given nine months to live. She chose to move to Oregon and qualify through their Death with Dignity Law. She did secure the medicine to end her life and announced that she would end her life on November 1st (the announcement has been removed from the web since this was posted). Taking the medicine on her own is an important requirement of the law. Her symptoms and debilitation from her cancer were growing. Brittany was afraid to wait any longer for fear that she would not be able to take the medicine on her own because of the growing cancer in her brain. And indeed, she made the choice and died on November 1st.

Her mother has taken the courageous step of advocating that the California legislature pass a “Death with Dignity” bill. Her mother explains how Brittany was forced to establish residence in Oregon in order to qualify for this humanitarian program. It is a both heart-breaking and inspiring presentation.

If you support this initiative, you can advocate for Death with Dignity in your state. Contact you senator and representative.

DYING SHOULDN'T BE SO BRUTAL

- At February 11, 2015
- By [Mark B. Peterson](#)

Dr Ira Byock, a well-known advocate for palliative care for the dying, has recently taken a strong position that it is time for citizens to begin to protest the failure to make death with dignity a central political theme for advocacy. I think his view reflects some of his frustration with the slow progress made by the medical profession thus far. He also voices a concern over the growing movement for assisted suicide an act he staunchly opposes.

It would be best if we didn't need assisted suicide, but the medical profession and medical schools have failed to focus on helping patients deal honestly and openly with impending death. Several recent books and articles have detailed horrific end of life experiences and advocated the need for change.

Buttressing this concern, a recent study found that the pain and suffering at end of life has actually *gotten worse* over the last ten years. If this is not a call to action, then what will it take?

Inadequate communication may be at the heart of the issue. Physicians vary in their ability to communicate about end of life and patients and their families are often no better as they are struggling with the emotion of losing a loved one. A recent PBS Frontline program entitled *Being Mortal* based on Atul Gawande's recently published book of the same name addresses the difficulties doctors, patients, and families have in addressing this issue.

While it would be easy to blame physicians for not being better communicators, medical schools often provide little to no training in communication. Instead, training focuses on scientific knowledge, research, technical methodological skill acquisition, and most importantly – preserving life. In watching *Being Mortal*, even the best

efforts of doctors to communicate feelings lacked much depth and exploration.

An ideal would be a palliative care team that included social worker, family therapist, or psychologist – professionals better trained in communication skills – to assist doctors in interfacing with families when treatments fail and there appears to be little hope

- *At* January 24, 2015
- *By* **Mark B. Peterson**

PBS News Hour October 14, 2014: a debate about Brittany Maynard's decision to take her life rather than continue to suffer with terminal brain cancer.

Brittany a 29 year old married woman decided to move to Oregon because of her terminal brain cancer diagnosis. She knew that she could receive the medications to take her life legally in Oregon. She announced that she was intending to take the medications on November 1st. Part of her reasoning was that she was experiencing more and more intense seizures from the growing tumor and she feared that she would not have the physical capacity to do so if she didn't act. (Oregon requires that the patient physically take the medicine by themselves). Brittany wanted the opportunity to have a dignified ending and posted a statement on [YouTube](#). She was supported by Compassion and Choices, a nationwide organization advocating for Death with Dignity.

Brittany reserved the right *not* to carry out her plans on November 1 but she ultimately did take her life on that date. The announcement that Brittany would take her life on November 1 stirred up a controversy that the PBS news hour aired on October 14th, 2014. The segment is about 24 minutes into the program and features a debate by Ira Byock,

MD, a palliative care physician, who is opposed to assisted suicide and Barbara Combs Lee, the President of Compassion and Choices.

I personally disagree with the characterization by Dr. Byock that Brittany was being exploited by Compassion and Choices. The very nature of the organization does not suggest that they would be exploitative of terminally ill patients. Note that Dr. Byock acknowledges that the medical profession is not currently adequately trained to care for terminally ill patients with the compassion and dignity that they deserve. This acknowledgment should be taken seriously by you, the reader. You cannot depend on the medical profession to do what you desire.

This is a controversy that you should discuss with your loved ones and your medical proxy.

To do so, you have to ask yourself the question: What would I do if I was diagnosed with a terminal illness?

Then share your thoughts with those important to you.

Then ask those you love: what would you do if you were diagnosed with a terminal illness?

Here is another easy way to start a conversation...one of the most important of your life.

AN ARGUMENT FOR MAKING YOUR PLANS IN A SHORT VIDEO

- At January 24, 2015
- By **Mark B. Peterson**

The Wisconsin Medical Society produced a video, released in October 2014, that is designed to encourage you to make your end of life plans and to begin having the “difficult conversations” about what you want at the end of your life.

Take ten minutes to watch people of all ages, faiths and races talk about their ideas as to what they would want. The areas of concern are quite varied and some of them will surely stimulate you to think about what you would want. Particularly poignant is a young adult in his late 20s who was diagnosed with leukemia whose wife was struggling to make decisions without knowing what he wanted.

It is truly an act of love to let people know what you want so they are able to respond. We need to take responsibility for communicating our wishes should we suddenly become ill and unable to make decisions for ourselves.

Here are some suggestions:

- *View the video and reflect on the comments particularly meaningful to you.*
- *Invite your loved ones to watch and then talk together.*
- *Challenge family members to engage in preparing their own medical directives.*

SOME THOUGHTS ON VENTILATORS AND THE FRAGILITY OF OUR DECISION MAKING...

- *At* March 14, 2014
- *By* **Mark B. Peterson**

In most end of life documents you are asked whether you would like to have assistance with breathing if you can't breathe on your own. The process usually involves inserting a tube down your throat through which air is rhythmically pumped to inflate your lungs and oxygenate your blood.

Because of their size, these devices are not pleasant to experience and have a number of side effects including (1) not being able to talk and (2) having to be provided with water and nutrients through a tube. In some cases, heavy sedation and paralytic agents are introduced so that your body will not fight the rhythm of the breathing machine. You can read more of the details in an article by McConnell who has declared that she sometimes considers having "Do Not Intubate" tattooed on her upper lip!

If you are unconscious or in a deep coma and someone is making decisions for you, these decisions will be made by your proxy and your physician.

Consider the following actual examples with special attention as to what you would do if you were in a similar situation.

A 77 year old, who had executed end of life documents indicating that he did not want to be placed on a ventilator, contracted a severe lung infection. Lying on a hospital gurney, a physician approached him, told him of the grave diagnosis and asked whether he had advanced medical directives. The man's instant response was to lie and say that he did not and that he wanted everything possible done to save his life. An operation was performed after which he was placed on a ventilator for

two weeks. In his recovery he stated that he had no clear notion as to why he was so quick to respond as he did – he just *knew* that he wanted to survive. Although he lived another two years, he was tethered to nasal tubes and tank which provided supplementary oxygen for his badly damaged lungs.

The drive to survive is powerful. Be aware that we cannot be too glib and that many factors contribute to decisions that are made about treatment when we are very sick.

Robin Henig wrote a cover story about a 70 year old man who experienced a catastrophic injury to his spine in a biking accident. Even though he had completed end of life forms stipulating that he did not want to be sustained in a diminished state, he subsequently revoked that expressed intention and asked to be continued on a ventilator He lived four more years in this severely paralyzed state at a cost of \$250,000/year.

Note:

Soon after Henig's article was published, the patient concluded that he did not want to continue living because he felt his mind was failing. He stopped the life sustaining treatments that kept him alive. You can read about him elsewhere on this web site.

A New York Times article written by a doctor addresses the complex ethical environment in which he practices. He describes a case of a man who had completed advanced medical directives that specifically said that he did not want to be placed on a ventilator. When the man became unconscious from severe bleeding into his lungs from being on a blood thinner, his doctor diagnosed that the patient was drowning in his own blood. Knowing that there was a good chance that the patient could recover if he were placed on a ventilator, the doctor chose to intubate him and the patient recovered. Afterwards, the doctor apologized for violating that order and the patient who survived thanked him for doing so.

What meaning does this have for you as both a proxy holder and a proxy grantor?

Here is an alternative response to the ventilator.

A 32 year old hunter who had climbed a tree for a better view, fell and sustained a spinal injury such as Henig describes above. He had been very clear with his family that he never wanted to live in a diminished state. His sister was a nurse and asked the hospital to bring him out of a medically induced coma to ask him if he still did not want be on a ventilator for the remainder of his life. He affirmed that decision and the family gathered for a period of praying and conversation with him prior to his dying. You can watch a conversation about this case with a Medical Ethicist on CNN.

This is a most courageous choice. Would you be able to do this? If you have adult children, do you know what their choice would be?

Some obvious conclusions...

- We may be more courageous when there is no eminent threat to our life.
- The probability of recovering is critical to consider as are the side effects and compromises that the treatment will impose.
- Ventilators, while unpleasant, may allow you to recover and live many more years.
- As a person who wants to have your voice at the end of life, you may want to consider stating that you want a trial and if there is no improvement, you want the ventilator removed. How long would you want the trial to last? A week? A month? Three months?

Your doctor, your family, and your proxy need to know what you want. Your comments and personal opinions on these dilemmas are welcome.

LOST IN CLINICAL TRANSLATION... COMMUNICATING AND UNDERSTANDING WHEN YOU'RE SCARED

- *At* March 14, 2014
- *By* **Mark B. Peterson**

Theresa Brown, a nurse, describes the problems of communication between the medical personnel and the patient. It addresses the role that fear and anxiety play in making it difficult for patients or their families to hear and process information. The article was provoked by witnessing what Ms. Brown thought was a clear and effective communication with the patient who then asked her what all of it meant after the medical team left. It became clear that the patient was terrified and unable to grasp what had been said.

The article addresses the importance of empathic conversations with both patients and loved ones as a way to encourage making sense of difficult and complicated diagnoses and treatments.

The implications for both patients and their proxies are clear.

- It is obvious that we should have physicians who are willing to take time with us and who encourage questions.
- We should have others in attendance when conversations about treatments and their implications are undertaken.
- We should ask physicians to use familiar words to describe what is ongoing, and to explain other medical terminology or procedures in simple terms.

HOW LONG HAVE I GOT LEFT?

- At March 14, 2014
- By **Mark B. Peterson**

Paul Kalinithi, a 36 year old neurosurgery resident, was diagnosed with cancer. Even as he describes an overwhelming desire to know what his chances are for recovery, he recognizes how imprecise the statistics can be in a rapidly changing medical research field and how quickly they can become out of date.

Our quest for information, regardless of how inaccurate, speaks to the vulnerability we experience when told we may have a serious or fatal disease. Psychologically, we are likely to latch onto the “survival” rate rather than the death rate because it is less uncomfortable. If we are asked to focus on the probability of death, we are inclined to avoid it. This is in part our “drive to survive” and is well illustrated in this article.

The author quotes a very wise comment from his oncologist as he attempts to gain reassurance which his doctor is reluctant to provide. When he asked how long he has to live, she replies, “I can’t tell you a time. You’ve got to find out what matters to you.” Based on that response, he elected to pursue a passion – writing.

Dr. Kalinithi did not survive his cancer. His wife published a posthumous memoir he had written entitled *When Breath Becomes Air* – a beautifully written book.

The article provokes some important questions...

- *If you are ill, what probabilities would influence you to not seek treatment? You might consider quality of life, side effects of treatment, cost, impact on family, loss of dignity, your age, etc.*
- *Despite the suggestion that we be wary of the accuracy of “probabilities” do you have a sense of what you would ask your*

medical proxy to do if you were unconscious and the probability of recovery was 5%? 25%? Or 50%?

- *If you have had a previous experience with this dilemma with a friend or relative, does it influence how you think about it now?*

AN INTRIGUING IDEA ABOUT CANCER AS AN EVOLUTIONARY DISORDER

- At January 28, 2014
- By **Mark B. Peterson**

Why Everyone Seems to Have Cancer

George Johnson, author of a piece in the *New York Times Sunday Review* 01/05/14, has an unusual and fascinating take on cancer as an evolutionary adaptive response that gets out of control. He remarks that as we are exposed to more and more sophisticated medicine we do not succumb as we age as our parents or grandparents did. He suggests that adaptations in our genes can sometimes result in cancer. Furthermore, he theorizes that everyone will have cancer if they live long enough.

What are the implications for your end of life planning? If you or a loved one is stricken in advanced years with cancer, how will you decide what you want to do? if you are younger...middle aged for example, what would you decide?

There are many different valid responses to this dilemma. Here are two examples:

1. An 88 year old woman was diagnosed with cancer and elected to go through the surgery, radiation, and chemotherapy.
2. A physician diagnosed with terminal cancer at a much younger age decided not to treat the underlying disease and opted instead for comfort care and the best possible quality of life for the time remaining.

Many of us will have to make choices as to how much we want to fight a potentially fatal disease. Many things will contribute to our decision including age, financial resources, leaving loved ones, the diagnosis and the prognosis, and the burdens (and side effects) of chemotherapy, radiation, and surgery.

These decisions are well documented in the reality show, “Time of Death” referenced elsewhere in this blog. Some patients elected extensive treatment and others chose none at all. Of note was the introduction of Hospice and Palliative medicine in helping many of the subjects of this documentary deal with their illness.

ROBIN YOUNG AND ELLEN GOODMAN TALK ABOUT “HAVING THE CONVERSATION”

- At January 28, 2014
- By [Mark B. Peterson](#)

Robin Young, host of *Here and Now*, interviews Ellen Goodman about the importance of communication regarding end of life issues. Go to the [Here and Now](#) web site to listen to this 7 minute interview. You will also find a second link to a site Goodman has created that provides suggestions on how to have this important conversation with both your family and your doctor. The script can be downloaded and printed to help guide you in your planning to have these conversations.

What worries you most about having these conversations? What would make it easier? Would you like a script to follow to talk with your family and your doctor? You can get them from Goodman's website.

“TIME OF DEATH”... A REALITY SHOW ON SHOW TIME

- At January 14, 2014
- By **Mark B. Peterson**

During the Fall of 2013, a six-episode series followed people who were terminally ill to the conclusion of their lives. (Note that there is a new term being used by some in the medical profession: “advanced illness”). “Maria”, a 48 year old mother of three children is featured in the first five episodes, documenting her struggle with stage four breast cancer. The episodes cover the progression of her disease, the impact of her illness on her children, and the family’s concerns about what will happen to them after she dies. During each episode a second person’s story is told as well. Each episode has lessons on how end of life is handled by different people with a terminal illness.

I found these stories of brave people and their families to be informative, inspiring and touching. Many faced the end with courage and grace. If you have access to *Show Time* you can watch on demand. Still available in 2017.

RECENT EVENTS RAISE IMPORTANT ISSUES FOR YOU TO CONSIDER.

- At January 13, 2014
- By **Mark B. Peterson**

January 2014

In December 2013 there have been several events which you might want to reflect on in terms of what you would want for yourself. Once you have become clear, have a conversation with your Medical Proxy and with your loved ones talking about what you would do in these situations.

1. Nelson Mandela died in early December of 2013. He was 95 and had been in and out of the hospital with recurring respiratory infections. In late summer or early fall he was transferred to his home along with substantial equipment to keep him alive but the suggestion was that he would not recover and there was little indication as to whether he was conscious. (In 2016 Bishop Desmond Tutu has criticized these decisions saying that it deprived Mandela of an opportunity for death with dignity.)

Would you want to be kept alive in this way? What do you think the impact on your family psychologically and financially? Are there religious considerations for you?

2 Ariel Sharon died on the weekend of January 11, 2014. He had been in a coma for 8 years after suffering a stroke. The cause of death was organ failure.

If you were in a coma from a stroke which might result in a long term stay in a hospital or nursing facility, how would you want to be treated? Would you want to be kept alive or would you stipulate to those who were caring for you to terminate life sustaining care... after how many days, months, or years would you want this to happen? What would be the impact on your family? These are tough decisions which you should talk about with your proxy and your family.

3. You may have read about a 13 year old girl in Oakland, CA who went into the hospital for a routine tonsillectomy and did not survive the operation. The doctors determined that she was brain dead from measurements showing no electrical activity in her brain.

Try thinking about this from the perspective of a spouse, yourself, or a grown adult child or sibling. What would you do if you were asked to make a decision about removing the ventilator which is keeping her/him alive? Talk with those you love about your thoughts and possible decisions in this circumstance.

WE CAN'T BE TOO GLIB... THE WILL TO LIVE IS STRONG... THIS ARTICLE IS HUMBLING

- *At* September 11, 2013
- *By* **Mark B. Peterson**

An article in the New York Times Magazine by Robin Henig chronicles the struggle of married professors Peggy, a nationally recognized advocate for the “right to die” movement, and husband, Brooke, who had clearly decided and agreed that they wouldn’t want to live lives compromised by a serious illness or accident. However, when Brooke experienced a catastrophic bicycle injury that paralyzed him from neck down, he was determined to live even in severely reduced circumstances. To date, he has been alive for four years at a cost of \$250,000 year in round-the-clock nursing care.

The article describes their everyday life and raises many interesting issues to consider in determining what you might want in a similar situation. It is a cautionary tale that illuminates the confusion and complexity of planning for the end of life. Among the thing you might want to consider are:

- The power of the will to live that can be seen as an evolutionary force related to survival.
- The ability humans have to adapt to compromises forced on us.
- The fear of dying.
- The bond between a loving couple that may influence the inability to let go or even to have a conversation about choosing to let go.
- The issue of deciding to live and what it entails in terms of the drain on the family’s material and emotional resources.

The article is humbling in how it displays the glibness of planning for life’s end when we are healthy. But when we are looking square in the face of dying...how will we respond? Obviously, it can change.

How would you respond in regards to these questions if you were faced with a similar situation? Follow the comments that the Times provides at the link for further stimulation and reflection.

THE BITTER END: WHAT DOCTORS WANT IS DIFFERENT FROM THE GENERAL PUBLIC WHEN FACING A HEALTH CRISIS.

- At September 11, 2013
- By **Mark B. Peterson**

On January 15th, 2013 “Radio Lab” broadcast a program called “The Bitter End” which focused on how doctors responded to questions about the kind of care they would want at a time when they had irreversible brain disease without a terminal illness. The program comments on a compelling contrast between what the general public wants and what doctors who know how treatment at the end of life actually works. Note the bar graph which shows that doctors do not want to have the same kind of treatment that the general public might think they wanted.

After listening to this program and looking at the graph, you may want to consider what you would want. Or at least ask: What is it that they know that I don't?

There is a second rich resource on the web site: it is the reader reactions which are quite variable and a few of the themes that stand out:

- Some physicians and nurses strongly criticized references to research as biased or lacking the latest data which shows higher levels of recovery from being resuscitated. Others disagreed and completely endorsed the program as being realistic and important. *What does the internal disagreement mean? The short answer is that “you are on your own.” Consistency of thought about what is the best course of action doesn't exist.*
- Comments about the use of ventilators and using drugs to paralyze the patient were also intense. Both doctors and nurses disagreed with each other as to what the effect was on the patient. *Again, what do the differences tell you about the state of treatment? Is it possible that nurses, who spend more time with patients have a deeper insight into the patient experience?*

- These two patterns of comments may leave you with an unsettled feeling that some rather basic procedures are viewed differently by different medical personnel. It can make decision making more complicated.
- There are also a number of comments by listeners who share their experiences with friends, relatives or loved ones who either recovered from very serious medical problems or died. Uniformly, the emphasis on having “the conversation” with your doctor, medical proxy and family members as to what you want is very important. “The conversation” is a frank discussion of the realistic aspects of the future health of the person in question. Some doctors are good at this and others find it both awkward and difficult. The latter group will be more inclined to avoid it.

Take time to read these comments with an eye to answering the questions asked. It may help you find your voice for your end of life choices. What is it that you would want in a life-threatening situation? If you are young, your answers may be different than when you are old.

BEING PROACTIVE ABOUT WHAT YOU WILL AND WON'T ACCEPT AS RECOMMENDED TREATMENT.

- At September 11, 2013
- By [Mark B. Peterson](#)

Butler, Katy *The Ultimate End of Life Plan*, Wall Street Journal, September 6, 2013. This is adapted from her 2013 book, Knocking on Heaven's Door: The path to a better way of Death.

In 2010 Katy Butler published an essay about her father's death which articulated the many problems she encountered in obtaining for him the care that he wanted. For a variety of reasons, it was not what he received. Butler's mother was profoundly impacted by this experience and elected to proactively manage her own passing by turning down opportunities for surgery – a decision which was based on her knowledge of the complications of heart surgery for someone her age.

The essay is both an homage to her mother and a realistic description of the good but less than ideal death that her mother experienced.

Read with an eye to what you would do if you were faced with the same choices of surgery which might extend your life but also might seriously compromise your life.

THE COST OF HOPE

- At May 25, 2013
- By **Mark B. Peterson**

Amanda Bennet was the Editor of the Philadelphia Inquirer when her husband died of a rare form of kidney cancer. She decided to apply her reporting skills to learn everything she could about his illness and the treatment he received by tracking his lab and treatment reports and interviewing his many doctors, some of whom she had never met.

Her book *The Cost of Hope* describes the course of his illness. It illuminates: 1) the complexity of the medical system, 2) how identical procedures done in different areas of the country can cost vastly different amounts, 3) how her love for her husband blinded her to the inescapable conclusion that he was not going to recover, and 4) how the medical community colluded in allowing her to retain this belief. A shorter article was published and is available online.

Perhaps most jarring was her discovery that his six-year illness cost an estimated \$617,000. In the course of investigating what procedures he had undergone, she was under the impression that he had 15 cat scans during the course of his treatment only to find that medical bills indicated that he had 76! She also learned that the last three days of his life cost over \$14,000.

It is clear that in a long illness, it can be challenging to keep up with all of the medical decisions being made and still remain aware of the overall circumstances.

Having Your Voice to the End of Your Life, a ten-hour seminar can help you to address some of these issues.

DECISION MAKING

- At May 24, 2013
- By **Mark B. Peterson**

When there is a medical crisis, decision making can be both crucial and complex with many forces at play and the urgency that life may hang in the balance adds to the pressure. If medical personnel hold out hope, it may be difficult to make decisions regarding the recommended course of action. Most importantly, consideration of long-term implications of a medical procedure or treatment and its side effects may not be addressed.

How can your loved ones know what decisions to make for you if you haven't given them any guidance?

THE COST OF HEALTH CARE

- At May 24, 2013
- By [Mark B. Peterson](#)

The media has been filled with stories regarding care and eventual death of someone who is terminally ill. Many of these situations are economic and psychological nightmares.

Consider the following:

- An 88 year old man with advanced dementia who had stated that he wanted to die naturally was treated for ten days with highly experimental drugs at a treatment cost of \$323,000. You can read about his situation [here](#).
- A woman who reported that she didn't understand that her husband was dying was treated for cancer in the last three days of his life at the cost of over \$14,000 per day.
- A man whose treatment for cancer over six years cost \$616,000 with the last three days of his life costing over \$14,000 per day. His wife reported that she was not aware that he was dying. You can read about this story [here](#).
- A man who was in good health and taking a blood thinner hit his head and experienced brain hemorrhaging when falling off a step ladder. He had no advanced medical directive, never regained consciousness, and died three months later. His partner was bankrupted by the costs.
- A family who rejected the medical advice that nothing further could be done for their unconscious father insisted that every measure be taken. Patient died three months later without regaining consciousness. The estimated cost was \$250,000.

A modest investment in *Your Life, Your Death, Your Choice: Having Your Voice to The End of Your Life* will help to express your wishes for the end of your life and could save you and your family hundreds of thousands of dollars and enable your family to make the decisions you desire.

CONSIDERING END OF LIFE IS HARD WORK...

- At May 24, 2013
- By **Mark B. Peterson**

It takes courage to think and communicate about end of life issues. Giving thought to this weighty subject requires developing a *fitness* to make tough decisions.

A way to prepare for making these decisions is to do three things...

- Face the fact that you are going to die at some point.
- Be aware that the medical establishment will be oriented towards keeping you alive, often at great cost.
- Know that you need to talk with your family to help them accept your decisions about end of life issues.

To develop a *fitness* you must examine what others have experienced when confronted with a serious or mortal illness or injury. To maintain *fitness* you must continue to consider what you would want to happen if you were afflicted with the same medical problem.