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# END OF LIFE

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DISRUPTIVE  
WOMEN  
IN HEALTH CARE®



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**A**t the end of 2011, the Disruptive Women in Health Care blog ran a month-long series on End of Life, a topic that is vitally important to discuss but all-too-frequently not addressed. With this in mind, we set out to start the conversation, hoping that if we did so, our readers would too – both with us and with their own loved ones. We were able to draw upon the insights of issue experts from all different backgrounds and disciplines, bringing to light a wide range of opinions, approaches and perspectives on this deeply personal and objectively universal topic.

I am pleased to be able to share this collection of posts with you. I hope that in reading them, you too are able to take to heart the complexities and ambiguities of End of Life; the juxtaposition between the fragility of life and the triumph of the human spirit.

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# 'Tis the Season to be Planning: Important Discussions on the End of Life

*November 2011*



*By [Randi Kahn](#)*

For many of us the holiday season is a time for family and fun, but for millions of Americans who have lost a loved one, it can instead be a season of depression, stress, and remembrance. In that way it also serves as a reminder to take a step back and wonder what it would be like if we were terminally ill and reaching the end of life. At what point would we want to stop treatment, remove a feeding tube or the plug from the ventilator keeping us alive? Would we want pain relief that would force us into a peaceful slumber? Would we prefer to die at home, in hospice, or in a hospital? How would we want people to bid us farewell?

It's a tough conversation to have with oneself, since most of us don't want to

admit our mortality, let alone with family who cannot imagine a world without us. Yet it's necessary that our opinions are clear and in writing to ensure our wishes are honored when the time inevitably comes, and the holiday season offers a unique opportunity to have these difficult discussions with family and friends gathering together.

According to a [Pew Research Center survey](#) conducted in 2006, only 29 percent of people had a living will; and in 2007, a Harris Interactive study put the proportion with advance directives at two in five. With the aging population growing, these statistics need to be improved upon, and that's where Disruptive Women comes in.

Last year, around this time, we featured a post from Disruptive Woman

[Alexandra Drane](#), who launched the [Engage with Grace](#) movement to make sure all of us understand, communicate, and have honored our end-of-life wishes. This year, to remind people to ask their loved ones Alexandra's five questions (for a reminder on what the questions are, [check out this post](#) from Disruptive Women's archives) and provide people with the resources they need to plan for the future, we're dedicating a whole month to end-of-life care issues. We're planning to feature discussions about where to start when making an advanced care directive, how clinicians are having these types of conversations with their patients, and what end-of-life care is like around the world.

We're excited to share new content from Alexandra, as well as posts from our newest Disruptive Woman, [Janice Lynch Shuster, PhD](#), author of a number of books on end of life care including the recently re-released [Handbook for Mortals](#), which she co-wrote with Drs. Joanne Lynn and Joan Harrold. Our man of the month, [Peter Ditto, PhD](#), Department Chair and Professor of Psychology & Social Behavior at the University of California, Irvine, will also share his expertise in end-of-life care in an interview with his daughter, Hope, a member of the Disruptive Women team.

Please feel free to contact the Disruptive Women team if you're interested in writing a post about end-of-life care, or if there is anyone whom you think we should approach about guest blogging on the topic.

# A Visa for the Dying: Travels to Another Country



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*By Janice Lynch Schuster*

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**S**eventeen years ago this month, my grandmother was dying of kidney cancer; given 2 days to 8 weeks to live, she made it 8 weeks to the day. During those weeks, even as she suffered the pain and indignity of her illness, she was very much among the living. She played with my children, did crossword puzzles, went through old papers, sorted out her knickknacks, admired the changing colors of the trees. Even as she was saying goodbye to us, she was living her life as best she could.

A decade ago, a dear friend died of pancreatic cancer. During the few months remaining to her, she and I got together for lunch as we always did; she worked on writing assignments for the newsletter I published, held a Christmas gathering, and finished her master's degree.

And just last year, a few days before her death, the mother of a dear friend was swimming laps in her community pool. In what proved to be the last months of his life, Steve Jobs got up, put on his black turtleneck and jeans, and journeyed to work, where, apparently, he tried to find ways to reinvent television. In the end, they say, he was troubled by the poor

design of his oxygen mask, and kept insisting on trying others. People remain themselves until the very end.

The point of remembering these sadnesses is to note what they all have in common: People who are dying have much living to do, whether it is measured out in days or weeks or months, each person wants to be counted among the living until the very last moment. It is no surprise—we all share passions, interests, loves, and a basic human desire to survive.

And the demarcation lines between the living and the dying might as well be drawn in pencil, so our doctors can erase and redraw them because their efforts at prognostication often miss the mark. My friend, geriatrician and hospice physician Joanne Lynn, refers to all of us as the “temporarily immortal,” and notes that the distinction between the living and the dying is as arbitrary and subjective as the one we make between people who are tall or short: Some quite clearly are on the edges of height, but most of us are somewhere in the middle.

Not wanting to categorize people as living or dying is not the same as not wanting to talk about the end of life and death and dying. Life, after all, is 100% fatal, and it's a jour-

ney each of us will make. In our culture, we are quite averse to these conversations, worried that somehow they will go from just words to realities—that if we talk about dying, we might somehow find ourselves there.

The truth is that it's important to talk about dying and what it means to each of us. It is especially critical that we address these issues now, as 78 million Boomers will, in 30 years

accidents or injuries, but those are relatively rare.) Along the way, we will need to have conversations and opportunities in which we can talk about our lives and their meaning, our hopes and our aspirations. We need others to understand that as much as we are engaged in the business of our lives, we are concerned about what the end means, and anxious to understand how it will be. We will need each other to get through, to nurture and love and comfort one another.

It is a hard business. It's hard to do. I've written about these issues for 15 years, and yet when my own father was gravely ill with a cancer (one that he ultimately survived), I could not bring myself to ask the questions I knew I ought to be asking, or to raise the conversations that would have been so important. Instead, I could only think about getting him through each difficult day. Counting him among “the

dying,” even when what he seemed to be, ran counter to what I wanted—him, living.

None of us wants a passport stamped for the country of the dying, but many of us will live there for a long time on a visa. While we can and while we are able, we should tell stories of what we find there, what's worth doing and what's worth passing by, where the five-star moments are to be had, and where the service is a little slow.

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## *It is no surprise—we all share passions, interests, loves, and a basic human desire to survive*

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or so, be knocking on heaven's door. Thirty years is a flash in time.

Unlike previous generations, Boomers are likely to live for many years with what were once immediately or quickly lethal conditions: cancer, cardiovascular disease, HIV/AIDS, Alzheimer's. Indeed, most will live for three or four years with a disease that eventually kills them. Over the course of that time, they will go from being robust, independent adults, to needing some degree of hands-on, round-the-clock, intense care and medical attention. It's not clear who will provide that care or how: because Boomers had so few children, they do not have a pool of family caregivers upon whom to rely. And their children did not save or earn enough to enable them to leave work for any length of time to serve as caregivers. The trouble is compounded by the insufficient numbers of geriatricians and other clinicians expert in meeting the needs of the elderly.

Magical thinking or believing, as so many of us do, that we will live forever will not save us from our future. Despite the multibillion dollar industry devoted to anti-aging and healthy living, most of us—if we are lucky—will grow old, get sick, and die. (Some few of us, unlucky ones, will perish quickly, due to

# Engage with Grace

*By Regina Holliday*

I don't know about you, but I love those promotional items I pick up at conferences. I think it is really cool that my five-year old has a Health 2.0 water bottle and that my 13 year-old has a Cerner backpack. I carry my Disposable Film Festival messenger bag on every trip and I wear my Practice Fusion t-shirt all over DC.

Yes, I love swag.

It gives me little happy chills to wash my brushes in my Microsoft Healthvault water bottle and my favorite re-useable shopping bag is from Kaiser Permanente. I know companies give us these things to remind us of their products as we live our daily life. Perhaps, I love them because I spent 16 years working in retail. I know the careful consideration that businesses take in choosing which items they shall adorn with their logo or message. And I rejoice in the wonderful conversations I have with people about health care just because of all the logos and conference detritus in my life. It is sort of like wearing a sports logo, but you are self-identifying as a fan in a far more obscure genre.

My favorite piece of promotional merchandise is my wallet. I have carried it with me everywhere for two years and five months. It is very special.



The nice folks at Newman's Funeral Home in Grantsville, Maryland gave it to me after Fred's funeral. Did you know Funeral homes had swag? I didn't know. I didn't know a lot

about the process of dying. It is not something we talk about very much in our daily life.

That is a shame.

This month is Thanksgiving and I will pull out my wallet and buy all the fixings for a Thanksgiving meal. And I will be standing at checkout thinking of end-of-life care. I will roll my cart down busy aisles whilst considering the wishes of my loved ones. This is a very special month for this is the time we congregate with family and have a chance to Engage with Grace.

I have written before about the amazing Alex Drane (another Disruptive Woman blogger). She founded a company called Eliza. In the summer of 2008, Matthew Holt of Health 2.0 and Alex came up with the idea for Engage with Grace after discussing the fact that most people do not share their end-of-life wishes with their family. The Engage with Grace project revolves around the One Slide. This is a slide that can be included in a slide set and has five questions about end-of-life care.

These are the questions:

1. On a scale of 1 to 5, where do you fall on this continuum?  
1= let me die without intervention, 5= don't give up on me no matter what, try any proven and unproven intervention possible
2. If there were a choice, would you prefer to die... at home or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a health care power of attorney, or completed an advanced directive?

I asked Rosemary Gibson (another Disruptive Woman blogger), author of **The Treatment Trap** and an authority on palliative care policy, "How do we prepare to ask such questions?" She told me such questions were part of the reason she wrote her book. She encourages readers to ask questions





about potential treatment options early in their medical care so they are empowered by this experience to ask the big questions later. So many people when they are diagnosed with a terminal disease find themselves on a scary rollercoaster of treatments not of their choosing.

She recommends starting with simple questions to gauge awareness of self and build toward these harder ones. I know that a life of research and asking questions of doctors helped me to help Fred through his cancer journey. The research I did as a mother led me to question the need for Pitocin in a natural delivery. It led me to question the need for a tonsillectomy if both parents genetically had large tonsils. These simple preparatory questions helped me be brave for the very hard questions to come. I am advocating that you begin to ask questions about your care, that you begin to take ownership of your life and of your death.

And why not start this Thanksgiving?

Why not start to ask these questions surrounded by love and light and family? Please do not wait to ask these questions as Fred and I did. We filled out Fred's advance directive at the first hospital. We did it all alone. Tears ran down my face as I read question after question to my newly diagnosed husband. We had never even spoke of this in theory; we had never practiced.

There was no one to help us.

Weeks later before going into hospice, we had to answer the questions again. Again I sat alone with my husband, his eyes as trusting as a child, while I explained the DNR forms that must be signed before transport. I stood steadfast at his side supporting his decisions and I was thankful our family

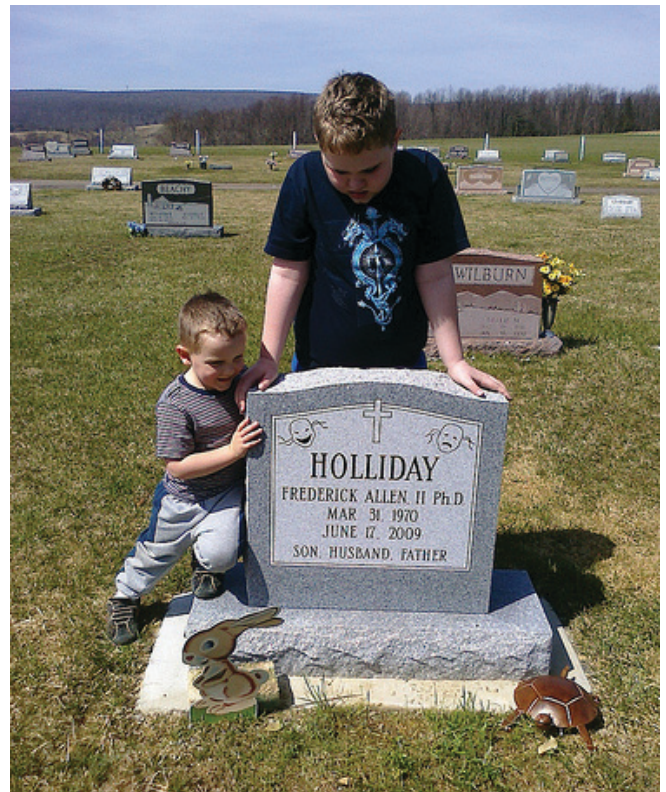
united around him with the goal of a good and peaceful death.

I did not know at the time that it could be so much worse, that this process can be fraught with more despair and anguish. I did not know it tears some families apart when they fight about their loved ones' final wishes. I did not know some wives and husbands disagree with mothers and fathers. I did know that providers could ignore an advance directive if one of the immediate family members fights against it.

And this is why you need to talk about this on Thanksgiving. You need to talk about this when every family member is there, so everyone is aware of your intent and decision. So every one can support your choice when the time comes.

I carry a funeral home wallet because the folks at Newman's were kind. They greeted my Father-in-law Fred Sr. and I, with soft words and acknowledged our grief and confusion. They did not leave us alone to pick out a casket by ourselves. They helped us fill out paper work and answered every question with dignity and respect.

I carry this wallet with me, and death becomes part of life. And every once in a while someone remarks upon my wallet and I can ask, "Have you heard of Engage with Grace?"





# Unrelieved Pain in Terminally Ill Patients: An End-of-Life Tragedy



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*By Glenna Crooks, PhD*

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**S**oldiers returned from modern-era wars addicted to medicines used to treat the pain of their wounds. Society has been fearful of the power legitimate medicines can have on the unwary ever since.

Over the years, solutions to this problem were placed in the hands of law enforcement, which, among other measures, monitored physicians to assure they were not enabling existing addicts or creating new ones. Later, pharmacists were monitored as well and soon became engaged in measures of their own to prevent abuse. Recently, under the guise of patient safety, FDA joined in.

Intrusions led physicians to fear prescribing pain medicines for legitimate medical purposes and warned pharmacists away from essential community-based pain management. Law enforcement and regulatory barriers made it more difficult—even personally

threatening and certainly more costly—for them to do so.

Isn't it ironic that the law and the healing arts should clash? Early civilizations considered both to have been gifts from God. Both were intended to serve man, not to victimize the most vulnerable. Yet, today's clashes have done precisely that, and jeopardize those in pain.

Those near death for whom society should have the most compassionate response have been harmed as a result. They have immediate needs that, in some cases, only powerful medicines can help.

Unrelieved pain takes a terrible toll on patients and their loved ones. Unable to get help from physicians and incapable of negotiating the maze of intrusive legal restrictions on their care, at one time families turned to politicians for intervention. They asked Congress to legalize heroin as a pain

treatment. Thankfully, that era's street drug-of-choice was not needed – we had better drugs than heroin. Congress did not grant their wish. But the families were right about one thing: those medicines were not being used. I know their frustration and anger. I was witness to the devastation they felt when loved ones had died, in pain unnecessarily.

Families took matters into their own hands in other ways. Some sued physicians for their failure to provide adequate pain relief. Imagine the physician's dilemma: law enforcement sanctions for prescribing vs. malpractice suits for not.

Some aspects of pain management have improved since then and quality care standards monitor pain relief in institutions. Whatever improvements we achieve, however, are at risk if hysteria about abuse of legitimate medicines resurges. Relatively recent news reports

about the illicit use of important medicines are only the latest—and certainly not the last—example. Press coverage about OxyContin abuse vilified—and victimized—the medicine, those who make it, and those who need it.

When law enforcement and medicine are at odds, dying people suffer all the more and my primary concern is for them. When some of us abuse medicines, those of us who use those same therapies for legitimate medical reasons become suspect.

Can't we find a better way? Can't we reduce suspicions about the valid use of pain medicines and correct the tragedy of under-prescribing and under-administering these critical solutions?

We can and we must. There are ways we can start:

- End the witch hunts against clinicians and protect them from harassment as they provide patients with medicines while we sort out our differences about legitimate prescribing and drug-abuse prosecution. Doing this will help patients now.
- Provide clinicians with immunity from malpractice litigation for failure to provide pain medications while we sort out the law enforcement issues. Doing this will help patients now.
- Radically accelerate improved clinical practices of pain management. Some efforts are underway nationally, but they're insufficient and patients with only weeks or months to live cannot wait the average 17 years for even simple changes in clinical practice to change.
- Require any individual who legislates, regulates, enforces or reports in the media on matters related to the abuse of pain medications work in hospice care with patients experiencing pain for a least one week. Doing this will help patients in the future, bringing better balance to future policy making, enforcement and reporting activity.
- All of us should resist the temptation to allow those of us who abuse pain-relieving medicines to numb our compassion for those who need them.

We must balance healing and the law better. Let's not forget the compassion we should have for those in pain, as they

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*We must balance  
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pain, as they live and  
especially as they die*

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live and *especially as they die*.

Can it be done? I believe so, and draw optimism for the future from my brother, Jim, and his wife Nancy, who for more than three decades volunteered their time to hospice. Jim wants to write a book. He'd call it, "You Live, Until You Die." It comes from his experience of seeing the old and the sick die well, living—and often laughing—right up to the last moments. It would be a book of warm, tender, and funny stories. His stories echo the words of one cancer patient who helped us understand the importance of pain management back in my government days. She said, "I found that when I didn't have the pain, I could forget I had cancer."

How can we not embark on these changes?

To do less is to diminish the living of everyone, the dying as they leave us and the ones they leave behind.

# How I Live, How I Die

*By Diana J. Mason, PhD, RN, FAAN*

The “death panel” rhetoric that arose during the debates about health care reform is an example of what’s wrong with the conversations about health policy in this country. The sound bite was fear-mongering at its best—or worst, depending upon your view. The phrase was based upon the fabrication that the health care reform law, if passed, would authorize a government panel to decide which Medicare recipients should live and which should die. Nothing could be farther from the truth.

The [proposed legislation](#) included the authorization of payments to physicians for conversations about advance directives and end-of-life preferences on a periodic basis, even among Medicare beneficiaries who were healthy. The “death panel” rhetoric created such a firestorm among average citizens that it stopped public conversations about informed choices about planning for how one prefers to die.

In October of this year, the American Academy of Nursing sponsored a public forum entitled “Critical Conversations on Advanced Care Planning and Decision Making: Models That Work” at the Kaiser Family Foundation with the intent of restarting a public conversation about these important issues. The event was co-sponsored by the [Archstone](#)



[Foundation](#), [California Healthcare Foundation](#), [Jonas Center for Nursing Excellence](#), Rita and Alex Hillman Foundation, and the [John A. Hartford Foundation](#). All of these foundations know that we cannot improve care at the end of life until we have more thoughtful conversations about how to educate the public, health care professionals, and payers about best practices in this realm.

One of the panelists, [Amy Berman, RN](#), Senior Program Officer for the John A. Hartford Foundation, has been sharing her story about being diagnosed with incurable breast cancer and her decision to forego aggressive treatment that may or may not prolong her life but would certainly have made this first year since diagnosis one of coping with major surgery and the adverse effects of chemotherapy and radiation

therapy. She announced at the forum that she was about to celebrate her first year post-diagnosis anniversary and that it had been the best year of her life. For Amy, her treatment choices have been about how she wants to live the rest of her life, not just how she wants to die.

In [the discussion](#) with the audience and other members of her panel—*NY Times* blogger and oncology nurse [Theresa Brown](#) and infectious disease physician [Manoj Jain](#)—she was adamant that all patients are entitled to full information about treatment options and adverse effects, including for “doing nothing.” She called upon health care providers to realize that the decisions about her care are hers alone—not the nurses’ or physicians’.

That’s a tough sell to many health care professionals, particularly physi-



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*We must do a better  
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cians, who are educated that dying is equated with professional failure. Supporting people in dying as they choose—as far as we can have choices in this matter—should be the pinnacle of best practices in health care.

To do so, we must do a better job of educating health professionals about supporting patients to make informed choices and show them how to have these constructive, but perhaps difficult conversations. But we must also take back the conversations with the public about choices in dying. In some cultures, people prepare their coffins before they know they are dying. In ours, we avoid even talking about it. As a result, too many people have too little information about their choices around what is being called “advanced illness” care. And we must identify the public and private policies that are needed to support these conversations between health care professionals and patients/families while being ready to provide access to different approaches to care, whether palliation, hospice, or intensive care.

[The Coalition to Transform Advanced Care, or C-TAC](#), is a multi-stakeholder group that is working to change this situation. The Academy event was one small step that was supported by C-TAC through the participation of its convener, [Bill Novelli](#), professor at George Washington University School of Business and the former CEO of AARP. Stay tuned to C-TAC’s initiatives and work by following them at [www.advancedcarecoalition.org](http://www.advancedcarecoalition.org). You can watch the Academy forum on Critical Conversations [here](#).

And, when you see your loved ones during this week of Thanksgiving, ask them whether they have an advance directive and talk with them about your own preferences around end-of-life care.

Let’s take back the conversation.

# Finding the Funny When the Diagnosis Isn't

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*By Casey Quinlan*

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It's not easy hearing your name and [insert dread diagnosis here]. I know this only too well after having to find the funny in my own journey through cancer. Cancer is, however, most often a diagnosis that you fight to a defined end. What's it like to find the funny in a chronic condition like multiple sclerosis?

I have a number of friends who are battling MS, one of whom, Amy Gurowitz, shared a link on Facebook the other day to Jim Sweeney's online empire of improv humor and chronic disease. Jim's MS journey started with vision problems in 1985, he was officially diagnosed in 1990, and has been dealing with the disease – finding the funny most of the time – ever since.

Jim's body of work includes decades of live improv, his one-man show "My MS & Me," which you can hear on the [BBC Radio 1 site](#). His MS has progressed to the point that he's now in a wheelchair, and his public presence is mostly limited to [Twitter](#), where his profile describes him as a housebound hedonist (hey, it made ME laugh) and [YouTube](#).

How much courage does it take to laugh out loud, in public, at an incurable disease? Jim certainly has courage at the level required.

Other examples of funny-or-die in managing chronic disease include Mark S. King's fabulously funny [My Fabulous Disease](#) blog (Mark is HIV-positive). The aforementioned Amy Gurowitz laughs out loud about her MS in a number of places, including [MS Soft Serve](#) and [MS-LOL](#) (life of learning OR laugh out loud, you pick).

On the provider side, there are a number of docs who are breaking up the waiting rooms and wards.

[Dr. Patricia Raymond](#) is a gastroenterologist whose mission



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# *Humor keeps us in touch with our humanity*

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in life is to take the “ick” out of colonoscopies. She bills herself as The Fabulous Butt Meddler. Since she looks like Bette Midler, the joke works on every level.

Dr. Zubin Damania, a/k/a [ZDoggMD](#) (“Slightly Funnier Than Placebo”), is a hospital medicine specialist in Palo Alto as well as a veritable buffet of medical humor, some G-rated and some most definitely NSFW. His videos alone guarantee hours of laughter.

There’s an entire site dedicated to clinician humor called [GiggleMed.com](#) – both ZDoggMD and Dr. Butt Meddler are featured there, along with a host of other find-the-funny MDs and RNs.

I even found a scholarly article entitled [The Use of Humor to Promote Patient Centered Care](#) – be warned, though, that (1) it’s a “scholarly article,” meaning that it’s probably had all the laughs surgically removed and (2) they want \$34.00 for it. You have been warned.

What’s my point here? I actually have two:

1. Laughter really is the best medicine. Humor keeps us in touch with our humanity, and – unless it’s insult comedy, which I do not recommend in the health care arena, unless it’s insulting bad health care – it helps to comfort others in the same situation.
2. Patients and providers need to work together to help

each other find the funny. If you’re a doctor, don’t just say “you’ve got [insert dread diagnosis here], here’s the treatment plan, call if you have any questions, ... NEXT!” Look your patients in the eye, and channel your inner comedian whenever it’s appropriate. If you’re a patient, connect with other people in your situation and see how they’re finding the funny. And help your doctors find their funny. If they can’t find it, you should find another doctor.

We all need to work together to break each other up.  
Laughter can comfort, can calm, it can even heal.  
That’s real disruptive health care, no prescription required.



# Things We are Grateful for This Year

*By Alexandra Drane*

For four years running now, many of us bloggers have participated in what we've called a "blog rally" to promote [Engage With Grace](#) – a movement aimed at making sure all of us understand, communicate, and have honored our end-of-life wishes.

The rally is timed to coincide with a weekend when most of us are with the very people with whom we should be having these unbelievably important conversations – our closest friends and family.

At the heart of Engage With Grace are [five questions](#) designed to get the conversation about end of life started. We've included them at the end of this post. They're not easy questions, but they are important – and believe it or not, most people find they actually enjoy discussing their answers with loved ones. The key is having the conversation before it's too late.

This past year has done so much to support our mission to get more and more people talking about their end-of-life wishes. We've heard stories with happy endings ... and stories with endings that could've (and should've) been better. We've stared down political opposition. We've supported each other's efforts. And we've helped make this a topic of national importance.

So in the spirit of the upcoming Thanksgiving weekend, we'd like to highlight some things for which we're grateful.

**Thank you** to Atul Gawande for writing such a fiercely intelligent and compelling [piece](#) on "letting go" – it is a work of art, and a must read.

**Thank you** to whomever perpetuated the myth of "death panels" for putting a fine point on all the things we *don't* stand for, and in the process, shining a light on the right we all have to live our lives with intent – right through to the end.

**Thank you** to [TEDMED](#) for letting us share our story and our vision.

And of course, **thank you** to everyone who has taken this topic so seriously, and to all who have done so much to spread the word, including sharing The One Slide.

**Can You and Your Loved Ones Answer These Questions?**

1. On a scale of 1 to 5, where do you fall on this continuum?  
1 ————— 2 ————— 3 ————— 4 ————— 5  
Let me die without medical intervention Don't give up on me no matter what, try any proven and unproven intervention possible
2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advance directive?

ENGAGE WITH GRACE engagewithgrace.org The One Slide Project

We share our thanks with you, and we ask that you share this slide with your family, friends, and followers. Know the answers for yourself, know the answers for your loved ones, and appoint an advocate who can make sure those wishes get honored – it's something we think you'll be thankful for when it matters most.

Here's to a holiday filled with joy – and as we engage in conversation with the ones we love, we engage with grace.

*To learn more please go to [www.engagewithgrace.org](http://www.engagewithgrace.org).*

# November 2011 Man of the Month: **DR. PETER DITTO**

*By Hope Ditto*



Dr. Peter Ditto

**F**or me, November's Man of the Month needs no introduction (... because he is my father).

For the rest of you for whom he is not a genetic relation, here goes...

*The Disruptive Women in Health Care team is pleased to introduce our November Man of the Month — [Dr. Peter Ditto](#), Department Chair and Professor of Psychology and Social Behavior at University of California, Irvine and a leading authority on the psychology of advance medical directives and end-of-life decision making.*

*Dr. Ditto is best known for the series of studies he conducted examining key psychological assumptions underlying the effective use of advance medical directives, so much so that he was one of the few psychologists invited to participate in the 1993 Squam Lake conference convened to establish a national agenda*

*for research on advance care planning. He is also a member of the Advisory Panel for the American Psychological Association's Ad Hoc Committee on End-of-Life Issues.*

*I sat down with Dr. Ditto (who I more commonly refer to as Dad) to learn more about the psychological aspects of end-of-life decision making, his research on the subject and more.*

**You often use the [Terri Schiavo case](#) as an example of the decision making challenges families who must make choices about the use of life-sustaining medical treatment for an incapacitated loved one face. In what ways does the Schiavo case encompass your “traditional” case? In what ways does it diverge?**

In many ways, the Terri Schiavo case is not at all typical. She was a young woman who was struck down unexpectedly in her 20's. Most end-of-life decision making occurs with elderly people, often with a lot of advance warning that a situation is approaching where the person is going to lose decision making capacity. It is actually interesting that the cases that have most captured the public's attention and most shaped law and policy on end-of-life decision making have involved these quite rare and unusual cases of young people left in persistent vegetative states (Schiavo,

[Karen Ann Quinlan](#), Nancy Cruzan).

This is likely because these are cases where the issues are displayed most poignantly – a person who has lost the ability to speak for herself, about whom everyone is uncertain what the incapacitated person would want done if she could speak, and where family members (and public opinion more broadly) have strong and differing opinions about what is the morally appropriate course of action.

But it is important to point out that these are exactly the problems that occur writ small – in less dramatic and less poignant forms – in homes, hospitals and hospices every day in the US. It is typically older people who have become too sick to speak for themselves, have not completed a living will or conveyed their wishes in any way to their loved ones, and this uncertainty can easily lead to family conflict because people have differing beliefs about the person's likelihood of recovery, and bring different moral views and emotional vulnerabilities to the situation.

**You say that, while many think the presence of a living will would have negated what quickly disintegrated into an ugly situation for the Schiavo and Schindler families, it is not always that simple. What steps can**

**people take to avoid (to the extent it is possible) leaving their loved ones in a similar situation?**

In many ways, my scientific work on end-of-life decision making can be seen as a psychological critique of living wills. The problem with living wills isn't the idea – it is a wonderful and noble concept to try to honor people's wishes near the end of life by having them record those wishes while they are still able – it is the execution. Quite simply, it is just a really difficult situation to find oneself in, and there are no simple band aids that are going to fix it all up.

I remember during the height of the Terri Schiavo controversy watching an attorney on the Today Show saying that spending 15 minutes filling out a living will would have solved the whole thing. Nothing could be further from the truth. Our research identified a whole host of problems with this idea – people often complete living wills that are very vague (“no heroic measures”), people's preferences of life-sustaining intervention change over time as people's health waxes and wanes, and even a quality living will doesn't necessarily communicate wishes in a way that helps your loved ones (what we refer to as surrogate decision makers) predict your wishes any more accurately than they can without having seen that living will.

The best advice I can give is to talk to your family about your end-of-life medical wishes. This is especially crucial if you develop a medical condition where one possible trajectory is that it might leave you unable to communicate. I really don't believe it is cost-effective to try to develop policy and law to encour-

age every 20-year-old to write a living will or take other elaborate measures like that. It is so unlikely that a Schiavo-like incident will happen to them, and even if it does, the situation they are trying to make decisions about is so

both yourself and your loved ones – if you lost the ability to speak for yourself. And, most importantly, to make this an opportunity to talk to your loved ones – your spouse, children, whomever – and try to convey to them the core values

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inconceivably different from their current situation as a healthy 20-something, that it just isn't worth a major societal investment to encourage that level of planning [editorial note: forget 20-year-olds -- an AP article published this week suggests that 64% of Baby Boomers also feel this way]. But as one gets older, and especially if future incapacitation is one possible outcome, that is the time when talking with your loved ones and your physician about your wishes for end-of-life treatment make sense, and it is a time when it all becomes psychologically “real” enough to allow someone to really make reasonable wishes.

Let me also say though that completing a living will is not sufficient all by itself, but it is helpful to think of it as a means rather than an end. The key is to make completing a living will the process that stimulates you to think about what you would really want – for

and feelings that motivate your wishes.

**Do you have any advice for families who find themselves in this situation but whose loved one did not leave a living will? Is there a precedent that should be used to guide decision-making in that case?**

The advice I always give people is to simply try your best to take your own feelings out of the situation, and try to make the decision for your loved one that they would make for themselves if they were able. This is both something that I think makes good common sense, and is precisely consistent with the fundamental ethical principles that have always been held to guide end-of-life decision making.

That is, the goal of living wills and other forms of advance directives has always been to maintain an incapacitated person's personal autonomy, their right to self-determination that is



enshrined in the Constitution. But how can a person in a coma make decisions for themselves? They can't directly, but if you make the decisions for them that they would have made for themselves, then your judgment can be substituted for theirs (hence the technical term substituted judgment) and it is as if they are making the decision for themselves.

It is a beautiful, elegant idea – especially if your substituted judgments are informed by documents or discussions completed prior to the person losing their decision making capacity – and as I said before it is terribly difficult to actually bring to fruition in real life. We are often not very good at predicting our loved ones' wishes – think about the last time you totally miscalculated on a birthday or anniversary gift for your spouse – and complicated medical situations flooded with emotion are not likely to maximize the accuracy of your predictions.

But another finding from our research is that many, perhaps most people are more concerned with who makes judgments for them than in trying to micromanage the judgments that will be made. Many people say that the most important factor for them is that they want someone they trust to make judgments for them. They are happy to let those people make judgments in real time, with all of the information available to them, and thus are more interested in appointing a trusted loved one as a designated surrogate rather than completing a detailed living will where they feel like they are ill-equipped to address specific and inherently proba-

bilistic medical decisions.

This is why I think policy should be focused on encouraging opening up dialogue between physicians, patients and their loved ones – and encouraging the completion of durable powers of attorney for health care (legally appointing a surrogate/proxy) rather than long, complicated advance directive documents. The focus should be on discussion not documents, recognizing that documents are most useful as a stimulus to dialogue.

**Obviously the cost of care is a factor in any medical situation; no one wants their family to become destitute as a result of paying for their care. How do you think changes to Medicare/Medicaid and long-term care [i.e. the repeal of the CLASS Act] might affect the public's end-of-life wishes?**

I will say upfront that I don't know a lot about specific policy details, but regardless, here is what I do know. No one wants to mix up end-of-life decisions with financial considerations. It is not about saving money, it is about allowing people to make their own decisions about prolonging their own lives versus letting go and not prolonging the process of dying. And, versus someone else making that decision for them – whether it is ending their life prematurely, or the problem that most people really care about – continuing treatment past the point that it makes sense and leaves people suffering or losing their essential dignity. That is why end-of-life decision making works best in the context where medical care

costs are irrelevant. It is only when people know they can get all the care they need, that they will be comfortable making decisions to forgo that care. It is important that people are provided the ability to get the care they need at the end-of-life, and that physicians are incentivized to discuss end-of-life concern issues with their patients – not to counsel them to check out early, but to help them make their end of life as dignified and free of unnecessary suffering as it can be.

The ironic thing about all this is that virtually every analysis shows that a key problem in end-of-life care is overly aggressive treatment that has little chance of success and that the patients likely would not want if we could ask them. So if people are allowed to make their own decisions, and we invest resources in helping them do that in the most effective possible way, it actually would cut the exorbitant costs of end-of-life care in a natural, humane way that honors every American's right to make their own choices about their own lives.

*Thank you Dr. Ditto, we appreciate you taking the time to discuss this important element of the End of Life with us.*

*What do you think about living wills and advance directives? Do you and/or your loved ones have them? Do you know what your loved ones would want, should they [heaven forbid] be unable to speak for themselves?*

# Disparities in End-of-Life Care and the Barriers that Facilitate Them

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*By Randi Kahn*

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As many of you may have read, [Evelyn Lauder](#), the senior corporate vice president of Estee Lauder Companies and daughter-in-law of founder Estee Lauder, a champion of breast cancer research, died of ovarian cancer at her home in Manhattan Saturday. Her death came on the same day I finally got around to watching “[The Education of Dee Dee Ricks](#),” a documentary that follows the journey of a woman battling breast cancer while attempting to raise millions of dollars to help treat other breast cancer patients without resources, and also shares the story of a woman named Cynthia who was uninsured and ended up passing away in a hospital after her breast cancer, which was caught late, spread to her liver.

I have been unable to get these strong, Disruptive Women out of my mind, and could not help thinking about both Evelyn and Cynthia while listening to the [National Journal's “Living Well at the End of Life”](#) event on Tuesday, wondering what their conversations about end-of-life care were like with their clinicians, and if there was a difference between them as a result of their insurance and financial statuses. Did Cynthia choose to live her final days in the hospital? Did her medical situation necessitate it? Was she given proper information about her hospice and palliative options?

Although we'll never know the answers to those questions, it is interesting to take a look at barriers that exist for clinicians in end-of-life care that are likely impacting potential disparities.

First, there are Medicare and Medicaid reimbursement issues. Although both programs currently provide some



coverage for hospice and palliative care, there is not reimbursement for the tough conversations doctors should have with their patients about their care options at the end of life. Former Obama advisor on health reform and now chair of the National Institute for Health's Department on Bioethics, [Ezekiel Emanuel](#), MD, PhD, said at the *National Journal* event, that those consultations can take anywhere from a few minutes to several hours and that without reimbursement for them, some clinicians don't take the time to conduct them. His statements align with a [survey](#) of 500 board certified physicians conducted by the *National Journal* and the [Regence Foundation](#) where 82 percent of respondents identified inadequate reimbursement from Medicare, Medicaid and private insurers for end-of-life consultations as a significant barrier for palliative care.

There is also the issue that some clinicians put off the conversations because they do not know enough about end-of-life care options, or about how to talk to a patient about the decisions that need to be made as they near death's door. The poll data found 73 percent of physicians 39 or younger reported "a great deal or some exposure to palliative care during medical school" compared to 36 percent of those 40-49, 23 percent of those 50-59, and only 6 percent of those age 60 or older, highlighting the need for continuing medical education courses on palliative care, hospice care, and the development of an advanced care directive. The poll didn't inquire about communications training that, according to Dr. Emanuel, would help clinicians overcome their own psychological barriers to having these discussions and enable them to better address the patient's psychological needs to make the conversations more effective.

With entitlement reform almost inevitable, and much of continued medical education focused more on health care reform related topics like coordinating care and utilizing health IT, what will the end of life look like for women like Cynthia and Evelyn in the future?

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# Disaster Preparedness: Lessons for an Aging America



*By Janice Lynch Schuster*

Public health officials are sounding the alarm over the looming catastrophe of an aging America, a time in which 78 million Boomers will arrive at old age, only to find a health care system that can't meet their needs or sustain their lives. Social and financial costs will be devastating: Boomers will live longer and with more chronic conditions than any other generation; they will need more years of care than any of our current systems can provide. Half of those who live to the age of 65 will require nursing home care at some point in their lives; half of those who make it to 85 will experience dementia.

A health care system predicated on acute illness and injury is not equipped to meet the long-term, ongoing needs of people who have multiple chronic conditions—a situation Boomers will face. In short, it's a disaster we know will happen, but whose impact we might, with planning, lessen.

So how could we prepare? We might take a page from the Federal Emergency Management Administration (FEMA), which, in the aftermath of Katrina, stepped up preparedness

planning. Indeed, it has outlined eight principles of disaster management. These principles will sound familiar to anyone interested in creating a better health care system. According to the disaster planning experts, good plans are comprehensive, progressive, risk-driven, integrated, collaborative, coordinated, flexible, and professional.

These principles will sound remarkably familiar to anyone engaged in public health and health care. Where today America has fragmented, uncoordinated systems of care, we need a future in which coordinated, comprehensive care is the norm. Where today there are unconnected silos of activity, we need to foster improvements that lead to collaborative systems, ones in which each participant knows and understands how, when, and why to interact with other elements of the system.

America needs a progressive system, in which, in the words of FEMA, "managers anticipate future disasters and take preventive and preparatory measures to build disaster-resistant and disaster-resilient communities." Mapped to the health care system, a progressive system would mitigate the ways in

which things go wrong in our current system, fix those errors, and learn from them to prevent their recurrence.

In terms of being risk-driven, the health care system needs communities that know how to assess their strengths and weaknesses, understand their risks, and plan accordingly. We need a flexible system, one that is just as effective at caring for a dying patient as it is at caring for a newborn; we need

Recent efforts to improve care transitions – the time when patients move between hospitals, nursing homes or home, offer a promising glimpse at how better planning might lead us to better outcomes. In this arena, care providers who rarely interact have learned to do so, and develop and standardize processes that work for everyone. The hope is that improved transitions will lead to less fragmented care, more continuity

of care, and better coordinated care.

Improving these factors could improve care in general.

The emergency preparedness literature talks about the problem of apathy, and how it prevents individuals, organizations, and communities from really taking the steps necessary to prepare for any sort of hazard.

In planning for the tsunami of aging Boomers, we will also have to overcome apathy and inertia, the very-human belief and hope that bad things won't happen to us, or that we are likely to continue as we are forever. We won't: life is 100% fatal. And those of us who will move into old age will find our

current systems and policies will make old age more difficult than it should be. As a society, we could and should prepare for the eventuality.

Unlike natural disasters, the coming crisis of aging is entirely predictable: We know what dangers lie ahead. Now we must work — and plan — to avert them.

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## *Recent efforts to improve care transitions – the time when patients move between hospitals, nursing homes or home, offer a promising glimpse at how better planning might lead us to better outcomes*

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systems that work, regardless of a patient's prognosis or diagnosis. And we need a skilled and professional workforce that is ready to deliver the care individuals and families will need.

Disaster preparedness plans are built on actual experiences. The catastrophes of recent years, from 9/11 to Katrina, showed planners just where our weaknesses and vulnerabilities lay. Using experience as a guide, disaster planners quickly learned how important it is to forge community alliances and to organize interaction among groups that don't usually talk much. Planners routinely conduct tabletop exercises and real-time simulations, so that people can experience what it is they would need to do when disasters hit. Along the way, planners develop and cultivate public interest and trust through communication campaigns. We've stocked up on batteries and plastic sheeting, water and dried goods; we've had to learn to trust our leaders when they tell us to shelter or seek higher ground. And we've developed a sense of neighborliness, the notion that we need to help each other.

# Palliative Care: A Humanitarian Need

*By Nasreen Sulaiman*

The following is a guest post by Ms. Nasreen Sulaiman a Senior Instructor at Aga Khan University School of Nursing. She has worked with palliative patients.

Palliative care is an urgent humanitarian need for people worldwide with cancer and other fatal diseases as it provides comfort and eases suffering. Nearly 80% of the cancer patients in Pakistan present late in stages 3 & 4 with terminal disease. In Pakistan, the concept of palliative care is in its infancy stage and needs to be strengthened. In Karachi, one of the mega cities of Pakistan, only two hospices, each of 20-25 beds, provides palliative care services where the health care professionals' main focus is on providing the physical aspects of care. Pain management, a crucial aspect in palliative care still remains partially addressed due to lack of narcotic supplies and other medications. Furthermore, I strongly feel that other than providing pain and symptom relief measures, the social, emotional, and spiritual needs of the patient should also be given prime importance in order to provide holistic care to the patients. Nurses need to learn to utilize various non-pharmacologic measures such as thera-



peutic communication techniques, use of humor, guided imagery, therapeutic touch, relaxation exercises, religious songs and other diversional activities in order to ease the suffering, emotional distress and provide optimal comfort and support to the patients as well as their caregivers. Moreover, in palliative care settings, caregivers hold a great importance as they are the ones who are providing the total care and spend most of the time with the patients. Caregiver role strain is an essential area to be looked at. Caregiver support is another area to be studied. We need to establish caregiver self-help groups or other avenues to support the caregivers as they go through emotional pain. Caregivers need immense help and affection which in turn may assist them in performing their roles effectively — alleviating the patient suffering from disease.



# Why Do We Fear Death?

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*By Ufuoma Lamikanra*

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**W**hy do many people fear death? I believe that it is a fear of the unknown.

If you do not know what will happen to you at the end of life, it is a normal feeling to be afraid. This fear appears to be common among both young and old persons. When my then four year old daughter (she is now about 33 years old) was bitten by a dog, she kept on asking if she was going to die. A colleague told me of a man who always left a gathering of friends whenever the discussion turned to issues on or related to the end of life. Others took advantage of his fears and regularly excluded him from their midst by discussing such “unpleasant” issues.

However, my grandfather was not afraid to die. He desired death instead. At about the age of 90 years (calculated, since there were no records when he was born), many of his age mates – friends and relatives, no longer visited him and he suspected that they had died. He was always told that they were alive. Nobody was bold enough to tell him the truth. One of his almost daily wishes was to join them, as he could not understand what he was still doing on earth while all his contemporaries were gone.

Many Africans, especially men, loathe leaving the world without leav-

ing behind certain “achievements.” A man is regarded as a failure, if he is unmarried, does not own a house and more importantly, has no male child at the time of death. The absence of a male heir means the tragic end of a lineage as that family name becomes extinct. The pain of death is somewhat

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*A notable feature of the end of life in many African cultures is the belief that most deaths are not natural, but occur through supernatural means*

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lessened by the fact that the deceased left behind male children, to carry on the family name.

A notable feature of the end of life in many African cultures is the belief that most deaths are not natural, but occur through supernatural means. There is always a strong suspicion that someone, usually a close relative, must have been responsible for a death in the family. Sadly, wives are usually accused of killing their husbands, while husbands are rarely accused of ending their wives’ lives. So, who is responsible for womens’ deaths? According to my auntie, women kill their husbands, while women die as a result of their sins.



# Requiem and Renewal

*By Annekathryn Goodman, MD*



**The following is a guest post by Annekathryn Goodman, MD, Assistant Director, Vincent Gynecologic Oncology Division, Massachusetts General Hospital, Boston; Associate Professor, Department of Obstetrics, Gynecology and Reproductive Biology, Harvard Medical School and a resident of Boston.**

**T**he loss of one loved soul punches a hole in the fabric of our universe. We experienced sadness and tragedy this past week when journalist Anthony Shadid died while reporting on the horrors of Syria's war against its people.

Shadid was known to those of us who work at Massachusetts General Hospital in a small way – through his daughter, Laila. We know her through MGH's own Marcela, ex-partner of Anthony's first wife, Julie. Marcela is one of my work partners in the gynecological oncology department here. She and Julie broke up last year but Marcela has been an important part of Laila's life since she was a baby, and remains so.

I am struck with how I can grieve for a man I have never met because I grieve for the people who love him. His death will now be a part of Laila's identity. Growing up fatherless starting at the age of 10 will be part of the lens through which she views the world. We cannot protect her from that real-

ity. But we can support her and the others who are impacted by this new hole in the universe. There is a circle of grief and meaning that radiates out from each death. In my imagination, I see this whole cloud of connection and meaning, sympathy and love that vibrates with each loss.

Of course as oncologists, we are all too familiar with that cloud. Now, one could imagine that these clouds of loss, familiar and sometimes daily, could bring us down. Maybe we should all be on anti-depressants. But, paradoxically, most of us are empowered by the work we do. The losses are unavoidable when dealing with cancer, but our reactions to it are completely in our control.

Reacting with love and support empowers us all. When Marcela called to tell us of Anthony's death, John — the division chief of our department — immediately signed out her beeper so he could answer all of her calls. Whit, another doctor in our division, took on all her surgeries so she could be with

Laila. Dr. Schiff, the chief of obstetrics and gynecology who no longer performs surgeries, donned scrubs and came down to the OR to ensure we were all okay. Texts and emails with words of support flew. We are a big village. Acknowledging this terrible pain honors the meaning of the life lost and how that life affected everyone else.

There was another, more personal, loss on Friday – my dog, SammyBear. I put him to sleep that evening after a two month illness with renal failure. Again, John helped me finish my last surgery so I could have time with SammyBear. I felt surrounded by love.

I learned how to be a better doctor from Sammy's dying. I learned how horrible it is to have someone you love stop eating. I learned how you can give family members tasks to do to help care for the sick one. Those tasks keep you focused and sane. I learned how hope just does not go away, no matter how much your rational mind knows that the end is inevitable. I also learned how hard it is to say goodbye. And when the vet was crying with us as he put Sammy to sleep, I learned that it is okay to cry with your patients.

Once, when walking Sammy on the Boston Common, a man stopped me to say that Sammy was put on earth to heal people. I think we are all put on this earth to do that. And it is in our control to give out kindness, compassion and generous sympathy. We will never be in control of loss, only the way we frame its meaning. As Anthony Shadid once wrote, "Never accept things as they're portrayed; only stories matter."

# Resources

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For people looking to make change happen, we suggest a few books:

1. Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life by Dr. Joanne Lynn
2. Never Say Die: The Myth and Marketing of the New Old Age by Susan Jacoby
3. The Denial of Aging: Perpetual Youth, Eternal Life, and Other Dangerous Fantasies, by Dr. Muriel Gillick
4. A Bittersweet Season: Caring for Our Aging Parents and Ourselves by Jane Gross
5. Two Weeks of Life: A Memoir of Love, Death and Politics by Eleanor Clift

As general resources on end-of-life issues, we recommend the following websites and books:

1. Handbook for Mortals: Guidance for People Facing Serious Illness, by Joanne Lynn, MD, Joan Harrold, MD and Janice Lynch Schuster, MFA
2. Tuesdays with Morrie: An Old Man, A Young Man, and Life's Greatest Lesson by Mitch Albom
3. The Last Lecture by Randy Pausch with Jeffrey Zaslow
4. Too Soon to Say Goodbye by Art Buchwald
5. Jane Brody's Guide to the Great Beyond: A Practical Primer to Help You and Your Loved Ones Prepare Medically, Legally, and Emotionally for the End of Life by Jane Brody
6. End of Life: Helping With Comfort and Care by the US National Institute on Aging <http://www.nia.nih.gov>
7. American Academy of Hospice and Palliative Medicine <http://www.palliativedoctors.org>
8. Caring Connections by the National Hospice and Palliative Care Organization at <http://www.caringinfo.org>
9. Hospice Foundation of America <http://www.hospicefoundation.org>
10. <http://www.growthhouse.org>
11. Center to Advance Palliative Care <http://www.getpalliativecare.org>
12. National Family Caregivers Association <http://www.nfcares.org>
13. The Coalition to Transform Advanced Care, or C-TAC, <http://www.advancedcarecoalition.org>
14. The American Academy of Nursing's Critical Conversation: Best Practices in Advanced Care Planning and Decision Making <http://www.aannet.org/pr-10311-critical-convo>
15. Dr. Peter Ditto <http://socialecology.uci.edu/faculty/phditto>
16. Rosemary Gibson <http://jamaevidence.com/resource/preface/648>