

Lessons Learned

Love in the Room

# Natural Transitions

Sharing conscious, holistic approaches to end of life

Magazine



**Isabel Stenzel Byrnes:  
WITNESSING AND SURVIVING DEATH**

Pathway to a  
"Good Death"

National Healthcare  
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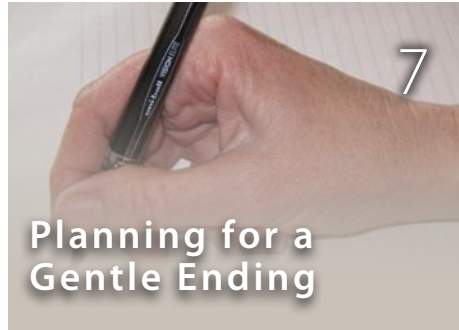
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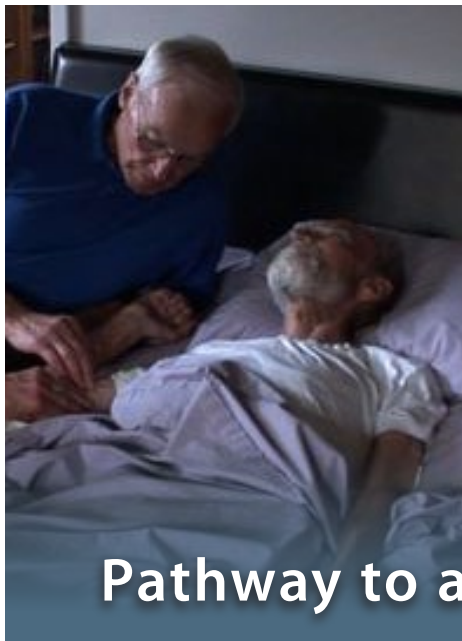
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Advance Directives (ADs). Medical Power of Attorney (MPOA). Big words that cover so much territory. They are the legal conduit of our love for ourselves, for those we might advocate for that we will survive, and for those who will survive our deaths.

It is our love of life that guides our choices. Clarifying what makes life alive for us not only informs the Advance Directives choices – it makes our everyday lives more meaningful. While we may make plans concerning death, the process is about what is important to our lives.

Jennifer Ballantine outlines the big picture on ADs and MPOAs in “Paths to a Good Death.” Learn about National Healthcare Decisions Day, which focuses on updating (or completing) our ADs each year. Find out about one simple, legal way to end life that is already terminal with “Voluntary Stopping of Eating and Drinking.”

There are also personal stories. Isabel Stenzel-Byrnes shares what it is like to live with cystic fibrosis attacking her lungs and then receiving the gift of life through the loving generosity of a stranger expressed as an organ donation.

The prospect of sudden death hit Joshua Slocum in his 30s. As director of the Funeral Consumers Alliance, he had always advocated for Advance Directives – but hadn’t completed his own. He wants everyone over 18 to know that ADs are not just for the aged and infirm.

We hope you come away from this issue resolved to contemplate and share your wishes for end of life with your loved ones in writing – or, at least, with your primary care physician. It’s only through these expressions and the determined efforts of our chosen healthcare advocate that our last wishes have a chance to be honored.

# Natural Transitions

Sharing holistic approaches to end of life

Magazine

## Issue 4 - Winter 2012: Advance Directives

### Our Vision

- Acceptance of death, loss and grief as a natural part of life

### Our Mission

- Sharing conscious, holistic approaches to end of life
- To provide a forum for end-of-life care-givers and educators

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### Natural Transitions' Mission

- Conscious, holistic education and support for dying, death and after-death care - including green, home funerals

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## natural transitions news

### *How powerful it was...*

Sherry was knocked off kilter emotionally by the sudden death of her middle-aged sister-in-law, Peggy. Normally a calm and grounded, go-to-it person, Sherry needed and wanted support around Peggy's unexpected departure. It was such an honor for our organization to support Sherry who, so many times, without compensation, reorganized her busy schedule as a holistic wellness practitioner to help families at their time of loss. Quite memorably, last summer, she joined three other NT guides to help a homeless family whose newborn had died. So when four women showed up at her home, to be there for her, at her own time of need, she received us with deep

gratitude. How powerful it was for us, five women, caring sisters, to lay out one of our own in the most gentle, loving way.

January has traditionally been a time for NT to offer our trainings in end-of-life transition guidance. The month of May and the fall are other common times for our workshops. What Sherry received and what we gave is something that lives within us all, and something we nurture through our trainings. Confidence and a little knowledge can go a long way in transforming a time of tragic loss into one of healing. Across the US, there are now many trainings in family-led, green after-death care. NT trainings are just one option. We encourage you to find a training near you, to access that innate knowledge of being with death that resides in us all.

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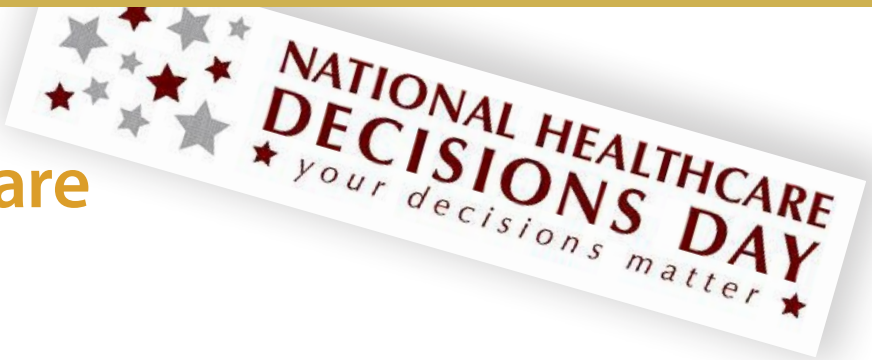
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# National Healthcare Decisions Day

by Deedee Carr



How do you feel about artificial nutrition and hydration? What do you think about organ donation? Would you amputate a limb to save your life? Do you want to live on a ventilator? These are only some of the questions and decisions to contemplate and answer prior to your decline toward death. However, many still do not know or understand the importance of advance directives regarding these end-of-life decisions. To address this, April 16th has been designated as National Healthcare Decisions Day (NHDD), and 2012 marks its fifth year. The purpose of this day is to instill awareness about the importance of making end-of-life decisions and to inform the public about available resources.

The goal for NHDD is to ensure that all adults with decision-making capacity in the United States have the information and opportunities to communicate and document their healthcare decisions. There are many different ways for various stakeholder entities – hospitals, organizations, associations, businesses, interest groups – to commemorate the day. One possibility would be making advance directive forms available on a table staffed by a knowledgeable person in a high-traffic area within a hospital, clinic, or senior residence. Another could involve a talk or seminar in the workplace. Federal law requires having the necessary forms and information regarding end-of-life options available to patients in healthcare facilities, free of charge. Some states may require notarization upon signature, which

should be the only fee involved. This is another good reason to get involved in NHDD. According to Nathan Kottkamp, founder and director of NHDD, the most important question to answer regarding end of life is, “Who have you appointed as your agent to make these decisions for you if you are not capable of doing so?” This should be a person you trust, someone you have talked to in-depth about your life and death beliefs, your concerns, your spiritual views, and what you want as well as what you don’t want when you face death.

Kottkamp became convinced that every adult in the country needed to know what an advance-directive form was and how to go about completing one after serving on hospital ethics committees. (Ethics committees help facilitate final decisions by getting all involved parties together and mediating issues of communication to resolve issues in a patient’s final hours.) Kottkamp witnessed the painful turmoil as friends, families, and medical practitioners tried to make last-minute decisions for patients without advance directives, documents designed to relieve those burdens for all involved.

He also noticed that not all hospitals, nursing homes, ambulance services, dialysis centers, surgery centers, and other recognized health-services organizations were in compliance with the law to provide information and forms to the public. Much greater public awareness and reminders of compliance were needed – and National Healthcare Decisions Day was born. It is important for each of us to think about, talk about, and complete

a healthcare directive, because doing so empowers each of us with degrees of autonomy, even when we are no longer able to communicate. It eases the burdens of the designated healthcare agent, family, and friends when they are faced with hard choices for their loved ones. It gives healthcare practitioners guidelines about how to proceed and respects the last wishes of the patient. The legal resources composing an advance directive include a form to designate a healthcare power of attorney, a living will, psychiatric advance directive, and organ donation preferences. [See Advance Directive Documents, page 7, for more about these forms.] Many groups have joined Kottkamp’s campaign. Among them are national and state associations of medical practitioners, nursing organizations, hospitals, disability groups, healthcare providers – but grassroots support is the most important. You can help by visiting the NHDD website (“<http://www.nationalhealthcaredecisionsday.org/>” [www.nationalhealthcaredecisionsday.org](http://www.nationalhealthcaredecisionsday.org)) and by spreading awareness by word of mouth, e-mail, and social media. If you have not discussed your wishes, fears or concerns, religious or spiritual views, wants and absolute don’t wants concerning end of life with someone you trust, the next National Healthcare Directive Day, April 16th, will be a good reminder to do so.

---

*Deedee Carr is a University of California - Irvine writing fellow, retired teacher, member of writing groups in Colorado and California and one in a long line of writers who write for the sake of it.*

# Strange and Unusual Facts About Death

## Physical signs of imminent death, and how you can help keep a loved one comfortable during the dying process

**While no one knows exactly when death will occur, when nurses and doctors see the following physical signs, they know it is time to prepare the family. While this is, by no means, a complete list, it includes many common signs of approaching death.**

- **Breathing:** The jaw often drops, and the dying person breathes shallowly through the mouth. Breathing may stop for a few seconds to a minute or more (apnea) or become irregular. During the last few moments or hours, the person may gasp for breath, much as a fish out of water does, or you may hear gurgling or rattling sounds.
- **Responsiveness:** The dying person may be disoriented or non-responsive to your voice or touch but might moan, talk, or gesture. He or she may open the eyes and seem to be staring at nothing, and the eyes may diverge or focus in slightly different directions. Talk and touch may calm or agitate the patient – each person is different.

**Hearing is the last sense to leave, so do not discuss anything in front of a non-responsive person that you would not discuss with him or her directly.**

- **Lack of hunger or thirst:** As the patient declines, he or she will eat and drink less, so the body can conserve energy for vital functions. Before refusing food and drink, the patient may have trouble swallowing. The urine becomes concentrated and may darken or turn tea-colored.

**Do not try to shame or force a dying person to eat if he or she refuses. Eating and drinking can make a dying person physically uncomfortable.**

- **Vital signs:** Blood pressure drops dramatically and can plummet to 70/50 or below. Internal temperature goes down, and pulse and respiration rates slow significantly.
- **Temperature:** As the body loses its ability to regulate temperature, the skin may feel hot or cool to the touch, and the temperature can fluctuate.

**Check with your doctor or nurse first, but washcloths rinsed in cool water and applied to the forehead, neck, hands, and feet may help keep the person comfortable. If the patient feels cold to the touch, you can put a light blanket on him or her, but watch for signs of discomfort.**

- **Skin:** Discoloration of the skin is common as death approaches, and the limbs may have blotchy bluish or purplish spots, called mottling. Darkening of the skin around the mouth and eyes often occurs, and the lips or gums may turn bluish.

# Essential End-of-Life Documents: Planning for a Gentle Ending

by Sue Bensman

One almost universally procrastinated decision is our end-of-life planning – specifically, writing our Advance Directives. To address this issue means that the very reality of our own dying and death must be contemplated and confronted.

Everybody does it – die, that is – but, in our culture, we don't like to “go there.” The fact is that we can't avoid it, so, by facing our own inevitable demise ahead of time, we can make choices about how we would choose to be cared for before, during, and after our death, and who we want to speak for us when we can't speak for ourselves. The task can seem daunting and overwhelming, especially if we don't understand the elements of what constitutes an Advance Directive.

The place to start – at the very least – is to choose your Medical Durable Power of Attorney (MDPOA), also known as your Health Care Agent. This is the person you believe is most qualified to speak on your behalf if you are medically compromised and unable to speak for yourself. This person may or may not be your spouse or your child – who may be too emotionally entangled. The person you choose should be someone who not only knows you well but also will be able to set aside her/his values and beliefs to act as an extension of you, making decisions based upon your values and beliefs. Choose someone who can make tough decisions under pressure and be a strong advocate on your behalf when in stressful medical situations.

Ideally, the MDPOA form should be completed after you have had thorough and frank conversations with your Agent, to share, most importantly, how you define quality of life and any strong feelings you have about how you want decisions made if you cannot speak for yourself. Choose two alternate Agents in case your primary Agent is unable to act for you; again, make verbal conversation a priority. Have these conversations with your Agent, alternate Agents, and family, even if doing so is difficult. Predetermining and stating your preferences, your “musts” and “must nots,” will be a gift to them. They will not be left to guess what you would want under different medical scenarios, which will simplify the entire decision-making process.

Despite the belief that writing one's Advance Directives is for later in life, everyone over 18 should learn their options, in case they lose decisional capacity, *and* choose a Health Care Agent (i.e., fill out an MDPOA form) who knows their preferences. These actions serve to prevent costly judicial proceedings or unnecessary suffering. Most are familiar with the seemingly endless stories of Karen Ann Quinlan and Terri Schiavo – sad reminders of what can occur when end-of-life wishes have not been documented.

The second document to consider is your Living Will. This outlines your specific preferences about life-sustaining procedures, such as artificial nutrition and hydration, being put on a respirator, etc. These written preferences come into play if two physicians verify in writing that you have a terminal illness or are in a persistent vegetative state (PVS) *and* lack decisional capacity. A Living Will, combined with the MDPOA form, is state-specific and can be found on the Caring Connections website, [www.caringinfo.org](http://www.caringinfo.org). Additionally, the state of Colorado has succinct and thorough MDPOA and Living Will forms that reflect the most recent state legislation at [www.irisproject.net](http://www.irisproject.net). Both forms are best witnessed and notarized – even if it is not required in your state – in order to facilitate the forms being honored in case of travel to a different state.

Your state-specific Advance Directive also includes an Organ Donation Form to fill out if you would like to be an organ and/or tissue donor, including specificity about which organs and/or tissues.

A CPR Directive is a doctor's order (it must be signed by a physician) and is important to fill out if you are elderly, frail, medically compromised, and/or frequently access the medical system for a chronic condition. Performing CPR for these patients is generally considered to be more detrimental than beneficial and results in unnecessary pain and suffering. First-responders are required to initiate CPR unless a CPR Directive is available. Most patients keep a copy of the directive on their refrigerator and also carry a wallet card or wear a CPR Directive piece of jewelry. The original CPR Directive is blue, but a copy is considered as valid as the original. One's Health



Care Agent also has the power to prevent CPR from being performed. To clarify, a DNR (Do Not Resuscitate) is similar and is generally for patients in nursing homes. It does not require a patient's signature but is also a doctor's order and requires a physician's signature. If you are young and healthy, it is unlikely you would choose to include a CPR Directive.



The Final Wishes portion of the Advance Directive is considered optional, but it may be the most compassionate and caring section of the document. This is an addendum that you write that expresses who you are and what you are about, what gives you meaning in life, your sense of spirituality, what you value, and how you want to be treated. The third, fourth and fifth of the Five Wishes (a popular Advance Directive form available through [www.agingwithdignity.org](http://www.agingwithdignity.org)) address these topics in a prescribed format. Cross out any items you don't agree with. It will help you think but is not personal. Because the form is filled out by hand, changes require an entire rewrite. Recommendation: Write your own personal Final Wishes on your computer; future changes are easily made and printed. Review your documents often, at least yearly, especially if you have significant changes in your medical condition.

The Final Wishes sections can be written mostly from a values-based perspective: What makes your life worth living? At what point would you no longer have quality of life? How does your spirituality influence your views about your own death? If you have strong feelings about particular medical circumstances, express them here. Mention finances, if that is important to you.

Take the needs of your caregivers into account in this section. Acknowledge that this is hard on them. Include compassionate directions to your Agent and others for their own self-care and suggestions for support, including names and phone numbers.

Living Wills do not address mental illness or dementia; give direction here about what sort of treatment would be acceptable if you developed such a condition.

Also include your wishes about what would make you feel most comfortable if you were ill, your feelings about hospice admission, and even your description of what your ideal last days and weeks might look like.

Because your MDPOA ends at your death, you may want to include a Declaration of Disposition of Last Remains

([www.funerals.org](http://www.funerals.org)), which will also outline your choices about cremation or burial and funeral or memorial decisions. Your signature on this document must be notarized.

More detailed preferences for your Funeral Arrangements can be included in this section. Make music selections or plan guidelines for your celebration-of-life party.

Avoid requests that your loved ones might not be able to afford. Consider the needs of those left behind. Allow them to make arrangements that will be meaningful and comforting to them.

You may choose to include an Ethical Will as part of your Final Wishes. This is a narrative legacy to those you love. It can be a short message of what you've learned in life or what you hope you have taught or what personal values matter most to you. You can find great ideas online for possible ways to share your stories and personal messages. You might also record a farewell message.

Once you complete your Advance Directives, please don't store them in your safe deposit box – they must be readily accessible in the event of a hospitalization. Make many copies; give them to your physician and family members. Online storage companies, such as Docubank or Legalvault, can upload your important documents for storage and easy access by others. These companies provide stickers for drivers' licenses or IDs to alert medical personal where to access Advance Directives.

Statistics have proven that those who have written Advance Directives *and* discussed them with and given copies to their doctors and loved ones are much more likely to have peaceful deaths, with less trauma from the intrusions of medical treatments that only postpone the inevitable and create massive financial burdens on our healthcare system. Medical advances are excellent for those with a chance of quality recovery. But for those who are inevitably terminal, the most humane approach is to allow natural death, which can often only happen if you communicate your wishes ahead of time.

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*Sue Bensman is a board member for Natural Transitions in Boulder, CO. She is the founder of Kitchen Table Talks, offering hands-on education and support for small groups to come together to address their end-of-life preferences and complete their Advance Directives documentation. [NTAdvanceDirectives@gmail.com](mailto:NTAdvanceDirectives@gmail.com)*

a time to die...



## Love in the Room

By Rebecca Teague

Rebecca Teague

On Saturday, February 19th, 2011, my friend Morgan died from cancer. She was a beloved mother, daughter, friend, African dancer, beautiful red-headed wonder and gifted body healer. The next day, I was invited to Morgan's home to visit with her family, partner, friends, and her awesome son, who is one of my students. I will forever be grateful for this invitation.

Before I entered, I did not know that Morgan's family was having a private wake and funeral. I did not know that Morgan's body was in her living room, where she was lying upon beautiful blue velvet and covered in a rainbow of flowers, gemstones, tears, and peace.

I did not know how much love would be in that room. I will never forget that day, but, most of all, I will never forget that moment when I first saw her. She looked so beautiful. This was the first time in my life that death had ever made sense, in my mind and heart, and it was in that instant that I knew that everything I had seen about caring for our loved ones was wrong – or, at least, very incomplete. There was another way! There was a way to honor the living and

the departed and a way that allowed us to take care of our own when they passed.

*...the light...  
the peace!*

Death has had a bad rap. It is usually depicted as shrouded in darkness, morbid and somber. Since that Sunday, I have wanted to tell all who will listen about the light. I want them to know about the peace. I want to show this other way of grieving that was...beautiful and necessary.

I realized during that week after Morgan passed that I have an important story to tell – and I needed to use my camera.

Death is sacred and not so sacred. It is shared by us all, and I have learned now that there can be joy mixed in with the sadness, kindness for the living and the departed, and laughter bubbling up from the tears. I wish for everyone to be able to honor themselves and their loved ones in this beautiful final passage.

---

*Rebecca Teague is the child of two artists, who gave her her first camera at age 4. She currently teaches photography to middle school students. [www.rebeccateague.com](http://www.rebeccateague.com)*



# Understanding Voluntary Stopping Eating And Drinking (VSED)

by Roland L. Halpern

Various end-of-life options that are supported in law and medicine enable individuals to hasten their own deaths. Competent adults – or appointed healthcare agents for incompetent or incapacitated clients – may have the power to direct the commencement or discontinuation of any medical treatment in accordance with individual state law. Competent adults are permitted to refuse any unwanted treatment regardless of the reason for their refusal or the nature of their illness – they need not be terminally ill. What does matter is that individuals make voluntary, informed and considered decisions that reflect their own values and wishes.

Healthcare professionals are expected to provide patients and families with medical information about the risks and benefits of, and alternatives to, various treatment options – and to make clinical recommendations. Once a patient or healthcare agent makes a decision regarding continuing, withholding, or withdrawing treatment, clinicians should either honor that choice or refer the patient to a willing provider, regardless of whether the decision is to stop life-sustaining medications or treatments, including medically provided nutrition and hydration.

## Forgoing Artificially Provided Nutrition and Hydration

Healthy people obtain nutrition and hydration naturally by eating and drinking. However, when illness or disability interferes with an individual's ability to swallow, digest, or receive sufficient nutrition orally, medical procedures may become necessary to provide sustenance via surgically implanted tubes in the patient's veins, stomach, or intestine. This artificially provided nutritional support, however, carries none of the pleasure commonly associated with eating and drinking or sharing a meal with loved ones.

Medically provided nutrition and hydration may

be refused or stopped like any other life-sustaining treatment by an informed, decisionally capable adult or by the healthcare proxy agent for an incompetent or incapacitated person, depending on state law. However, when a currently incompetent person has not completed an advance medical directive (e.g., has not appointed a healthcare proxy or written a living will objecting to use of artificial nutrition and hydration), it can be difficult to have these treatments stopped. Counselors from a Compassion & Choices agency may be able to help guide those who wish to forgo the continued use of life-prolonging interventions that have become overly burdensome to an incapacitated client.

## Voluntarily Stopping Eating and Drinking (VSED)

A person who is not receiving any life-sustaining medical treatments, such as artificial nutrition and/or hydration, may still hasten his or her own dying by choosing to refuse all further oral intake. This decision, sometimes known as VSED, differs from the naturally occurring loss of appetite or disinterest in eating and drinking that often accompanies the final stages of many illnesses.

A VSED choice is made by a decisionally capable person who has the physical ability to eat and drink but consciously refuses further oral intake to hasten his or her own death with minimal suffering. Death occurs within one to three weeks after intake stops, depending on the individual's underlying physical condition and disease state. To be ideally successful, this end-of-life option requires a determined and well-informed individual who has significant support.

## Advantages and Potential Disadvantages Associated With a VSED Decision

The most significant advantage of VSED is that the



decision relies solely on a competent person's preference and determination to control his or her own dying. Patients who consider this option need not seek permission from their primary-care physicians before stopping all oral intake, although the organization Compassion & Choices recommends ongoing hospice or other palliative medical support once the process has begun.

For most people, discomfort associated with this process is generally well tolerated, and caregivers can usually manage any distressing symptoms. The most frequently reported symptoms tend to occur early in the fast and include thirst or dry mouth, occasional hunger, and feelings of uncertainty about this approach. Dry mouth can be relieved by use of lip salve, mouthwash, toothbrushes and cool water rinses. It is important for clients and their caregivers to understand that, in order to facilitate a death within the one-to-three-week interval, all liquid intake must stop, even ice chips.

Once all oral intake stops, there is an interval of at least several days before an individual loses consciousness. This interval provides an opportunity for the

client to reconsider his or her desire to hasten death and for family members or other loved ones to gather, share memories, and say goodbye. If, however, the client decides to resume eating or drinking, caregivers must honor that choice, which might occur if:

- **the client is ambivalent about hastening death,**
- **the process is experienced as more arduous than expected, or**
- **cognitive changes undermine his/her ability to be self-determining.**

An informed client's choice about his/her own end of life must be respected and supported by all caregivers. For some patients, the prospect of lingering in a comatose state for days before death may be considered an intolerable circumstance.

Most Compassion & Choices clients want to remain at home as death nears, to be surrounded by familiar objects and loved ones and without strangers at their bedsides. A VSED decision facilitates that preference and provides a gentle, peaceful slipping away that is very much a natural death. Rarely, as death nears,



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clients experience agitation or delirium related to organ failure and dehydration. Access to hospice or other medical support is important for the provision of sedation should this occur.

Because VSED is a legally and ethically supported end-of-life option, it does not have to be kept secret from anyone. The process can be openly discussed with caregivers, and plans can and should be made ahead of time: caregiving staff interviewed and hired, a hospice bed rented to facilitate better care, music chosen, funeral arrangements made, and a date to begin the fast set by the client.

This option is not for everyone. For some, choosing the dates to initiate fasts that will result in death requires more self-control and determination than they possess. For others without family, caregivers, or other social support, this option also may not be feasible.

### **What is the Process of Dying From VSED Like?**

The exact process of dying from VSED unfolds in a unique way for each person and depends on physical, emotional, and spiritual circumstances, as well as the disease-state.

In the first few days of the fast, individuals may stay as physically active as they have been but soon will become weak, tired, and increasingly sleepy. Once they begin to feel light-headed and weak, movement requires assistance in order to prevent falls or accidents.

Mental alertness is replaced by longer and longer periods of sleep. Symptoms of discomfort can be readily managed. If patients previously took oral pain medications, those medications are available in alternative ways, such as by skin patch. When planning to VSED, we urge clients who are not already enrolled in hospice to seek their physicians' assurances that hospice referrals will be made once the fasts begin. Hospice staff are experts at providing symptom management and comfort care.

Once the client can no longer move independently and remains constantly in bed, caregivers may need to prevent skin breakdown by using lotion, massage, and regular repositioning. Providing this attention can be an opportunity for family members to engage in acts of loving care. Excellent oral hygiene should continue throughout the duration of the dying process as well.

Eventually, the individual cannot be aroused. For someone at the end of a terminal illness, this comatose state could occur as soon as the second or third day of the fast. For those who are not terminally ill, it may take longer to completely lose consciousness. One study reports the average time to coma is six days, but there is no way to predict exactly what will happen in any individual case.

Each organ system in the body slowly begins to shut down. For a terminally ill patient, the average length of time before death occurs is 10 days; for those without an underlying terminal illness, the length of time might vary from one to three weeks. This difference depends on several factors: age, overall physical condition, the underlying disease burden, the ability to remain completely free of all fluids, and, perhaps, a readiness to "let go." Stopping oral medications, such as for heart disease or diabetes, may secondarily speed up the dying process without increasing client discomfort. These clinical decisions should be discussed with healthcare professionals.

As death nears, breathing becomes more shallow and irregular. Moaning may occur but is not believed to be an indication of pain or distress. Death from VSED is essentially a natural process that follows a fairly predictable pattern.

---

*Roland L. Halpern is the community relations coordinator for Compassion & Choices, an organization that seeks to improve care and expand awareness regarding end-of-life choices, in Denver, CO.*



## Lessons Learned

by Silvine Marbury Farnell

*When Josephine Worthington Marbury of Baltimore died in March 2011, her body was cared for by her daughters, Silvine Marbury Farnell, from Boulder, Colorado; Francie Marbury, from Brattleboro, Vermont; Marian Marbury, from Baltimore; and by her extended family. They learned a lot in the process about knowing everyone's rights and educating others about them. Silvine wrote this article to share what they learned.*

**M**y mother wanted to be cremated so she could be buried in the same grave with my father. In the spring of 2008, she confessed she was afraid being cremated would hurt.

Everything unfolded from there, naturally, inevitably. Even our mistakes seemed part of the rightness of the whole thing, and this article feels like the completion of the process. Taking care of our own after death is so natural and right that we don't have to be afraid of making mistakes. No mistake can "ruin" this experience or lessen the deep satisfaction it brings.

I had mentioned my mother's fear in a group I had attended, and a woman had told me how beautiful it had been to have three days with her father's body before the cremation. She had shared that other cultures believed that this delay was important, because it allowed the spirit time to let go of the body. She had also told me about a woman named Beth Knox, who lived near where my mother was living in Maryland.

I emailed Beth – could this three-day vigil be arranged for my mother in the Health Center at Blakehurst, a traditional retirement facility? She assured me it could: "You tell them that you intend to act as your own funeral director, which is supported by Maryland law." When I told my mother she could have three days to "get used to being dead," with us taking care of her, the relief on her face was obvious. Cousins offered their home for the vigil, my sisters were willing, and my mother began to think about what she would wear.

Beth also told me about a group called *Crossings* in Baltimore. When I told my mother I was going to a meeting, she said, "I'm going with you." We both got some key questions answered. For one thing, I found out that



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stopped breathing. I had been taking a nap; when I rejoined them, the minister kept praying with us, and those prayers allowed me to take in what had happened and express my deep grief and sob.

## LESSON LEARNED:

Even a ritual from a religion one is no longer part of can help enormously.

We called Lee Hoyt, who helped my sister and me with washing and dressing, which was as right and simple as everyone says it can be. We went ahead with our plans to transport her body to

our cousin's house ourselves, oblivious to the fact that we had said nothing to prepare the staff at Blakehurst. Five stalwart cousins arrived – only movie director John Ford could have done justice to the beauty of those guys as they came walking down the hall. They carried her body to their van – and a nurse who had always taken good care of my mother, in a panic, summoned the director of the Health Center. Speaking as kindly as he could and with great regret, he told us he would have to call the police if we did not desist.

It was not a time to argue. The cousins carried her back to her room, I called CAFA, and my sister and I had some quiet time with our mother's body, which we needed. The man from CAFA was big and kind and reassuring, and it did not seem wrong to put our mother into his hands for the ride to my cousins' home.

I later wrote letters of apology to all concerned and learned the director had since researched the law, learned what we had been doing was legal, and was working on a policy for handling similar situations in the future. I learned that several residents of the Health Center, after hearing the story, seemed drawn to similar choices. And those noble cousins have a story to tell for the rest of their lives about the night they were almost arrested as body-snatchers.

## *No mistake can 'ruin' this experience*

a funeral home not far from Blakehurst, Cremation and Funeral Alternatives (CAFA), would do as much or as little as we wanted.

During the next two years, I took three workshops and downloaded the resource guide at [crossings.org](http://crossings.org). But it was hard to assimilate what they had to teach me, and I dragged my feet on practical preparations.

In the fall of 2010, my sisters started prodding me to get something down on paper to help them if our mother died when I was unavailable. Using Beth Knox's resource guide, I sent out a list to friends and family members, who signed up for various jobs. Lee Hoyt, a co-leader of Crossings in Baltimore, volunteered to help if I were absent.

Even after my mother's bad fall in mid-March, we believed her when she said, "They talk as though I'm dying. I'm not dying, I'm going to Patrick's [her grandson's] wedding." So, when my sisters and I took advantage of being together at Blakehurst to firm up our plans, we thought we still had plenty of time. We had discovered we could not ride with our mother in the CAFA van because of insurance issues, so decided we could handle everything ourselves. I didn't remember Beth Knox' advice to tell Blakehurst I would act as funeral director or that such a decision was supported by Maryland law.

We had a weekend of showering our mother with love and songs and poetry, and she rallied to enjoy it. After the weekend came precipitous decline. Late Tuesday afternoon, as the minister who happened to visit prayed with my sister and my cousin, our mother

*...everything was as our mother would have wanted it*



## LESSON LEARNED:

People really don't know this option is legal (in most states), and it's only fair to educate them ahead of time. Yet, even as big a mistake as failing to do so cannot take away from the rightness of caring for the body of someone we love. Good can come of the mistake.

As it happened, few people ended up doing the jobs they signed up for. Many had other obligations, and I was in no state to be checking my list. Others stepped in, and, somehow, everything got done – but it's hard to imagine we could have managed without Lee.

## LESSON LEARNED:

Preparations are all helpful, but it can still be hard to wrap your mind around the realities of the death of someone you love. Many of us need a guide who is not personally involved. I rejoice that home funeral guides are being trained.

There were awkward moments, yet we had the clear sense that everything was unfolding as it should. Yes, dry ice can be impossible to get in the evening, but a bathtub full of real ice can always be managed. Once our dry ice was in place, Lee's attention to detail made the quiet room beautiful with flowers and candles; everything was as our mother would have wanted it, especially the calm and beauty of her face.

Through it all, we had the constant, loving support of our extended family. I was too exhausted to remember to schedule someone to be with our mother Wednesday night, but a cousin said, "If we're gonna do this, let's do it right. I think it's gonna be sweet!" And it was – at least one person was always with her, and they have all told me how right it felt.

The deepest satisfaction for me came when my Baltimore sister, who sat quietly with our mother most of Wednesday and Thursday, told me she had gone along with caring for our mother's body ourselves because it was important to me – but it had turned out to be

healing for her. After doing so much for our mother for so long, she had needed that quiet time to come to peace with her dying.

## LESSON LEARNED:

Even if others in the family don't really understand why you want to make this choice, it may still make sense to go ahead. They may come to feel how right and how healing it is.

The hardest part was the cremation. I'm sure I had been told at workshops that ritual around a cremation is important, but I had not taken that in. We had no context for seeing cremation as having any spiritual meaning, as some religions do. It was almost unbearably stark – a body slid through a door into a furnace.

During the graveside ceremony the next day, I wished we could have been laying that beloved body to rest in the earth, to nourish the life of the soil. I had been in favor of green burial previously, but I now feel passionately about it.

## LESSON LEARNED:

If you opt for cremation, and you have no religious or spiritual context with which to offer comfort to those who mourn the loss of their loved one, you might consider a meaningful ritual to humanize the experience.

It comforts me to believe that, for my mother, the cremation did not "hurt," as she had feared it would – the three-day vigil had let her "get used to being dead." As it turned out, at least one person who watched by her during the vigil sensed a tranquil, even joyful presence – perhaps the presence of a spirit freed from its attachment to a body.

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*Silvine is a retired literature professor whose passion is helping people get all poetry has to give by bringing poems alive in their mouths, in their bodies; her current focus is on bringing poetry alive in schools, especially Montessori schools. [www.deeperintopoetry.com](http://www.deeperintopoetry.com).*



## Pathway to a "Good Death"

by Jennifer Ballentine, MA

**Y**ou wouldn't think dying would be that hard. Besides birth, daily bodily functions, and – some would say – paying taxes, death is the only guaranteed experience for every individual on the planet. But as it turns out, in today's America, it's difficult to die.

Whatever problem exists, there is (seemingly) always one more procedure or drug that can be tried to keep a person biologically "alive." If you are inclined to pull out all the stops, insist that "everything" be done, and take advantage of all that 21st-Century medical technology has to offer, stop reading now. If you are more inclined (as the vast majority of Americans are, in poll after poll) to opt for a less impeded, more peaceful and comfortable death, then carry on. There are well-marked paths to a "good death" – legal and ethical alternatives to the "do everything" directive – but they take reflection, awareness of personal values, insistent communication with providers, and strong advocacy.

### Just Say No

The notion that patients might have a say in the direction of their healthcare is relatively new – barely 100 years in the 5,000-year-long history of medicine. Landmark court cases in the early 20th Century established the doctrine of "informed consent": Patients must be informed of any proposed medical treatment and give

their consent to the treatment before it is performed. If consent is not given, and treatment is, the law considers that treatment a form of assault.

Likewise, a patient's right to refuse treatment has been affirmed by the courts, as a sad consequence of personal tragedies turned into public disputes. The Karen Ann Quinlan case of the mid-1970s, which involved a young woman irrevocably unconscious and dependent on both a mechanical ventilator and feeding tube, established important rights of patients to refuse even life-sustaining treatment and the rights of authorized others – guardians, in this case – to exercise that right on behalf of the patient. The case of Nancy Cruzan, also a young woman dependent on a feeding tube in the 1980s, was appealed to the U.S. Supreme Court, which affirmed:

1. a patient's right to refuse any treatment at any time for any reason, *even if the result is death*;
2. that artificial nutrition and hydration are medical treatments that can be refused; and
3. the rights of states to establish guidelines as to evidence of patients' likely preferences and the authority of surrogates to act on behalf of patients.

Throughout the middle and latter half of the 20th Century, as these and other such cases were being

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else must*

played out, medical practices and ethics slowly began to acknowledge the importance of patient autonomy – the rights of all competent adults to self-determination and decision-making. Some might say that the emphasis on autonomy has gone too far. As medicine is generally practiced now, patients are expected to have not only a say but *the* say in complex choices, perhaps based on incomplete or overwhelming information and without benefit of personal experience or medical expertise.

Physicians can and do recommend courses of treatment, and, in the beam of the headlights of a health crisis, many patients simply acquiesce. The more serious and advanced the illness, the more irresistible the current of proposed treatments and procedures can be, and some patients find themselves swept downstream and over the falls toward a prolonged and/or ugly death. However, the choice really is each patient's to make. In the context of advancing illness, few decisions have to be made immediately.

To make a truly informed decision for yourself about any and every proposed treatment for advancing illness, ask for each item detailed in Box 1. Consider your options. Talk them over with your family, close friends, spiritual or personal advisors, or just sit with them for a while. You have three choices:

1. Agree to the recommended treatments,
2. Select alternatives, or
3. Refuse treatment.

Even when you refuse *treatment*, you should always expect and demand care, and you should never succumb to pressure or allow yourself to be rushed into saying “yes” to any particular choice.

## **Especially, Refuse the Tube**

A person approaching the end of life, whether by progressive disease or old age, naturally begins to lose appetite and interest in eating – a phenomenon called *cachexia*. This loss of appetite, body mass, and energy cannot be nutritionally reversed, and it signals an underlying disease or approaching death – or both. In the end stages of many progressive diseases, people eventually lose the ability to swallow. Before the days of medically delivered nutrition and hydration, this symptom would signal that death would arrive within days, eased by the body's own naturally soothing and pain-relieving substances.

Artificial nutrition and hydration, like many life-sustaining treatments, was originally developed as a stop-gap intervention – a way to sustain life during a period of prolonged but curable illness or unconsciousness. It

## *For persons in the final stages of life, feeding tubes do not help*

was not intended as a maintenance measure, but that's what it has become.

In a classic example of the “dark side” of life-saving techniques, between 3 and 8 percent of nursing home residents – about 77,000 people, many with advanced dementia or other end-stage illnesses – now have feeding tubes. The majority of feeding tubes are installed during an acute hospitalization, and median survival following feeding tube insertion is just 56 days. For those in the final stages of life, feeding tubes do not help: They do not heal bedsores, they do not aid in weight gain or improved energy – and *they do not prolong life*.

In fact, the opposite is the case. In progressive, end-stage illness, the body shuts down, and the liver and kidneys cannot handle artificially delivered nutrients and fluids. The result is terrible fluid retention in the limbs, the tendency to gurgle and choke on secretions that cannot be swallowed, and pneumonia caused by excess fluid in the lungs. Chemical and physical restraints are often required to keep patients from dislodging feeding tubes, which results in further deterioration and isolation. Refusing or removing tube feedings at this stage of illness is not only ethically valid but medically appropriate.

## **VSED – Voluntarily Stopping Eating and Drinking**

Some patients might take this natural phenomenon a step further and, even before losing the ability to swallow, voluntarily stop eating and drinking as a way to accelerate the final stages of dying and achieve a peaceful death. [See p.11 for a detailed article on VSED.]

## **Appoint a Healthcare Agent**

As death nears, many people lose their decision-making capacity. From 10 to 40 percent lose capacity in their last months of life, and 85 percent do so in the last days of life. When you cannot make your own decisions, someone else must. A healthcare agent – the most essential end-of-life choice for every adult in the country – is your advocate along the path to a good death.

Fortunately, while affirming the rights of competent adults to make choices about their own healthcare, the U.S. courts also have established the rights of “duly appointed” surrogates to make decisions on behalf of adults who have lost their decision-making capacity. In

## Appointing a healthcare agent and considering treatment choices is not just for seniors

other words, while you have your wits, you can appoint an “agent for healthcare,” who will have complete authority to speak for you when you can’t. A healthcare agent – the most essential healthcare choice for every adult in the country – is your advocate along the path to a good death.

Every state has some version of this authorized surrogate, although the labels differ: medical durable power of attorney, healthcare proxy, healthcare representative, patient advocate, etc. Every state also has specific documents that must be completed in order to establish the appointment of the surrogate (see Box 2).

The cases of Karen Ann, Nancy, and (most recently) Terri Schiavo ended up in court precisely because they had not appointed healthcare agents and had not provided clear instructions as to their wishes. It is worth remembering that these women were all under the age of 30, in good health, and with robust futures when tragedy struck. Appointing a healthcare agent and considering treatment choices is not just for seniors. [See “Do As I Say” on p. 29.]

The job of the agent is to make decisions and choices *as you would make them*, according to *outweigh reasonable* preferences and values. When considering your candidates for healthcare agent, you should pick someone who is available, willing, informed, assertive, and backed up (see Box 3). Spouses and adult children tend to get picked as agents, which is fine as long as you are confident that your agent can set aside her or his own considerable emotional investments and preferences and fiercely advocate for yours. If wavering is likely, consider appointing a close friend or other third party.

Whoever you pick should not be left to read your mind about your choices, however. Even best friends and longtime spouses are not good at guessing what you might want. Frequent discussions of the “what-if” variety can be helpful, but providing written documentation in the form of advance directives can alleviate doubt and provide an additional form of back-up for your agent.

### Complete Advance Directives

Advance directives, so-called because they are completed in advance of the need for the decisions they document, take different forms in different states, with

#### Box 1: Information to get from your doctor before consenting to treatment:

- A clear description of your condition and prognosis (where the disease is likely to go from here, how likely it is that you will recover, stabilize, or decline, and when)
- Recommended treatment(s), along with why this option is likely to be effective and what uncomfortable side effects might be expected
- Alternatives to the recommended treatment(s), their likely effects and side effects, and why they are not recommended
- The consequences of not pursuing any treatment at this time
- What support (medical, emotional, psychological, spiritual) will be available for you and your loved ones during treatment

varying preconditions and limitations. In general, advance directives are used to limit or refuse certain treatments in certain situations. For instance, many “living wills” instruct physicians to withhold or withdraw life-sustaining treatment once they have determined that a patient has an irreversible, incurable illness or injury; a CPR directive instructs emergency medical personnel to not perform cardiopulmonary resuscitation if a person’s heart or breathing stops or malfunctions.

There are numerous operational and even philosophical challenges with advance directives – primary among them is that so few people have completed them. Even when they have, the documents often are not on hand when needed or don’t really apply in the circumstances. A living will, for instance, does not tell a physician whether to treat the third pneumonia in a person with advancing Alzheimer’s disease.

In answer, a growing number of states are adopting a new process: the Physician Orders for Scope of Treatment (or POLST). The POLST is a one-page summary of advance directives and key treatment choices, which, when signed by a medical professional, becomes medical orders that are accepted in any healthcare setting. It is intended to travel with the patient and provide seamless documentation of decisions in a form that gets more attention than simply an expression of personal preference. The POLST is intended for those with serious or advanced illness, in frequent contact with healthcare providers and/or frequently transitioning between healthcare facilities. In states where POLST programs

## Box 2: Resources for advance care planning and advance directives:

- **Caring Connections:** This website offers a wealth of information for advance-care planning and downloadable advance directive forms for every state: [www.caringinfo.org](http://www.caringinfo.org).
- **POLST:** For more information on the Physician Orders for Scope of Treatment and its variant programs: [www.polst.org](http://www.polst.org)
- **Five Wishes:** A popular user-friendly, all-in-one directive that conforms to the requirements of many states: [www.agingwithdignity.org](http://www.agingwithdignity.org).
- **Caring Conversations.** A booklet produced by the Center for Practical Bioethics that helps clarify treatment preferences and quality-of-life values. While not an advance directive, it provides guidance for arriving at healthcare treatment choices: [www.practicalbioethics.org](http://www.practicalbioethics.org); select the “Caring Conversations” button on the home page.

have been operational for some years, improvements in completion of advance directives, communication among providers, and adherence to patient wishes have been significant.

Which directives or tools you use depends on the state in which you reside, your health status, and your goals. The key point is to provide written documentation as proof of your preferences and guidance for your agent. It is critically important to keep these documents handy (not in a safe deposit box) and update them frequently. April 16 (with a nod to that death-and-taxes adage) is National Healthcare Decisions Day – an annual reminder to update your directives. [See page 5 for more about National Healthcare Decisions Day.]

Advance directives are not magic, but at least they provide pointers in the directions you would choose to go.

## Opt for Hospice or Palliative Care

At some point along the line of many progressive illnesses, doctors may say something akin to, “We really don’t have a good way to treat this disease, but we can manage the symptoms,” or, more bluntly, “There is nothing more we can do.” The dread of hearing these words leads many patients to go along with more and more treatments. However, when disease processes start to outpace treatments, or when the burdens of treatment outweigh reasonable hopes of benefit, much more can be done – by hospice or palliative care.

## *Palliative care provides a structure within the healthcare system for keeping the focus on patient goals*

Hospice care is designed to maximize comfort, independence, and control in patients with a prognosis of six or fewer months, who are willing to forego treatments intended for cure. Care is provided by a team – physician, nurse, social worker, chaplain, nurse’s aide, and volunteer – and is usually delivered in the patient’s home, wherever that may be. For patients who require acute levels of care, some hospices have inpatient facilities or contracts with nursing homes. The care team addresses pain, discomfort, and emotional-psychological-spiritual distress in patients and immediate family members or caregivers. Hospice care is fully covered under Medicare Part A and by many private insurance plans.

Enrollment requires a physician’s certification of a six-month prognosis, which is sometimes challenging to obtain. A study by medical sociologist Nicholas Christakis, MD, compared physicians’ predictions of death in their sickest patients to actual death dates, and found that more than half the physicians had *overestimated* prognosis by a factor of five. In other words, estimates of patients’ likely remaining lifespan were five times too long. Furthermore, the better the physicians knew the patients, the more likely they were to overestimate. Not only are many doctors lousy at predicting death – many are reluctant to refer to hospice until death is truly at the doorstep.

The result is that half of hospice patients are enrolled for fewer than three weeks, which may be long enough to control pain and physical distress but is nowhere near long enough to provide the full range of hospice services. Some tip-offs that a person might be eligible for hospice are:

- frequent hospitalizations,
- declining effectiveness of treatment,
- increased side-effects and burdens,
- unmanageable pain and symptoms,

If you ask your mother’s doctor: “Would you be surprised if Mom were alive in a year?” and the answer is, “Yes,” a hospice evaluation is in order. For patients with advanced dementia, one of the foremost Alzheimer’s researchers, Dr. Joan Teno, suggests that, if the patient “can’t walk, can’t talk, can’t eat,” it’s probably past time for hospice.

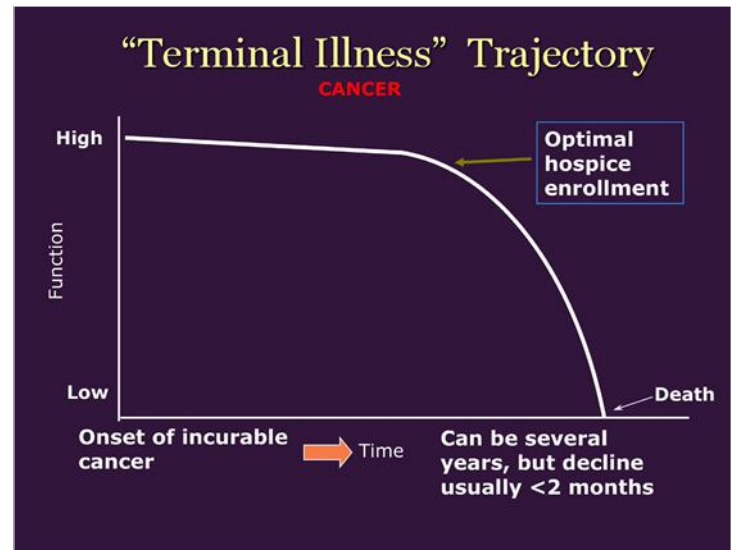
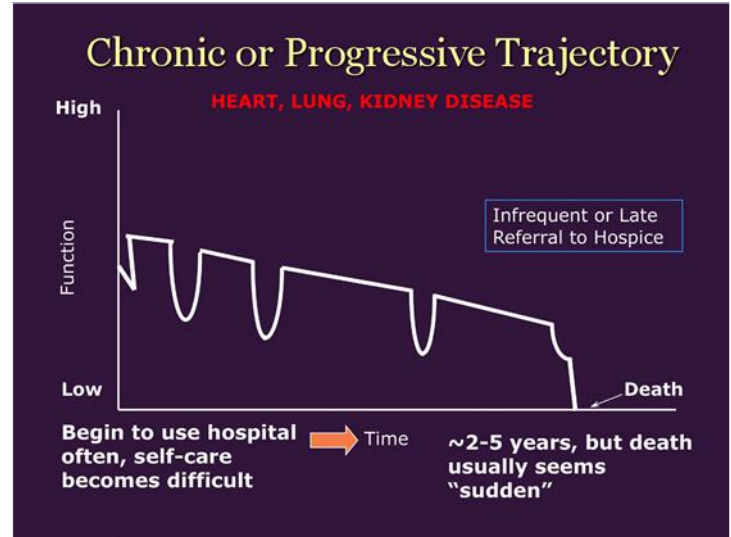
...for many common, progressive diseases, palliative and hospice care actually extend life.

### Box 3: Important qualities in a healthcare agent:

- **Available.** Preferably, your agent should live in the same city or at least the same state as you do with access to your healthcare providers. Privacy regulations and other logistical issues can make acting as an agent from a distance difficult.
- **Willing.** In cases of progressive illness, a myriad of big and little decisions must be made over a possible span of years. Your agent must be in it for the long haul.
- **Informed.** As the person appointed to speak for you, your agent must know what you would want and what you would do. It's impossible – even if you already have a specific diagnosis – to anticipate all the decisions that might need to be made, but identifying some basic values and “bottom lines” can provide guidance. Several tools noted in Box 2 can be helpful in this process.
- **Assertive.** Your agent must be able to go toe-to-toe with numerous medical professionals in many facilities and situations. You don't want a shrinking violet or a ditherer in this job. Backed up. You should appoint a primary healthcare agent as well as a backup, in case the primary agent cannot serve or isn't available immediately.

Another factor that delays enrollment in hospice is that the shift from aggressive disease-focused treatment to comfort-focused care can feel abrupt, almost like an abandonment, and this reinforces the idea that hospice is a form of “giving up.” However, 98 percent of patients and families who have experienced hospice care report that they would recommend hospice care to others, and 94 percent have rated the care they received from hospice as excellent or very good.

The trajectory of some conditions, however, can make the “right time for hospice” even more elusive. The course of most cancers is somewhat predictable, but for illnesses like dementia or heart, lung, or kidney disease, decline can be very slow and indeterminate, punctuated by crises and seeming recoveries (see Figure 1). For patients with these and any other serious illnesses, palliative care offers many of the benefits of hospice without requiring a six-month prognosis or rejection of curative treatment.



Palliative care is a relatively new subspecialty (as of 2006) but has great affinity with the way medicine was practiced for thousands of years. Palliative care focuses on relieving pain and suffering, discovering the patient's goals for care, and adapting treatments to those goals, ideally beginning at diagnosis of a serious illness and continuing alongside curative or disease-focused treatment. If, as with many progressive illnesses, curative treatments become less effective, care may become more of a focus than cure over time, as shown in Figure 2. By the time a patient becomes eligible for hospice, the transition is natural, logical, and smooth, without a sense of “giving up.” Palliative care provides a structure within the healthcare system for keeping the focus on patient goals and preferences and providing the opportunities to discover, discuss, and decide.

Palliative care is most commonly available in hospitals (in 85 percent of hospitals with more than 300 beds and 54 percent of mid-sized facilities) as a consultation

with an interdisciplinary team (typically composed of a doctor, nurse, social worker, and/or chaplain) when goals need to be clarified or treatment plans adjusted. It is also offered by independent providers (typically, physicians and nurse-practitioners) and by some hospice agencies as an alternative or precursor to hospice enrollment. Because Medicare and most private insurers do not have a palliative care benefit, per se, standards and the depth of services offered under this label vary, especially when provided by long-term care facilities. For more information and assistance with the location of palliative care services in your area, see Box 4.

Palliative care and hospice maximize *quality* of life by focusing on comfort, control, and care at home whenever possible – exactly the kind of death most Americans claim they want. There is also recent research indicating that, for many common, progressive diseases, *palliative and hospice care actually extend life*.

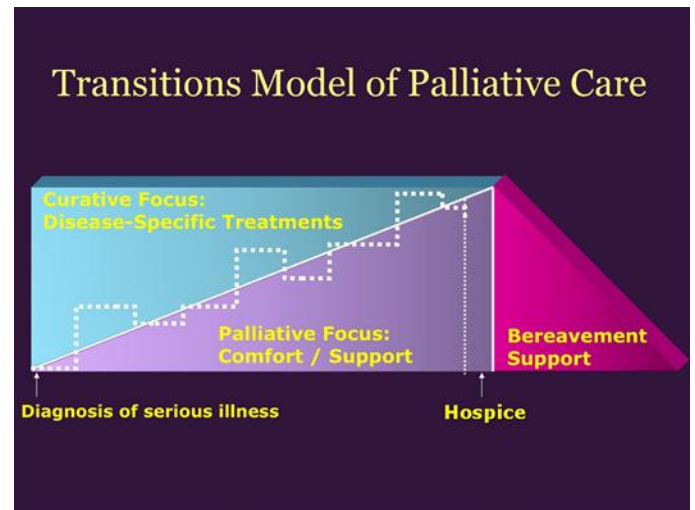
## Obtain a Lethal Prescription (Legal in Three States)

No discussion of how to die would be complete without acknowledgement of physician-assisted death (PAD), which is only legal in three states: Oregon, Washington, and Montana.

Proponents of PAD see it as the ultimate expression of autonomy and a rational alternative to a prolonged dying process, no matter how well symptoms are controlled or patients and family members are supported. Opponents see it as a practice subject to abuse and motivated by glib evaluations of “quality of life” based on a person’s ability to function and produce, denying the inherent preciousness of human life. Still others are shocked that our culture is so focused on independence and self-determination that we would rather die than be cared for. Whatever your ethical position, you cannot legally obtain a lethal prescription outside these three states.

## Consider Palliative Sedation (Maybe)

For a small number of patients (fewer than 5 percent by most estimates), pain or other forms of suffering is severe and “intractable,” which means that it has not responded to repeated interventions. For such cases, palliative sedation is an option of last resort. Under the supervision of qualified palliative physicians, patients are sedated to unconsciousness. In some cases, this sedation is temporary, and patients are “brought back up” to see if the respite from suffering has brought relief. In



### Box 4: Hospice and palliative care information and resources:

- **Life Quality Institute:** [www.LifeQualityInstitute.org](http://www.LifeQualityInstitute.org). An organization dedicated to palliative care education, LQI offers consumer-oriented information on palliative and hospice care, advance directives and advance care planning, and caregiving.
- **Hospice Analytics:** [www.hospiceanalytics.com](http://www.hospiceanalytics.com). Offers a searchable database of all hospice organizations nationally, with general information about the field and quality indicators for hospice care.
- **Caring Connections:** [www.caringinfo.com](http://www.caringinfo.com). In addition to copious information on advance directives, Caring Connections provides basic information on palliative care.
- **American Association of Hospice & Palliative Medicine:** [www.aahpm.org](http://www.aahpm.org). Offers a directory of certified palliative physicians by state.

other cases, sedation is maintained until the natural progression of the underlying illness causes death.

This practice is controversial and teeters on the thin line between not impeding death and actually facilitating it. As a result, rigorous medical and ethical criteria established by national associations and professional consensus carefully control its application. Most of these criteria limit palliative sedation to circumstances of physical pain and suffering from out-of-control symptoms when death is “imminent” (meaning a matter of hours or days), and most require evidence of repeated attempts at more standard interventions.

## Conclusion

Death is inevitable, but it doesn't have to be a tortuous road. Most American deaths are preceded by several years of decline and disability, so ample opportunities are usually available for considering and making choices. You can decide on your options – in the moment, if you are able, or in advance – by documenting them in advance directives and discussing values, preferences, and goals with your appointed healthcare agent. You can make sure your agent is tough and vigilant and that palliative care professionals are on hand to clarify options and recommend the best treatments to meet your goals (not your doctors', not your family's) and keep you comfortable and supported. When treatments cease to be effective or when their burdens outweigh their benefits, you can opt for hospice care. Further, you can be assured that if your pain is extreme, there are strategies for its management and companions to be with you and support you all along the way.

The end of life can be a time of

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“It is true, there is death...  
It is true, there is no death.”

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tremendous personal growth, discovery and meaning, deepening relationships, and even spiritual transcendence. However, these opportunities are unlikely in the midst of machines, sterile environments, and repeated medical intervention. Woody Allen once quipped, “I don't mind dying, I just don't want to be there when it happens.” A good death actually requires that you “be there,” giving the process your attention and your clear intention

*Jennifer Ballentine, MA, is executive director of Life Quality Institute, co-chair of the Colorado Advance Directives Consortium, and principal of The Iris Project. Iris is the messenger of the gods; she cuts the cord that binds the soul to the body. Her name also means “rainbow” – symbol of hope, forgiveness, redemption..*

What must we do to increase the likelihood of dying peacefully, where and as we want?

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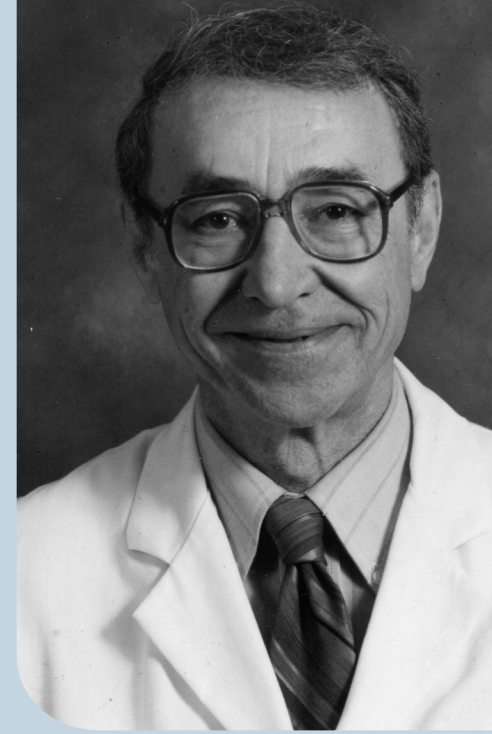
by Merilynne Rush, home funeral guide,  
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## 'Dying Wish' a story of VSED

The film *Dying Wish* documents the dying process of a cancer patient who chose to refuse food and water, and wished to have his story told. It's questionable whether Dr. Miller actually died any sooner than he would have otherwise, given the advanced stage of his cancer. It is certain that his stopping eating and drinking was made much easier by the natural processes of cachexia already underway, and, clearly, the sense of control over his own fate afforded by his decision was comforting to him. Another person, further from death, might find the experience more difficult physically and might encounter more ethical “push back” from providers.

Visit [www.dyingwishmedia.com](http://www.dyingwishmedia.com) for more information on the documentary and voluntary stopping of eating and drinking.

*Dying Wish*  
A dying doctor's decision to stop eating  
and drinking and die with grace.

A WordWise Production

An extraordinary, beautifully made film of a courageous physician facing his final days with the help of a loving family and supportive hospice team. It is thought provoking and reassuring. Highly recommended!

Porter Story MD, Author, Executive Vice President, American Academy of Hospice and Palliative Medicine

***Dying Wish* has featured at the National Hospice and Palliative Care Organization's annual clinical conferences and film festivals nationwide. It is a valuable tool for facilitating difficult conversations about voluntary stopping of foods and fluids at end of life. Order DVDs from [www.dyingwishmedia.com](http://www.dyingwishmedia.com)**



## Being Prepared for the End of Life: My Story as a Witness and Survivor

by Isabel Yuriko Stenzel Byrnes

Isabel Stenzel-Byrnes

Years ago, I found myself sitting at a desk of the admitting department in my community hospital. The clerk asked if I had an advance directive. I got flustered and filled out the paperwork in haste, with sweaty palms. I was slightly offended. I was only 25 years old, and this was a routine hospitalization. Was this hospital going to kill me? Would I jinx myself by filling this stuff out? And wasn't I too young? I thought advance directives should be for folks in their sunset years who were dealing with wills and estate planning – not for me!

Then reality hit. Of course, I did have a serious health condition, and, although my health was stable at the time, I was the exact person who most needed to have my wishes in writing. I had been in and out of the hospital throughout my first 25 years because of cystic fibrosis (CF) infections, but, overall, nothing too critical had ever happened for which I would need an advance directive. But still, I was growing older and it was time to think this through.

*I had to be responsible  
and think through my  
own choices*

I came from a Japanese grandmother who believed in all things natural. She died at 94, peacefully, at home, without health insurance and without being seen regularly by any doctor. Like most Japanese people, she never even knew what an advance directive was. When she moved in with my uncle in Hawaii and died in his home, a detective soon arrived to investigate the “crime scene.” Aside from a few scribbled notes in her bedside drawer (in Japanese) that said she “was ready to go to Heaven,” she did not have a “Do Not Resuscitate” (DNR) order. The detective wanted an autopsy, which is taboo in Japanese culture. Needless to say, the lack of any written wishes caused significant distress for all of us grieving family members.

My grandmother's approach to death was in stark contrast to American culture, where medical practitioners seem to perceive death as unnatural and as a failure, especially for the young.

As one deeply involved in the cystic fibrosis community, I have stood at the bedsides of countless friends

who were unconscious on ventilators for weeks on end in Intensive Care Units, their bodies swollen and sweaty with strained mechanical breathing. I have seen doctors do everything possible to keep my friends from dying – even when there was no hope for recovery. In most cases, it has been the parents who have simply wanted their kids to be kept alive. That’s their instinct. I have heard words murmured like, “She’s a fighter,” or, “He wouldn’t want anyone giving up on him.” Only in rare cases would a parent confess, “I’m not sure what she would have wanted.”

After watching such prolonged suffering for both the patients and the families, I had to be responsible and think through my own choices in graphic detail. What did I want?

There were other reasons, too. I was born in 1972, when most kids with CF died before their teen years. In the past 25 years, however, lung transplantation has become available as a miraculous option when CF lungs finally fail. This possibility has made end-of-life planning more challenging. My options to die peacefully at home or in the ICU had increased, and I had to balance the chance of receiving donated lungs with heroic measures to keep me alive. As more transplantations succeeded and saved many of my friends, I wanted to make sure my desire to donate my organs was clearly stated in my advance directive.

In the ensuing years, I made sure to keep my wishes updated and accessible. Since that first exposure to pre-arranged care planning, I have had various iterations of my advance directives taped to my refrigerator at home. I have made decisions about what I would want for pain control, feeding, and life support. My medically knowledgeable twin sister, Ana, rather than my emotional husband, serves as my Power of Attorney.

Fast forward to the moment of truth. I had continued to struggle with lung infections, which had dramatically reduced my lung capacity. By age 30, I used an oxygen tank to breathe, and my world revolved around respiratory treatments, medications, nutrition, and doctors’ appointments. I still went in and out of the hospital for treatments.

On one otherwise normal hospital stay in January 2004, I didn’t respond to the usual heavy doses of antibiotics, and my breathing got progressively worse. I celebrated my 32nd birthday in the hospital, not knowing

what lay ahead. I finally accepted my degree of severity after much denial and was placed on the waiting list for a lung transplant. With 200 people waiting for lungs in my region, I hoped it wasn’t too late.



My breathing became so labored that I couldn’t take a shower, walk to the sink, or, eventually, even move at all. Ana and my husband stayed with me, along with limited visitors. Within days, I was placed on a BIPAP machine to help blow air into my failing lungs. I was tormented by fatigue but too scared and short of breath to sleep. Inside, I was terrified. This couldn’t be happening. I couldn’t be dying.

Amid this haze of gasping, I remember my doctor stopping by one day and sitting on my bed. In a serious tone, she admitted that things weren’t looking too good. I adamantly told her, “I’m NOT dying.” She nodded and said, “Okay.” Then, she asked me what I wanted

to do if I continued to decline. Would I want to be placed on a ventilator? Would I want comfort care? My mind was foggy and confused, probably from high carbon dioxide levels. I told her no, I didn’t want to be placed on a ventilator. I knew that CF patients died on vents, and I didn’t want to die. Fortunately, my husband reminded me that, years earlier, I had posted my advance directive on my refrigerator, and it read, “I would like to be on a ventilator ONLY in cases where lung transplant is a real possibility.” I didn’t want to be on a ventilator, but, if it provided a bridge to the chance of a new life, I would accept it.

Within 36 hours, my respiratory failure had progressed. As my CO2 levels continued to rise, I became highly confused, and my body gradually lapsed into a coma. My emotions were shut down; my total essence was focused on the physical act of breathing.

Before slipping away, however, I felt a powerful spiritual presence within me that there would be a miracle. I told people around me several times, “There’s going to be a miracle.” It wasn’t the narcotics – it was a deep conviction that I would be okay. Then, I coded on February 3, 2004, with my husband and Ana by my bedside, devastated and convinced that this was my end. However, thankfully, my doctor obliged my request, and I was placed on a

## *I made sure to keep my wishes updated and accessible*

## *Inside, I was terrified ... I couldn’t be dying*



Isabel Stenzel-Byrnes

Isa celebrates having lungs by playing bagpipe.

ventilator. Ana took over and became my advocate, asking what medications would be used or what hour-to-hour treatments I would receive. It wasn't easy for her, but I was in good hands.

Twenty-three hours later, amid my family's tears and despair, a team of doctors approached my family with the five words that changed everything: "We have lungs for Isabel." At the eleventh hour, on February 6, 2004, donor lungs had been located. A young man named Xavier Jesus Cervantes lost his life in a car accident – and saved mine. Two months before his car accident, Xavier had told his mother that he wanted to be an organ donor, so he could help people. He had registered when he received his driver's license. His family had known what to do.

As I write this, I recognize that two people had their end-of-life wishes respected. That is why I am able to tell this story today.

In a few months, I will be 40. The past eight years have given me the gifts of becoming an athlete, traveling the world, publishing a memoir, learning to play

the bagpipes, going back to work, celebrating the births of three nieces, witnessing my twin's wedding, and watching our memoir inspire a documentary film. I am extraordinarily blessed.

*... two people had their end-of-life wishes respected*

However, as a transplant recipient, I have new concerns for my ultimate end: Do I want dialysis? What do I want if I have a stroke or end-stage cancer? This borrowed time and personal resurrection has made me much more accepting of dying – even dying young. And, as I am still surrounded by courageous CF and transplant peers with their own stories of living and dying, I am keenly aware that I still need to have an updated end-of-life plan for whatever comes next. My whole process of dying has prepared me for the next round. I will be as prepared as I can be.

---

*Isabel Stenzel Byrnes is a patient advocate, social worker, and author, who lives in Redwood City, California, with her husband, Andrew.*



## Movie Review

### The Power of Two

reviewed by Karen van Vuuren

For Anabel “Ana” Stenzel and Isabel “Isa” Stenzel-Byrnes, American-born identical twins of Japanese and German parentage, every breath is a precious gift. In their nearly 40 years with cystic fibrosis (CF), a fatal genetic disease that affects the lungs and pancreas, they have cultivated a deep appreciation of life as athletes, authors, CF educators, and advocates for organ donation.

*The Power of Two* is a feature-length documentary by Academy Award-nominated director Mark Smolowitz, inspired by Ana and Isa’s memoir of the same name, which illuminates their spirited approach to life with CF and all its challenges. In *The Power of Two*, we meet two deeply philosophical and charismatic women whose determination to live well with CF meets a wall when their health drastically declines in their mid-20s. Organ transplantation provides the only hope for life, and the two undergo double-lung transplants in 2000 and 2004, respectively. The success of their surgeries allows them to climb mountains, participate in running races, and compete in the U.S. Transplant Games.

Following Ana and Isa on their speaking tour of their mother’s Japanese homeland, *The Power of Two* takes a hard look at the cultural gulf in attitudes toward donation that separates the United States and Japan. As living, breathing advertisements for organ donation, Ana and Isa impress upon their Japanese hosts the importance of educating their public about organ donation and transplantation. The Japanese are reluctant organ donors, because the practice is still largely culturally proscribed, and transplantation rates are extremely low.

One of the most poignant and beautiful images in this superbly shot documentary is of Ana and Isa blowing bubbles underwater. The ability to blow bubbles is synonymous with the capacity for breath – the breath on which their lives so obviously depend. *The Power of Two*, currently on the film festival circuit, is part of a broader call to action to raise awareness about organ donation, both in the United States and internationally.

For more information, visit [www.thepoweroftwo.com](http://www.thepoweroftwo.com)

## Book Review

### Hard Choices For Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-threatening Illness

by Hank Dunn

Fifth edition, published by A&A Publishers, Inc, 2009

reviewed by Terra Rafael

When my father-in-law, Hendrick, was dying from Parkinson’s Disease, I gave my mother-in-law, Johanna, a copy of *Hard Choices For Loving People*. Although both my husband’s parents had already written their advance directives, Johanna found that the book provided facts that bolstered her through the difficult period when the care facility staff recommended that Hendrik be hospitalized – even though he was near death. Newly empowered from her reading, Johanna refused the advice – and she even bought more copies of the book to share with her friends!

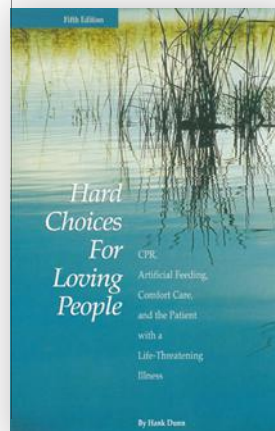
Hank Dunn wrote the first edition of *Hard Choices* as a guide for the end-of-life decisions those he served as a chaplain would eventually have to make. From that modest beginning, the book blossomed; more than 2,500,000 copies have been sold throughout the world since 1990.

According to Dunn, the four most common end-of-life decisions are:

- 1) Shall resuscitation be attempted?
- 2) Shall artificial nutrition and hydration be used?
- 3) Should a nursing home resident or someone ill at home be hospitalized?
- 4) Is it time to shift the treatment goal from cure to hospice or comfort care only?

Dunn thoroughly addresses these questions and provides specific information regarding choices about ventilators, dialysis, antibiotics, and pain control. An incredible amount of clear and compassionate guidance is contained within this portable, easily readable 80-page book.

Dunn has remained true to his mission to spread this valuable, practical information. On the publication’s website ([hardchoices.com](http://hardchoices.com)), a free copy of the book can be downloaded or purchased in bulk for reduced rates.





## Do as I Say

By Josh Slocum

Wordwise Productions

Joshua Slocum

**I**t was about 6:15 when I got home from work on December 7, 2010 – not directly home, mind you – I had just returned from a depressing veterinary appointment. Yes, diabetes was the reason my gray-and-white long-haired cat was skin and bones, constantly thirsty, and urinating all over the house.

Pouring oil into a skillet to start supper, I obsessed over whether I could handle the insulin injections, the constant blood-testing, the worry while traveling.

And I wasn't feeling well. Strange, really – I felt tired but sort of weighted down with a general malaise. And why was my heartburn coming back when I had taken my medicine less than six hours ago? One glass of water with baking soda later, and I felt worse. This wasn't heartburn; I know what that feels like. But what else could be causing that pressure behind my breastbone? Why was I sweating when it was 60 degrees in the house?

I turned off the stove and walked around the living room. I lay down on the couch. I sat back up. Now, something more than an ache and less-than-white-hot pain was creeping down the left side of my face and down my left arm. Sweat plastered my shirt to my chest. This was a job for Google. "Symptoms of a heart attack" – I felt foolish typing it in. This was awfully melodramatic for a 36-year-old guy – and the Internet-user who diagnoses himself online has a fool for a patient.

But, oh, boy, the list of symptoms was a good match. After a little more fretting, I called 9-1-1. The operator stayed on the line with me while I unlocked the doors, pulled on pants (I cook dinner in boxer shorts, a perk of bachelorhood), and wiped my face. Within five minutes, the medics were in my living room, taking blood pressure and asking me to rate the pain on a scale of 1 to 10. "Four-point-five," I said – definitely uncomfortable but not the worst thing ever.

During the short trip to the hospital, I started to feel better (and a lot more foolish). The aspirin I chewed on and the oxygen, I now know, were responsible. They wheeled me into the ER, and nurses hooked up an EKG. Glancing at the clock, I wondered if I'd get out of whatever this was in time to have a glass of wine before bed and forget the whole day altogether.

The EKG at the foot of my bed slowly spit out a piece of paper into Nurse Tracy's hands. She looked at it and started running. In seconds, I had a team of doctors ripping off my clothes, inserting an IV, and scaring the hell out of me. "Who's your family – how soon can they get here?" asked the nurse. I felt utter terror. "Is it really like that?" I asked. "Yes. They need to be here right now." I'd had the foresight to call my co-worker, Sherry, and ask her to call my family, who all live eight hours away. The nurse was handing the phone to me as a doctor came over to report that – surprise! – I was having a heart attack and needed immediate catherization and a stent.

The only way I can describe the horror is to compare it to the old Alfred Hitchcock camera trick where the lens moves in on the actor while it zooms out, distorting perspective. And that's a feeble comparison. Knowing you'll spend your last minute-and-a-half of life looking at beige polyester curtains is dire.

It was a trick trying to comfort my mother on the phone while the voice in my head screamed, "OH, MY GOD! I'M GOING TO DIE AT 36! I CAN'T DIE – NO!" As they pushed my gurney to the cardiac lab, I saw Sherry and my good friend Lisa Carlson. Ever practical, Lisa asked, "Where are your advance directives and your 'Before I Go' planning kit?" By this point, I was on so much morphine and so many sedatives that sentences were becoming a problem, but this woke me up. "I don't know." If the heart attack didn't kill me, the look from Lisa easily could: "You idiot."

Gentle readers, I was beyond stupid. I didn't practice what I preached. I'm the executive director of the Funeral Consumers Alliance (FCA), and I hadn't committed my medical and funeral wishes to paper. I put my friends and family in the terrible position I routinely cajole Americans to avoid. How many times have I barely suppressed a curled lip when someone under the age of 50 looks at me like I'm nuts for suggesting they actually make provisions for their death because, you know, they could walk in front of a bus?

It wasn't because I was afraid of death per se (although I was very much afraid of it happening at my age in the ER, thank you). My family and friends and I have talked about it many times, and I have made my wishes clear. But, lo and behold, I'm not a Special Snowflake, and I fell prey to the same casual indifference that all younger people do. After all, "Tomorrow is another day."

Except when it isn't. Most of you reading this will be between 50 and 90 years old. Most of you are probably not nearly as dumb as I am, and you have completed your paperwork. But I will bet you a month's prescription of Plavix® that your kids/nieces/nephews/young friends haven't. Do not let them get away with it. The fact that most FCA folks are middle-aged to elderly is strange when you look at our beginnings in the 1960s. Consumers Union had remarked on how most movers and shakers in the memorial society movement were in their 30s and 40s. The social-justice mission of protecting the bereaved from exploitation had motivated these people to face their own mortality decades before most of them would really need to.

Let's bring that back. It's not okay that most FCA members are "old folks." It's not okay that many of us complete our paperwork but, then, tuck it away after a brief mention to our kids. It's not okay that we talk about whether we want the plug pulled, but we avoid suggesting that our younger friends also articulate their wishes.

Put my public mea culpa to good use. Show your young friends and family this piece. Get them a "Before I Go" kit, and sit down with them over a Sunday lunch to fill it out – perhaps using yours as an example. Get them a membership in your local FCA. Don't give in to whining, squirming, or cries of, "I just can't talk about this." Yes, they can – and they must.

I have rectified my own situation now. My advance medical directives and funeral wishes are complete, and I have sent copies to my closest friends and family by email and on paper. The hospital that saved my life now has a copy on file, and, with its new electronic records system, that copy will be disseminated throughout the network so my primary-care doctor and anyone else who needs it can get it.

What did I put down once I finally got my act together with regard to funeral planning? "What do you want?" is one of the most common questions reporters ask me. They assume that, since I'm "the funeral guy," I must have a 5-foot-long scroll filled with specific demands. Nope. Having spoken to thousands of people over the years who say, "I want to be cremated," "I want a Catholic burial," or "I've instructed my kids that they are not to do X and that they are to do Y," I have changed my mind about funeral-planning. This sepulchral micro-management is common among FCA members; most of us recognize the money-pit our kin may fall into if we don't make plans that take affordability into account. But I don't think long lists of specifics are helpful.

In fact, I am convinced that guidelines are more helpful than dictates. So many loving children have cried into the phone at me, flagellating themselves because they couldn't "follow my mother's last wishes." They have said they have felt like they were failing Dad if they couldn't afford to have him shipped across the country for whole-body burial in the old hometown. Some women have felt resentful when their husbands have demanded a simple cremation with no services.

Consider whether your funeral plans have taken into account the needs of your survivors – and whether you have given them the flexibility to change course if circumstances make your first choices impossible, unhelpful, or financially untenable. Folks, while you're the guest of honor – in spirit, if not body – the funeral isn't all about you. It's also about the people you have left behind. Excessively detailed funeral planning can become an emotional or financial straitjacket for the people you love, the people you're trying to help.

Here's how I have done it: First, I have told my family all about how the funeral industry works. They understand the FTC Funeral Rule [see sidebar], and they know what services are necessary and which are not. We have talked about what is meaningful to them and what isn't, and they know how much they can afford. Talking with those you love gives them concrete tools,

and this can lead to conversations about what funeral rituals are valuable or irrelevant both to you and to them.

Here is what I have written as part of my advance medical directive (Vermont allows one to include funeral instructions and the designation of authority to carry them out within the advance directive):

## DISPOSITION OF MY BODY AND ASSOCIATED CEREMONIES

I do not believe in dictating absolutes from beyond the grave, but guidelines can be helpful. I have only two extremely strong wishes I ask my survivors to observe:

1. Do not spend a dime of my money or yours at a funeral, cremation,

or cemetery facility owned by Service Corporation International (SCI), which goes by the trade name "Dignity Memorial," or at any other publicly traded chain of funeral homes. I consider them unethical, and I have spent my career helping consumers who have been exploited by these companies.

2. I do not wish to be embalmed, if that can be avoided (and it usually can – don't let undertakers push you around).

I want my friends and family to make funeral arrangements that are meaningful and affordable to them, even if they might not be the ones I'd pick were I still around to have a say. Some suggestions are listed below, but the emotional needs of the people left behind are more important, and my survivors should feel free to override those suggestions. For those of you who feel the most put-together at the time of my death, please be kind and defer to others (within reason) who may be having a harder time.

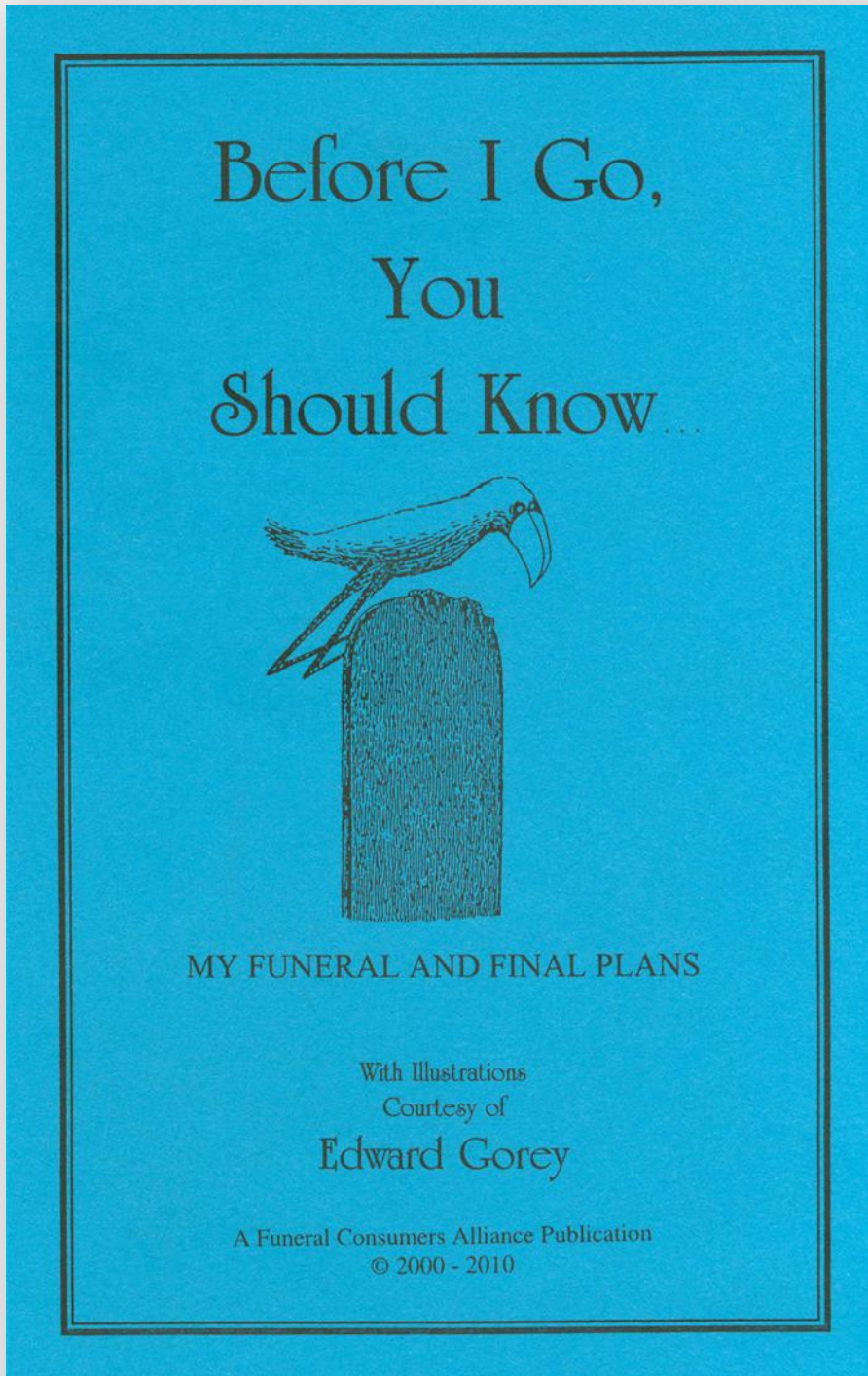
If my friends and family cannot agree on arrangements, then I appoint my mother, Bonnie Cook, to have the final say in the disposition of my body. If she is unable or unwilling to make such decisions, then my healthcare agent should do so. If my survivors end up fighting over my dead body, they should be ashamed of themselves – so don't.

If possible:

- Please donate any organs that can be used for live transplant.
- Please donate any tissue or other body parts to a legitimate, non-profit tissue organization.
- Please consider whole-body donation to a medical school if the suggestions above are not feasible.

Whether my survivors choose to bury or cremate me in the end is of no consequence to me. Please stay within your budgets, and remember that you cannot show me how much you love or respect me by what you do with my corpse. I'm already gone.

Friends and family should feel



Before I Go, You Should Know, a booklet on funeral and final plans published by the Funeral Consumers Alliance



free to organize a memorial service they find fitting. Please ensure there is plenty of alcohol, food, and ribald humor. While I would like to be remembered as an atheist who does not believe in gods or the supernatural (but who does believe in the importance of human kindness and service to others), my survivors should feel free to observe any religious rituals that are important or comforting to them.

### CODA

In case you're wondering, yes, I'm fine – healthier, in fact, than I've been in 20 years. I have quit smoking, and, by changing my diet and adding exercise, I have lost 30 pounds. I have also discovered that I have cheekbones and a waist. I'm very grateful to all of you in the FCA family who wrote, called, and sent me get-well gifts – it was really touching.

Beyond prodding some of you into making or altering your funeral plans, I hope my experience will encourage people to know the signs of a heart attack and not to ignore them. Thousands of people die too young because they don't face what is happening to them. If you have unusual pain, or pain accompanied by a strange mix of symptoms – or you just feel that something is wrong – call 9-1-1. And for those of you with family and friends who are at high risk, remember that support is good, but nagging is obnoxious. No amount of kibitzing about my weight or my smoking ever did a thing to make me change my ways. I knew full well what the risks were, and I made my own choices. Most people are like this; they have to want to change for themselves. It's their life – and yes, maybe their death – no matter how well we think we could manage it for them.

---

*Josh Slocum is the executive director of Funeral Consumers Alliance, a national non-profit education and advocacy group. He is also the co-author of Final Rights: Reclaiming the American Way of Death, a consumer guide to the funeral and burial business and the only comprehensive guide to federal and state funeral laws written in plain English.*

## FEDERAL TRADE COMMISSION

### The Funeral Rule

Most funeral providers are professionals who strive to serve their clients' needs and best interests. But some aren't. They may take advantage of their clients through inflated prices, overcharges, double charges, or unnecessary services. Fortunately, there's a federal law that makes it easier for you to choose only those goods and services you want or need and to pay only for those you select, whether you are making arrangements pre-need or at need.

The Funeral Rule, enforced by the Federal Trade Commission, requires funeral directors to give you itemized prices in person and, if you ask, over the phone. The Rule also requires funeral directors to give you other information about their goods and services. For example, if you ask about funeral arrangements in person, the funeral home must give you a written price list to keep that shows the goods and services the home offers. If you want to buy a casket or outer burial container, the funeral provider must show you descriptions of the available selections and the prices before actually showing you the caskets.

Many funeral providers offer various "packages" of commonly selected goods and services that make up a funeral. But when you arrange for a funeral, you have the right to buy individual goods and services. That is, you do not have to accept a package that may include items you do not want.

### According to the Funeral Rule:

- you have the right to choose the funeral goods and services you want (with some exceptions).
- the funeral provider must state this right in writing on the general price list.
- if state or local law requires you to buy any particular item, the funeral provider must disclose it on the price list, with a reference to the specific law.
- the funeral provider may not refuse, or charge a fee, to handle a casket you bought elsewhere.
- a funeral provider that offers cremations must make alternative containers available.

<http://www.ftc.gov/bcp/edu/pubs/consumer/products/pro19.shtm>

## ntm resource directory

### **Sacred Crossings**

Olivia Bareham  
sacredcrossings.com  
olivia@sacredcrossings.com  
310-968-2763

### **CycledLife, Inc.**

Ed Gazvoda  
CycledLife.com  
303.459.4953

### **Threshold Care Circle of Viroqua, WI**

thresholdcarecircle.org  
info@thresholdcarecircle.org  
1-608-606-8060

### **Rayne Johnson**

tearcups.com  
rayne@tearcups.com  
780-642-8703  
Grief Coach/ Educator on EOL issues.

### **Merilynne Rush, Home Funeral Guide**

AfterDeathHomeCare.com  
info@AfterDeathHomeCare.com  
734-395-9660  
After-death home care in SE Michigan.

### **Funeral Ethics Organization**

funeralethics.org  
info@funeralethics.org  
Informing about and promoting ethical  
business regarding funerals.

### **Minnesota Threshold Network**

mnthresholdnetwork.wordpress.com  
mntresholdnetwork@gmail.com

### **Holly Blue Hawkins**

LastRespectsConsulting.com  
831-588-3040

### **near and dear**

Anita Garcia  
nearanddear@vpweb.com  
drgarcias1100@msn.com  
520-896-0516 / 520-307-0028

### **Green Burial Council**

greenburialcouncil.org  
Setting standards, offering training and  
technical assistance, and certifying  
providers of green burial options.

### **Natural Transitions**

naturaltransitions.org  
info@naturaltransitions.org  
Trainings and support with Advance  
Directives, Home Funerals and more.

### **Eternity Cardboard Casket**

eeternity.com  
Affordability, simplicity, dignity,  
environmentally friendly-perfect for  
green cremation and green burial.

### **Final Passages**

finalpassages.org  
finalpassages@softcom.net  
707-824-0268

### **Manena Taylor**

heartmemorials@gmail.com  
Heart Centered Memorials in the Pacific  
Northwest.

### **Reva Tift MA**

AHCDguidance.com  
Guiding you through the process of  
End of Life wishes & decisions  
303-444-0152

### **Blessing the Journey**

info@blessingthejourney.com  
Olympia, WA  
Sacredly guiding families through  
the home funeral journey.

### **Life Quality Institute**

lifequalityinstitute.org  
Advancing Palliative Care Through Education  
Offering trainings on palliative care.

### **Compassion and Choices**

compassionandchoices.org  
info@compassionandchoices.org  
Rights of individuals to choose their  
end of life scenario.

### **National Organization for Hospice & Palliative Care**

nohpc.org  
Find a hospice, learn more about  
palliative care.

### **Funeral Consumers Alliance**

funerals.org  
Consumer friendly information on all  
aspects of funerals, including consumer rights.

### **A Natural Undertaking**

naturalundertaking.org  
A Pennsylvania resource center for home  
funeral care.

### **Sacred Ceremonies, Ltd**

sacredceremoniesltd.org  
Webster, Wisconsin  
715-866-7798  
715-566-2462

*To be included in the Directory, please contact [adsnaturaltransitionsmag@gmail.com](mailto:adsnaturaltransitionsmag@gmail.com).*

## ntm calendar

### **2012**

#### **Natural Transitions Trainings**

Upcoming trainings in end-of-life transition  
guidance in May & September, 2012  
Check website, [www.naturaltransitions.org](http://www.naturaltransitions.org)  
for details.

#### **Ongoing**

##### **Life Quality Institute- Colorado**

lifequalityinstitute.org

Offering series of monthly talks regarding  
palliative care and end-of-life issues in these  
locations:

Reality of Care - Denver, CO  
Called to Care - Pastoral issues -  
Cherry Hills, CO  
Prepared to Care - Denver, CO

See website for topics, times, and locations.

# Natural Transitions Magazine

## PLEASE SEND US... your upcoming events!

To be included in the ntm calendar, please contact us at

[adsnaturaltransitionsmag@gmail.com](mailto:adsnaturaltransitionsmag@gmail.com)

# Dying

By Emily Elizabeth Dickinson

I heard a fly buzz when I died;  
The stillness round my form  
Was like the stillness in the air  
Between the heaves of storm.

The eyes beside had wrung them dry,  
And breaths were gathering sure  
For that last onset, when the king  
Be witnessed in his power.

I willed my keepsakes, signed away  
What portion of me I  
Could make assignable, -- and then  
There interposed a fly,

With blue, uncertain, stumbling buzz,  
Between the light and me;  
And then the windows failed, and then  
I could not see to see.

*Natural Transitions Magazine fills a unique and much-needed niche in the social conversation around approaching the end of life with intention and care.* Jennifer Ballentine, Life Quality Institute

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NATURAL TRANSITIONS MAGAZINE is a project of Natural Transitions, a 501(c)3 organization dedicated to education on conscious, holistic, and green approaches to end-of-life, including after-death care. **We are the only magazine publishing thought-provoking, inspirational articles from leading professionals in the end-of-life care field, as well as from family members at the bedside of those who are terminally ill.**

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