



# Natural Transitions

Volume 5 Issue 1

Conscious, holistic approaches to end of life



Who Controls the Dead?

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Law and Sausage: Physician-Assisted Death

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Death Café Build Out: A Piece of Cake?

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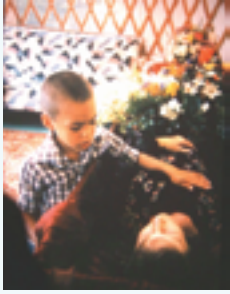
Field Notes of a Buddhist Home Vigil Guide

**Death and the Law**



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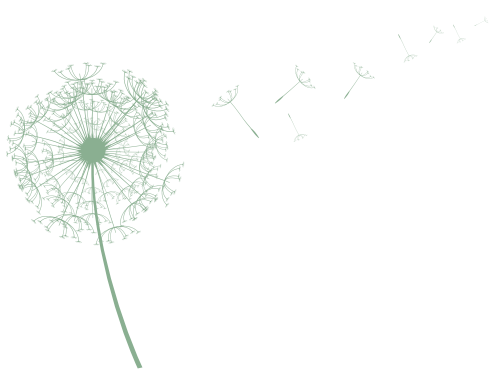
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## Good Law!

by Karen van Vuuren



*Karen van Vuuren*

The law is a mechanism of protection, but it can also stymie change because it can be rooted in old paradigms. Here's a recent example I encountered.


A group of dynamic, changemakers seeks to open an eco funeral home. Green funeral establishments are popping up around the country as a few funeral industry daredevils and holistic death educators-turned-funeral-directors decide to revolutionize the funeral industry from within. Their vision is more than a funeral home: It is a resource center with other end-of-life complementary services, as well as green funeral care.

The funeral dynamos create a vision that pops. They begin the search for a place to locate their new business. Alas, the pickings are slim. Zoning restrictions reduce the number of properties that are appropriate for the new deathcare center. These zoning restrictions are predicated on a view of a funeral service provider who engages in polluting, resource-intensive practices, and whose presence in any neighborhood is undesirable.

Funeral homes used to be in the heart of towns and cities (and of course, before funeral homes existed, families cared for their own in the parlor). But now, zoners have relegated them to industrial areas - and with good reason.

The entrepreneurial dynamos find a spectacular property but subsequently learn it is incorrectly zoned for a funeral service business. They appeal to the town board, explaining their "green-ness," the beautiful, contemplative ambience they will create, and the educational programs they will offer as a resource to the town's residents and others. But the law prohibits a mortuary. So what's to be done? The town is known for its progressive stance. The board's members are keen on the vision for this innovative business, but their hands are tied. They can't allow this business to open because of zoning based on a paradigm that does not, in this case, apply.

This is not an uncommon scenario. I've heard from a number of progressive funeral directors who have encountered the same, often insurmountable obstacles.

In this issue of *NTM*, we look at how lawmakers unknowingly limit consumer choice in the name of consumer protection. We highlight the key areas of dissent between the pros and the cons in the debate about aid in dying (also known as physician-assisted death, depending on which side of the fence you are on). And we learn the facts about who really controls the body at death. Informing our readers and stimulating thoughtful debate, that's at the crux of *NTM*'s mission. Read on! 



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#### OUR VISION

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

#### OUR MISSION

- To share holistic approaches to end of life
- To provide a forum for end-of-life caregivers and educators

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## Time for Change

by Josh Slocum



It is exciting and encouraging to me that Funeral Consumers Alliance (FCA), the Green Burial Council (GBC), and the National Home Funeral Alliance (NHFA) have formed a united front to share the cost of a legislative tracking service to keep watch on upcoming funeral-related legislation. Terri Skovronek, a Pennsylvania-based FCA and NHFA member, has stepped up as a volunteer to keep an eye on what this service reveals.


Right now the FCA is very concerned about Alabama's law, which requires a funeral director to be present at any and all kinds of funeral services. The Alabama law is the most overreaching and restrictive of any funeral law I have ever seen. It is simply stunning that families are expected to hire a licensed funeral director to preside at not only funeral and burial services, but also at memorial services, where the deceased may not even be present. This could mean a group of friends gathering in a living room without the corpse. Alabama's law is blatantly unconstitutional.

People have an incontrovertible historical and legal right to be with their dead. This right is not a gray area in American jurisprudence. It is even more fundamental than a patient's right of self determination.

As executive director of the FCA, I have no intention of advising consumers to obey this law and in fact, I will help them do everything they can to get around it. The state of Alabama will find itself in court. Alabama, you are on notice!

At the moment, there is no formal plan of action to more widely address obstacles to funeral consumers' rights, but activists in the NHFA, GBC, and FCA are interested in challenging New York state's restrictions. A few years ago we heard from a hospice nurse who was upset that her supervisor would not give a dead infant to the bereaved family, and this nurse has joined the effort to change the law in her state.

Lee Webster of the NHFA and I were reflecting on how we used to say that it was better to "let sleeping dogs lie" regarding restrictive or ambiguous laws that weren't being actively used to suppress consumer rights (although they could have been). When I took over my job as executive director of FCA, only five states restricted families' rights to care for their dead. Now that number is up to 10. So experience has shown that we need to actively intervene and make families' rights a constitutional issue and an urgent legal issue.

We who stand for consumer rights need to be unequivocal about demanding the right to our own funeral rituals without government intrusion. That government intrusion is almost always in service of protecting the funeral industry from consumers and from competition. Lawmakers are not necessarily at fault; they may be unaware of the effect of legislation on the consumer. But we who know need to continue to plan and strategize as a united front to bring out change. I'm encouraged and optimistic that we will make great strides on behalf of consumers in the long term. 

*Natural Transitions* has always focused on building community. With that goal in mind, our Community Forum page is to encourage communication among our subscribers and within this movement for more conscious, holistic, and greener approaches to end of life. We welcome comments on the articles and sharing news and inspiration from your part of the world! Email your letters to [mag@naturaltransitions.org](mailto:mag@naturaltransitions.org).

*Joshua Slocum is the Executive Director of the Funeral Consumers Alliance (FCA), a nonprofit dedicated to education and advocacy surrounding funeral consumer rights. He is the author of Final Rights: Reclaiming the American Way of Death, an in-depth look into the funeral industry. [funerals.org](http://funerals.org)*

# What Saying Goodbye Really Means: My Twin's Story

by Sarah Crews

My cousin Gwen and her husband, Mark's, third child was born with Down Syndrome. They named her Sarah, after me, and we lovingly and laughingly refer to each other as "my twin." She and I have always shared a special bond. Her family has responded to her intellectual disabilities in a beautiful way. Sarah was raised in a household with three loving siblings and two incredible parents who encouraged her daily to develop fully into the unique, creative, social, loving and spectacular person she is today. Like others with Down Syndrome, Sarah is a person who shares her emotions freely and deeply. Her joy is palpable, as is her sorrow and pain.

In 2007, Sarah's father was diagnosed with advanced metastatic prostate cancer. Seven years later, having beat the odds by surviving four years longer than originally predicted, Mark was nearing the end of his journey. For most of those seven years of treatments and procedures, the family chose not to tell Sarah that Mark had cancer. She knew he was sick, but didn't know he had a terminal illness. I think there was a valid concern in the family that if Sarah knew her dad would die from his cancer, she would anguish over it every day. Sarah would regularly burst into heaving sobs when she recalled that her grandfather, who lived several states away, had died ten years earlier. In order to make her daily life, and theirs, more bearable, it was easier to speak about Mark being "very" sick without mentioning the "d" word.

By the time Mark's disease rendered him mostly bedridden, Sarah, 26, was living independently in a group home in Albuquerque, a city well over a hundred miles from Gallup and the house in which she grew up. Because of the distance and her many activities, she saw her parents about once a month. The physical changes Mark was experiencing were shockingly

pronounced the last few months of his life, and there was no denying that he was very, very ill. Gwen gently started preparing Sarah by talking with her about how hard it was for Mark to eat, to move, and to cope with the pain he was experiencing. She reminded Sarah that after Grandpa became very weak and ill, the family had to say goodbye to him, and we would have to say goodbye to Daddy too someday.

Gwen and I had spoken quite a bit about home funerals, and she and Mark had decided that it was what they wanted to do; Mark did not want to involve a funeral home. We selected a direct cremation facility in Albuquerque, who provided us with the cardboard container for cremation and agreed to accept the body directly from the family. Since no transit permit was needed to transport the body within the state, we just needed to call the crematorium when we were on our way.

During the summer of the year Mark died, Sarah had her own brush with death. She had stumbled and fallen on her knees, and unbeknownst to her or her family, a clot had formed in her leg. Over the course of a week the clot made its way into her heart. Sarah's life literally hung in the balance in ICU when she "coded" twice. (When a patient "codes" it means the heart has stopped and resuscitation begins.) Gwen was by her side throughout the ordeal. Mark made the journey from Gallup to the hospital in Albuquerque with one of his sons, and I made the 11-hour drive from Kansas to be with the family. The doctors warned Gwen and Mark that, because she had been without a blood pressure for up to 20 minutes in one instance, it was unlikely that Sarah would survive without some significant brain damage. On the third day, we all gathered around her bedside as they took her off the ventilator. After her initial struggle, gasping for air and

frightened, she found her bearings, looked at every person in the room, and said something personal and profound to each one of us. We knew then that we had her back completely.

While sitting vigil at Sarah's bedside, I spoke with Gwen and Mark about the green burial ground I was working on establishing in Kansas. Mark said he wished there was something like that where he lived because he was afraid that explaining cremation to Sarah might prove to be difficult. I promised him then that I would explain it to her at a level she would be able to grasp. Gwen later asked me if I could do so without using the words *fire* and *burning*. They also asked me if I could talk with Sarah about what it would be like when Mark died. Although they were coping as well as could be expected with Mark's impending death, it was too emotional for them to talk about it with Sarah. They wanted to make the event less frightening for her, and they wanted her to have a chance to ask questions.

When Sarah was released from the hospital, she went home to Gallup for recuperation. It was then that Sarah experienced Mark's decline firsthand. He stayed in a hospital bed in the little library off the living room, ate a bland liquid diet, and vomited a lot. Less than two months later, Gwen called and asked if I would come. The doctors had told Mark that he was looking at, maybe, a couple of weeks.

I arrived in Gallup at the beginning of August and stayed for almost three weeks. Mark was very weak but continued to hold on in the loving presence of his family who had all gathered around him, except Sarah. She had decided after her last visit home that it was too hard to be near him. She couldn't bear to see him weak and confined to bed. Her mom and I talked to her on the phone and tried to encourage



*Sarah and Mark*

her to change her mind and come home. Her “twin” was there, after all, and I had always been a pretty big draw for Sarah. But she continued to refuse. “I struggle,” she would say when I’d tell her that her daddy would love to see her. Finally, we convinced her to come for one night. And I would help with her transportation.

For the better part of a decade I had found my calling working with people at end-of-life—as a musician, a bedside vigil volunteer, a bereavement counselor, and more recently, as a home funeral guide. I consider honest and compassionate conversations about death and grief, and all that arises when we grapple with mortality as humans, as one of the most important things we can do to support one another. I suspected that whatever Sarah had imagined dying and death looked like, and the fear those images had instilled in her psyche, were far worse than the reality that was about to take place. I knew that I had to have a conversation with Sarah about what was really happening to her dad. What “saying goodbye” really meant: that he was dying and would soon be dead. Most importantly, I wanted to tell her how she could be involved in his care and support him on his inevitable journey. I had this one chance to get it right.

In the car, I expressed my gratitude to Sarah for agreeing to come. She told me it was “so difficult” and made her “uncomfortable” to see her daddy so sick. I said that I understood. I also told her that I wanted to talk more about it with her after dinner. She said that would be okay. When we entered the house, she walked right past the room where Mark lay, saying a quick “Hi, Dad” but not looking at him on her way to the back of the house and the kitchen. After she greeted her siblings and mom, I asked if she would go with me to see her dad. We walked in holding hands. Mark normalized the moment right away, greeting her warmly and saying how happy he was to see her. She showed him one of the detailed drawings she was working on and spent about 15 minutes sitting in the chair next to his bed and chatting about all sorts of ordinary things until he drifted off to sleep. We left quietly and she confessed to me that it wasn’t so bad after all.

After dinner, I asked Sarah if she was ready for our talk. We retreated to the back bedroom and cozied up together in the bed. I started by saying that I wanted to talk to her about what was happening to her dad. At first, she made a gasping sound and said, tearfully, “I don’t want to lose my dad.”

I said, “I know. It’s so sad to think about and it hurts.” She said it was hurting her right in her chest. I said, “I’m so sorry that this is happening. It is so sad for all of us, and for your dad too, but I want to explain it to you so that you can understand.”

Sarah looked me in the eyes and said, “I want to understand.”

I described how the cancer had spread through his whole body and had made it so it wasn’t working anymore. She could see he was getting weaker and weaker. I told her that the medicine wasn’t going to help him get better, that her dad was dying. As I spoke, Sarah would say, “I know” or “It’s so sad for me.” I explained how the medicine he was taking made it so he wasn’t in pain. It made him so comfortable that he was able to sleep for most of the day. Eventually, I said, his breathing would just slow down so much that he would finally take his last breath and he would die. I stopped to check in with her, “Are you struggling?”

She held up her thumb and forefinger about half an inch apart, “I’m struggling this much.”

I continued, “After he dies he’s going to look pretty much just the same as he looks when he is sleeping, but his chest won’t be rising and falling anymore because he won’t be breathing. And, even then, it’s okay to touch him.” I told her that his skin would start to feel cool and he might start to look a little pale. “You can hug him, you can stroke his arm, you can tell him you love him, you can say goodbye.” Checking in again, I asked, “Are you uncomfortable with this?”

“Only a little bit,” she responded, but kept listening.

“And after that,” I said, “you know how we’ve been taking care of him, making sure he’s comfortable and has a clean t-shirt on, and clean sheets on his bed.



*We can do it! by Sarah Wilson*

Well, after he dies, we'll keep taking care of his body. We can give him a bath, clean clothes, and sheets, and get him ready for his traveling box."

"His what? Where is he going?"

Then I told her about cremation, just as I'd promised Mark I would. I said, "Sometimes, after a person dies, their body is buried in the ground. But your dad doesn't want to be buried in the ground. He wants his body cremated."

"What's that?"

I explained that it was a funny sounding word but what it meant was that we would put his body in a big cardboard box and take him to a place in Albuquerque where they have a special room, like a chamber, and they'll put him inside. "He'll stay in there for about three hours and a special process happens that will turn his body, and the box, into dust." Hoping that was enough information, I asked if she had any questions. She didn't.

I told Sarah that I had brought paints and brushes. "I think that one of the

ways you can help is by painting that traveling box with all your beautiful designs and messages to your dad about how much you love him." I told her I would show her the paints and asked if she'd like to see the box. She said she would. I realized now that it was dark outside and the box was in the garage. We got a flashlight and headed out back. I was a little concerned that she might find it creepy, but she was fine about it. She just wanted to see the traveling box.

Before she went to bed, Sarah told me she was going to stay in Gallup and help take care of her dad instead of driving back to Albuquerque with me in the morning. When I said my final goodbye to Mark before leaving, I told him about the conversation I had had with Sarah. He teared up and thanked me, saying it was really the last thing he was worried about, but knew he didn't have to worry about it anymore.


Mark died on October 6, 2014. Sarah spent the last six weeks of her father's life living at home with her family, helping to care for him. During the last day of Mark's life, he was able to speak to all his children and tell them how much he loved them. At her youngest daughter's suggestion, Gwen slid into Mark's narrow bed and held him for several hours until he quietly passed. Sarah decided to sit vigil with his body all night and requested that her mattress be brought into the room with the body. The next day she moved a chair right next to the bed and laid her head on the pillow where her father's head rested. She stroked his arm and his head and held his hand. She talked freely to him about how much she loved him and that she would always keep him in her heart. Later that day she helped her mother and siblings bathe, anoint, and dress Mark. She welcomed visitors to the home and took them into the room to be with her dad. On the morning of the third day, Gwen and her women friends lifted Mark from the bed and placed him in the beautifully painted box that Sarah and her siblings had decorated, complete with maps of the many places Mark had traveled in his life, and a cross that Sarah had painted. A photo of Mark kissing



*Sarah and Mark*

Sarah Crews

his mom, who had died just three weeks before, was pasted on the box.

Sarah was the one who called me to share the news. "I have something very sad to tell you." She then told me that her dad had died in her mom's arms. She said it just like that. I asked her how she was feeling. She said, "I'm okay. I'm feeling strong and I'm sad." And she was. She wasn't falling apart. She wasn't hysterical. She had experienced the truth of her father's death. She had cared for him before and after he died. Sarah was given the chance to understand what was happening to her dad and contribute meaningfully to his last days. It made all the difference. She felt the strength and the sadness of going the distance with this man whom she adored more than any other. 



*Sarah Crews is a singer/songwriter and dabbler in the arts who also serves on the board of the National Home Funeral Alliance.*



# Field Notes of a Buddhist Home Vigil Guide

By Lucinda Herring

It is a Monday afternoon, and we are about to close up for the day at our little funeral home, A Sacred Moment, in Everett, WA. Char (Barrett), founder and owner, has just left for a much needed vacation. The phone rings and I hear a frantic voice on the other end. “My mother has died in the hospital, and I heard you support home vigils. We want to bring her home. We are Tibetan, and my mother was a great practitioner. We need time and space to find a lama so we can do the rituals and prayers from our tradition. Can you help us?”

The perfection of the moment does not escape me. I have picked up the phone, and I’m the only practicing Buddhist on staff. I contact Char, but I’m already setting things in motion. I ask the women of my Whidbey Island sangha to alert Rinpoche. I arrange for the other staff members to meet me at the hospital, and I contact our removal team to see if they can transport the deceased woman to her home. I ponder how we are going to accomplish this with minimal disturbance to her body; as a Vajrayana practitioner, I know this is important. I imagine how I am going to apply dry ice without disturbing her. I am grateful to have 24 hours before I legally have to refrigerate her body, as this will offer her a greater opportunity to be left in peace once we get her home.

I wish there was room here to share all the intricacies and gifts of my remarkable journey with this Tibetan woman (whom I will call Ani) and her family. I learned so much from the three-day vigil we created: having Rinpoche come so he could lead the appropriate bardo prayers and practices; working with the family and close-knit Tibetan community in Seattle; having to “wing it” and translate into Western funeral practice all that the monks and teachers in India were asking me to do; adapting, by the hour at times, the family’s goals for practice and prayers, for when and

how to take the deceased out of the house, and what day the cremation should occur. All this was discerned through divination and astrological interpretations we received via cell phone from a network of lamas, monks, and practitioners from all over the world. It was such an honor to serve as home funeral guide/funeral director, and to have the privilege of caring for this great practitioner’s body, while doing prayers and practice myself. Because I was at home in the lineage and tradition, I could join in.

This experience changed me in ways I am still exploring. It also set me on a quest to discover tangible and specific after-death care that can best support the spiritual needs and wishes of traditional and Western Buddhist practitioners. The information I will share here can also benefit anyone who believes that the moment of death and afterward are a precious opportunity, a chance to awaken to our innate luminosity or true nature as a human being. Such a belief and intention asks that a dying person be given as much undistracted time as possible, with minimal disturbance to the body from outside sources, so the departing consciousness can focus on the sacred intention of “waking up” at the threshold of death.

The recommendation that a practitioner’s body not be touched, if possible, in the hours after death is based on the belief that there are actually two dissolution processes: an outer and an inner death. Taking one’s last breath marks the first, outer death. This is the only “time of death” that Western medicine and our existing funeral industry recognize. The second death is within, as our consciousness finds its way



out of the physical form. The timing for this final departure is different for each person, depending on who he/she is, and the circumstances surrounding the passing. Many Buddhist teachings speak of a lingering warmth in the heart area long after the last breath, signifying that the inner dissolution is still happening within the central channel and the chakras/nadis (pathways of prana in the body), and that the person with this warmth may still be meditating or experiencing some form of awakening. Hence, having enough undisturbed time to focus on this inner process could make all the difference in a practitioner’s spiritual journey.

Home funeral vigils (where a person lies in state in a home or sacred space after death) provide practitioners with this needed time and opportunity at the threshold—both for the person who

has died and for the spiritual communities who support them. Yet, even within the home funeral movement, there remains, at the time of this writing, a lot of unanswered questions about how to best aid practitioners in practical, legal, and sacred ways.

One challenge is that spiritual needs vary, depending on what school or lineage one follows. Some traditions recommend bathing and ritually dressing a person's body before rigor mortis sets in. Others, like Ani's Nyingma Vajrayana lineage, ask that a person's body not be touched, preferably for three days, especially the lower parts of the body and the hands and feet. Such interference might draw a person's consciousness back into the body and away from the crown chakra (considered the most ideal gateway for departure). One can see that, with such a view, normally accepted care of the body during home funeral vigils—bathing, dressing, closing the eyes and mouth—should not happen right away, if at all, and refrigeration should be delayed until the time required by law.

This article shares what I call my field notes and explorations into these inquiries. In many ways, we Westerners simply have to make things up when it comes to translating these ancient teachings into after-death care protocols that will work for us today. I therefore humbly offer these ideas, not as a teacher, but as a student, learning alongside everyone else. Fortunately, we have a lot of opportunity within the home funeral movement to experiment and, through trial and error, hone what works best within existing practical and legal parameters. I am grateful for the chance to explore my experiences with you here.

There are three areas of after-death care that need attention when supporting



Buddhist practitioners in a vigil space: how to move or transport a body with minimal disturbance; how to preserve/refrigerate a body so that the departing consciousness is best supported in its journey; and the importance of preplanning and preparation before death to strengthen the chances that a practitioner's wishes can be fulfilled.

## Moving or Transporting the Body

Obviously, the home is the ideal place for a practitioner to die—where the body can remain in the same place without being disturbed or transported elsewhere. But with 65% of all Americans dying in hospitals, there is a real need to explore ways to support practitioners in clinical settings, just as I did with Ani and her family.

One very positive thing about Ani's experience was that she was able to remain in her hospital room for several hours before we moved her. Monks and family came to the room and did practice and prayers and were there as spiritual support when our removal staff person arrived. I had to stand my ground about not putting Ani in a body bag, or

even wrapping her up in plastic. We figured out how to use the sheet under her as a hammock so we would not be touching her body directly. I also asked that we use only one strap to fasten her to the gurney and to fasten it only loosely around her chest, avoiding the second strap entirely, since this would mean touching the lower part of her body. My removal man was not happy with the arrangements, but he complied and we managed well enough.

For hospital deaths of practitioners, I recommend that family and friends be proactive with nurses and staff (before the death if possible). They can

ask that the deceased be able to remain in the room for a time, preferably the three to five hours that many traditions recommend. If the room is needed right away, ask if there is another room to which your loved one can be wheeled (without moving them to another bed).

One can also ask that all IVs, tubes, and machines be taken away before death, if that is possible. This will serve two purposes. It will allow your loved one a more natural and peaceful death, and it will also prevent having to remove all that paraphernalia right afterwards, which means touching the body at the very time when it might be most distracting to the departing consciousness. If it is not possible to remove equipment beforehand, ask hospital staff to wait for a time before unhooking machines and removing catheters, etc., so that everyone can focus on spiritual practice first.

**Field Notes:** The use of a strong sheet as a hammock is a simple and easy way to transport a body with minimal disturbance—whether it be from a hospital or from room to room in a house, or, at the end of a vigil, when a person is placed in the container/shroud in which he/she will be either cremated

or buried. Keep this in mind, and always have a strong sheet or cloth under a practitioner's body if possible.

This method can also be used to lift a body up to replenish dry ice or Techni-Ice, and to change bedding without directly touching the person. Obviously, any movement and transport with a hammock is a form of disturbance, but at least no one is directly in contact with the deceased.

An even better option, if possible, is to transport the body in a cardboard cremation container, if that can be obtained. This provides greater protection for the body. Also, sacred objects can be placed within the box with the deceased without fear of being dropped or lost.

## Refrigeration/Preservation of the Body During a Home Vigil

In Washington State (where I live and work), a person's body must be "refrigerated," at the latest, 24 hours from the time of actual death. Fortunately, the use of dry ice or Techni-Ice is considered "refrigeration" under the Washington code. (Note: It is important to check your state laws about refrigeration where you live.)

As a Buddhist practitioner, I instinctively want to delay refrigeration for the entire 24 hours allowed by law, as any method is going to be a disturbance to the body. But, as a licensed funeral director/home funeral guide, I have to consider the consequences of such a decision and inform the family and friends of possible problems that might arise by waiting. The National Home Funeral Alliance has come out with this statement on their website: (Some families) decide at the eleventh hour



(actually, it's often at 23.5 hours) to keep the body for another two days, and then expect dry ice to miraculously cool the body and maintain the body's current condition. By then, it's typically too late. Nature has already begun her process, and this is when bodies may experience purging. Cooling the body within the first four to six hours following death helps to achieve a much better outcome.

It is important that family and sangha members consider all the implications of their choices. They should be prepared to work with the consequences of applying refrigeration immediately and risking interfering with a person's spiritual journey, or delaying and risking problems with the state of the body.

With my practitioner's hat on, I will say this: I have been at vigils for practitioners where the state of the deceased's body was not something that anyone worried about. Purging rarely happened, and if it did, was simply dealt with. If needed, a silk cloth or white sheet was placed over the face, because the appearance of the body was of secondary or no importance to those whose main intention was to support the deceased person through spiritual practice.

With my funeral director/home funeral guide's hat on, however, I would probably recommend that refrigeration be applied sooner in these situations:

- If a person has a wound that will not heal; dry ice can be effective in shutting down bacterial/decomposition during vigil time.
- If a person's intestinal health is compromised, and there is already purging, or the abdomen and belly swell, dry ice can be applied to slow these processes. (There is a condition in which a body can become putrid after death and gases form. It is rare, but in this case, a funeral

director should be called, and it is likely the body should be taken away.)

- In very hot weather conditions, it may be more important to consider dry ice/refrigeration sooner.

Whatever method of refrigeration one uses (dry ice, Techni-Ice or gel packs are the three I will discuss here), keep in mind that, in supporting a practitioner, the main consideration is one of minimum disturbance to the body. I will discuss the pros and cons of each method from that perspective.

Dry ice is solid carbon dioxide that usually comes in ten pound blocks and sublimates at -110 degrees F.

Pros: Dry ice has been used successfully for many years in the home funeral movement and is included in many state laws as acceptable refrigeration for a dead body. It can be purchased at the time of need from grocery and packing stores in many areas (unlike Techni-Ice, which has to be ordered online before the vigil). Once the ice is applied to the body, it does not have to be replenished for 24 hours, minimizing the amount of times one is disturbing the person. The intense cold of dry ice is effective in retarding the decomposition of the

body's organs, thus supporting longer vigils. (We have used it to preserve a body successfully for five days.)

Cons: Dry ice is intense to work with. One must always wear gloves to handle the blocks, and it can literally freeze the body of the deceased if too much is used or there are not enough protective layers placed between the ice and the person. I have instinctively not wanted to apply dry ice to a practitioner's body right after death, as it feels to me that this intense cold might directly affect the departing consciousness. Freezing the core of the body feels invasive to me, especially if one is placing the blocks of ice directly beneath the central channel and the heart, where the inner journey may still be unfolding.

Cons: Though dry ice is plentiful where I live, it can be hard to find in some areas of the country. It is also the most expensive method, running \$30-50 a day for 20-30 lb. (\$100-\$150 for a three-day vigil.) And it is not re-usable, like Techni-Ice supposedly is.

**Field Notes:** Placing dry ice beneath a person's core requires lifting the body up and then adjusting the body, as the blocks will make the trunk higher than the head or feet. This is a lot of fiddling and movement. Lifting a body with an under-sheet as a hammock can help, but if the motive is to not move the body at all, one can simply place the dry ice along the sides of the trunk so that the whole body does not have to be moved. This does not cool the body as effectively as placing the ice beneath the central organs, but it has sufficed. When I decide to use this method, I usually keep the room quite cold as well.

## Techni-Ice

Techni-Ice is flat sheets of a non-toxic material that, when soaked in water, swell up in pockets that are then frozen. Apparently, there are different manufacturers of Techni-Ice. Here is the recommended brand: Techni-Ice

HDR 4-Ply Reusable Ice and Heat Packs. ([techniiceusa.com](http://techniiceusa.com) or [amazon.com/Techni-Ice-Reusable-Packs-Special/dp/B000ZOWG62](http://amazon.com/Techni-Ice-Reusable-Packs-Special/dp/B000ZOWG62)).

Pros: Techni-Ice sheets can be purchased in packs of six or twenty, and can be stored in a refrigerator freezer; dry ice can be kept only outdoors in a styrofoam container. Techni-Ice is more economical (packs of six can be as cheap as \$25), and it is re-usable, unlike dry ice, which evaporates with use. The sheets can also be cut to size before freezing, which allows ease of placement alongside the body. If one is worried about intense cold affecting the body, Techni-Ice may be a better choice as well.

Cons: Because Techni-Ice is less cold, it needs to be replenished more often, probably every four-eight hours, rather than every 24 hours with dry ice. This means disturbing the body more often, something that could be more invasive in the long run. Techni-Ice has to be ordered beforehand from online sources, whereas dry ice can be purchased immediately. You also have to allow time for the sheets to freeze, and have replacement ones ready every four-eight hours. In my experience, used sheets emit a slimy film when thawing. This is unpleasant to work with, though manageable by placing the sheets in another plastic bag.

## Frozen Gel Packs, ChiliPad Cooling Mattress or Blanket

I have personally not had experience with using the methods described below. I was taught that frozen gel packs are not cold enough to sufficiently retard decomposition of organs in deceased adults. However, if the choice is between using gel packs and not using refrigeration at all, and if gel packs are legally acceptable in your state, this could be a gentle and easy way to proceed. I have talked to some Buddhist practitioners, who, after experimenting

with other methods—such as the ChiliPad cooling mattress and blanket—now use only gel packs.

A ChiliPad cooling mattress pad has tubes for water that can be kept at 45 degrees ([chilitechnology.com](http://chilitechnology.com)). This method probably offers the best refrigeration possible for practitioners, as the body can be placed on this mattress and essentially not disturbed again, while complying with legal refrigeration requirements. A practicing sangha could invest in this option and use it for numbers of deaths in their community.

Cons: The ChiliPad mattress is expensive (\$500-\$1000). In one sangha, the mattress broke down after only five years of use. It also may be inconvenient to transport the mattress to different homes, etc.

The ChiliGel cooling blanket, essentially a blanket of gel packs, is another option.

Pros: This blanket can be laid on top of the body, eliminating the need to lift the deceased to place gel packs underneath. It also covers a greater surface area than individual gel packs and is likely to keep the core of the body cooler in the long run.

Cons: The cooling blanket absorbs body heat quickly and must be changed every two-three hours. This is more labor-intensive for the sangha and means more frequent disturbance to the body.

**Field Notes:** I have always thought that someone should design and build a special massage table with a big drawer underneath for the dry ice or Techni-Ice (although dry ice would be best as it is coldest.) This way the refrigeration method is never directly in contact with the deceased's body, and can be replenished without ever disturbing the person. One could also, as a solitary caregiver, attend to refrigeration and not have to depend on others to help lift and position the body each time. This could be useful in many home vigil situations.

**Field Notes:** I recommend allowing any major movement/changes to the body (in terms of cleaning/removing equipment, etc., or transporting someone to another place in a house or vigil space), to happen at the same time that dry ice/refrigeration must legally happen, which, in many places is 24 hours after the time of death. This is a good, overall guideline for caregivers to follow.

## Pre-planning After-Death Care Directives

It is incredibly helpful if a person has created what I am calling an “advance after-death care directive,” for spiritual and practical support at the time of death—preferably long before the bardo of active dying begins. Indeed, in my work, I have found that those who planned ahead, and were thorough in relaying their wishes and intentions to the family and/or sangha, ended up having deaths closest to what they imagined and hoped for. This has made me passionate about getting people to do the (admittedly tough) intentional work of really thinking in great depth about the gap time between the moment of cessation of breath and the time of final disposition by cremation or burial.

In Buddhist circles, these directives are often called Dharma Wills. Dharma Wills are very important and helpful to complete, but the emphasis on spiritual wishes means they may not be specific enough when it comes to imagining the actual hands-on care of the body after death. At the time of this writing, I am working on an addendum to include in a Dharma Will that specifically focuses on the practical implementation of one’s spiritual wishes and intentions after death, and how to relay this information to one’s teachers, sangha, friends, and family. The document is too extensive for the scope of this article, but the following are examples of questions that can help with advanced planning in particular and tangible ways to plan for home deaths.

**1.** Do you wish to be left completely alone—no touching or moving, no matter what the state of your body—when you die? For how long? Three hours? Seven hours? 24 hours? Three days if possible? Whatever your spiritual teacher recommends? It is important to state this wish clearly and specifically, and to educate those who will likely be with you when you die about the possible consequences of this decision.

**2.** The above directive may mean that your eyes and mouth will be open when rigor mortis sets in. Does this matter to you? (Though most home funeral guides suggest using bags of rice or an eye pillow, and tying the mouth shut with a scarf or elastic band, I do not recommend this for practitioners who wish to remain undisturbed in the first hours after death. You can therefore direct caregivers to cover your face with a silk cloth or pull the sheet over your face.)

**3.** Would you prefer to have catheters, ports, or other medical devices removed, and your body cleaned before lying in state, even if this means people touching or moving you? You can be specific about the timing for this kind of care.

**4.** Do you wish to remain in the bed/place where you die for the duration of your vigil? Is there another place you would prefer to be, such as a massage table or bed in another room, or in a temple space if possible? (This will require moving/disturbing the body, so state when you wish this to happen.)

**5.** Are there special clothes you’d like to be cremated or buried in? If you want caregivers to wait a length of time before touching your body, loose clothing can be helpful if rigor mortis is present. Alternatively, choosing to be placed in a shroud lessens the above challenges and, simplest of all, one can just be covered with a clean white sheet or blanket and placed in the cremation or burial container for transport. These are all specific directions to consider.

## Practical Preparation Before a Death Occurs

If a person wishes to be left undisturbed after death, and is dying at home, or a place where he/she can remain in vigil space afterwards, it can be helpful to get as much in place before the person enters the active stages of dying in order to minimize any touching or moving the body after death. Here are suggestions for that kind of preparation:

**1.** Decide beforehand if the bed in which a person is dying can serve as a vigil place for a few days. If not, you may wish to move the person to a hospital bed with rollers that can be moved to another room if necessary. A bed that is against a wall makes it harder to care for the body, so this could be addressed before the person actually dies.

**2.** Place a heavy blanket as a first layer on the bed where the person will die. This protects the mattress from the intensity of dry ice (which has been known to damage the plastic mattress coverings of hospice beds). Then place a plastic sheet on top of the heavier blanket and a clean flat sheet right under the person. The sheet should be of strong enough material to be used as a hammock if the body has to be lifted or moved.

**3.** Keep tabs on the signs of imminent death. Help the person release any urine or feces beforehand if possible. (Often, however, these organs/functions begin to shut down, so this may not be necessary or possible.) Change any soiled sheets or blankets before the death, weighing the importance of doing this versus disturbing a person’s practice right before they enter the active stages of dying.

**4.** Bathe the person thoroughly in the hours right before he or she seems to be going into the active dying stage. Wash his/her hair, wash all the body’s creases, the genital areas, and anywhere odors tend to collect. You will probably need

to replace the hammock sheet after bathing, to insure it is clean (not damp) and still suitable for use.

5. The use of lavender soap, shampoo, and lavender infused spray on the body can be used to counteract any odors that might occur after death, if it feels appropriate and non-invasive.

6. The easiest course to take is to simply have the person remain in the clothes he or she is wearing at the time of death, so that minimal touching or disturbance of the body takes place. At some point (often determined by one's lama or Rinpoche), the Buddhist death shroud can be placed on the person. If this is a specific request of the dying practitioner, it can be accomplished with little disturbance, as it is light, and can be placed gently on the body.

As I complete this article, Char and I are engaged in helping a great Tibetan Buddhist teacher have the time and space after death he needs to transition from this world. We are working

closely with his family and community, helping to translate their cultural and spiritual wishes into concrete plans and practices that are within the law and in relationship to the way we "do death" in American/Western society. It is a daunting and beautiful challenge, and we are hopefully forging the way for others to have such opportunities in the future.

May my explorations and field notes inspire you to delve more deeply into what you truly want when you die. May they help you re-imagine what is possible, and get your wishes and plans in place and shared with teachers, sangha, and family members—now. If each of us can actively bring death back into life in such a way, we can help transform the fear, denial, and avoidance so prevalent today. Buddhist teachings have always emphasized that conscious and intentional dying is a gift and that, if we see it as such, our deaths really can be what they are meant to be—moments of transformation and awakening. 🌱



*Lucinda Herring's consulting and educational work supports people from all walks of life to have more natural, healing and sustainable after-death care. She is an interfaith minister and a long time Vajrayana Buddhist practitioner. See more at her website: [lucindaherring.com](http://lucindaherring.com). Click on Spiritual Support for specific information about her Buddhist consultation offerings.*

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# Hair Care for the Dead

by Margy Henderson

Have you ever washed your lover's hair? I recommend it. There's something tender about the closed-eyed surrender to sensation they feel.

I'm a barber and I worked in a shop in San Francisco during the '90s at a time when hundreds of our clients became ill. I was willing to go to homes and hospitals to give my clients haircuts during their dying months. Over the years I heard many gay men say, "You know, you're the only woman who ever touches me." I began more consciously to rest my hands on my clients' shoulders after draping them with the cloth that protected their clothes. Each day, I heard stories of their lives. When washing someone's hair, I often heard "This is my favorite part."

Our barbershop was a stealth healing center. Each morning, my partner Danielle and I would burn sage, pray for the day's coming encounters and put on beautiful music. We always had flowers and candles. This is how we loved and healed ourselves. Enough love apparently spilled over, because the women and men who visited each half hour often told us how they too felt the healing.

After someone dies, washing the hair, bathing the body, and massaging fragrant oils into the skin honors the transitioning life force we have loved. The intimacy of these gestures toward the dead has deeply healing ramifications. Our hands and eyes inform us that, indeed, the loved one has reduced her presence in the physical form. The body cools, stiffens, and pales. "She's really dead," the disbelieving voice whispers. I imagine that it also offers the dead a sort of physical prayer for their transition.

Often, because of pain or disinterest, the person has not bathed for days or even weeks. Suffering and dying can be frightening—and devastating

to witness. But after the shampooing, washing, essential oils, prayers, tears, and dressing of the body in the chosen garments, there is a visceral awareness that the dead can be beautiful. So often those who fear death will say, "I don't want to remember her that way." Yet, how divorced from basic reality are we, without trusting that we will one day be our own corpse?

The beauty, peace, and (what I call) sacred presence that occur during a home funeral help heal that fear. We burn sage, put on beautiful music, and gather flowers, candles and favorite photos. As the loved one's body relaxes into its new countenance, those in vigil tell stories about their shared life.

I am a Threshold Choir singer. Our soft, bedside songs help to bring the focus toward the continuing, now different, presence of the precious body. They are songs that allow tears and a deeper realization for the family that what has just happened is real.

We are not helpless and alone in our grieving. We are together with important death-bed tasks. "You stay with her, I'll go get the dry ice," and, "Do you have anointing oils ready?" "Ask the children to bring in some flowers and to help us say good-bye." These are holy tasks, done not by strangers, but by loved ones who now know that we, too, will be safely tended at our deaths. In this spirit, I share with you my approach to shampooing a loved-one's hair at death.

## Margy's Recipe for Lying-Down Hair Care

Materials needed at bedside:

- Three towels
- Plastic sheet or other waterproof item to protect the bed from spillage
- Bucket or wastebasket to catch the water
- Large plastic bag
- Big bowl of very warm water
- Two medium-sized glasses
- Pitcher
- Large-toothed comb
- Shampoo
- Conditioner
- Essential oils



Death educator Heather Massey looks on as Margy Henderson demonstrates her hairwashing technique at the 2015 NHFA conference. Photo: Karen van Vuuren

## Here's How

1. Standing behind the person's head, draw him or her close to the top corner of the bed or massage table.
2. Put the waterproof barrier underneath the shoulders and head, then cover the plastic with a towel.
3. Roll a second towel lengthwise to create a circle, and position it under the person's neck with the ends of the roll open at the edge of the bed.
4. Cut one corner of the large plastic bag for water to drain into the bucket. Place the large opening of the bag between the head and the rolled towel to allow water to flow through the opening and into the bucket. For best results, be sure the bag is large enough for the cut corner to extend into the bucket.
5. Place an extra towel under the neck, on top of the plastic bag.
6. Mix together warm water and some shampoo in one of the glasses for easier washing and rinsing.
7. Place the entire top of that glass firmly against the head; move it gently over the scalp while lifting and turning the head with the other hand to ensure all the hair is dampened.
8. Massage the scalp and hair thoroughly.
9. Using the pitcher, pour clean water to rinse; repeat this washing and rinsing process if there has been blood.
10. Mix some conditioner or essential oil drops and warm water together in the second glass.
11. Again, with the top of the glass against the scalp, move it around the head to disperse liquid evenly, turning the head as needed.
12. Continuing to hold the head with one hand, use the pitcher to pour warm rinse water onto the scalp. The water should flow easily into the bucket through the bag.

13. Remove the bag and towel roll and use the underlying towel to dry the hair.

14. Comb, blow-dry, and style to whatever degree the loved one would have wanted.

Be aware of always supporting the head as the body is being moved. I do all this from the side, respecting the possibility that the crown chakra may be a portal through which the life force exits. I generally hold the jaw closed until rigor holds it. It can be done with a scarf tied under the jaw and over the head, but I tend to pray during those minutes of being still, observing the face and eyelids to help them set in a way she looks most like herself.

There's no hurry, nowhere more important to be. This body. This dear one. So soon gone from sight.

A last suggestion: practice all this with your loved ones. The hairdresser doesn't need to be the only one to share in this pleasure. 🌱

*Margy Henderson, death midwife, home funeral guide, death educator, threshold singer, sound healer, barber. We Are Gatekeepers, Ukiah, CA. Contact Margy at planetsounds1111@yahoo.com*

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# Rest in Peace and Social Justice: Wisconsin's Natural Path Sanctuary

By Mary Reilly-McNellan

“A thing is right when it tends to preserve the integrity, stability, and beauty of the biotic community. It is wrong when it tends otherwise.”

– Aldo Leopold

When I first started working as a park ranger in the early 1980s, a colleague introduced me to *A Sand County Almanac*, a compilation of lyrical essays written by environmentalist and conservationist, Aldo Leopold. This simple, elegant book about nature, ecological balance, and humanity's potentially destructive interference would dramatically change historical land management techniques in the United States. Sadly, Leopold would never live to see the colossal impact of his compelling prose—he suffered a heart attack while fighting a fire on a neighbor's property in Baraboo, WI, and died just one year before the publication of the *Almanac* in 1949. Best known as the “father of wildlife management,” Leopold advocated for a responsible relationship between people and the land they inhabit, and his support of a land ethic and wildlife preservation has had a profound impact on the environmental movement. They have also been taken to heart by another Wisconsin resident, Shedd Farley, whose family opened Natural Path Sanctuary, a conservation burial ground that epitomizes the land ethic Leopold embraced.

Located near Verona, WI—and just 35 miles southeast of Leopold's beloved Baraboo farm—Natural Path Sanctuary (NPS) is a 25-acre conservation cemetery on the larger, 43-acre Linda and Gene Farley Center for Peace, Justice, and Sustainability. As longtime family physicians and Quakers, Linda and Gene had dedicated their lives to healing the underprivileged, promoting social justice, and advancing sustainability.

Their six-sided, passive solar home served as a gathering place for activist groups dedicated to socially progressive change, community partnership, sustainability, and ecological justice.

When Linda died in 2009, the Farley family donated their Wisconsin home and land so that others might be inspired to create a sustainable legacy. They also honored Linda's wish to contribute to the ongoing cycle of life by interring her remains in their front yard. The burial was simple, safe, and “green”—no fancy funeral, no toxic embalming fluids, and no expensive tombstone. In the tradition of one of her adopted African children, Linda's family helped to prepare the gravesite. They found the experience so profoundly meaningful and healing that the Farleys wished to share it with others. Shortly after his wife's death, Gene began the necessary steps to establish an ecologically sustainable natural cemetery on their property. He spent the next two years attending meetings, testing the soil, and jumping through the various hoops required by local governments—a sad irony considering that this was how our ancestors were buried for centuries, and

with no ill effects until the mid-19th century debut of toxic embalming fluid and metal coffins.

Dubious neighbors questioned the proposed cemetery, citing concerns about decreased property values, increased traffic, contamination of ground water, potential disturbance by animals, and even ghosts. Gene





and his family hung in there, however, addressing their apprehensions and educating the community about the benefits of “green” burial in the process. “Green cemeteries are burial grounds where care of the land is a primary concern,” notes NPS coordinator Shedd Farley. “Burials are permitted on only 10-30% of the land, and statistically, they make property values go up. The neighbors are all fine with it now.”

Natural Path Sanctuary opened in 2011, and Gene Farley was interred in his legacy when he died later that year. The family has subsequently sold approximately 170 lots for future use, and all graves are dug by hand to reduce the use of fossil fuels. This can be problematic given Wisconsin’s long, cold winters, so two or three holes are prepared in advance each year for any burials required while the ground is frozen. If a family wishes to help dig or fill their loved one’s grave, they are welcome to do so at NPS. Local funeral directors support the cemetery by stocking shrouds, providing refrigeration and transportation, and even serving as pall bearers when necessary.

Today, ten acres of the Farley Center land are cultivated by seven farm businesses run by Hmong, Thai, Mexican, Columbian, and Euro-

American women and men, and the property serves as an innovative training ground to teach small-scale organic farming techniques. Key to the operation is the Natural Path Sanctuary, which helps to raise money for the center. Like most states, Wisconsin law

requires that a percentage of the cost of a burial plot be placed in a permanent endowment for land maintenance and care of the space—15% in the case of NPS. This amount may seem small, but a natural burial ground requires very little maintenance when compared to



*Large gathering deep in the woods. Homemade casket*



*Family and friends digging Gene Farley's grave*


a conventional cemetery: Mowing is infrequent, vegetation grows naturally, and native plants that are adapted to the local environment thrive.

There is minimal human intervention at the site other than natural burials, maintenance of simple unpaved paths, and removal of potential walkway safety hazards. Cemetery regulations ensure that no toxic embalming fluids or chemicals, non-biodegradable materials, or other harmful substances alter the natural ecosystem. Tangles of diverse vegetation provide homes for a rich variety of birds and other animals. It is a place of peace, tranquility and beauty, and families and friends of the nearly 70 persons interred within are welcome to enjoy the meditative quiet of the nature preserve/burial grounds.

Besides being one of only about 133 natural burial cemeteries in the United States, Natural Path Sanctuary also educates the public about sustainable end-of-life choices and burial practices. NPS is notable, too, for its unique peace and social justice component. But perhaps most importantly, the cemetery serves the higher purpose of preserving and protecting land in perpetuity—an ethic embraced and promoted by Leopold himself.

This protection may prove to be even more critical as the controversial natural gas mining technique known as hydraulic fracturing, or fracking, proliferates across the state. An especially desirable variety of Wisconsin sandstone contains extraordinarily fine, rounded grains that are a key component in the mix of chemicals and water injected into the earth during the fracking process. As a result, Wisconsin's sand mines have boomed, and new quarries and processing plants pose a significant threat to the sandy soil ecosystems so revered by Aldo Leopold. Thankfully, establishment of the Farley Center and NPS ensures

that the natural beauty of the land and the sensitive ecosystems within will be preserved and protected for generations to come.

Aldo Leopold would be pleased. 



*Mary Reilly-McNellan has been a volunteer editorial assistant with NTM for the past three years. Her interest in environmental conservation has led to a new-found passion for promoting green burial, and she is currently working with a local team of volunteers to bring this sustainable tradition to Boulder.*



*Lowering a shrouded body*

# Who Controls the Dead?

## The Right to Make Funeral and Disposition Decisions

By *Tanya D. Marsh*

Death is a transformative event with profound consequences for the individual and her community. Promptly following this emotionally significant moment, decisions regarding the disposition of the corpse must be made. In a basic sense, the process of disposing of human remains is simply the solution to a practical problem. But the manner in which we dispose of remains matters, to many people, quite a bit. A human cadaver is no longer a person, but neither is it an item devoid of meaning. Anthropologists tell us that one of the key differences between humans and other animals is that we do not easily discard the remains of our species. Instead, we attach profound spiritual and emotional significance to their treatment and ultimate disposition.

Americans, pushing back against the commercialized “American way of death,” are exploring their options in death care to an unprecedented degree. The most significant evidence of this is the rising popularity of cremation. Before the mid-1980s, the US cremation rate was in single digits. In 2015, for the first time, more Americans were cremated than buried. The growing interest in cremation is driven by concerns about cost, the environmental impact of embalming and ground burial, and a desire for a closer connection between the living and the dead. These same concerns contribute to a growing interest in home funerals, alkaline hydrolysis, and green burial.

Socially conscious entrepreneurs, responding to these concerns, are pushing the accepted boundaries of death care. Katrina Spade and the Urban Death Project are working to create a community compost-based renewal system where human remains are transformed into life-giving soil.

Jae Rhim Lee’s eco-friendly Infinity burial shroud and suit are infused with fungi that hasten decomposition while neutralizing toxins. Capsula Mundi is developing a biodegradable egg-shaped pod that will encapsulate human remains, serving as a metaphorical “seed” for a memorial tree planted above the pod. Jevon Truesdale and Qico promote an environmentally friendly, sustainable, water-based alternative to fire cremation known as alkaline hydrolysis. Progressive funeral directors like Amy Cunningham and Caitlin Doughty are providing education and services to allow families to take back as much control over remains as they feel comfortable with, subject to legal limitations.

Of course, these new frontiers in death care are controversial. In some American communities, cremation is still controversial. As a result, there may be tension between what disposition methods individuals might choose for themselves, and what choices their families and communities may be willing to support. The law limits choices in various ways and provides the framework to mediate those disputes.

### The American Law of Human Remains

The American legal system includes two kinds of law—common law and statutory law. Statutory law is the collection of acts adopted by state legislatures and Congress. The common law is a framework of legal principles derived from custom and judicial precedent. It is sometimes known as “judge-made law.” Recognizing that elected legislatures cannot possibly address every kind of legal dispute, the common law fills in the gaps in statutory law. American common law is based upon and incorporates the

body of English common law that existed as of the Revolution. The law of human remains was almost exclusively common law until the turn of the 20th century. At that time, state legislatures began to enact laws to regulate funeral directors and embalmers. Those occupational licensing statutes make up the bulk of the statutory law of human remains. Funeral directors are very concerned about clear rules regarding who has the authority to make funeral and disposition decisions. State statutes are therefore primarily concerned with creating that certainty, even at the expense of the interests of decedents and their families. There is very little federal law on these topics other than the Federal Trade Commission’s Funeral Rule, which mandates certain disclosures and presentation of pricing information.

### The Rights of the Dead

At common law, the dead have rights. Strong and longstanding social and legal norms permit broad freedom to direct the disposition of our property after death and promote respect for dying wishes. With respect to the disposition of human remains, the common law grants two rights to the deceased: (1) the right to a “decent burial,” and (2) the right to direct the disposition of their remains.

Although the common law promises decedents that their wishes will be honored, it does not provide a specific mechanism for decedents to leave evidence of their disposition preferences. Many courts have honored the oral expression of dying wishes. The use of a will is more common, although it remains legally controversial. In some states, a decedent may not dispose of his remains in a will because human remains are not property. In other states, courts have held that a decedent may

leave binding disposition instructions in a will.

Given the lack of clarity in the common law, and the need of funeral directors for certainty, it is not surprising that the state legislatures have intervened. Thirty-one states and the District of Columbia have statutes that provide that the decedent has the general right to express a personal preference regarding the disposition of his remains. I call these rules personal preference statutes. There is significant variety among the personal preference statutes. One important difference is the theoretical basis for the statutes. Only three states (Florida, Oklahoma, and South Dakota) expressly grant decedents a statutory right to determine the disposition of their own remains and then provide a mechanism for executing that right. The remaining states do not expressly establish a statutory right, but implicitly assume a common law right by specifying a mechanism for a person to declare how they would like their remains disposed of after death. At first glance, the failure to establish a statutory right seems inconsequential. After all, what is the purpose of the statutory process if not to effectuate an express common law right or an implicit statutory or constitutional right? But the formulation and placement of these statutes in their respective state codes strongly suggests that the point of the process statutes was to make it more difficult for survivors and estates to invalidate contracts for funeral goods and services (i.e., pre-need contracts)

entered into by decedents before death. Indeed, in four states (Georgia, Idaho, Mississippi, and Rhode Island), a decedent's wishes will be respected only if he or she purchased a pre-need funeral contract. Three states (Kentucky, New Mexico, and South Carolina) permit individuals to pre-authorize their own cremations, but not to identify any other personal preferences.

A key corollary in state statutory law to the personal preference statutes is the absolution of liability for those who rely upon documents that comply with the statutory process for memorializing preference. Although some states generously forgive all persons from liability for following the written instructions of the decedent, most statutes are clearly intended to relieve only funeral professionals from liability. Other statutes primarily aim to give the funeral director clear legal authority to resolve inconsistencies between a decedent's written instructions and the contrary wishes of survivors. The combination of release of liability for funeral directors for following directives that comply with the statutory requirements, and the emphasis of the statutes on the selection and prepayment of funeral goods and services are clear signals that the personal preference statutes were heavily influenced by the funeral services industry. The result is that in many states, commercial consumer preferences are easier to enforce than non-commercial preferences. If, for example, a person in Wisconsin desired

to have his body prepared by his religious congregation and buried in a shroud in a (legally-permissible) backyard cemetery, a choice that would not require the services of a funeral director, crematory authority, or cemetery authority, the law would say that those wishes should be honored, but would not shield those who carried them out from lawsuits brought by surviving next of kin.

The personal preference statutes also vary greatly in terms of the manner in which an individual is required to express his preferences. Some of the states set a very low bar—they simply require that instructions be in

writing. Other states require a particular form set forth in the statute. A few states require a notarized declaration. Many states require the written instrument to be witnessed by one or two people. Several provide alternative methods, including setting forth preferences in a will, a health care power of attorney, or pre-need contract.

If a person does not leave instructions regarding the disposition of their remains, or if the relevant state law does not permit them to, the law establishes a framework to determine who may control the remains and make decisions regarding disposition.

## The Rights of Next of Kin

Since the early 1850s the general rule in the United States has been that the next of kin have the right to possess and control remains after death, subject only to the wishes of the decedent. In the highly influential 1904 case of *Pettigrew v. Pettigrew*, the Supreme Court of Pennsylvania attempted to establish a process for sorting out conflicts among surviving kin:

The result of a full examination of the subject is that there is no universal rule applicable alike to all cases, but each must be considered in equity on its own merits, having due regard to the interests of the public, the wishes of the decedent, and the rights and feelings of those entitled to be heard by reason of relationship or association. Subject to this general result, it may be laid down: First, that the paramount right is in the surviving husband or widow, and, if the parties were living in the normal relations of marriage, it will require a very strong case to justify a court in interfering with the wish of the survivor. Secondly, if there is no surviving husband or wife, the right is in the next of kin in the order of their relation to the decedent, as children of proper age, parents, brothers and sisters, or more distant kin, modified, it may be, by circumstances of special intimacy or association with the decedent.

The order of priority set forth in *Pettigrew* is the most structured that



the common law has accomplished. As the court suggests, this individualized, equitable approach creates uncertainty that, in the event of a dispute among interested parties, can only be resolved by a court. Again, given the understandable interest of funeral directors for certainty in identifying the person or persons with the legal right to make funeral and disposition decisions, it is not surprising that state legislatures have intervened to establish a more orderly process.

Forty-six states and the District of Columbia have statutes that establish a personal obligation or right with respect to the disposition of human remains. These statutes are primarily focused on mediating the competing claims between survivors. Most of the statutes establish a priority list that roughly tracks the hierarchy set forth in Pettigrew and state intestate succession statutes. Not surprisingly, top priority is assigned to the surviving spouse. A few states qualify the spouse's right and obligation based on competency or estrangement at the time of death. A few states put domestic partners or, in the case of Vermont, civil union partners and "reciprocal beneficiaries," on equal standing with spouses.

If a decedent left no surviving spouse or domestic partner who meets the qualifications set forth in the statutes, 39 states identify the children of the decedent as the next in priority. Most states disqualify minor children, while a few do not. Some states permit "any" surviving child to assert the right to control the decedent's remains, while others require a majority of surviving children to agree before they can act. Only two states—Arizona and New Mexico—put the parents of a decedent in a higher priority position than children of the decedent.

If a decedent has no qualifying spouse, parents, or children, 34 states then defer to siblings. As with other classes of kin, most states require the siblings to be adults, but a few do not. Some states allow any sibling to assert the right, while others require a majority to agree.

After siblings, there is significant divergence among the priority lists. A few states include detailed lists of kin.

After relatives are exhausted, the lists generally call for an interested friend or stranger. For example, Minnesota seeks "an adult who exhibited special care and concern" for the decedent, while Missouri will take "any person or friend that will assume financial responsibility." Some states end their lists with the public official charged with indigent relief, so that she may organize a pauper's funeral. Only 15 states have statutes that obligate the government to bear the expense of indigent burials. A number of states (including my home states of Indiana and North Carolina) give authority to the funeral director with custody of the body or "any other willing person" to organize the disposition and charge the estate if kin cannot be found within a few days after death.


## The Decedent's Right to Designate an Agent

The common law granted decedents the right to dictate the disposition of their remains, but did not expressly give decedents the right to name the person who would control their remains. Many states, however, have statutes that expressly grant decedents the right to designate an agent to control their remains. These agents generally trump all persons in the statutory priority list who would otherwise have the right to control the remains. Presumably, a person would take advantage of a designated agent statute in order to choose a person who will be more likely than his next of kin to effectuate his wishes. Thirty-seven states and the District of Columbia have adopted designated agent statutes. Related statutes allow decedents to grant powers of attorney with respect to health care or similar purposes. Three states only permit the designation of an agent for limited purposes, such as authorizing cremation or making anatomical gifts. The remaining nine states do not allow individuals to designate agents under any circumstances.

## Planning

What can, and should, a person do with this information? First, you need

to understand your state's laws and how they may allow you to express your personal preferences, choose the disposition method that you prefer, and appoint an agent if you would like one. An estate planning attorney in your state is a good resource. Some estate planning attorneys, however, are not familiar with the intricacies of these laws. Armed with the information in this article, however, you can ask informed questions that should get you the guidance you need. You can also consult resources like *Final Rights* by Josh Slocum and Lisa Carlson, which provides an overview of the relevant laws in every state. If you spent a significant amount of time in another state, you should also follow this process for that state as well. Remember that the laws that apply are those of state in which a person dies, and unless we never leave home, we cannot ultimately guarantee the location of our death.

Second, if you decide that one of the newly emerging methods of disposition appeals to you, but that the laws of your state will cause problems or prevent you from making that choice, get involved! Write a letter to your local newspaper. Talk to your friends. One of the main reasons that the funeral industry's concerns have trumped consumer concerns in these state laws is because we don't talk about death and they are happy to. If we want better laws and more choices, then we have to begin and sustain a lot of conversations about death. If we are unwilling to engage in those conversations, then we will have to accept that the choices we want and the choices we have may be radically different. 



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## Green Burial News

from Kate Kalanick, GBC Executive Director  
and Ed Bixby, GBC Board President



### Green Burial in the Media

A recent *Huffington Post* short video that profiled natural burial received more than 10 million views over little more than a month, a statistic that proves that the natural burial option is here to stay. Not only is the public embracing it, the funeral industry now also sees it as a viable option. Other publications that have covered the work of the GBC have included Marketwatch.com, *Smithsonian Magazine*, *USA Today*, as well as others.

### Friends of GBC Is Up and Running

Due to this increased media attention, the GBC has experienced burgeoning interest from the public and inquiries from people who want to become actively involved with the work of the GBC. The growing number of requests to be informed, to volunteer, and to donate have led us to launch the “Friends of the GBC” network, giving consumers and activists access to vital information about the natural burial movement, as well as details of upcoming talks, and events around the country. We are engaging volunteers who are interested in the GBC cause, and we continue to urge natural burial supporters to join our network. We need your voices if we are to educate our communities and change laws that restrict access to natural burial options and natural deathcare.

### Green Burial for Veterans

GBC visited Washington D.C. this year to speak with the Veterans Administration about green burial. The information we shared was well received, and we are working with the VA to bring the freedom to choose green burial to those who have served our country.

### The GBC Chapter Program and In-House Consulting for Providers

We know that the success of GBC certified funeral homes, cemeteries, and product providers also depends on the services we in the GBC provide to them. If we educate the public well and in a way that is regionally specific, this will raise public interest in our GBC certified providers. With this in mind, we’ve begun our GBC Chapter Program to spread the word about green burial. We hope these chapters will also shine a spotlight on our GBC funeral homes, cemeteries, and product providers. We now also have an in-house consulting service for our providers to equip them to better face the possible pitfalls of creating green options and help ensure their success.

### New Products in the Green Marketplace

The GBC has been keeping a keen eye on the latest products and disposition techniques. In order to pay attention to these, the GBC has created an active and engaged advisory council of industry professionals who will conduct research and report their findings to the GBC leadership, allowing us to make informed assessments of what is available in the marketplace.

### The GBC Video

Finally, we’d like to encourage all Natural Transitions readers to visit the GBC website, [greenburialcouncil.org](http://greenburialcouncil.org), and watch “A Green Burial Video.” This powerful 28-minute film is a valuable tool for education, capturing the true meaning and essence of natural burial. [greenburialcouncil.org](http://greenburialcouncil.org)

# Unintended ? Consequences

## *Virginia Bill Casts Spotlight on How Funeral Laws Are Made*

When the Virginia assembly took up a seemingly innocuous bill in the 2016 session, legislators were unprepared for the enormous public outcry that eventually changed the trajectory of the bill and may contribute to the way funeral laws are made.

SB595 called for mandatory refrigeration of dead bodies after 48 hours of their dispatch to a professional. It was the legislative answer to a situation reported to the bill's sponsor, Senator Kenneth Alexander (R), a funeral director who saw it through the lens of his own experience. He was informed about a body that was awaiting autopsy and was allegedly left for the weekend in a cramped hospital room with no attention to preservation measures of any kind.

Before home funeral advocates could launch efforts to educate lawmakers about the bill's far-reaching consequences for Virginia's home funeral families, it passed the first of the Senate's three readings. By the time the bill crossed over from the Senate to the House, a storm was raging in the form of a Change.org petition floated by Springfield resident and National Home Funeral Alliance member Denise Klasen. Registered letters, emails, and phone calls from Virginia citizens along with NHFA leadership and members inundated House delegates and members of the subcommittee responsible for moving SB595 to the final vote.

Those subcommittee members heard the commotion and made accommodations in the bill to restrict the reach to institutions that may have need of

such direction, leaving home funeral families free to care for their own at home without government interference. In a unanimous vote on February 29, the amended bill passed the House, just five weeks after the effort to stop it began.

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Would it have been the end of the world if the original bill had passed? No. Home funeral families could have continued to stage home vigils for up to 48 hours with no problem: dry ice, Techni-Ice, cool room—business as usual. This was never at issue.

Then what was at the crux of the matter? Why were so many people around the state, the country, and the world up in arms about this proposed law? This is where we have to go down the rabbit hole of the law to see what the potential ramifications might have been, and where the path of home funeral advocacy is leading.

Let's start with the broad stroke this bill would have painted on the home funeral landscape in Virginia. The law, however inadvertently, carried the potential of impeding families by compelling them to hire a professional if they were unable to meet the stringent temperature requirements after 48 hours.

Dry ice and other techniques are effective at 65 degrees for three days, but cannot guarantee a uniform 40-degree temperature that mimics walk-in refrigerators. Although clearly not intending to require refrigeration units in home settings, the bill still posed a problem for would-be home funeral families who feared running afoul of

the law should they not achieve this unreasonable and unnecessary goal.

Additionally, the original bill did not require funeral establishments to ensure that they could achieve the stated temperature either; in point of fact, not all funeral homes even own refrigeration units. And on closer examination, it exempted them from having to follow the law anyway, leaving us to wonder who exactly this bill was written to protect.

It's hard to know what policymakers were thinking when confronting the language of the bill that stated in part, "...any person or institution, other than a funeral service establishment...shall ensure that the dead human body is maintained in refrigeration... or shall enter into an agreement with a local funeral service establishment." But clearly, they were not thinking about fundamental American rights to privacy in their own homes.

Nothing about this law as it pertained to private citizens was enforceable without funeral police standing by with a clock in their hands. And since there is no such thing as funeral police, how were lawmakers planning to compel families to give up their loved ones at the appointed hour?

In what other commercial arena does the government mandate that its citizens incur thousands of dollars of expenses to do something they do not want or need to do? That, in fact, they have historical precedent and right to do. When we are sick, we choose whether to see a doctor or not. When our car




breaks down, we consider our goals, our budget, and our needs, and we choose to fix it or replace it. These are choices. We don't get to choose death; it comes and we deal with it. But we do so according to our own economic circumstances, our own spiritual and emotional needs, our own capacity for managing life and its complicated affairs.

We send young parents with no experience whatsoever home with infants, and the government does not have the power to require how that child will be raised or cared for, how much money his or her parents spend on childcare, schools, weddings, or any other life passage, no less tell them what temperature to keep their home at or insist that they hire a professional for something they do as parents.

No doubt lawmakers considered public health safety and made assumptions according to popular thinking, regardless of the fact that the World Health Organization, the Centers for Disease Control, the Center for Infectious Disease, and the Pan American Health Organization have all issued statements declaring that dead bodies do not pose increased health risks.

What was wrong with this bill was that the citizens of Virginia were never part of the equation beyond the lawmakers erroneously trying to protect them from something they have no reason to fear. We cannot expect all lawmakers to know the scientific facts that inform home funerals, or what exactly home funerals entail. But we do need to make them aware of the fundamental rights

of all Americans to care for their own after death in the privacy of their own homes. 



*Lee Webster is the current president of the National Home Funeral Alliance, treasurer for the Board of Directors of the Green Burial Council, and director of New Hampshire Funeral Resources, Education and Advocacy.*

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Photo courtesy of Marion Spadone

# Law & Sausage:

## Physician-Assisted Death and the Solution to Suffering

by Jennifer Moore Ballentine

Since 2014, proponents of physician-assisted death (PAD) have introduced legislation in 26 states and the District of Columbia. Additionally, court cases have been filed in New Mexico, California, Tennessee, and New York. All these efforts and the likely millions of dollars and person-hours of impassioned advocacy have so far been successful in expanding legalized PAD to only one new state, albeit a big and important one. In June, 2016, California joined Oregon, Washington, and Vermont<sup>1</sup> as states with legal frameworks allowing physicians to prescribe lethal medications to qualified terminally ill patients.

A longtime student of issues related to the end of life in America, I have been immersed in the PAD debate: active in the legislative process in Colorado and California, engaged in policy conversations with numerous state and national organizations, and participated in spirited public dialogue. Through all this, I've become absolutely convinced of two, if only two, conclusions:

- › Suffering at the end of life is not new, but it is an increasing and increasingly intolerable problem, and
- › Establishing a legal framework for the prescription and ingestion of lethal drugs is not only a completely inadequate solution to the problem of suffering at the end of life, but a misguided and potentially dangerous one.

### Suffering at the end of life

On the first point, proponents and opponents of physician-assisted death would likely agree. In fact, suffering is not limited to the end of life, but is too often present at unacceptable levels

throughout any serious, chronic, or life-limiting illness or disability. It is worth stipulating here that “suffering” is a multidimensional experience. It includes pain. Research cited in the 2014 Institute of Medicine’s landmark report, *Dying in America*, indicates that patients are not receiving enough help with pain 18–43% of the time. Pain management is best in hospice care and hospitals and worst in home health care and nursing homes. (IOM, 2014) But suffering also includes other symptoms: shortness of breath, weakness or paralysis, fatigue, nausea, agitation, delirium, incontinence, and so on.

Suffering also includes emotional, psychological, social, spiritual, and existential distress. Numerous clinician-researchers—among them Cicely Saunders, the founder of the modern hospice movement; Herman Feifel, Elisabeth Kübler-Ross, Sherwin Nuland, Ira Byock, David Kuhl, Joanne Lynn, Christine Pulchalski, Betty Ferrell, Harvey Chochinov, and more recently Atul Gawande and Paul Kalanithi, to name a few—have probed the phenomenology of dying. Their scholarly findings confirm what the many “die-ographies” of the past 20 years or so have made clear: Some of the worst suffering at the end of life comes from loss of connection, activity and productivity, meaning, purpose, a future, even hope.

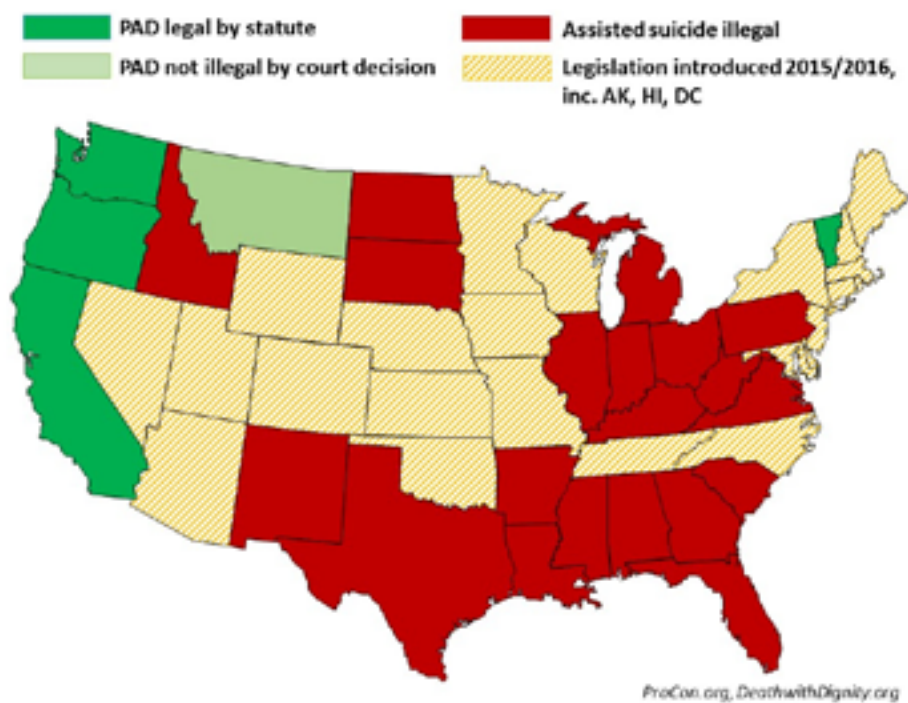
Suffering has attended both life and death since consciousness first lit up the human brain. Our ability to experience suffering and to recognize it in others, and our efforts to relieve it, are hallmarks of humanity. It informs our literature and art and infuses our spiritual and philosophical systems. As all the major religions teach us, some amount of suffering in life and indeed

in death is inevitable—it’s the cost of consciousness and of love.

Suffering is not new—but in the context of serious illness, it has gotten worse. As medical technologies and interventions have advanced and become ever more effective at beating back disease, they have exacerbated suffering. Antibiotics and surgery, not to mention dialysis, organ transplants, radiation and chemotherapy, mechanical respiration, and feeding tubes have saved countless lives, but at a cost. By the end of the 20th century we were reaping a heap of what we had sown: longer, often significantly better lives; longer, often significantly worse deaths.

Suffering at the end of life comes not only from illness itself, but from how we as persons are treated in our fragmented, discontinuous, and technological (not to mention expensive) healthcare system. (In the 1970s, newsman Walter Cronkite famously quipped, “Our American health care system is neither healthy, caring, nor a system.”) Despite billions of dollars spent on pharmaceutical research and advertising and sophisticated medical technology and facilities, we still cannot ensure that any patient will receive the right care at the right time in the right place. Much more attention is paid to capturing and crunching data than to asking patients how they are doing and what matters most to them right now.

There’s even a word in medical jargon—*iatrogenic*—for suffering that occurs as a direct result of actions taken by physicians and others, almost always with benevolent intent. In every effort to heal there is the potential of harm. Harm, like suffering, comes in many forms, from disrespectful communication all the way to



serious medical error and under- or overtreatment.

## Legal frameworks for physician-assisted death

Against all of this, a solution is offered up in the form of legalized physician-assisted death (PAD). Like the problem it purports to solve, the PAD (and euthanasia) movement is nothing new. Efforts to establish a legal framework in which competent persons might exercise—with the assistance of a physician and without legal, social, or financial sanction—their “right to die” have a long history in the United States. The first bill to propose such a framework was introduced in the Ohio legislature in 1906. (Zucker, 1999) Though soundly defeated, the bill sparked a loud social and political conversation that extended beyond Ohio and reverberated down the decades. It was not until the 1990s that the movement enjoyed both its seminal success in the passage of the Death with Dignity Act in Oregon and the creepy-uncle embarrassment of Dr. Kevorkian and his “Thanatron.”

This time around, a serendipitously attractive and articulate spokesperson for the cause, Brittany Maynard,<sup>2</sup> emerged in 2014, and any hint of creepy has been carefully scrubbed from the movement. Most of the bills proposed have been closely modeled on Oregon’s successful law but have borne amendments necessitated by state law or answering concerns voiced by the opposition, bringing to mind the old saw, “Laws are like sausages—you should never watch them being made.”

Liking sausage, I have charted the provisions of each of the enacted laws and most of the proposed bills. (see summary next page) Rhetoric from proponents of these bills tends to focus on two points: (1) Terrible suffering is coming at the end of life, and (2) Persons have a right to control over their own lives and deaths and should be allowed to exercise that right without the interference of government. Ironically, legalizing PAD offers no “fix” on either point.

Taking the second point first: No law is required to allow any person in the United States the right to self-annihilate. While it is not a right protected by the U.S. Constitution (Waimberg, 2015),

it is arguably a natural human right. The last U.S. laws imposing criminal sanctions for attempting suicide were repealed by the 1990s and only weakly enforced for decades prior. (Mental Health Daily, 2014) Suicide may leave a wake of trauma and complication, even if the act is rational and understandable in the circumstances, but no new law is required to allow it.

While suicide is not illegal, assisting a suicide is, either by statute or common law. PAD laws are not needed to give legal imprimatur to an act of ultimate autonomy; they are needed to protect physicians from prosecution. The steps to qualify patients for PAD are promoted as safeguards to bar ineligible patients, ensure informed consent, and discourage coercion by greedy, exhausted, or abusive caregivers. Even so, some physician groups have objected to the legislation solely because of this bureaucratic intrusion—*government interference*—into the physician-patient relationship. The steps will not safeguard patients; they are far too easily circumvented by anyone of ill intent. They are intended solely to carve a narrow, legal lane for physicians to act between manslaughter and murder. In short, dear patient, it’s not about you.

Regardless of the intent, these laws have the practical effect of making assisted suicide legal—and rare. Here’s another problem. These laws offer relief to only one very small class of persons: mentally competent adults, physically able to self-administer the drugs, and with a terminal illness. Each element excludes wide swathes of the suffering population; for instance, anyone terminally ill who happens to be under 18, and all those with diseases that impair cognitive function or the operation of limbs and the ability to swallow. What of their suffering?

In fact, the terminal illness requirement may be the most restrictive and paradoxical feature of all. Actually getting a physician to say, let alone certify, that a patient is terminally ill is extremely difficult. Many physicians flatly refuse to offer any predictions of

likely survival. They honestly do not know, and they have seen many patients who succumb earlier than expected and others who outlive all expectations. Studies of prognosis have shown that on average, physicians tend to greatly overestimate likely survival, and the better they know the patient, the more they overestimate. (Christakis, 1999) On the dark side, two physicians in southern California were recently convicted of Medicare fraud by falsely certifying patients as terminally ill. (Day, 2016)

What does all this mean for physician-assisted death? (1) Many patients who are actually terminal will not be judged so until it is too late to complete the legal process. (2) Patients who are not actually terminal may be told they are and lose opportunities for successful treatment or longer-than-expected survival.

(3) Vast numbers of individuals who are suffering but not terminal are prohibited from accessing this form of relief, while the social and political will to help them is depleted. In short, the law fails to achieve its aim and sets up potential for other great harms. (Don't misunderstand me—I am not arguing for expansion of the criteria for qualification; I'm simply pointing out an inherent injustice in the laws as they are and must be constructed.)

Laws are important: They express, enshrine, and enforce a society's values. The law, as an instrument of the commonalty (the State) is intended to promote the common good and, above all, to protect members from harm. Like medicine, law traditionally, historically errs on the side of protecting the vulnerable and preserving life. On

this basis, as well as inadequacies of the so-called safeguards, the Manhattan Appellate Court just rejected the latest effort to legalize PAD through the courts. ("New York Judges," 2016) Sanctioning a physician's direct facilitation of a sick person's death upends both medicine and law. To set aside a class of non-criminal individuals and define and determine them as eligible for State-sponsored death because they are ill, not economically productive ("takers not makers"), likely dependent on others for their care, mostly old, and expensive to maintain, sends a strong message that these people *and anyone like them* are of no worth.

Apparently, we have already sent that message. Our society has so prioritized independence, autonomy, productivity, and activity that some for whom those

## Summary of main provisions of enacted physician-assisted death laws

Physician-assisted death laws establish a legal framework in which a physician may prescribe lethal drugs to a terminally ill adult patient for self-administration to end his or her life.

### The person seeking physician-assisted death must:

- ♦ Be an adult.
- ♦ Have mental capacity (variously defined) to make medical decisions.
- ♦ Be a resident of the state in which the option is legal.
- ♦ Be certified as having a terminal illness, usually defined as incurable, irreversible, and likely to cause death within six months, by both the prescribing physician and a consulting physician.
- ♦ Voluntarily express the wish to die.
- ♦ Make two oral requests for the lethal prescription, separated by 15 days.
- ♦ Make one written request, signed in the presence of two witnesses (in Oregon, Washington, and California

but not Vermont: one witness may be related to, stand to inherit from, or own or operate the facility in which the patient is receiving care).

- ♦ If deemed necessary by either the prescribing or consulting physician, consult with a mental health practitioner.
- ♦ In Washington, Vermont, and California, be capable of self-administering the drug.
- ♦ In California only, complete a final written attestation as to their voluntary and self-administration of the lethal drugs within 48 hours of ingestion.

### The prescribing physician must:

- ♦ Certify that the patient has a terminal illness as defined above; possesses mental capacity to make medical decisions; is not suffering from any mental illness that would impair judgment; and is acting voluntarily.
- ♦ Inform the patient of diagnosis and prognosis; alternatives such as

- hospice, palliative care, and pain control.
- ♦ Refer the patient to a consulting physician to confirm the diagnosis and prognosis.
  - ♦ Refer the patient to a mental health practitioner if mental illness that might impair judgment is suspected.
  - ♦ Prescribe and directly, or through a pharmacist, dispense the lethal drugs.
  - ♦ Fulfill documentation requirements.
  - ♦ Provide specified additional counsel.

If this process is followed, then the physician and others (presumably, though not specified, other family or professional caregivers) are immune from any civil or criminal prosecution and professional sanction. The act of self-administration of lethal drugs is not, per the statutes, considered "suicide, assisted suicide, homicide, or mercy killing" and has no effect on a laundry list of contracts, agreements, and policies (notably life insurance).

powers are diminished would rather be dead. Overwhelmingly, the persons who have used the law in Oregon say that their primary motivations are loss of autonomy, loss of dignity, and loss of ability to engage in activities that make life enjoyable. Further down the list are: loss of bodily functions, feeling a burden to family, and, nearly at the bottom, pain or fear of pain.<sup>3</sup> Loss of agency, pleasure, and meaning are symptoms of existential suffering and bear a close resemblance to symptoms of depression, which can lead to suicidal ideation. Anyone else expressing such despair, even in the context of serious illness, would receive intensive intervention to prevent self-harm—but because these persons are “dying anyway,” the framework of physician-assisted death would just hand them the poison.<sup>4</sup>

Once the bills have passed, the legislators move on to next year’s cause célèbre, the activists tweet out a big win, and healthcare reformists and policy makers under pressure to do something about end-of-life care point and say, “Look what we did!”

It’s a cheap deal in big type for everyone. The fiscal impact estimate for California’s law pegged the cost of setting up the regulations, collecting the data, issuing annual reports, and following up on concerns at about \$323,000 in the first year and \$245,227 each year after.<sup>5</sup> At an anticipated utilization rate of 1000 patients/year, that’s roughly \$300 each. The California proposed budget for 2017 includes \$2.3 million for the state’s Medicaid program to pick up the tab for the prescription (\$1500 to \$3000). (Leonard, 2016) All-in, the cost per person is just about spot-on the average cost of a *single hospital day* in California in 2013. (Rappleye, 2015) Make no mistake, private insurance providers will take note, and in an era of increasing financial pressure and constrained resources, cheap, expedient options will always end up as the preferred treatment.

## A different solution: Whole Person Care

Legalizing PAD helps only the privileged few (and most often they are economically, socially, financially privileged; OPHD, 2016) who qualify and have the sophistication and tenacity to navigate the process. Brittany Maynard and others who have advocated for PAD have rejected the label of “suicide,” insisting that they do not want to die, they just don’t want to suffer. Anticipating suffering is a kind of suffering in itself, and when people are suffering, they just want the suffering to stop. Now.

***To set aside a class of noncriminal individuals and define them as eligible for State-sponsored death because they are ill, ... sends a strong message that they and anyone like them are of no worth.***

The rhetoric of the PAD debate offers only one stark choice: Suffer horribly or die early. Door #1 or Door #2. In that choice, Door #2 looks far preferable and even reasonable. However, if there’s a Door #3—stop or significantly reduce the suffering without having to die early—the vast majority will choose it.

Two studies conducted in Oregon (Ganzini & Dobscha, 2004; Tolle, et al. 2004) examined the decision process that led patients to not pursue PAD. From interviews with family members of nearly 2000 patients who would have qualified for the option between 2000 and 2002, the researchers determined that for every one person who ingested lethal medications in Oregon in that timeframe, 200 seriously considered it, and about ten discussed it with their doctors. Why did only one in 200 follow through? Reasons varied, but the authors estimated that nearly half (about 46%) changed their minds *because their suffering was addressed* and relieved by an aggressive intervention including symptom control, treatment for depression, or referral to hospice care.

Suffering may be common at the end of life and throughout serious illness, but

it is neither guaranteed nor necessary. Two rapidly expanding sectors of healthcare—hospice and palliative care—are highly effective in providing multidimensional relief. The entire hospice movement, in fact, was launched by Cicely Saunders in England in the 1950s, in reaction to the suffering and neglect of a then-rising population of cancer patients and a vocal faction advocating euthanasia as the only humane solution. At a time when pain management was minimal and cancer treatment both ineffective and brutal, Saunders refused to grant a place to the expedient option. Instead, she dedicated her energy to pioneering an approach that addressed “total pain,” by which she meant all dimensions of suffering. (Hanks, et al., 2010)

Today, almost half of all American Medicare beneficiaries die in the care of hospice, mostly at home with their symptoms controlled and family supported. Admittedly, many enroll too late to enjoy the full benefit of the care. Administrative barriers such as the requirement that patients give up all curative treatment, the difficulty of terminal prognosis, the proliferation of aggressive curative interventions, and lack of awareness and advance planning on the part of patients and families have suppressed full utilization. Still, in a summary of survey results collected from 1610 hospices in 2014, the National Hospice and Palliative Care Organization reported that 93.2% of hospice patient family members rated the care they received as “excellent” or “very good” (NHPCO, 2015). Better than Geico.

Palliative medicine, initially a hospital-based consultation approach to symptom control and personal support, has taken off in the past 15 years: the Center to Advance Palliative Care currently reports that 67% of hospitals with 50 beds or more and 90% with 300 beds or more offer palliative care hand-in-hand with therapies focused on cure or disease management. (Morrison, 2015) Increasingly, hospitals and hospice agencies are extending palliative care

## Death is not a medical treatment. It should not be offered as any kind of solution to suffering

services into the home and outpatient settings, focusing on symptom management, goals of care, psycho-social-spiritual support to patients with serious and chronic conditions, as well as terminal disease.


The growth of hospice and palliative care has spurred research into new approaches, pharmaceutical and complementary, to pain and symptom management as well as counseling and companioning approaches to confronting existential suffering. What is emerging as a new paradigm of “whole person care” is in equal parts a return to traditional ways of being with fellow human beings and ultra-modern evidence-based technique. It necessitates a shift in perspective from “What is the matter with you?” to “What matters most to you?” This high-touch, low-tech approach has not only pioneered highly effective methods of relieving suffering, it has reclaimed the care in healthcare and the end of life as a time rich in potential for significant personal growth and transformation. (Byock, 1997; Callanan & Kelly, 1992; Casarett, 2010)

In systems and structures, whole person care has been proven to be highly efficient as well as effective, hitting the bullseye of the “triple aim” of healthcare reform: providing a better patient experience, improving health and outcomes for populations, and reducing per capita cost. (IHI, 2016) It has spurred other efforts to re-prioritize the patient and re-humanize healthcare, among them the Right Care Alliance (Lown Institute, Boston), Choosing Wisely Initiative (ABIM Foundation), and the Slow Medicine movement. Whole person care is getting institutional push from several health systems in California, spearheaded by Dr. Ira Byock’s new Institute for Human Caring. Indeed, Dr. Byock and others believe that whole person care holds the key to improving care across the board, and is not only possible but imperative for the future of healthcare. (Byock, 2012)

All of this is hard work, an upstream slog involving all the energy, commitment, and stakes of the salmon run.

It requires incremental and systemic culture change within our organizations of care and in our communities, families, and civic institutions. It takes legislative, regulatory, and policy changes. It takes money. All of which is at risk of dilution and diversion by a movement that focuses solely on a narrowly constructed and barely accessible legal solution to a major healthcare and human problem. That the solution being proposed is also corrosive to the healing intention of medicine and societal values of true dignity, compassion, and care only makes it worse.

### In Sum

Death is not a medical treatment. It should not be on offer as any kind of solution to suffering. Making it so is an admission that our healthcare system has failed, that we as caring companions in life, dying, and death have failed in our humanity. I understand, and even share, the frustration of those looking down the long barrel of a difficult end of life now, next year, or ten years from now and their impatience with the slow pace of change. Legalizing PAD will only slow it further. We cannot, as Cicely Saunders did not, afford to throw up our hands and accept failure or leap ahead to an expedient way out. The only solution is to focus our talents and treasures on the singular goal of expanding whole person care throughout healthcare and into our communities. Our humanity no less than our healing depends on it. 

### Endnotes

1 Montana is typically included in the list of states where physician-assisted death is legal; however, there is controversy surrounding this characterization. Regardless, the state does not have a statutory or regulatory framework for PAD, and there is no reliable data on the prevalence of the practice.

2 For a recap of Brittany’s story: [https://en.wikipedia.org/wiki/Brittany\\_Maynard](https://en.wikipedia.org/wiki/Brittany_Maynard)

3 Based on statistics gathered over 17 years of the Oregon Death with

Dignity Act, <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx>

4 It is worth noting, though whether cause or correlation is unclear, that over the years since the Death With Dignity Act was enacted in Oregon, suicide rates in the 35- to 64-year-old cohort have risen 49% vs. 28% nationally.

5 According to Assembly Committee on Finance analysis of CA AB2X15, [http://www.leginfo.ca.gov/pub/15-16/bill/asm/ab\\_0001-0050/abx2\\_15\\_cfa\\_20150903\\_190734\\_asm\\_comm.html](http://www.leginfo.ca.gov/pub/15-16/bill/asm/ab_0001-0050/abx2_15_cfa_20150903_190734_asm_comm.html).

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# The End of Sentience:

# Aided Dying in a Human

by Bart Windrum

I'd like to offer a reasoned essay on why I support physician-aided dying (in the United States, the provision of lethal substances by prescription that a dying person can consume, should he or she choose) but I'm not sure I can any longer. Deep engagement with aided dying has changed my basic position. I no longer believe, as I used to, that reasoning matters when it comes to support of or opposition to aided dying. I care that people opposed to aided dying hold heartfelt concerns, yet I find myself caring less about those concerns. I've come to see the issue simply. I support aided dying, think we ought to enact it nationwide, and that it ought to be more broadly available than current and proposed legislation allows. Aided dying ought not preclude a range of meaningful end-of-life reforms in the medical, social, and political spheres, nor should any such reforms preclude the availability of aided dying.

I became an end-of-life reform advocate after experiencing each of my parents' error-prone terminal hospitalizations in 2004 and 2005. Mom's demise occurred in a very callous ICU; Dad's was induced by the conflation of ill-advised cardiac testing and hospital acquired MRSA. I detailed those events, the meaning I came to make of them, and solutions to the problems they represented in my first book, *Notes from the Waiting Room: Managing a Loved One's End-of-Life Hospitalization*. Aided dying does not figure prominently in my end-of-life lexicon although it occupies a well-anchored place within it.

In *Natural Transitions Magazine*, dying and death are usually discussed in loving terms. In our lives, loving people die while loving people attend to them. Love is aided dying's foundation, but

working for and agitating against aided dying are not loving pursuits. And although my own work is borne of love, through it I address an ongoing lack in practical end-of-life guidance: how to identify and assess, then learn to mitigate and even overcome the range of prevalent everyday obstacles to dying in peace. Thus my senses, my work, and this essay emanate from a "let's get down to business" framework. I view aided dying as a practical solution for a systemic problem to provide us all with at least one guaranteed option to die in peace.

My readiness for aided dying debate has subsided since reaching an apex throughout 2015, beginning in February when aided dying was first introduced in the Colorado legislature. I'd been a fervent enough supporter that Compassion & Choices invited me to stand in the statehouse during the bill's introduction and press conference, and you can see me pictured there. For the hearing I rehearsed my testimony to ensure I could shoehorn it into three minutes while still offering an intelligible delivery. I felt discontent with the inequitably managed speaking signup process, disenchanted at how disabled activist leaders took advantage of the proceedings and the inordinate deference shown by legislators to them—especially given the overflow crowd signed up to speak (all day and into the evening).

During mid-2015 I was able to offer readers of a Facebook group I curate, *To Die in Peace: Overcoming Obstacles*, a substantial aided dying debate of unusual depth when a friend and I exchanged contrasting views. The effort tested, and improved, our friendship but contained some fraught moments.

Then, at an intimately small October 2015 end-of-life ethics and management conference in Los Angeles, I presented Windrum's Matrix of Dying Terms. Over several days aspects of aided dying, which had by then been passed into California law, were presented, heatedly debated, and lamented over. I learned even more about how opponents view and experience the reality, ethics, and implementation of aided dying. I learned on a gut level how intractable the issue is. And I tired of the controversy.

I don't share opponents' ethical concerns; I consider most of those arguments unethical because they would deny a guaranteed method for dying people and their loved ones to experience peaceful dying in a society where dying in peace requires more of us than should be necessary—often impossibly more. I believe that human beings have a fundamental right to die in peace, and if our medico-social construct makes this goal inordinately difficult, to obtain reliable means by which to do so. To be clear, the context for this is advanced irreversible disease that would result in horrible or protracted dying, as defined by each dying person.

I have long held the baseline viewpoint that some aspects of our lives as high-order sentient creatures transcend social constructs. Simply: we are advanced sentient beings on a planet in a solar system in one galaxy among billions. Our last moments in this place are sacrosanct—which means that our last months-weeks-days must be, too. Only Hollywood offers *deus ex machina* endings; in our everyday world a peaceful death almost always requires that truly peaceful dying time precedes it. For me, aided dying is the only way to guarantee peaceful dying under a range



# Comas

of circumstances that remain the default norm in today's societies. Although the universe owes us nothing, I view peaceful dying as a human right within human society, and if it was guaranteed available without physician assistance, I wouldn't seek physician assistance.

Previously, I would passionately present a range of reasoned arguments supporting this position. An article like this requires that I offer them, and I will. But now I'll preface them by saying to all the arguments against, "I no longer care." Part of not caring about the arguments against (I do care about the people making them) is having realized (a) how intractable support of and opposition to aided dying are—they are completely mutually exclusive; (b) especially in the United States, how limited any aided dying provisions will be, constrained to the most narrowly framed circumstances; (c) the socio-political meanness of our times that makes meaningful reform across the dying spectrum unlikely; and (d) that the interests of a minority of disabled and religious figures are able, so far, to forestall the enactment of aided dying legislation.

My primary argument for aided dying is that sentient beings have the right, and deserve the opportunity, to control, shape, time, and achieve a peaceful death when circumstances prove or predict that the opposite is likely. This viewpoint is predicated on accepting humans primarily as universal-planetary beings, and on the idea that each of our individual dying experiences ought not be controlled by corporate, religious, and social constructs—especially when those constructs are so lacking in sanity and justice, seemingly inured to positive development, and likely to be predicated upon the meanest spiritual, experiential, and fiscal policies.

On a practical level, my short answer to the irony of being suspect of authority yet wanting a state-legislated process controlled by medicine to assist peaceful dying is "quality control." One benefit of a legal framework for aided dying is that the drugs procured would be of known origin and quality (which I doubt may be said of extra-legal overseas or internet procurement). I have thoughts about softening the direct link between doctors writing lethal prescriptions and the dying people who'd take them, but our society is not ready (the scheme would make being terminal a class, with a range of resources available and rights given to class members who would pick and choose based on personal need and preference).

The likelihood is that most peoples' dying will remain medicalized, if for no other reason than that medicine's beneficent success in saving and extending life will probably result in most of us engaging medical treatments as we age and as we near death. So it's not a stretch for individuals to seek a way to have a medicalized death which is guaranteed to be peaceful and which we can control ourselves.

Disabled people have fears that deserve addressing. I'll do so with the same outspokenness that disabled activist leaders (DALs for short) offer in their opposition. Because I believe that their fears are outsized and are accorded undue influence, I'll preface with my assessment that the disabled leaders I encountered during aided-dying proceedings are strong people who overplay their hand at the expense of broader society (their personal websites I viewed in 2015 documented and celebrated their civil disobedience). Lately I muse about how much society has done to accommodate the disabled: curb cuts, ramps, transit access, parking, building and room access. This is all just. We have helped enable the disabled,

as we should. But when it comes to aided dying, the DALs want to disable everyone else.

Some disabled people support aided dying (one family member of mine among them). The DALs don't; they argue their fears that if aided dying were legal, insurance companies would not pay for ongoing treatment. Another fear is being coerced into applying for and consuming the lethal prescription. Yet the narrowly drafted aided dying statutes all include requirements for being actively terminal, wanting to die, and having to navigate an involved application process. Circumventing any of these provisions remains illegal.

DALs speak of the "slippery slope" on which they foresee legions of disadvantaged people being pushed off to die. "Slippery slope" has become an accepted euphemism used by aided dying opponents to describe a future in which bureaucracy terminates citizens at will.

Conversely, consider the millions of people dying horribly year in and year out, since the introduction of life support technology in the mid-twentieth century. Add some number of harmed survivors per deceased, whose haunted memories of their loved one's dying times become fully reanimated at any mention of their dying even years later—you may be one, as am I. We're already at the bottom of a society-wide slippery slope spanning generations. Unlike the DALs' fears, mainstream society has and will continue experiencing enormous numbers of needlessly mean deaths of which millions of people are legitimately afraid—the deaths have in fact happened. Aided dying is the legitimate grassroots response to horrific dying of genocidal proportions. Even aware, non death-denying, spiritually-

engaged people must be broadly skilled and hyper-vigilant on their own and their loved one's behalf so as not to get ensnared in inhumane dying situations.

Coloradans will vote during the November 2016 election on establishing ColoradoCare, a state-wide universal healthcare system. Enactment of a universal coverage system suggests that Colorado's disabled activists could lay to rest their fears of being denied treatment and herded toward premature dying. Regardless of whether ColoradoCare passes, if the disabled want medical treatment reform, perhaps the DALs ought to lobby for that rather than against aided dying.

Aided dying opponents suggest that other end-of-life reforms would benefit more people and should be pursued in lieu of aided dying. I have some history proposing medical reform. In 2008, early in my transition to an end-of-life reformer, I submitted a public initiative to the Colorado Blue Ribbon HealthCare Reform Commission, "The Option to Die in Peace." It was the only one of 31 submissions to mention "dying" and "death." Over its 12-month meeting period the 27-member commission never once discussed it. Interestingly, my proposals foreshadowed Dr. Ira Byock's proposals in his February 2015 op-ed published in the *Los Angeles Times* opposing aided dying in California. We both suggested medical school reform with palliative, pain management, and eldercare components. We both called

for enhanced physician licensure. I went further, proposing a statewide hospice public education campaign. Aside from an email from an old business colleague turned end-of-life professional, I neither received nor heard of any statements or action from anyone in the Colorado end-of-life community about the initiative. I thought it curious that professionals didn't take the public opportunity to advance an even more meaningful proposal than my admittedly lightweight one (I offered no financials).

I heartily support a wide range of reforms to our dying scene. They ought not be exclusionary. I continue to wonder why the medical community does not broadly enact sensible treatment reforms within its own sphere, or hasn't organized to propose the reforms legislatively, or why a man of Dr. Byock's stature endeavored in an op-ed to piggyback worthy medical reforms on an aided-dying bill he staunchly opposed (the reasons that occur to me—a desire to torpedo the legislation, an inability to effect meaningful reform—in themselves support the justice of aided dying.) Meanwhile, generations have gone by without sensible reform. I'd happily support both palliation/

hospice and aided dying reforms, but opponents won't.

Safeguards and reporting in aided dying statutes are meaningful to ensure that only people who want to avail themselves of aided dying do so. Front-end safeguards are built into the application process, which spans multiple weeks, requests, and meetings. I agree that application safeguards have room for improvement through better inclusion of palliative treatment and hospice information. During the LA conference the California Compassion & Choices campaign chair responded to a challenge about the lack of usage reporting by saying "we view safeguards as obstacles." This honest assessment resonated with me. I don't mind reporting requirements but no longer view them as necessary. Reporting serves social oversight and costs money to implement, but it does not aid dying in peace.

The issue of narrow versus broad use is raised against aided dying legislation, the criticism being that only old, well-educated white people use it and then rarely, hence it's not worth the time

## Terminology

\***Suicide** is the taking of one's own viable (non-terminal) life.

\***Euthanasia** is the taking of someone's life by another person. The context is medical and usually beneficent, but can be devious (which would be criminal).

\*Some distinguish between **rational suicide** (which might arguably be applied to those suffering from cognitive decline who would request euthanization after declining past benchmarks they've established while still competent) and **irrational suicide** (jumping off a bridge due to existential angst).

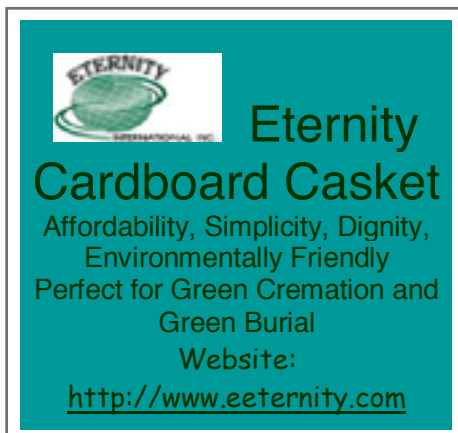
\***Aided dying** in the United States is the provision of lethal substances by

prescription that a dying person can consume, should he or she choose.

\***Medicalized dying** is dying under the control of mainstream medicine, usually in medical facilities or social-medical facilities. It's possible for medicalized dying to be humane and peaceful; it's possible for medicalized dying to literally be torturous and existentially harmful for all involved.

\***Natural dying** is intended to mean non-medicalized dying under peaceful circumstances (although it could apply to being eaten by a bear!). I suggest that natural dying doesn't really exist in today's world except in few instances.

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and effort. I say “if we build it they will come,” and if we were to expand access more would come. Thousands if not millions of us could benefit from aided dying to die in, and at, peace when other pathways fail us.


Catholicism has brought this planet much good and much bad. In any case the power the Catholic church wields is disproportionate to the number of its adherents, and even some of those disagree with its end-of-life strictures. If the Church wants to deny aided dying to its members that proscription ought not affect anyone else.

Some say that those wanting aided dying do so mindlessly. To the contrary: people wanting aided dying have given more thought over more time to their dying process and death than anyone in our death-denying culture. Aided dying proponents are among the most death-literate and death-accepting members

of society. For newcomers, the statutes’ application processes offer many weeks of off-ramps for anyone reconsidering. And, of course, there are no requirements that any prescription be consumed.

**I**n an ideal world the US Supreme Court would issue a finding as Canada’s has, that the option of dying peacefully, guaranteed through aided dying, is a human right that cannot be abridged and set the States to making their own provisions for enabling it. As things are, it takes an average of six tries to enact aided dying in any state. Each state’s effort could span a decade. Currently Colorado has gone through two, with the effort advancing slightly on the second try. (A new initiative, in the signature gathering phase, strives to place the issue on the November 2016 ballot.)

We’re first and foremost sentient beings in a cosmos and only secondarily subjects in an increasingly oppressive

socio-medical system. Sentient beings ought to have available sane, peaceful dying options, to optionally use under adverse dying circumstances which remain the norm in our society. This is the overriding and only ethical aspect. Denying aided dying is unethical. The rest is policy, which for me has devolved into noise. 



*Bart Windrum is the author of the 2009 Colorado Book Award finalist, Notes from the Waiting Room:*

*Managing a Loved One’s End-of-Life Hospitalization. His forthcoming book is tentatively titled The Promised Landing: A Gateway to Peaceful Dying. You may reach Bart at [Bart@AxiomAction.com](mailto:Bart@AxiomAction.com) and [AxiomAction.com](http://AxiomAction.com).*

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# WAKE UP TO DYING

By *Nina Thompson*

## It Started with a Box

My father's death, and my family's response to it, set me on this path. When my dad died, I said to my family, "I am going to build a box for his ashes."

And they said, "Don't be ridiculous; go buy one."

My grandmother even said, "Nina, I will pay for it. Go to the funeral home and pick it out - that's what funeral homes do."

And I said, "I'm a lesbian from Vermont. We build things - that's what we do."

Then I came home and had to follow through. I'm not a woodworker, and I don't have a wood shop, so I asked a friend who did for help, and the process of building the box became a beautiful, contemplative exchange between the two of us. Over a few hours we slowly crafted the box together. Periodically I'd go outside and look at the mountains around his farm and cry, and when I'd return, I'd find he'd kept the work going. Then he'd show me how to shape the next piece of wood or use the next piece of equipment - all in a beautiful, even sacred, silence

At the time I was considering becoming a hospice volunteer, and as I thought about my friend, I realized he was one - even without training, he was a hospice volunteer.

When I showed the box to another friend, he said he thought it wasn't done, that it needed more sanding. The same thing happened: a process of quietly, contemplatively, and deeply connecting with a person around creating the box for my father's ashes. I could see, halfway through the process, that he was gently mourning, and I thought about the fact that he didn't even know my dad. But his father had died when he was nine, and I

guarantee that he didn't get to build his father anything. He might not have even known - this was almost 40 years ago - maybe he wasn't even told right away.

In the wake of this experience, it dawned on me that we have become wholly and unhealthily removed from death and dying in the United States, and I became very focused on doing what I could to shift that cultural norm. I became a hospice volunteer and envisioned different organizations that might begin the work. I researched building a green cemetery, explored how to start a cooperative funeral home, and pulled together a team to test the viability of a residential hospice in my community. While none of these options was pursuable, together they revealed the heart of what I felt at the time and still feel is most important in this work: stories and community.

## Stories Connect Us

I had long dreamed of offering an audio story library to share the voices of those who had died, their families, and their caregivers. Stories are powerful. Stories are how we learn from each other and how we connect with each other in this most profound and mysterious human experience. Not long after I had put to rest the prospect of a hospice facility, I met audio story producer Erica Heilman, and the Wake Up to Dying Project (WUTD) was born.

The Wake Up to Dying Project is a nonprofit organization with the mission to encourage people to think and to talk about dying. We believe that if we pay more attention to the fact that we die, we will pay more attention to the way we choose to live. Thus WUTD's mission is twofold: to help people become more prepared for this shared human experience, and to help them get

more out of life. In all our activities, we find ourselves facilitating a community coming together to empower itself, using story to begin and deepen these conversations about death and dying.

To date, we have archived more than a hundred short, first-person audio stories on our website. The stories are tagged by topic for easy searching, and topic tags include care-giving, grieving, living life, and reflections. Among our wide range of stories, some are deeply moving, some are quite funny - just like life.

The audio stories are free and available for anyone to use. I know a hospice director who uses them for volunteer training and a bereavement group that listens to them to prompt conversation. I often suggest specific stories to friends and acquaintances who have a family member who is dying or has recently died. For example, in the story "It Comes in Waves," a woman tells of her emotional ups and downs after her partner died, likening them to the unpredictability of driftwood floating on waves. I played that story for a group of high school students, and one young woman reacted with tears and said, "That's how I felt after my grandmother died. I was all over the place, and I didn't tell anyone how I was feeling because I thought I was going crazy." I let her know that what she felt wasn't crazy - it was grief. Stories have that power - to make us feel less alone in what we are experiencing. That can be truly healing.

I encourage everyone to spend 10 or 15 minutes on our website to listen to a few stories. Most are less than three minutes, which makes it easy to get a sense of their diversity within a short amount of time. Then, share a particularly interesting or touching story with someone - a friend, colleague, or family member - and start a conversation. I like to ask, "What do you think?" and see where the conversation goes.



Almost inevitably, the story prompts an intimate conversation about a personal experience with death, dying, or loss – the kind of conversation so many people are aching to have but don't know how to start.

Some of our stories include a touch of humor, the kind that's possible when we're open to the fact of death. In "Go to the Light," a woman recounts the last exchange between a man and his mother, a poignant interaction that sums up the whole of their life together in just a few words. Other stories delve into topics that many people find especially challenging, such as the death of a child. In "Sandbox," a palliative care doctor shares how one family thoughtfully incorporated a play space for their older child into the cemetery plot for their baby who had died at birth. In "First Call" and "A Knitting Story," hospital chaplains share some of their early experiences and lessons learned about the art of talking with dying people and their families.

## Into the Heart of Community

Right now, the most public venue for these stories is our Traveling Exhibit,

a multiday event that offers visitors various entry points for interacting with end-of-life. At each event, we set up our big white tents in the heart of a community and stay for four days. There is a comfortable listening tent in which visitors can settle in to listen to a professionally produced loop of 50 WUTD stories. Nearby is the resource tent, with literature and resources from local community organizations. We also offer a full slate of workshops and panel discussions, as well as daily "death chats," which are facilitated hour-long, lunchtime conversations.

Visitors have described the space created by the Traveling Exhibit as contemplative and peaceful, and we regularly witness people being moved to share their stories openly with each other. Last year in the resource tent in Burlington, VT, a visitor asked if we had any materials about suicide on hand. When she heard that we did not, she said, "That's too bad. My son killed himself a couple of years ago," prompting another person in the tent to turn around and say, "My son killed himself two years ago." They talked for a long time, these two strangers with a shared experience who found each other in a 10' x 10' tent on the lawn of the public library. That kind of thing happens a lot at our events.

At one of our first death chats, I started by asking people why they came. The second person who wanted to speak couldn't express herself clearly because she was crying. Her husband spoke up and said, "We're here because I have lung cancer and I'm dying, and I wanted to see if there was anything here that could be supportive to my wife at this time." He went on, "I'm happier than I've ever been in my life. I'm not sweating the small stuff, I'm completely enjoying every moment. But I'm worried about my wife, I don't want to leave her alone, and I don't want her to have to take care of me alone."

Later, one of the last people to speak said, "My husband died about eight months ago. He said it was the best time of his life, that he got so completely clear. And he was worried about me. My community stepped in and helped me. You have to ask for help." She offered to share some other thoughts after the discussion, and she and the couple talked for a long time.

This is what happens when we pay more attention to the fact that we die. We share our stories, and we learn from each other. We learn that we are not alone. At our events, people think and talk about death and dying together, with each other, in community. We offer the opportunity and the tools for members of the public to move from fear and avoidance of death toward familiarity and acceptance. Our surveys tell us that after attending our event, more than three-quarters of our visitors say they will do one thing to increase their own or others' awareness about end-of-life.

On an organizational level, our events turn communities toward themselves as their own teachers. To produce each event we fill more than 90 volunteer slots, and we work with 20–30 panelists recruited from the local community. Using grassroots organizing in the year leading up to the event, we also develop community partners that include hospices, medical centers, home and traditional funeral groups, health-insurance companies, advance-directive organizations, elder law firms,

and bereavement centers, just to name a few. In the experience of participating on panels together and working volunteer shifts together, members of these organizations strengthen existing connections with each other and the community at large that endure long after we've packed up the big white tents and left town. This sustained effect is critical to me because so much of our mission is about bringing back into community death awareness and the capacity to engage with death.

## Diving Deeper, Reaching Further

We're at the point now where we're transitioning our event structure somewhat. For the past two years, we've brought the Traveling Exhibit to host cities with the help of community partners who provide some financial support, serve as panelists in our workshops, and help recruit volunteers. This year, for the first time, we will be returning to a city we've visited before (Burlington), and the response has been phenomenal. Last year we had six community partners in Burlington, and this year we have 11. Some of them are helping us design new workshops. It's enormously encouraging to collaborate with partners who see the potential of our platform and help us tweak it to better serve their specific community.

In addition to piloting a second event in Burlington, we are developing a three-year collaborative event model in which host communities gradually take over ownership of the WUTD event until they are producing an annual event on their own. (We'll continue to share production concepts and audio stories with them.) This community-owned model will help us reach deeper into local communities, and we believe now is the time for that growth. Culturally, Americans are demonstrating that we are ready to begin talking about death and dying, as many creative organizations – Death Cafes, Death Over Dinner, and the Conversation Project,



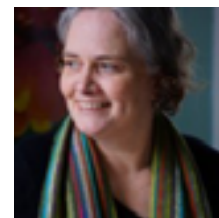
for example – begin finding a ready audience.

We want to maximize WUTD's capacity to bring our collaborative, community-based physical stage and our first-person audio stories into the heart of as many communities as possible to take advantage of this moment of shift. By 2020 we hope to have visited 15 communities, and I encourage individuals and organizations interested in bringing our Traveling Exhibit to their town to contact me so we can begin planning together about making that happen.

We're also beginning to expand our reach in other ways. We welcome National Home Funeral Alliance as our first national sponsor, and we look forward to working with other national organizations when our missions align. We are also excited to be using our audio stories to start a podcast series, a move that seems like a natural progression for our audio library. At this point we can bring our Traveling Exhibit to only a few towns a year, but a podcast can reach thousands of individuals – at a time and location of their choosing – who we hope will talk about the stories with others. If you don't already receive our newsletter, we hope you will sign up

for it on the website to be notified when the podcasts are distributed.

Since founding this organization three and a half years ago, I've been thrilled by the number of people who have engaged with me and with WUTD to talk about death, dying, and life. The North American culture is shifting; there is an emerging readiness to explore our end-of-life experiences through conversation, through story, and through creative community dialogue. It's exciting to be part of a movement that truly is changing the way our culture approaches the shared human experience of death and dying – and in the process, is changing the way we live. 🌍



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*Join us in 2016 in Burlington,  
Vermont, July 12-17. Information at  
[wakeuptodyingproject.org](http://wakeuptodyingproject.org)*

# Death Café Build Out: Why it is, and isn't, a piece

NTM's Karen van Vuuren speaks with Death Café's Jon Underwood.

In 2014 when I met Jon Underwood, Death Café founder, we rendezvoused on a wall outside a busy London train station as he awaited the arrival of his wife and kids from a trip to meet family. A local council employee, techy person, modest, unassuming Buddhist chap, Jon appeared simultaneously bowled over and at ease with the popularity of the death café (DC) concept.

Since 2011, when Jon and his psychotherapist mother, Sue Barsky Reid, hosted the first death café in his mother's East London home, death cafés had been popping up in some of the most unlikely corners of the globe. The menu of tea, cake, and death talk was meeting a seemingly unquenchable thirst for honesty and authenticity about end-of-life.

As London's frenetic commuter world buzzed around us, Jon told me about his idea for a bricks-and-mortar version of the death café in London. It was a dream he'd been pursuing for a time, and the launch was on the horizon. I asked about the other members of the DC team and was amazed to learn that DC was a solo act. Jon was running the entire show from his home.

Recently Jon and I reconvened so I could catch up on some DC news, including the ambitious 2015 campaign to launch a real death café in the UK capital.

**Karen:** When we met in 2014, you were pretty much a one-man band. Has anything changed?

**Jon:** No (laughs).

**Karen:** Can you say more? Tell me what you do with the DC on a daily basis, about your support team, and the people really backing you up.

**Jon:** What I do is mainly website moderation. When people submit a post to the DC site, I check that it is in accordance with our guide, and if it isn't, then I talk to them and explain to them why it isn't. Then I manage the main inbox. We get a lot of questions about DC. Some are basic, like the email this morning asking for the address of the website! And I thought, okay! But I try to be polite and just answer everyone. I deal with password resets, that sort of thing, and I spend my time speaking to various people: maybe people interested from a press perspective, or people working in the sector, maybe people who want to run their own DC. Then I am generally in charge of organizational development, so holding the model that we've got and iterating that. I'm currently working on a new version of the DC guide. DC has a quite specific, clearly defined event format.

**Karen:** What are some of those changes?

**Jon:** I'm not going to say at this point, but there will be a couple. When the guide's ready, we'll get people to look at it and give input.

**Karen:** Back to what you've been working on...

**Jon:** I've been trying to develop things like the real DC project and writing and pulling together a book, a community book rather than something I've written. We don't have any income streams, which makes DC very vulnerable, so we're trying to develop those without doing something silly. We might have some nice merchandise like a nice teacup and t-shirts. I'm doing this kind of development work as well.

**Karen:** You mentioned the book idea. What do you mean by a community book?

**Jon:** It's not very clear at the moment, but what we want is something that represents DC. One of the unique things about DC is that it is very much a community project. There are other more successful death initiatives going on, but ours is unique. DC has tied people together now across 35 different countries, all of which have held death cafés. People have made it happen and DC has given them a tool to shift attitudes about death a little bit. A book wouldn't be about my personal views because DC is diverse and it's a community thing, kind of by the people, for the people. It would have that kind of flavor, representing diversity, but also the commonality of people finding DC helpful. It would reflect the different countries and cultures that are involved, and I think there's so much richness in that. The kind of book I'm thinking of at the moment would be a kind of collage of DC.

**Karen:** Would you solicit stories from DCs around the world?

**Jon:** Yes, that's how the book would be sourced. We've got a lot of stuff already. There is a lot of material because our website is the most community-owned site around death and dying, as far as I know, as all the content is submitted by the community. We've got about 600 reports of death cafés and loads of blogs, so we'd use some of that with people's permission and then solicit more. I'm talking to Lizzy Miles about that. Lizzie started the first DC in the US in Columbus, Ohio.



# of cake

**Karen:** Back to what you do and the other team members...

**Jon:** There are other people involved in DC. Megan Mooney is really important. She runs our FaceBook page,

which is huge now. It's got nearly 25,000 likes, and she does that really well. It's a lot of work because she posts four pieces of content a day to keep it going. There's Lizzie Miles in Ohio and loads of other "senior" people like her who do all kinds of work behind the scenes that I don't even know about in terms of mentoring and advising and holding everything. Then there are also the people doing DCs and attending them.

**Karen:** So, no one is a paid employee yet?

**Jon:** No. We haven't got any money at all. There's a button on our website, but so far, I think we've had only four donations.

Death and money is really interesting. A lot of people who've done amazing work around death and dying haven't made a dime from it. The Natural Death Centre UK celebrated its 25th birthday recently.

They've just done amazing work and inspired me, but they find it hard to function as a sustainable organization. The fact they've managed to exist for 25 years is due to their tenacity and to the amazing people who're involved. If you want to make a lot of money in this world, don't do it around death. Although there are people who are breaking through like Caitlin Doughty who is a sort of trailblazer.

**Karen:** You had the idea for a bricks-and-mortar London Death Café. You launched the crowd-funder in 2015 to raise 250,000£ by selling shares at 50£ a share (read more at: <http://deathcafe.com/theme/deathcafelondon/>), but you didn't reach your target. What did you learn from that experience?

**Jon:** I learned that the world is ready for it. The bricks-and-mortar plan was kind of a left field proposal by most people's standards, but it was received very credibly. No one said this is not a good idea. Everyone was very positive about it, and that enthusiasm continues to grow. I'm asked about it pretty much every day.

Before, I was the guy pushing this idea, going all out to give this thing life, and then we did the crowd-funding and now it feels like, in some form,



it is in the world and the vision is there for people who want to look at it. The crowd-funding kind of did its job in a sense. I think the concept remains really robust and is very viable. Whether it's here in the UK or somewhere else, I'm sure places of this ilk will manifest in the short to medium term.

I am still very committed to setting up a bricks-and-mortar café myself. At the moment, there are still paths open to me, which would enable me to proceed immediately, but they are risky to say the least. I'm not inclined to do it right now. I'm more inclined to wait until the right circumstances present themselves and then proceed in a way that sets us up for it to work well. But I am determined to make it happen. I'm still convinced that this kind of thing is desperately needed in the world and would help so many people.

**Karen:** Do you know of any other countries where someone is trying to do something like this?

**Jon:** No, but one of the London hospices, Royal Trinity Hospice, which is where I volunteered, has said it wants to take death onto the high street and open a kind of death center. But they are looking to raise several million pounds over five years, which is kind of what it takes to do something in this city. London is just ridiculous.

People want a real DC to happen, but it takes a lot of guts to do it. You need to be a really brave person. People don't do something like this flippantly.

I don't regret doing the crowd-funder, as it made it more likely that the bricks-and-mortar DC will happen. It shifted things, but I think the universe was really being very kind by not giving me enough money at that moment to proceed.

**Karen:** So do you have a next step for creating a real DC at this point?

**Jon:** I'm not actively pursuing it. But I am still talking about it.

**Karen:** Did anyone notable come out of the woodwork to support the crowd-funding campaign?

**Jon:** No. Some of my family pledged. My mum pledged and my aunt pledged.

We got just shy of 40,000£ pledged and of that, 20,000£ was in two 10,000£ offers from people, both of whom I know personally, which just shows that you have to lay the groundwork for this kind of thing very carefully. I just don't know enough rich people, or I probably do know enough rich people, but I don't talk to them in the right way. A lot of people are going to be put off by doing something like a DC, and you know the whole model is not-for-profit, and I chose a very austere legal structure. So anyone who invested would never get any profit, although they could potentially sell their shares. It wasn't a donation either. They bought shares, so they would own a proportion of the DC and, in theory, they could sell that share and recoup their interest. But there is no profit motive in there for people.

**Karen:** What was the hardest thing about running the campaign? Was it asking for money?

**Jon:** Yeah, because putting the campaign together cost me personally about 10,000£ in consultancy fees mainly, and some capital costs, and that was with a fair bit of volunteer support. But anyone who looks at the business plan on our website and the share offer can see they were really good and forward thinking, and I'm very proud of them.

**Karen:** What are some of your other hopes for DC in the future?

**Jon:** I'd like DC to be sustainable, for it to pay me for my work. That would be nice! I'd like to offer a proper training. We do have a DC guide, but we don't even have any video tutorials. I'd like there to be films for public viewing, and I'd like those to be of DC events involving specific communities. For example, if you had a DC for Jewish people, hearing them talking about death, you'd get to learn a lot about their customs and about their community in a wider sense. I keep pitching the film idea to TV companies I talk to occasionally.

**Karen:** What's one of the most surprising places that a DC has emerged? And what have you heard about some of the significant consequences of a DC happening?

**Jon:** I was recently speaking with a woman, Celin, from Taichung City in Taiwan, and she was just doing her 72nd DC. They're holding a DC in a government funeral parlor or something, and it's a big event.

I don't hear about many significant consequences of DCs. I think people enjoy going to a DC and that's it. I did hear a story from Megan Mooney about a couple who started dating after a DC and became romantically involved.

But going to a DC is a little thing. Sometimes at DCs we'll do an evaluation, and people will generally evaluate the event really well and often times they'll say, "When's the next one? I'll definitely be back!" But there is significant turnover with DC events. On average, 60 percent of the people who come have never been to one before. So it's almost like going to the movies. It's something you do every once in a while, unless you're a real buff. It's just a pleasant kind of interlude. It is life-changing in a small way, but I wouldn't overclaim it either. We've never done any kind of longitudinal evaluation about the impact of DC, but I'm wary of overclaiming it because it's just two hours of chatting.

I think the big gains are what DC shows and what it says. It says that you can't say that no one wants to talk about death. When I first started DC, my stepdad said, "The problem with this is that no one wants to talk about death." That's the generally accepted view, but it's not true. There are a lot of people who at a certain time do want to talk about death.

Culturally, death is generally perceived as wholly negative. So the act of engaging with death in a not wholly negative way, with cake and comfort, changes the atmosphere around death in subtle ways and has considerable, often unexpected and positive reverberations. [📍](#)



*Jon Underwood is the founder and executive director of Death Café. Find out more at [deathcafe.com](http://deathcafe.com)*

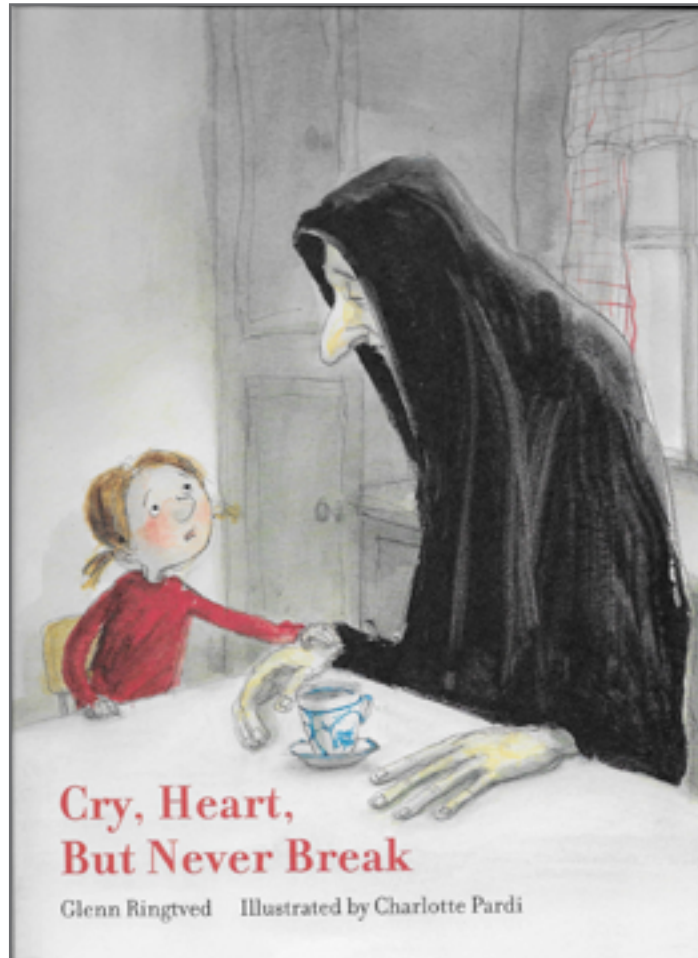
# Cry, Heart, But Never Break

Book Review by Margaret Pevec

Death became a part of my consciousness early; I was only 22 months old when my father committed suicide. Apparently I absorbed the knowledge of his death through my pores as a result of a miasma of acute family despair that lasted until I was four or five. I don't remember ever being told by my mother, my two brothers, or my grandmother that he had died or how he had died. I just knew. Death was never spoken about in our family, but it was always there. A constant presence.

It's no wonder I had a nearly visceral reaction to *Cry, Heart, But Never Break* by Glenn Ringtved and illustrated with skillfully painted watercolors by Charlotte Pardi. How supportive it would have been to all of us if my mother had had this book to read to me and my two older brothers as children, opening the door to our feelings and questions about losing our father. I was too young to have many words, but knowing that death was something we could share with each other would have made a world of difference.

In *Cry, Heart, But Never Break*, Death is a character who visits four children while their grandmother is dying in an upstairs room. Death, draped in black, is sad and reluctant to do his job. The children, cleverly, slow him down with cup after cup of coffee throughout the long night. Finally Death puts his hand over the cup to signal that the time had come. Courageous Leah, the youngest child, who had stared straight at Death for hours, asked the critical question: "Our grandmother is so dear to us, why does she have to die?" Death's answer is wise, comforting, and something all of



adult's unresolved grief than a child's ability to absorb and understand the profundity of death.

This precious and beautiful book should stand on the shelves of any parent or grandparent, to be read as appropriate—whether at the death of a beloved pet, a wild animal, or someone dear—to make the topic of death just another thing we, as humans, talk about with our children. Death is our common burden—and a reality that makes life precious for us all. [i](#)

*Margaret Pevec lives in Boulder, CO, works with her brother in his small handyman business during the week, and plays with her toddler granddaughter on Saturdays. She has been copy editing and proof reading NTM since its first issue.*

us humans intuitively know, even as we grieve the loss of those we hold dear.

By picturing Death as a sensitive, reluctant actor in the game of life, the density around the topic of death is transformed. In the words of the author: "Some people say Death's heart is as dead and black as a piece of coal, but that is not true. Beneath his inky cloak, Death's heart is as red as the most beautiful sunset and beats with a great love of life." Allowing the four children to encounter death without an intervening adult to shield them from that reality is also masterful. Children have deep capacities to understand life and death. Shielding them speaks more to an

*Cry, Heart, But Never Break* by Glenn Ringtved, a Danish author. This is a translation of the original book he wrote for his children about 15 years ago.

Charlotte Pardi (Illustrator)  
Robert Moulthrop (Translator)

Hardcover: 32 pages, 8.6" x 11.08"  
Publisher: Enchanted Lion Books  
February 16, 2016  
ISBN: 978-1-592701-87-2

# Death My Consort and Teacher

By Karen Wyatt, MD

As I look back at my life it seems now that Death has always been hovering over me, waiting patiently to teach me certain lessons I needed to become fully alive. From the time I cared for a baby bird that lay dying in our yard when I was eight, to the unexpected deaths of my cousin and two friends during my teens and twenties, I was given many opportunities to study and learn from Death at a young age.

These experiences confronted me with the reality that Death can come for anyone at any time, and there was no assurance that I would be around long enough to accomplish all that I was setting out to do with this one lifetime. In my youth, I feared Death because it allowed for the possibility that I might die “before my time” and with my life’s purpose unfulfilled. But I had not yet begun to learn all that Death wanted to teach me.

I eventually came to the conclusion that the true purpose of my life is to learn to love. No matter how long or short my life might be and no matter what career or occupation I pursued, I would spend my days seeking the knowledge of love, in all its manifestations. I embraced love as the primary focus of life at that time and made no room for Death, which I saw only as a force of destruction—the opposite of love.

But a tragedy occurred and Death made its presence known, just as I was beginning my medical practice, when my father took his own life. I felt the full force of Death, ripping me into an infinite number of pieces that no amount of love, I thought, could ever reassemble. For three years I wandered through my life, totally broken, and totally in doubt about the presence of love in this world. I could no longer feel or see love anywhere as I floundered in my grief.

Eventually I was inspired—from something that called deep inside me—to begin working with hospice patients. I decided I would finally surrender to Death and let it become the teacher for my life as it had been calling to me since my youth. When I welcomed Death across the threshold of my awareness I discovered the truth that had been there, waiting for me, all along: Death is not the destroyer of life. Rather, Death is the consort of life. Death provides the means by which all of life is enriched with love. Death prepares the channels through which love flows to every atom in existence. Indeed, Death allows creation itself to exist by enabling constant change and expansion within the Universe.

From Death I learned compelling lessons about life that inspired me to write the book *What Really Matters*. As I continued to grow in awareness, I sought even more knowledge by reaching out to others who had been called to work at Death’s doorstep in many different capacities. Through dozens of conversations with wise and fearless workers who looked Death in the eye every day, I began to broaden my understanding of the impact of Death on other people, on our society, on the planet, and on life itself. When I realized that these discussions should be shared so that everyone could learn the wisdom of Death, I created the End-of-Life University interview series.

Within these deep and profound “Death Talks,” I discovered certain threads that were woven throughout the lives of my speakers: Nearly everyone I spoke with, who now carries the torch for positive awareness of Death in our society, was once torn apart by grief, as I had been. In the process of confronting the ravages of Death in their own lives, each

of these people had transcended their brokenness to find a new purpose, a new calling for their existence. And each of them had used their pain to fuel the passionate life’s work they were now pursuing.

An epiphany occurred for me as I recognized that Death, that clever teacher, had shaped us into pathfinders who would bring Death’s message to the world, no matter what obstacles were placed before us. Despite the discomfort of society, the resistance of Western medicine, the obstacles within the legal system, the power of the funeral industry, the unawareness of the masses, we were the ones chosen and honed by Death to work toward change in our society, and we would not give up that struggle.

Eventually another common thread began to emerge from my End-of-Life University conversations. A significant number of speakers had revealed with the telling of their stories a powerful connection to the AIDS epidemic that swept the world in the 1980s and ’90s. I remembered the terror that gripped our society during those dark days, as tragic and unexplained deaths occurred all around us, including the death of one of my medical school classmates. AIDS represents one of the cruelest and most unjust aspects of Death and is, no doubt, responsible for some of the fear that still haunts the Baby Boom generation.

But through the interviews I was conducting, I was seeing a new face of the AIDS epidemic. From the ashes of that seemingly senseless destruction had risen several powerful movements that are still shaping how we manage death and dying today. These are some of the stories that revealed to me the transformative power of the AIDS tragedy:

Zen Hospice was started in San Francisco to care for AIDS patients and is still a leading innovator in hospice care.

William Peters, who did volunteer work with AIDS patients at Zen Hospice, went on to study shared death experiences and start the Shared Crossing Project.

Kate Munger began the Threshold Choir after singing for a friend who was dying of AIDS.

Esmerelda Kent, who made the first biodegradable shroud, got involved in the green burial movement after losing several friends in the entertainment industry to AIDS.


Jim Towey, who was inspired by volunteer work he did with AIDS patients, went on to found Aging With Dignity and design the Five Wishes document.

Carolyn Jones, a photographer in New York City, created her award-winning book *Living Proof: Courage in the Face of AIDS* after her friend died of the disease, and more recently she was inspired to make the film *Dying in America*.

Mitchael Metzner became involved in hospice work and ultimately the Social Model Hospice movement after losing his own partner to AIDS.

As I recall each of these stories, I can see a miraculous pattern unfolding. Death has used the horrific tragedy of AIDS to not only inspire individuals to transform their own lives, but Death has also been sculpting entire movements that will one day change our society and bring our relationship with Death back into balance. This is at once a terrifying and exhilarating conclusion: Through the devastation and suffering it brings, Death releases the seeds of grace that enable us to transcend our pain.

Through a combination of my own life experiences and the wisdom

gained from the End-of-Life University interviews, I have reached an entirely new understanding of Death. It turns out that Death is truly the wise teacher, leading us into the darkness so that we can finally perceive the beauty of our own light. And when we share the stories of our grief, we discover the same light in others, and together we can illuminate the uncertain paths that lie before us. Ultimately, I have concluded, our lives and the life of this planet depend on the lessons we learn from this teacher Death, who waits patiently to show us how, in this human life, destruction and transformation are inseparably woven together—stitched and entwined with multicolored threads of love. 



*Dr. Karen Wyatt is a family physician who has spent much of her 25 year career as a hospice medical director, caring for dying patients in their homes. The author of A Matter*

*of Life & Death: Stories to Heal Loss & Grief and What Really Matters: 7 Lessons for Living from the Stories of the Dying, Dr. Wyatt has lectured and written extensively on end-of-life issues with an emphasis on the spiritual aspect of illness and dying. She is the recipient of numerous awards for her volunteer work and the compassionate care she has provided to thousands of patients throughout her career.*

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# Remembering Maria



In 2015, Maria Dancing Heart Hoaglund and I sat across from each other in Julia's Kitchen, a fragrant vegan eatery in Boulder, CO. We hadn't seen each other since her first book, *The Last Adventure of Life: Sacred Resources for Transition*, was published in 2005. Not long after its publication, Maria visited Boulder to address a modest audience of "deathies" (as a fellow death educator refers to the growing number of "death aware" folks in our city).

Maria Dancing Heart's striking presence—those long, long tresses, the passion with which she presented her beliefs, her skill at oratory—all left a lasting impression.


On April 22, 2016, in Olympia, WA, Hoaglund and a friend were struck by a truck driven by a 19-year-old man. Hoaglund died as a result of her injuries. She was 61.

Hoaglund trod a unique path in life. Born and raised in Japan to missionary parents, she came to the United States for college, engaged in religious studies

at Yale, then entered the ministry with the United Church of Christ. After ten years with her own parish, she transitioned into hospice spiritual counseling and bereavement support.

Hoaglund was a prolific speaker and writer on all matters death. Her life's work focused on transforming cultural antipathy towards our mortality, encouraging us to face and embrace our inevitable birth into spirit. "Death, Nothing to Fear" exhorts a headline for one of Maria's regular columns in Washington state's Mason County Journal.

Hoaglund called death "a homecoming" in the spirit of African-American tradition. She dared to say we could even be "happy" that we would be returning to our spiritual home.

Hoaglund's second book was entitled, *The Most Important Day of Your Life: Are You Ready?* The shock of sudden departure notwithstanding, I would bet that for Maria, on that April day, the answer was, "Yes." 

## LAST WORDS

*Rosebud* by Tricia Grable  
Tricia is a Colorado artist interested in the balancing power of making things by hand in the digital age. She has particular interests in veil painting and handmades for children and daily household use. [Luminousarts@gmail.com](mailto:Luminousarts@gmail.com).

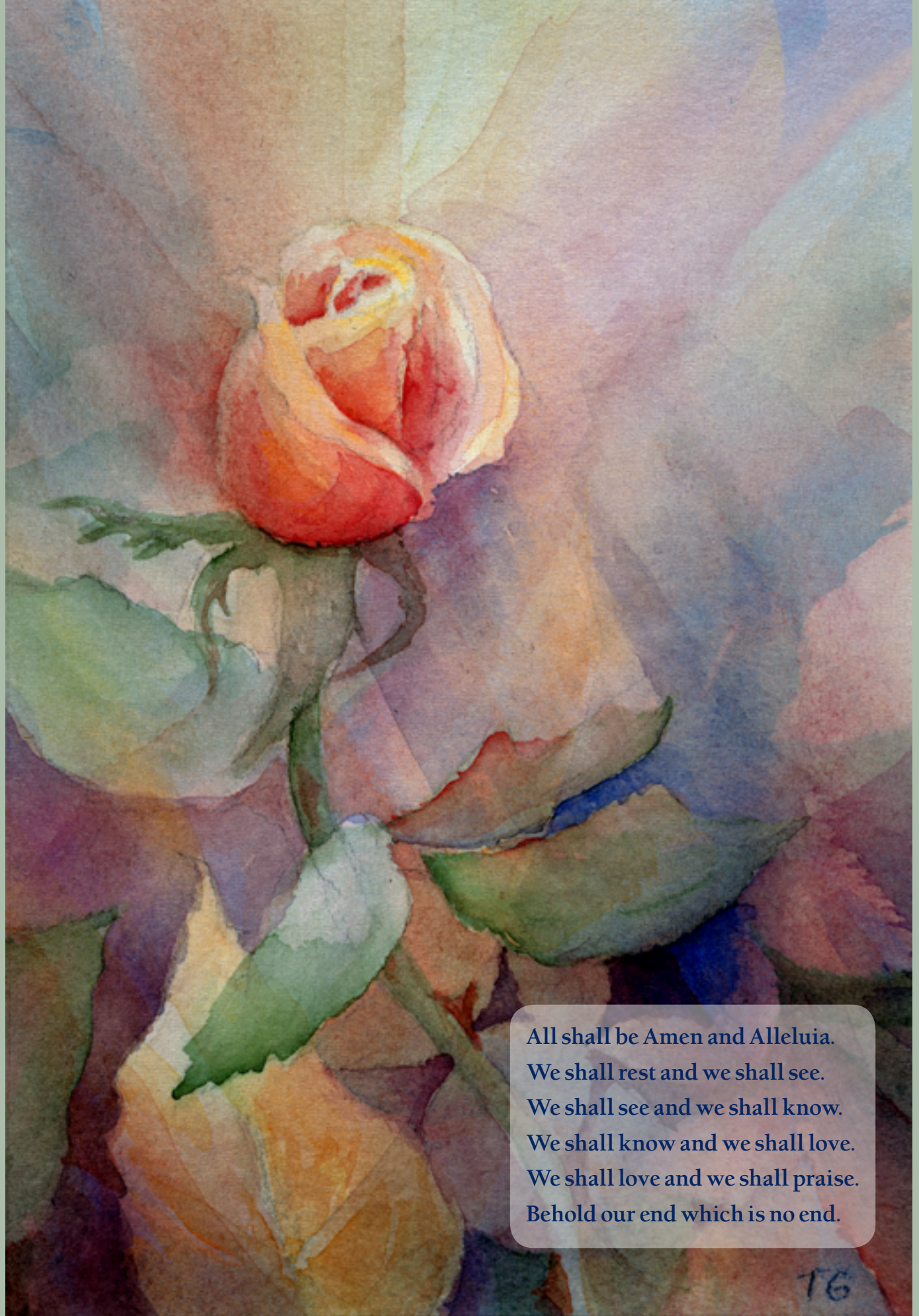
Resurrection Prayer of St. Augustine  
Born in Roman N. Africa to a devout Catholic mother and a pagan father, Augustine was a notoriously rebellious Catholic teenager who cohabitated with a girlfriend, joined an exotic Eastern cult, and ran away from his mother. He became a brilliant and renowned teacher of public speaking and was appointed by the emperor to teach in Milan, Italy, the administrative capital of the Western Roman Empire. While there, he happened to hear the preaching of the bishop of Milan, Ambrose, who baptized him in AD 386.

St. Augustine ultimately renounced his secular career, put away his mistress, and became first a monk, then a priest, then the bishop of Hippo, a small town on the N. African Coast. The voluminous writings of this Early Church Father span every conceivable topic in theology, morality, philosophy, and spirituality. He died in AD 430.

**COVER ART** Raven Goddess  
by Willow Arlenea

The raven represents the mysteries and entering the mystery. The goddess of the raven can take you into the magic of a full moon night or into the underworld where the cauldron of death and rebirth resides. She can also take you deep into your soul where your hopes and fears reside. There she will be with you as you bring your own darkness into the light of love.

Willow is a visionary artist, psychic reader, archetypal energy psychotherapist and trauma specialist. She lovingly helps her clients through the journey of pain, grief, and loss. Her newest book, *The Path through Emotional Pain*, will be released soon. She is also the author of *Tarot of Transformation tarot deck*, and *Seasons of the Goddess*. [MysticLifeDesign.com](http://MysticLifeDesign.com).



All shall be Amen and Alleluia.  
We shall rest and we shall see.  
We shall see and we shall know.  
We shall know and we shall love.  
We shall love and we shall praise.  
Behold our end which is no end.



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I came upon a tattered scrap of owl feather  
this morning cleaning house  
while you were dying far away  
carried it outside between my thumb and forefinger  
carefully as if it were still alive  
then I simply let it go  
and to my surprise  
though I thought there was no wind  
a hidden breeze lifted the feather  
dancing upwards over the rooftop  
off into the trees where the owls live  
may it be so easy

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