

Are You Afraid to Plan for Your Own Death? |

Exploring our rights to make the death and funerary process more personal and less of a consumer affair.

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When Beth Knox lost her 7-year-old daughter in a car accident, she was told the hospital could only release her body to a funeral home. At the time, Knox didn't know she had the legal right to drive her daughter's body from the hospital to her house in the same van in which she took her to school every day. What she knew was that her family needed time.

"I was required by law to care well for her," she writes on [her Web site](#), "but now that her heart had stopped beating, I was being told that her care was no longer my concern." Finding it unacceptable, she found a funeral home that agreed to bring her daughter's body back to her house. "I cared for her at home for three days, bathing her, watching her, taking in slowly the painful reality that she had passed from this life, and sharing my grief with her classmates and brothers and grandparents and our wonderful community of friends, before finally letting go of her body."

For more than a decade, a growing number of Americans have resurrected the ancient practice of "do-it-yourself" funerals. Like Beth Knox, now a funeral rights educator in Maryland, these home funeral guides and educators are spreading the word that after-death care is not the funeral industry's birthright. You have the legal authority, in most states, to care for your loved ones after they die. It will transform your life, with the added bonus of saving you money.

A Sacred Rite of Passage

As a society we have distanced ourselves from the dying process," says Dr. Ronald K. Barrett, professor of psychology at Loyola Marymount University in Los Angeles. "We now have hospices and institutions where people go to die. In former times the dying process was an integral part of the life experience of the

community; people were born and died at home. To the extent that we have relocated those experiences to death care professionals, the experience of death itself has become alien, and it has complicated our ability as humans to do what we have so naturally done since time immemorial, and that is to grieve."

Jerrigrace Lyons, director of the non-profit organization Final Passages in Northern California, has made it her life mission to educate her community in the exploration of choices surrounding the death of a loved one and compassionate alternatives to current funeral practices. "When you keep your loved one at home," she says, "the process has a natural beginning, middle and end, and everybody who is around you is benefiting from this rite of passage. There is such a vast difference between a family coming to that place of letting go on their own and the funeral home's transportation service showing up at the door two hours after death to take the body away in a plastic bag."

When Lyons serves as a home funeral guide, one of her first duties is to help friends and family members walk through what she calls "the doorway of fear." "As guides," she says, "we model touching the dead body, rubbing the head, holding the hands, brushing the cheeks. The family's original reluctance melts away as soon as they see that we're normalizing it."

One funeral industry practice that gets the blood of these otherwise gentle educators pumping is the embalming of the body. The Federal Trade Commission's Funeral Rule dictates that funeral directors inform families that embalming is not required by law and doesn't prevent decomposition of the body. In my state of California, the only legal requirement for a body that will not be cremated or buried within 24 hours is that it must be refrigerated. According to Lyons, who has participated in more than 150 home or family-directed funerals, a body can be safely preserved by keeping dry ice under the vital organs right after death and while the body stays at home.

"During embalming, morticians poke, slap, and prod around in places that a few hours before were your very private and sacred parts," says Olivia Bareham, a home funeral guide in Los Angeles. "Your body is subjected to torturous toxic poisoning with formaldehyde. And then, your 'former home' is hosed off with freezing water, the bits that won't stay down or shut are sewn or glued in place, and your body is shoved back in the fridge. There is nothing holy, kind, sacred or beautiful about it. It is barbaric."

In the haunting PBS documentary *A Family Undertaking*, Lisa Carlson, executive director of the Funeral Ethics Organization, describes the piercing of all internal organs and the sucking out of the juices as "assault and battery." If you have the stomach for it, the film allows you a quick look inside an embalming room. Compared to the predominance of corpses in all stages of decomposition on popular crime shows, it might seem tame, except in this case there is no suspension of disbelief at play: you are looking at a real body. In the film, a South Dakota man who recently buried his mother and whose father is dying finds it inconceivable to send his loved ones away to be "bled and pickled" by strangers.

One would argue that once someone is dead, whatever happens to their body is only painful to the living. However, for those among us who believe that we have a soul and that it detaches from the body after death, some religions and spiritual practices argue that it hovers around the body for a few days. What if this soul or spirit has the same need as we survivors have, to keep near the body in order to make peace with this most precarious severance?

For Lyons, it's always about the living. "People are not comfortable reaching out and touching the body too much during a formal viewing of an embalmed body in a mortuary. You can lean over and give a little peck but that's it. If you want to stay there and put your arms around your loved one, forget that. It's not going to be acceptable. At home you can sit with them, cry, meditate, and talk to them for as long as you need to."

"Most Germans do not embalm," says Barrett. "They do not engage in a lot of cosmetic preparation. They believe the more the family confronts the reality of death, which at times includes the smell and the natural

process of the breaking down of the dead body, the easier it will be for them to accept that this is a dead person."

Lyons concurs: "It's helpful for the family to see a subtle change in the face. It looks like the spirit is not there anymore, the life force energy wanes and the body looks more like a shell or an earth suit that used to carry the person's spirit. Families are ready to let go of the physical and cremation or burial can finally take place."

A home funeral also gives friends and relatives an opportunity to contribute and show their support. It is a communal experience. "You let others take care of you," says Lyons.

For Olivia Bareham, one of the highlights of a home funeral is when family and friends gather around a cremation casket: a simple cardboard box painted white to allow for scribbles or elaborate designs. "One family chose to draw a tree of life and each relative and friend put their handprints on the branches, indicating that they all belonged together," Bareham remarked. "Kids are natural," she added. "They can't wait to draw on the casket. It reminds them of white paper. Soon everybody's taking pictures of this final tribute and of the adorned casket." In *A Family Undertaking*, sons and grandsons fabricate a wooden casket in their South Dakota barn while the elder proudly looks on and is invited to brand his final resting place with his initials.

The Challenges

It's not for everyone," admits Lyons. "If your loved one died after a long illness, the family might be too exhausted." Depending upon your culture and religious inclinations, you may need more or less time than the amount of days your state allows you to keep the body. According to Lyons, people on average keep the body in the home for three days, but a body can be safely preserved with dry ice for up to five or six days.

"Orthodox Jews and Muslims typically aim or try to bury by sundown the next day," Barrett remarks, "and in the African American tradition, the participation of all significant family members is an honorable tradition. It's often considered insensitive, impolite and an insult to have a funeral before a family member who is away is trying to get home. That's one of the reasons why they need seven to ten days before burial."

Another obstacle is space. The families featured in *A Family Undertaking* live in rural areas. "Since the 1950's, people have evolved to smaller and smaller living accommodations," notes Barrett. "In urban environments, apartments with stairs, hallways and corners make it impossible to negotiate a full casket for a full adult." Barrett also raises another specter: "When the cause of death is violent or a protracted illness where there is a disease process, then the idea of trying to care for a body at home raises all kinds of health concerns depending upon the environment. The idea of moving back to a home death-care situation probably would have to be regulated to protect the health and welfare of the population at large."

The funeral industry is already trying to regulate home funerals. "In Oregon they have passed a bill to license home funeral guides," says Lyons. "They can educate in a classroom situation but not at the time somebody dies unless they pay for the licensing. Funeral homes are angry because they have to pay to go to school, pay for their licenses, they have to carry insurance and all the overhead, and some home funeral guides like me just want to help families do their own home funerals."

How Death Became a Stranger

Ironically, up until the late 1800s, American families cared for their dead at home without any government oversight and women were usually responsible for preparing and caring for the dead body. That all changed with the Civil War and its 600,000 casualties. Deceased soldiers were often hastily buried on the battlegrounds. Only families of significant financial means could afford to hire funeral directors to find the bodies and ship them home for burial. The rest of the country not only endured the unnatural loss of their sons but was robbed of the healing rite of caring and preparing the bodies of their loved ones for burial. Add to this

traumatic shift the lower mortality rates that slowly made death a stranger in American homes, as well as an ever-expanding consumer society pushing to embellish funeral rites, and funeral directors slowly took over the familial duty.

Keeping home funerals more affordable than traditional ones is another challenge. "Even if the family does the funeral at home," says Lyons, "even if they have their own ceremony, even if they do the paperwork, file it with the state and drive the body to the crematorium, the crematorium might give them a little discount but mostly they're going to charge them the full amount of a direct cremation. They're going to say that their basic fee is \$1,000 and that they have their overhead fees. Luckily, in our area I know two funeral homes that are willing to only charge for the cremation. It's \$250. The families will have done everything else."

In this country, the average cost of a mortuary-directed funeral with burial is \$7,000; with cremation it's \$5,000. Lyons holds the vision that "eventually communities will come together and will cooperatively own their own green cemeteries and their own crematoriums, because as long as it's controlled by the funeral industry in the way that it is, we will always be subject to paying whatever they're going to charge."

Ronald Barrett agrees, "In many cases the way packaging is done by most funeral homes, there is a disincentive for families to be personally involved. You are almost encouraged to purchase a package in order to save on the individual items." This practice is in direct violation with one of the Federal Trade Commission's Funeral Rules, called "The Customer's Right to Choose." The rule was implemented in 1975 to curb the questionable practices of the funeral industry exposed by Jessica Mitford in her 1963 best-seller *The American Way of Death*.

I asked Lyons if there is any possible collaboration with funeral homes. "Some funeral homes are starting to offer home funerals. One woman, whose father owns a mortuary in the Midwest, took our class and wants to bring in the home funeral aspect. Some people see that this isn't going away. There is a difference in the quality of care. I know some funeral directors are well-meaning but they don't realize that they're disempowering families. They think they're taking the burden off of the family. When we teach, we talk about the difference between funeral directors and home funeral guides. It's important to guides that the family is made to feel that they are in charge, that they are making informed decisions and that everything is done legally and correctly. We guide, we facilitate but we don't direct."

Home funeral educators and guides also have to contend with people's resistance to the inevitability of death. Our consumer society would rather have us focus our energies and money on the possibility of delaying the aging process rather than on facing the reality that we are born to die. "Lots of people come to our workshops because they have aging parents and they want to know how to take care of them, so they're not caught off guard," says Lyons. "Other people do it because they want to prepare for their own death. We never know when we're going to die. In our culture not many people acknowledge that." Lyons likes to quote this Buddhist commentary: "America is the only culture that considers death as optional."

Lyons is in the process of forming a California Home Funeral Alliance to organize the community of home funeral educators and guides, as well as friends of the home funeral movement. Currently she relies on her educational workshops and private grants to keep her organization going. Lyons deplores that foundations offering funding for death and dying projects do not as yet include categories for after-death care, and home or family-directed funeral guidance.

There is an urgent need to educate hospitals, hospices and coroner's offices, who often don't know that families have the legal option to care for their dead. At the time of death, they usually give the grieving relatives a list of local funeral homes to choose from. On the Funeral Consumers Alliance Web site a chaplain working in a Georgia hospital leaves a comment asking for help in the case of a family member who requested to take the body of their dead relative. The chaplain admits to being "unprepared for that" since they always release the body to funeral homes. Lyons contends that people can't be blamed for being uninformed when

nobody wants to talk about death.

"We don't have any death education in school, yet every one of us is going to die," Lyons says. "We have sex education but no death education. If we introduced this reality at an early age we'd get more comfortable. In my workshops, I show the first episode of Greg Palmer's four-part series 'Death: The Trip of a Lifetime.' In it a teacher, after the death of a colleague, decides to instruct his 4th-graders about death and dying. She has them write their own epitaphs, what they'd want people to say about them at their funerals, what would be on their grave site. The kids get to be so comfortable with the whole concept of dying. That's where it needs to begin."

There are currently 54 listings under "Home Funeral Guides and Consultants" on the Home Funeral Directory Web site and many books on the subject of do-it-yourself funerals are widely available. A new edition of Lisa Carlson's *Caring For The Dead: Your Final Act of Love*, published in 1998 is in the works and the Funeral Consumers Alliance adds updates on its Web site to changes in state laws since the publication of the book. The site also lists local organizations available for counsel and information is readily accessible from the Consumer Protection branch of the Federal Trade Commission as well as your local Department of Consumer Affairs.

"No one can care for our loved ones as tenderly as those who have loved them," says Beth Knox. Olivia Bareham founded Sacred Crossings, a company offering cost-effective alternatives to current funeral practices, in the wake of her mother's passing. Since she died at home, the nurse asked Bareham if she would help her bathe the body. "I had never seen my mom's naked body! I don't regret I said yes. The experience was unforgettable and deeply honoring of my mother."

A young woman was originally "creeped out" when her mother told her she wanted to have a home funeral for her husband who succumbed after a long battle with cancer. Upon viewing the body of her deceased father peacefully laying on his bed on the day of his passing, she spoke these words to me: "My dad worked so hard, he started out with nothing and he took good care of his family; he bought this house, this is his home; for him to pass here is safe for him, and safe for his spirit to relax for a few days. I wouldn't want to have it any other way."

Since we're all going to die, Jerrigrace Lyons wisely advises that we should have a death plan. Waiting to be grief-stricken or dead to get informed and shop for funerals is a bad idea. But beyond the financial aspect of after-death care, what these guides are asking us to consider is why would we want to miss out on this last chance to care for those we love? Maybe because we're all so busy working full-time jobs and conforming to society's material demands that we hand over one of our most important rites of passage to strangers at a significant cost to our own evolution.

Frankie Colmane lives in Los Angeles where she reports on local independent artists and activists. Links to her stories can be found on "[The Smiling Spider](#)" blog.

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