

The Positive Death Movement Comes to Life

Death cafes, death doulas, “Ask a Mortician,” DeathLab — once the province of goth subculture, death is having a moment in the sun.

“Art of Death Midwifery,” takes her turn in the shroud.

By John Leland
Photographs by Devin Yalkin

- June 22, 2018

It was the party of a lifetime, and Shatzi Weisberger wouldn't have missed it for the world. After all, it was her funeral. Or, as she pronounced it, her FUN-eral.

“Come on in,” she said. “There's lots of food. And a coffin that people are decorating.”

And so it was that a hundred or so people gathered in the common room of an Upper West Side apartment building recently to eat, sing, mingle and hear Ms. Weisberger's thoughts about death and dying.

“I hope we have fun,” she said.

A former nurse, Ms. Weisberger wore white slacks, white sneakers and a bright floral print blouse. A biodegradable cardboard coffin in one corner bore handwritten messages in colored marker: “Go Shatzi! (but not literally)”; “death is only the beginning”; “Shatzi, many happy returns ... as trees, as bumble bees, as many happy memories.”

Ms. Weisberger worked the crowded room. “I have been studying and learning about death and dying, and I want to tell people what I've learned,” she said. “Some people are coming because they love me, and some people are coming because they're curious about what the hell it's about.”

At 88, Ms. Weisberger has found a second calling in what has been labeled the positive death movement — a scattering of mostly women who want to break the taboos around discussions of death.

Some connect through blogs or YouTube channels; some gather at monthly death cafes; some find more institutional grounding at the [DeathLab](#) at Columbia University's architecture school or the [Art of Dying Institute at the Open Center](#), a six-month program touching on everything from green burials (bonus: they're cheap) to certified training for [end-of-life doulas](#).

Image



Friends at Shatzi Weisburger's FUN-eral decorate her coffin.

Nearly a million people have downloaded the starter kit for the [Conversation Project](#), a guide to discussing plans for the end of life. Others use the popular [WeCroak](#) app, which sends five daily reminders that we are all going to die.

All share a common idea: that Western culture has become too squeamish about talking about death, and that the silence impoverishes the lives leading up to it.

Ellen Goodman, a retired newspaper columnist who started the Conversation Project after caring for her mother at the end of life, likened the foment to the earlier movement for natural childbirth. “Birth was perceived as a medical event, and then in came the women’s movement and ‘Our Bodies, Ourselves,’” she said. “It wasn’t doctors who changed the way we give birth in America. It was women who said that giving birth was a human event. I think that we’re trying to do that now. Dying is a human experience. We’re trying to put the person back into the center of the experience.”

Ms. Weisberger is by no means a morbid person. She sings in the Brooklyn Women’s Chorus and shops at the new Trader Joe’s in her neighborhood. But a few years ago, after sitting with a friend who was dying of cancer, she realized that she was unsatisfied with the American way of death.

“She became terrified, so scared that she couldn’t even talk about it,” Ms. Weisberger said of her friend. “I kept urging her to talk about what was going on, but she wouldn’t. And then she died. So that was a problem. We had not dealt with the issue — myself, herself and the others.

“So I started studying about it,” she said. Down the digital rabbit hole she went.



Ms. Weisberger gets mic'd up before she addresses the crowd at her FUN-eral.

If there is a germinal moment for the positive death movement, it is 2003, when a social worker at a New York hospice center became disillusioned by the care that the medical staff were able to give to dying patients and their families. The social worker, Henry Fersko-Weiss, saw what doulas did for women during and after childbirth. Why couldn't dying people get the same level of attention and emotional support?

Using birth doulas as his model, he created a [training program](#) for end-of-life doulas, or midwives, to attend to patients' nonmedical needs — anything from helping them review their lives to sitting quietly in witness.

“There are tremendous similarities between birthing and dying,” he said. “There's a great deal unknown, there's a great deal of pain and a need for support for the people around the person who is going through the experience.”

For doulas in either setting, he said, “arranging the atmosphere, creating a special space around the event, is exactly the same.”

As Mr. Fersko-Weiss was getting his program underway, Joanna Ebenstein, a graphic designer in Brooklyn, was thinking about death from a completely different angle.

“We just don't know what to do with death anymore,” she said. “It's this big, scary thing. We don't have a set of rituals around it that contains it or gives it meaning. Ours is the first culture to pathologize an interest in death.”



Amy Cunningham, a funeral director at Fitting Tribute, with a biodegradable seagrass coffin.

In 2007, Ms. Ebenstein started a [blog](#) called Morbid Anatomy, highlighting ways different cultures represented death. Only in the United States, she said, were images of death absent from art and daily life. The blog opened conversations about death outside of the realm of hospice or advance health care directives.

From the first posts, she said, she started hearing from an audience she had not known was out there: people who felt isolated by their interest in death. Before then, the only people she knew who shared her interest in death had been in the goth subculture.

“We’re not supposed to be curious about death now,” she said. “But how can you not be? It’s a great human mystery. It’s the thing that defines our life, but we’re supposed to pretend it’s not interesting to us? It’s in horror movies and pop culture, but there was no high culture discourse around it.”

She withheld her name from the blog because she was afraid her design clients, especially Scholastic, would think she was creepy. This was the era when Sarah Palin warned that the Obama administration’s Affordable Care Act was trying to impose “death panels.”

Ms. Ebenstein, 46, sees her work as resurrecting a lost strand of American culture.

“This idea that we have now, that death is exotic and cannot be seen, is brand new,” she said. “Your grandparents tended to die in the house. They’d be laid out in the parlor when they died, which the Ladies’ Home Journal advocated changing to the ‘living room’ when the funeral parlor came around. The living room became the living room because it’s no longer the parlor for laying out the dead. And that’s around 1900. All of these changes are happening, and now we think of death as something that happens offstage, that we don’t see and children certainly shouldn’t see. But that was not possible until so recently.”



The Morbid Anatomy Library popup at Green-Wood Cemetery in Brooklyn.



In 2014, Ms. Ebenstein and Tracy Hurley Martin spun the blog into a small [museum](#) of the same name in Brooklyn, which [closed](#) in 2016 but has been succeeded by a pop-up residency at [Green-Wood Cemetery](#). By then, something had changed. “Now this stuff was cool,” she said.

Part of what changed was a funeral director in Los Angeles named [Caitlin Doughty](#), who dressed like a lost member of the Addams Family and posted a series of plucky YouTube videos called “[Ask a Mortician](#)” that spoke frankly about corpses and decomposition and routinely topped 400,000 views. A typical opening line, from a video titled “All My Fave Graves,” went, “Something I’m always trying to get you to do is hang out with dead bodies.”

In April of 2013, Ms. Doughty tweeted, “Why are there a zillion websites and references for being sex positive but nothing for being death positive?”

With that, an inchoate curiosity had a brand name, a cachet and an internet presence. All it needed was an occasion to gather.

On a Monday evening at Bluestockings bookstore on the Lower East Side, Emily Leshner, a graduate student in visual media anthropology, had a question about the end of life. Specifically, she wanted to discuss the issue of digital immortality: is it right for people’s social media profiles to live on when they die? “Our digital presence exists beyond our biological life,” she said. “It made me think what kind of person I’d want to be my legacy.”

It was the monthly gathering of the Lower East Side Death Cafe, one of a handful of death cafes that have formed in the last few years around the city. Jafar Al-Mondhiry, a resident in internal medicine, picked up Ms. Leshner’s question. He hoped to start a death-related podcast for other residents — a virtual death cafe. “Is social media a triumph over the body?” he asked.

Around two tables piled with carrots and other snacks, the conversations were lively and unstructured. Melanie Nilsson described taking her father’s cremated remains to all of his favorite restaurants for a year. Millet Israeli, a former corporate lawyer who changed careers to become a grief counselor, asked what sort of reactions the others got when they told friends they were attending a death cafe.



A volunteer at the “Art of Death Midwifery” course taught at Sacred Crossings that aims to demystify death. Credit

“They said, ‘Is that some sort of goth thing?’” Ms. Leshner said. “That it’s dark and trendy and cool.”

[Death cafes](#), as a formal institution, began in East London in 2011, in the basement of a man named [Jon Underwood](#), who quit his job as a business development director to create small gatherings where strangers could drink tea, eat cake and talk informally about death and dying. To encourage others to replicate his meetings, Mr. Underwood, who died at age 44 last year, published guidelines for discussions and a website for other death cafes to promote their meetings. The discussions have no leaders, are free or inexpensive, and are open to talk of all things death but are not support groups. The organization’s website claims to have initiated 6,503 death cafes in 56 countries.

Ms. Israeli, who facilitated the conversation at one table, met the women who started the Lower East Side group while they were all training as [volunteer caregivers](#) at the [New York Zen Center for Contemplative Care](#), which takes a Buddhist approach to the end of life.

The death cafe, she said, “is almost like my form of activism to create an atmosphere publicly that permits talking about death. If we can talk about death and dying, maybe that will spread to easier conversations about grief and terminal illness.”

Ms. Israeli recalled a guided meditation at the Zen Center imagining her own death: the mouth becoming dry, the body shutting down, the attention becoming more internal. Even with all her work as a grief counselor, Ms. Israeli said, she was nervous going into it. “It seemed scary,” she said. “But the experience was the opposite. As heavy as that sounds, it made it feel lighter. It felt safer than it did going in.”

This is the odd math of the positive death activities. Embracing mortality, practitioners say, helps them live with less fear, more life.

On a Saturday morning at the Art of Dying Institute at the Open Center, [Amy Cunningham](#) led a discussion of [different ways to hold a funeral](#), including at home. Ms. Cunningham, 63, worked as a journalist until she decided to go to mortuary school at age 54. “I thought it was going to be like becoming a real estate agent,” she said.

Ms. Cunningham discussed alternatives to embalming — which involves toxic chemicals — and coffins made of wool or other materials that decompose easily. The group included 24 women and two men.

“We’re part of a movement, and it’s really a return to a female presence at the time of death,” Ms. Cunningham said.

Several of those attending worked in hospice or in the funeral trade. Others had enrolled after the deaths of people close to them.

[Hillary Spector](#), who attended, teaches art in primary school and directs and acts in theater. Ms. Spector recently trained to volunteer as a death doula and joined a synagogue to meet people who might use her services.

“It’s a bit macabre,” she said, “but I’ve always been superfascinated by dying — the physiological processes, but also this idea of what happens to our consciousness. I don’t believe in heaven or an afterlife.



Hillary Spector, an art teacher, recently trained to volunteer as a death doula.

“I also feel that decomposition is deeply spiritual. One of the things that draws people to this work is that we don’t have a basis in religion. That’s why a lot of people are becoming part of this death positive movement.”

Others offer different explanations for why all this is happening now. The AIDS crisis transformed grief and caregiving into expressions of community. The mass shootings on the news call for examination: What if today was your last day? The rising interest in Buddhism introduced alternative concepts of dying. And the aging population brought more urgency to questions of how people want to consider the last years.

Also, death has a bright future: the number of Americans dying annually is [expected to rise](#) by more than one-third in the next 20 years. In a social media landscape where fringe topics find large constituencies, death is a taboo that connects to everyone.

“We got so far removed from death even being an option that we finally got sick of it being closeted,” said Suzanne O’Brien, a former nurse who now [trains](#) end-of-life doulas and hosts a podcast called “[Ask a Death Doula](#).”

“The first step is recognizing that death is a natural part of life’s journey,” Ms. O’Brien said. “We can have it go well or have it go poorly. They say death and taxes are the only things guaranteed in life. But people don’t pay their taxes. So I’m saying death is the only one that’s for sure.”

Image



Unlike most, Shatzi Weisberger knows exactly how many people came to her funeral.

At the FUN-eral, Ms. Weisberger showed off a burial shroud she plans to use when her time comes. She bought it online, from Amazon, she thinks. Three friends have agreed to wash her body according to Jewish tradition, and Ms. Cunningham — who supplied the cardboard coffin — will provide dry ice to preserve her body before burial, she said.

On the wall was a quote from Steve Jobs, the founder of Apple, who died in 2011: “Remembering that I’ll be dead soon is the most important tool I’ve ever encountered to help me make the big choices in life.” Ms. Weisberger found it on WeCroak.

“I was about to give up on WeCroak until I saw this,” she said.

Ms. Weisberger assured her friends that she was in no hurry to occupy the coffin in the corner. Her health was good and her studies in death and dying gave her motivation to keep going, maybe to age 100, she said.

After all, she had too much work to do to stop now.

“I really want to experience my dying,” she told the crowd. “I don’t want to die in a car crash or be unconscious. I want to be home, I want to be in my bed, I want to share the experience with anybody who’s interested.”

It has been the journey of a lifetime, she said, and the last chapter was still to come.

“There’s so much more to share, but I don’t want to go on — no, I really do want to go on,” she said.

Everybody laughed. For one afternoon, death did not get the last word.



Ms. Weisberger happily receives well-wishers, though is in no hurry to leave this world.