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Not all doulas deal with births. Some focus their work around death. Here's how a few are serving Chicagoland residents.



By DARCEL ROCKETT | drockett@chicagotribune.com | Chicago Tribune PUBLISHED: December 26, 2022 at 6:00 a.m. | UPDATED: December 26, 2022 at 11:00 a.m.

It's called the Death Cafe. On an overcast December Sunday afternoon at the Oak Park Main Library, a group of people — most over the age of 60 — shared their thoughts about death, dying and concerns about the process.

One attendee referred to the meeting as "a rare opportunity to talk about death."

One would think that because death is inevitable, there would be more talk about it, making the process less taboo. But according to Craig Klugman, Vincent de Paul Professor of Bioethics and Health Humanities at DePaul University, Americans have a death-denying culture.

"We don't talk about it. We protect children from it," he said. "We've got Halloween, where we make light of death, but that's really the only time we deal with it. Whereas for other cultures, death is much more real. Death happens at home. The funeral is not in a professional location. The funeral happens at home. In the mainstream U.S., we sanitize death. ... We warehouse people who are dying in hospitals and long-term care facilities and nursing homes. So we don't see it on an everyday basis, even though clearly people are dying every day."

Death doulas want to destigmatize death to ease the fear and anxiety around it. Klugman, who has been working in the area of death and dying for 25 years, recently completed training to become a death doula with the International End-of-Life Doula Movement in San Antonio, Texas.

After seven years of teaching a death and dying class at DePaul, he thought it would be beneficial to get a doula certificate so he could take his penchant for initiating conversations about end-of-life directives outside of the academic setting. He also did the training to see if he could incorporate what he learned in the certificate program into the classroom. His goal: Making death part of everyday conversation.



Host Jennifer Ostermeier stands as she leads a conversation about death as Nora Natof, 87, from left, Catherine Marienau, 73, and Mark Dawson, 62, listen. The Death Cafe discussion was organized by the company End of Life Chicago at the Oak Park Main Library on Dec. 11, 2022.

The role of a death doula is similar to that of a birth doula; it's a person who can educate you on what to expect at the end of life, who can provide emotional and spiritual support for the dying and their loved ones.

Death doulas are not licensed to offer any hands-on medical assistance or preparation services such as accounting or drafting wills. They do, however, counsel people on issues like what a medical power of attorney is and how to prepare the legal document, or how to get a do-not-resuscitate order written by a doctor, which instructs health care providers not to perform CPR if a patient's breathing stops or if the patient's heart stops beating.

Unlike a hospice care nurse, who comes in several times a week, a death doula is more likely to be bedside at the end of a person's life and help family members navigate the funeral, eulogies and obituaries.

"It's a process, not a conclusion," Klugman said.

While doulas are more likely to be on the scene for longer periods of time, there is no Medicare or Medicaid benefit paid for doula services, unlike hospice care. Health insurance does not cover death doulas. Klugman said many death doulas are former social workers, nurses and hospice volunteers.

"What a death doula can do that your local hospice can't do is talk about funeral options, talk about the grief process that the family goes through, talk about what to expect in the last hours, days and weeks," he said. "They provide support to the family; they can be present at the bedside during the vigil, death. They can do what we call legacy planning: How do you want to be remembered? Do you want to put together a scrapbook or a memory board? Do you want to arrange your photographs for your family to remember you?"

Jennifer Ostermeier is a death doula and owner of <u>End of Life Chicago</u> with friend Jessica Loesel. The company began in 2020. The pair have been facilitating the Death Cafe at the Oak Park library since 2019. Ostermeier said that during the pandemic, the company fielded a lot of calls from people who were curious about what the end-of-life process entails.

Jennifer Ostermeier, left, and Jessica Loesel are death doulas and owners of End of Life Chicago.

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"Your hospice worker is only able to be there a certain amount of time, but as an end of life doula ... we can be there as often as needed," Ostemeier said. "I think that one of the really great things that we're able to do is work with people on legacy projects. What types of things might you want to be able to leave for your loved ones whether that be letter writing, audio interviews, video interviews — and then putting those into some sort of condensed package so that people can go back. That's a real hard ask for a loved one to do that recording. But we can approach that in a way that is sensitive, that is respectful and that allows space for grief."

At the Death Cafe, Nora Natof, 87, spoke of her mother and grandparents dying. She said when she experienced those deaths, "The ritual in the dying process was not encouraged at all."

"It wasn't until many years later, when my first husband's mother, whom I called Mom, died. My reaction was 180 degrees different," Natof said. "She had very definite ideas about after she died. She died, it was a small service in a funeral home, she was in an open casket and I actually kissed her — a huge difference in how I then viewed the process."

Nora Natof, 87, listens to a conversation on death and dying with the End of Life Chicago company at the Oak Park library on Dec. 11, 2022. Natof spoke of her mother and grandparents dying and how ritual in the dying process was not encouraged at all.

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Natof sees great value in talking and learning more about the end-of-life process. At the Death Cafe, attendees discuss everything from literature about death to states that have passed <u>death with dignity legislation</u>, which empowers people with the right to die on their own terms. The laws help those with terminal illness have the control they want.

Natof wants to talk to her grandchildren about death and although she admits she doesn't know exactly how to proceed with the discussion, she is willing to have the talk.

"My great fear is not death. It's the dying process, because I've seen so much of it that isn't nice at all," Natof said.

Catherine Durkin Robinson, a death doula and owner of <u>Anitya Doula Services</u>, said that although many people fear the physical, emotional and spiritual suffering attached to death, the physical suffering doesn't have to be a part of the experience if the doula, family and medical professionals get on board early about pain medication. The emotional and spiritual aspects are trickier, she said.

"A lot of times what it comes down to is somebody needs to say, 'I'm sorry. I forgive you. I love you. And goodbye,'" Robinson said. "We go through that. Let's talk about who we need to say we're sorry to. Who do we need to make meaningful amends to? Who do we need to forgive? Who do we need to reach out to and say we love, and who do we need to say goodbye to? Our bodies know how to die, so what physically happens to us when we're dying? I can tell you, even though we're all different, our bodies slow down in a very similar way, and what that looks like."

End of Life Chicago can help people host an in-home funeral, host a living funeral (a celebration of life for the person who is dying), or set up a vigil. It also offers hourly support services. Consultations are given and prices vary for services.

Robinson relocated from Florida to set up shop in Chicago to offer the experience she gained as a longtime hospice volunteer.

Catherine Durkin Robinson, a death doula and owner of Anitya Doula Services, stands outside her Chicago home on Dec. 19, 2022. Catherine Durkin Robinson, a death doula and owner of Anitya Doula Services, stands outside her Chicago home on Dec. 19, 2022.

Both she and Klugman offer services where they attend a dinner with a loved one and their family to initiate a conversation about death planning. Most of Robinson's clients are people without illness who want to get things planned ahead of time, while in their 60s or 70s. Others call her because they've received a life-altering diagnosis and they don't know how to talk to their family about it.

"What's most important is that we know who is your surrogate decision-maker," Klugman said. "Somebody who is appointed as a medical power of attorney has different powers than somebody who just comes off a list because you didn't appoint somebody. Having it written down after having had a conversation with your family is really key. I used to have these parties in my house that were potlucks, but people would come and there'd be a presentation. People would have assistance in completing their advanced care directives right there."

Robinson also works on a sliding scale for those who have concerns about pricing. Death doulas are not regulated by a governing body. But Robinson is insured, a member of the National End-of Life Doula Alliance, a nonprofit membership organization, and received her certificate from the University of Vermont. There is no accreditation or oversight of the training programs to become a death doula.

Since coming to Chicago in July, Robinson has supported about five families with end-of-life services and gets calls from organizations in the Jewish, Catholic and LGBTQ communities asking her to speak to members about advanced care directives.

"They really want to hear about ways they can reduce their death anxiety, not only so that they have this joyful death, but that they also live without the fear. And that makes their life better while they're alive," Robinson said. "Everybody needs this – every city, every town can benefit from a doula providing that kind of support."

The next Death Cafe will be at 2 p.m. Feb. 26 at the Oak Park Main Library, 834 Lake St. Online registration is required.

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