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Not to Be Morbid, But Let's Talk About Death

The once taboo talk of end-of-life discussion finds its way into salons and doctors' offices as palliative health care becomes the new normal.

By Andrea A. Firth

Death Cafe discussions are as varied as their membership. They are not grief counseling sessions.

PHOTO BY PAT MAZZERA

On a Tuesday evening, 15 mostly-over-40 strangers sit on comfortable, padded chairs in a meeting room at the Chapel of the Chimes, the historic Piedmont Avenue crematory and columbarium. The visitors' seats are arranged in a circle; coffee, tea, and cookies are set out nearby as refreshments. These people, primarily women, have come together not for a celebration of life but to talk about death. This is Oakland's Death Cafe.

William Palmer founded Oakland's only Death Cafe in 2012 and often facilitates the evening discussions, as he does this night. "It's not grief counseling," said Palmer, whose warm voice and cowboy boots lend a relaxed vibe to the setting. "It's designed to be a friendly, welcoming environment for you to talk freely about death or any topic that relates to death."

Without much prompting, the attendees begin to share their stories and concerns. The mood is pensive and reflective, and those who speak are met with nods and reassuring smiles from the rest of the group. All participants registered online for their spot, and it is common for the curious to encounter a waiting list as the increasingly popular free salons fill up quickly.

On this night, a middle-aged woman talked about how her mother's passing after a protracted illness wasn't what she had hoped it would be. She said hospice wasn't an option until it was too late; her mother was unable to participate in her health-care decisions; and she and her siblings disagreed about the care of their mother. An elderly man acknowledged that he is getting physically weaker and beginning to forget things. He said he feels like a burden on his family and wonders how he and they will manage long term. When a 70-year-old woman described feeling overwhelmed by the practical side of death, the documents to be completed and the details of getting her estate in order, several offered suggestions regarding resources that will help. Another septuagenarian said she has been learning how to have a good death for more than a year and believes she is as prepared as she needs to be. "After all, in the end I'll be dead; someone else will have to deal with things then," she said, and the group laughed.

Death Cafe was launched in England four years ago and spread quickly across Europe, North America, and Australia. More of a group-directed discussion, a Death Cafe does not advocate any course of action, outcome, or product—religious, philosophical, spiritual, or otherwise.

"We listen, talk, and support each other," said Palmer, an organizational development consultant and a coach. His very positive experience with hospice, when his mother died 10 years ago, led him to become a hospice volunteer and subsequently to the Death Cafe movement. "In the past, talking about death has been taboo. It's a difficult conversation to have. But that's changing. There's more openness to death talk today."

After three years, Palmer has hosted more than 30 Death Cafes with about 500 attendees. (Another Death Cafe started up in Alameda about a year and half ago.) The topics discussed range from wills and advance directives—the legal documents that spell out your decisions about end-of-life care—to beliefs and fears about death. "In a global sense, people are looking for practical information and a way to support themselves in the face of death," Palmer said. "The question they often ask is, 'How do I get the treatment and care that I want to live my life at the end in a way that I can control?' When fear comes up, it typically comes out as, 'I'm not afraid of death; I'm afraid of suffering.'"

When it comes to health care, the issues surrounding death and dying are complicated and personal. The idea of paying doctors for talking about end-of-life care with their patients was greatly politicized in 2009 and nearly derailed the approval of the Affordable Health Care Act when former Alaska Gov. Sarah Palin claimed that these conversations would create "death panels" and enable bureaucrats to subjectively ration health care. While the myth of death panels has been repeatedly refuted, today Medicare provides only limited one-time reimbursement for end-of-life counseling. The process, however, requires many conversations over multiple visits, explained Louise Aronson, M.D., a geriatrician and palliative care expert with the University of California, San Francisco School of Medicine. Because these important conversations are not reimbursed, doctors are left to conduct these discussions on their own time or not at all, she added. "If we want people to make good, informed choices, they need to have these discussions, and they need the education."

Recently, Palin again raised the specter of death panels in the wake of the renewed proposal for Medicare to routinely pay doctors and other health-care providers for these conversations; a decision on reimbursement for advance care planning is expected later this fall.

In California, the state legislature has been engaged in debate over the rights of terminally ill adult patients to obtain prescription medication to end their lives. In the past three months, the End of Life Option Act was introduced, withdrawn, reintroduced, and ultimately approved. However, Gov. Brown's stance on the act has been unclear, and whether he would sign or veto the legislation was unknown at press time. "It's an important issue to be discussed, but we're expending a lot of energy on a situation that rarely happens," Aronson said. "Oregon's experience has shown us that. It's a small part of a much larger, more complex issue.

I would like to spend our time and resources on enabling us to live and age well." Welcome to palliative care.
Having the difficult conversations, and talking about end of life issues, are what palliative care specialists in the East Bay are doing with more patients each day. One of the fastest growing fields in health care today, palliative care is a way of

treating serious illness that focuses on comfort care. The illnesses could be terminal cancer or chronic conditions such as kidney disease, dementia, and congestive heart failure.

PHOTO BY PAT MAZZERA

William Palmer has facilitated Death Cafes for several years.

"The aim is to prevent and relieve pain and suffering and improve the quality of life for patients and families as they face life-threatening illnesses," explained Carla Perissinotto, M.D., a geriatrician and palliative care specialist with the Over Sixty Health Center in Berkeley, an integrated primary care clinic for the elderly and underserved. "The focus is on who the person is and what his or her individual goals are for that time."

To some, palliative care might sound like hospice care. Both focus on comfort and respecting patients' wishes, but there are distinct differences. One is timing. For a patient to be placed in hospice care, a doctor must affirm that the patient has six months or less to live. Anyone can opt for palliative care at any point during a serious illness. Patients who choose a palliative approach are often elderly, but not always; and many palliative care patients live years, not months. And while hospice patients agree to forgo further aggressive treatment to cure or abate the disease, with palliative care, life-prolonging treatment can be part of the patient's plan.

Palliative care comes with a paradigm shift—the emphasis is on the person's needs, not the disease. "A lot of what we do in medicine isn't helpful in the end," Perissinotto said. Opting out of treatment that doesn't work and makes life miserable turns a double negative into a positive. "Palliative care is less about what the doctor can do to you and more about what you want, how you want to live, and how your health-care team can support those goals," she said.

As a medical specialty, palliative care is relatively new and has galvanized interest over the past 15 years. It is a team-based approach to serious illness that involves specially trained physicians, nurses, social workers, pharmacists, therapists, and chaplains. Fewer than a quarter of the U.S. hospitals with 50 beds or more had palliative care programs in 2000; now more than three-fourths do. Growth in the specialty is evident in the East Bay, too. "Historically much of the palliative care has been delivered in the inpatient setting, but palliative care medicine has been working its way into the community," Perissinotto said.

Two years ago, when internist and palliative care specialist Bonnie Chen joined Oakland's Kaiser Permanente Medical Group, Kaiser scheduled two half-day palliative care clinics weekly. Today the clinic operates five full days a week, and

it's burgeoning. "There is a growing trend to push the conversation upstream, to talk with the patients much earlier about their goals and values, outside of the hospital, long before they experience a significant medical event and face acute, urgent decisions," Chen said. An oncologist or primary-care physician refers most patients to Kaiser's palliative care clinic, but Chen said she is seeing an increasing number of self-referrals. "Patients are coming to us because they've read about palliative care, or learned about it in a support group, and have decided that they want that kind of medical support."

A survey by the California HealthCare Foundation from 2012 found that a large majority, almost 80 percent, of Californians would like to talk with a doctor about end-of-life wishes, but only 7 percent had had a doctor speak with them.

"As doctors we typically aren't trained in the language of dying," Perissinotto said. "That's a big part of my job as a palliative care physician to have those difficult conversations. I find most of my patients have already begun to think about what they do and don't want to have happen as they age and approach the end of life.

They're just waiting to be asked."

The increasing number of elderly Americans living with serious illnesses is a significant factor in the need for increased palliative care services. "Another reason is that people want it," Perissinotto said. "Patients and families want choice and control over their medical care."

Palliative care physicians bring a unique set of communication skills to the doctor-patient relationship.

"Traditional medical training is primarily focused on treatment decisions," Chen said. "In palliative care training, physicians develop the ability to get to what the patient feels is important. It brings the conversation down to a more basic level."

Despite the increasing need for palliative care, there are too few trained specialists. Kaiser's Chen agrees that the demand for palliative care physicians has outpaced the supply, but she said she believes that interest among doctors in training is expanding. "It's fulfilling work and an exciting time for our field. Patients gain comfort and value from taking a step back from visits to their disease specialist to check in with another physician. They appreciate having a second set of ears to listen."

For more information, or to make a reservation to attend a Death Cafe, go to www.DeathCafe.com. Death Cafe meets in Oakland every other Tuesday from 6:30 to 8:30 p.m. at the Chapel of the Chimes, 4499 Piedmont Ave., and quarterly in Alameda on Sunday afternoons from 2 to 4 in the cottage at The Home of Truth, 1300 Grand St.

http://www.oaklandmagazine.com/Not-to-Be-Morbid-But-Lets-Talk-About-Death/index.php?cparticle=2&siarticle=1#artanc