Embodied to our end

Beth Landis

For the last several months of my father's life, his dementia had progressed enough that he did not recognize me, although he thought I looked familiar. Soon after he moved to a nursing home, he fell and broke his hip and then developed an infection. His quality of life had diminished, and he no longer roamed the halls, smiling and seeking conversation. He was confined to his bed, unable to understand his restrictions. His physician asked us whether we wanted to allow the infection to run its course and let Dad pass away.

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Several years earlier, I had insisted that my parents answer a set of questions about how they wanted to spend their last days and what medical treatment they would want in a variety of circumstances. My parents weren't especially happy with my request for this conversation, but they cooperated. To several of the questions, my dad had responded, "I don't know if you should spend money for that. I would rather have it go toward missions."

When the doctor asked us for a decision, my mother and my siblings were aware of these answers, which we knew to be consistent with Dad's lifelong values. We agreed that it would have been fine with Dad for us to accept this illness as the occasion of his death.

Care of the body at the end of life is a broad topic, and many books have been written about many aspects of such care, including wills, legalities, hospice, funerals, and burials. Obviously one cannot expect to address the subject in depth in a single brief article. Here, with pastors and faith communities as a focus, I will share from my experience in more than thirty years of work as a registered nurse and family nurse practitioner in dealing with people who are facing death.

Encouraging midlife conversation about death and dying

I advise conversations about end-of-life issues at all ages, but I take it up a notch with friends and patients in their fifties. I caution them that if they don't discuss these issues in midlife, situations involving care for themselves or their parents can get complicated. I encourage them to take up these conversations while the prospect of dying seems relatively remote, because I am aware that many people are not able to express their preferences as they approach their death. We spend a huge amount of time preparing for births and weddings and much less time preparing for death. In Idaho, where I live, a survey by the Boise State University Center for the Study of Aging found that "people in Idaho are comfortable talking about death but often they have not had key end-of-life conversations. . . . 4% talked to clergy/spiritual leaders, but almost ¼ (24%) want clergy/spiritual leaders to initiate conversation."[1]

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For years, ethicists have emphasized the importance of end-of-life discussions in families. But as our urban congregation contemplated having such discussions, we realized that most of us do not have family within three hundred miles, that in fact our church community knows us better than our biological families do. We agreed that we needed to have these conversations with each other. Special circumstances gave us a sense of the timeliness of such conversation and the importance of doing it in the congregation. A widow remarked that after her husband died she wanted to review her choices, because her perspective had changed, as had her significant others. Single people among us also needed to be included in our end-of-life conversations.

Advanced directives

One of the things we needed to consider was advanced directives.

These are legal documents that provide instructions about life-sustaining treatments when a person is no longer able to speak on her own behalf. These end-of-life directions may be called a living will, Physician Orders for Life-Sustaining Treatment (POLST), or Physician Orders for Scope of Treatment (POST); names and documents differ from state to state and province to province. The instructions found in such documents are usually specific for medical care and don't incorporate faith values. They tend to be geared toward chronic and terminal illness. For healthy people who don't know what crisis will arise, what they offer is limited. They are helpful as a baseline, but they may not provide much guidance for family and medical providers.

In 1995, the American Medical Association circulated "The Medical Directive," which included various scenarios.[2] Although it is an old tool, it does offer a range of options for several situations you may confront. That said, the situations it covers may well not include what will happen to you—but if you have talked about your preferences for the circumstances it does address, your family and friends will know something about the choices you would consider. I used this tool with my parents.

The "Five Wishes" booklet is popular; more than twenty-five million people around the world have completed it, and it does have some legal merit. A person using this resource indicates preferences for medical, legal, emotional, and spiritual care at the end of life.[3] The Conversation Project, another excellent resource, provides an outline and words to get discussions going. It also includes guidelines for a situation in which one already has dementia.[4]

In 2014, *The Atlantic* published an influential article by Ezekiel Emanuel: "Why I Hope to Die at Age 75."[5] In an interview, Emanuel says that the title given the article was not his choice and it shifts emphasis away from what he considers more important issues:[6] giving primary attention to quality of life and normalizing saying no to medical care (curative or preventative) intended to prolong life in one's later years. He asks readers to consider how they wish to be remembered and whether they want to prolong their living or their dying. Although he doesn't explicitly address faith perspectives, religious convictions could easily be incorporated in the position he articulates. Discussion of this article can bring into sharp focus one's views about quality of life and ethical considerations around medical technology and its costs at the end of life.

Everence, a faith-based financial services organization, has resources on its website for individual and congregational use. One of my favorites is the *Personal Financial Affairs Directory*, a booklet that enables individuals to compile in one location information about their finances. For education, the Everence end-of-life curriculum guide provides excellent videos and materials for families, adult classes, and small groups.[7]

Another part of advanced directives is naming someone to make healthcare decisions if you are unable to do so. Again, states and provinces have different nomenclature; this person may be called your healthcare proxy or healthcare attorney. People often assume they should name their closest relative, their spouse, or one of their adult children, but I wonder whether a close friend would sometimes be a better decision-maker. A family member may know life history but be immobilized during a crisis. Some family members don't want the weight of a decision about end-of-life medical intervention to rest on them. Asking a close friend to be the designated person or to provide back-up support may be a good choice.

Many tools are available for advanced directive discussions. And you may want to use your imagination to stipulate considerations outside the scope of what these generic tools offer. For instance, I remember reading about someone who did not want to be kept alive when she could no longer laugh.

Many folks want to die at home. If that works for caregivers, it is a good option. The general rule is that a person needs to move to another level of care when the caregiver can no longer handle the burden.

How do you want to be cared for at the end of life?

By your family. A century ago, many people died at home, because women were at home and available to care for dying family members. Now changes in external circumstances and income levels may make other options more advisable. One woman said to me, "I wouldn't want my daughters—who live out of state—to feel they needed to stop their fulfilling careers to come to care for me for weeks on end. As a society we haven't really figured out how to share the caring work that women traditionally were expected to do."[8]

Many folks want to die at home. If that works for caregivers, it is a good option. The general rule is that a person needs to move to another level of care when the caregiver or community can no longer provide care. The decision is not a matter of a certain diagnosis or disease. It is not about mobility or dementia or feeding oneself. Anything can be taken care of at home for a price. But when the caregiver can no longer handle the burden, for whatever reason, then it is time to make a change.

Some folks would want regular pastor visits after a terminal diagnosis. Some would want scripture reading and prayer. What our pastor wants from each of us is a completed "Facing Death Planning Form" on file in the church office.

When our body fails and we can no longer be cared for at home, we may express anger. Although the frustration is directed outward, the real loss could be our awareness that our body is deteriorating. Who are we and what does it mean to think of our physical self as our body when it will no longer obey our commands? People who want to be cared for at home may feel that their bodies have betrayed them when death doesn't come as quickly as promised or when an illness doesn't progress as expected or complications arise. Sometimes healthcare providers unwittingly set up unhelpful expectations about timing or a certain kind of death.

By your pastor. Our adult education class had a discussion with our pastor about care we want from him at the end of our lives. We concluded that if he brings Communion he should bring others from the congregation, because our theology says that the Lord's Supper is about relationships (among other things). Some folks would want regular pastor visits after a terminal diagnosis. Some would want pastoral visits to include reading scripture. Some would want prayer.

What our pastor told us he wants from each of us is a completed "Facing Death Planning Form" on file in the church office.

One pastor told me she likes to anoint dying parishioners with oil, as a preparation for burial. Sometimes she also leads a ritual in which the dying person anoints the rest of the group.[9]

By your church community. How do you want to be cared for by your church community at the end of life? Many people think first of music: they want people to sing outside their house, in the halls, or at their bedside. Food for family members is a common tangible expression of the congregation's care.

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Many congregations give prayer shawls or lap quilts as expressions of their desire to surround the dying person or their family members with warmth and comfort.

Dying

Preparation. Hospice care is now widely available in the United States and can be delivered in multiple settings, from home to a variety of institutional ones. Hospice nurses have become midwives in death. They are frequently the ones to explain to family members the particulars of the patient's medical situation and prepare them for the dying process. These nurses are present as the person passes away.

Palliative care is less well known but also valuable. The focus is on improving the quality of life that remains to the ailing person. This care may or may not include hospice and medical interventions.

Canadians tend to use the terms *palliative care* and *hospice care* interchangeably, with variation across the country in funding and settings of care. Both terms refer to end-of-life care that protects dignity and provides freedom from pain, surrounded by loved ones.

Preparation for death for people who are part of faith communities often involves reflections and final conversations with pastor, family, and community. When people know they are dying, they often want to share stories. Sometimes they talk for days and sometimes not until just before death. A variety of tools for life review are available. The big themes that emerge in this process are love, reconciliation, and healing. Something about facing death often makes the person dying and those being left behind more willing to release resentments and open themselves to love.

Death. Dying is something nobody can do for another. In an ultimate sense, we walk that lonesome valley by ourselves. What happens during death? What is the thin space between heaven and earth? A traditional explanation is that the soul leaves the body. Physiologically, medical practitioners define death in terms of certain criteria that address our need for legal clarity, but some bodily functions stop before these criteria are met and some afterward. At the end of the process some people report seeing bright light, angels, music, beautiful colors, and family members who have gone before them in death.

Sometimes we are told that the body is only a receptacle for the soul, but our bodies are more than that. They allow us to be present to others, to serve others, to enter into a wide range of experiences, from the awful to the ecstatic. The relationship between body and soul or spirit is a mystery which theologians and poets are better equipped than I to address.

Some Veterans and Catholic hospitals have volunteers take shifts to sit at dying patients' bedsides so that nobody dies alone. Some people want permission to die, and when their children or spouse assure them that it is okay to go, they die. Contrary to common belief, some people prefer to die alone. After four days of hovering at death's door, one of my patients slipped away when his family members had all stepped into the kitchen.

It is also a myth that Christians have more peaceful deaths. A hospital chaplain told me that "peaceful deaths have more to do with whether people get to die the way they want to."[10]

After death

In some cultures loved ones bathe the body as part of a ritual of saying good-bye. An autopsy or organ donation may leave a body with cavities, and the family members who touch the corpse should be prepared for these hollow areas.

Our day shelter for people who have been homeless bears witness to their lives with a prayer service after death and in an annual observance of National Homeless Person's Memorial Day, on December 21.

A corpse may be cremated, buried, or donated to science. A graveside service is the final act of care for the physical body in dominant North American culture. Memorial services to celebrate a life range in form from parties and picnics to church services and more.

Variations

Pastors get called when things don't go as planned in life and death.

Death early in life. With a miscarriage a dream, a future, and a fetal life inside a woman's body die. Churches traditionally have not done well at marking the grief that attends the loss of an unborn child. One friend told her congregation about her recent miscarriage. She was overwhelmed when so many women came to her afterward and told their stories. Miscarriage is more common than we acknowledge, and these women's wounds were raw. Their cumulative grief added to her pain. Another woman in a similar situation found it helpful to know that so many others had gone this way before her and understood how bereft she was. Young parents need pastoral conversation to help them figure out what kind of support and memorial will be helpful to them after such a loss. Planting a tree is a common ritual after miscarriage.

Stillbirths can be especially difficult for parents and for pastors. A good time to learn about the practices and policies of your local hospital and midwives surrounding stillbirth is now, not in crisis. One service available in the United States and Canada is offered by the nonprofit organization Now I Lay Me Down to Sleep, which provides the gift of remembrance photography for parents suffering the loss of a baby at birth.

The death of an older child is also deeply tragic, and a variety of books, websites, and support groups address the specialized needs of parents and children facing a child's death.

Traumatic injuries. Some medical technology enables practitioners to keep bodies alive but cannot restore people to their prior state of health. In the event of catastrophic injury, the injured person's family often faces questions about what should be done for their loved one. Families base such decisions on medical advice about the person's condition and prospects, on the person they knew, and on their love for this body and soul—this person. The choice might be between allowing death to come on one hand, and using technology to maintain breathing and heartbeat on the other; bringing back the loved one they knew may not be a possibility. In this circumstance many practical, ethical, philosophical, and theological questions arise. With what assurance can a surgeon or emergency physician speak about the likelihood of any change in function in the near or more distant future? What do we owe our loved one who is unresponsive and likely to remain so? If the merest physical function is maintained by machines and medications, is the soul present? Traumatic brain injuries that affect behavior and personality raise a host of additional questions about the nature of human identity and will. Wise providers and pastors will offer support as loved ones wrestle with these deep questions.

Disabilities. People with disabilities and their families may have specific needs around death and dying. One resource in addressing this important question is Duane Ruth-Heffelbower's book *After We're Gone: A Christian Perspective on Estate and Life Planning for Families That Include a Dependent Member with a Disability*.[11]

Toxic theology. Some stories about being present with the dying are filled with love and reconciliation and dignity. Other times, such crises bring a toxic theology to the fore. A family may fear that their loved one has gone to hell because he committed suicide. Parents may fear that their dying daughter will not be saved because she did not attend church. A dying parent may be concerned about her children and the condition of their souls. Or an elderly man may be fearful about what awaits him in the afterlife, despite a long and faithful life. Chaplaincy programs and classes in spiritual caregiving can help pastors provide sensitive support to such people, gently offering other perspectives on God's constant care for them.

Conclusion

It is no easy matter to begin to confront and talk about our mortality and to consider options and articulate preferences about the choices we and our loved ones may face as we come to die.

But the ancient Romans believed that remembering that we must die helps us gain perspective necessary to living well, and the psalmist asks God to help him number his days, so that he would gain a heart of wisdom. A recent book, *When Breath Becomes Air*, is a moving account of thirty-seven-year-old neurosurgeon Paul Kalanithi's attempt to learn how to die and how to live in the face of death. He writes, "Before my cancer was diagnosed, I knew that someday I would die, but I didn't know when. After the diagnosis, I knew that someday I would die, but I didn't know when. But now I knew it acutely. The problem wasn't really a scientific one. The fact of death is unsettling. Yet there is no other way to live."[12]

My hope is that our reflections and conversations about dying and death can help us, individually and as communities of faith, live and love better through all the stages of our living and dying. My prayer is that pastors will draw on wells of God-given grace as they accompany us in our walk through the valley of the shadow of death.

Notes

[1] Boise State University Center for the Study of Aging, Idaho End of Life Survey, Fall 2006, 1; http://hs.boisestate.edu/csa/files/2011/06/communicating-wishes-brief.pdf.

[2] "My Medical Directive"; http://endlink.lurie.northwestern.edu/advance_care_planning/directive.pdf.

[3] Aging with Dignity, "Five Wishes"; https://www.agingwithdignity.org. There is a charge to order or download the forms.

[4] Http://theconversationproject.org/.

[5] Http://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/.

[6] See James Hamblin's video interview with Ezekiel Emanuel, "How Long Do You Want to Live?" at http://www.jameshamblin.com/how-long-do-you-want-to-live/.

[7] "End-of-Life Planning"; http://www.everence.com/end-of-life-planning/.

[8] Anne Hausrath, interview by the author, February 28, 2016.

[9] Dawn Yoder Harms, interview by the author, March 7, 2016.

[10] Ibid.

[11] Duane Ruth-Heffelbower, *After We're Gone: A Christian Perspective on Estate and Life Planning for Families That Include a Dependent Member with a Disability*, 3rd ed. (Scottdale, PA: Mennonite Publishing Network, 2011).

[12] Paul Kalanithi, *When Breath Becomes Air* (New York: Random House, 2016).

About the author

Beth Landis, RN, MSN, is a member of Hyde Park Mennonite Fellowship in Boise, Idaho. She minored in gerontology and public health policy and has served on several ethics committees dealing with end-of-life issues. She welcomes your responses to this article; contact her at bethelandi@gmail.com.