

ONE WAY TO HONOR LIFE? PLAN FOR DEATH

Death accompanies our living.^{1,2} We know this, yet death is often pushed back from the daily routine of our lives.

And then, when death happens, it may take us by surprise or feel unanticipated. Despite the mental hurdles, taking time to think about choices related to our death and dying may allow us to better prepare for it.



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The book *A Heart That Works*, by actor and writer Rob Delaney, recently provided me with a window into such unexpected circumstances. Delaney is best known as the co-creator of the TV show *Catastrophe*. His book describes how he, his wife, Leah, and their family navigated the death of their 2-year-old son, Henry.³

Grief, love and uncertainty about how to feel and act are the measures of their experience, which makes this book so honest. This book reminds readers of our fragile ties with each other as we try to understand how to best care in imperfect circumstances.

Rory Kinnear described in *The Guardian* the theme of this book when he wrote, “When events fracture us, it is the love of others that binds us together again, however imperfectly. Those practical and physical expressions of love — the relatives who learn to clean Henry’s tracheostomy or the calluses that develop on Delaney’s fingers from operating his son’s suctioning machine — are some of the most moving images of the book.”⁴ I agree.

Death awaits us. However, we sometimes don’t anticipate the moments when we encounter it or ignore it when it comes. But to ignore death in our daily routine makes our lives less real and truthful.

In Rome, there is a rather unique memorial to the idea that death should be understood as a part of our lives. The Church of Santa Maria della Concezione dei Cappuccini includes a crypt where the bones of more than 4,000 Capuchin

Franciscan monks are arranged to bring home this message.⁵ Visitors are reminded of death in our lives through each step. In the last crypt, there is a plaque that reads: “What you are now, we once were; what we are now, you shall be.”

In my work as a clinical ethicist, I have come to know that many families have never encountered death close up until they have a critically ill family member or unexpected loss. For many, it is more of an idea than a lived experience. The clinical health care environment, of course, can push that encounter further away because the focus on curing often shadows the need for caring.

So, families can be confused when asked to talk about clinical decisions at the end of a loved one’s life. They tend to assume that life should be maintained at any cost out of a sense of love and obligation instead of weighing the personal cost of a treatment to its probable benefit, which is the Catholic moral tradition.

EVALUATING END-OF-LIFE DECISIONS

What is a Catholic approach to important end-of-life decisions, personally and for those we care for? The first step is to think about what we want to have happen and make some decisions. What do you think about medical interventions at the end of your life? What do you want to have done? Then, share those thoughts with those who will care for you.

This is an important point. Ideally, we would be able to make our own choices. If we are able to voice those choices, then we should. However, we are often unable to make our own decisions, and other people must do that for us. What you want to have done for you will often depend on the love and care of others.

The Catholic tradition suggests that medical treatments should be evaluated by weighing their probable benefits to their burdens on the patient. In other words, how likely is it that a treatment will produce a good outcome, in light of the pain and suffering to the patient? Catholics do not believe that the measure of a life is the number of days lived. Instead, the measure is a life lived meaningfully and thoughtfully for ourselves and others.

How are these final decisions made? First, we can make our wishes known through a written document called a living will. A living will expresses choices but may not meet legal requirements to direct clinical choices.

Alternatively, an advance medical directive for health care is more certain. It is a document that specifies your decisions, and there is a legal obligation to abide by those choices. That document requires legal assistance.

Thirdly, another legal document called a power of attorney for health care decision-making specifies that a particular person has the legal authority to make your health care decisions.

So, there are options: living will, advance directive for health care and power of attorney. Which is best? There isn't one right answer; it will depend on circumstances.

A living will expresses your wishes, but it does so to a general group. Those who will act on your behalf will depend on the laws of the state where you reside, and they will need to reach an agreement with health care givers.

An advance directive for health care obligates those who care for you to follow your wishes. But the interpretation of what you want still remains with your caregivers.

Lastly, a power of attorney for health care decision-making means that you appoint specific persons with legal power to make your decisions for you.

Between an advance medical direc-

tive for health care and a power of attorney for health care decision-making, the latter is more powerful. A person can be guided by your advance directive, but a health care power of attorney document empowers named individuals to act on your behalf. It is important to check with an attorney to make sure that you are following the correct laws.

It is also important that both documents are uploaded to your electronic medical record, or EMR. Each person should ask their primary care provider about how to do this. These documents should be readily available to clinicians in case of an emergency.

Lastly, if you or a loved one is permanently incapacitated and residing at home, it might be wise to consider a Physician Order for Life-Sustaining Treatment, commonly called a POLST in health care settings.⁶ The purpose of this order is to inform emergency responders about your choices regarding end-of-life care. Neither an advance directive nor a power of attorney for health care decisions will stop emergency responders from initiating CPR or intubating you in an emergency. However, a Physician Order for Life-Sustaining Treatment will do that.⁷ First responders are required to initiate emergency care unless this order is in place.

ACCEPTING — AND PLANNING FOR — OUR DEATH

So, to get the care you want, you should make decisions, document them and have an advocate who will defend those choices. Individually, you should consider and document what you want. At the same time, it is essential to include those you love to inform and empower them to choose what care you want. It makes the crisis time so much easier.

So, what is death to those who are faithful? Death and funerals are an ac-

knowledgment of our brokenness and the hope for a more perfect future. None of us are without failure. Yet, amid this, we believe in the redemption of God and the care of those who love us despite our imperfections.

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NOTES

1. Hospice and palliative care are essential if one wants to die with their family at home. But there are many challenges to ensure the “good death” we all want. Hospice, as an idea, has ancient roots in Christian care. The more modern interpretation is that proposed by Dame Cicely Saunders, a physician who was known for her role in the birth of the hospice care movement.
2. I would highly recommend Vigen Guroian's book, *Life's Living Toward Dying: A Theological and Medical Ethical Study* (Grand Rapids, Michigan: Wm. B. Eerdmans-Lightning Source, 1996) as a resource. Written from an orthodox theological lens, it has valuable insights.
3. Rob Delaney, *A Heart That Works* (New York City: Spiegel & Grau, 2022).
4. Rory Kinnear, “A Heart That Works by Rob Delaney Review — A Father's Raw Sorrow and Wit,” *The Guardian*, Oct. 21, 2022, <https://www.theguardian.com/books/2022/oct/21/a-heart-that-works-by-rob-delaney-review-a-fathers-raw-sorrow-and-wit>.
5. “Santa Maria della Concezione Crypts,” *Atlas Obscura*, August 9, 2009, <https://www.atlasobscura.com/places/santa-maria-della-concezione>.
6. National POLST, <https://polst.org>.
7. There has been hesitation from some Catholic authors about Physician Orders for Life-Sustaining Treatment. The objection has been that they think these medical orders approve not treating patients when care could be beneficial. I disagree. The purpose of these orders is not to provide unnecessary and futile treatment.

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