Ask an expert

Question

My husband always said he didn’t want to be kept alive on machines. But I never would talk about what would happen if one of us got seriously sick. I just avoided thinking about death, even though we were both 85 years old. Then, he got lung cancer. That’s when I learned he had completed an advance directive with a lawyer. So, I went along with his wish to not have feeding tubes or resuscitation while in the hospital. All he wanted was to come home with hospice care which turned out okay. But I feel guilty, like we should have done more to keep him alive. Also, I think I let him down by never talking about it. Does all this make sense?

Answer

First, of course, I express my sympathy at the death of your spouse. The loss of a life partner is a heartbreaking experience with many emotional challenges. Your struggle with advance directives both before and following your husband’s death is actually quite common, so I hope others may find this article of use.

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Grief is not predictable

by Kenneth J. Doka

When I speak or counsel people about grief, I am often asked questions such as: How long do you think he will stay in the anger stage? When do you think I will finally accept my loss? Questions such as this are based on what is called a "stage model" of grief. Early on in the study of grief, there were a number of varied stage models. The most famous is Kübler-Ross’ Five Stage Model. She proposed that persons who were dying experienced five stages as they approached death—denial, bargaining, anger, depression, and finally acceptance. Soon, she and her student, David Kessler, applied it to the study of grief.

The model quickly became popular. It was easy to remember. The model captured some experiences, such as anger and sadness, that often are part of the grief experience. Most importantly, it promised that at some time, we would finally accept the loss. One colleague, Dr. Robert Neimeyer, pointed out that the stage model had the narrative structure of a classic epic where the hero experiences all sorts of difficulties and trials before reaching new wisdom and a satisfying conclusion.

This model is now over a half century old, and during that time we have learned much more about grief. We now understand that while some of the feelings that Kübler-Ross described such as sadness and anger are common in grief, so are many other feelings including guilt, yearning, loneliness, sometimes even relief, to name a few. We know, too, that such feelings do not come in any order but can be all mixed together. We often feel that we are a hive of feelings, even contradictory ones, buzzing around inside of us.

We know, too, that grief is not just about feelings. It affects us physically. It can cloud our thinking. Grief influences our behavior in all sorts of ways. Some may withdraw...

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The hardest part of grief

Is giving it a name.

– Amanda Gorman, Call Us What We Carry
The Beatitudes are eight sayings attributed to Jesus in the Gospel of Matthew. These statements may be described in different ways, but each begins by preaching a blessing to: the poor in spirit; those who mourn; the meek; those who hunger and thirst for righteousness; the merciful; the pure in heart; the peacemakers; and those who are persecuted because of righteousness.

I am not qualified to offer religious or theological interpretations of these beatitudes, but from early childhood and much later as a professional student of loss, death, grief, and bereavement, I have been curious, “How can it be that those who mourn are blessed?” and “What does it mean when we are promised that they will be comforted?”

As I struggled to answer how those who mourn can be said to be blessed, the first thing I decided is that the word “mourn” is central. It is not a blessing to have been impacted by a loss. Nor does one feel very blessed when one is grieving. Both loss and grief are burdens with which we struggle in our bereavement.

But we can understand mourning in the sense that engaging in mourning is an active way of coping with, and adapting to, loss and grief. It identifies the ways in which we try to work through our journeys in loss and grief.

Over time, and in all the individuality involved in each bereaved person’s journey, mourning offers the hope of eventually gaining comfort. In other... continued on p. 3

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There are a variety of documents collectively referred to as advance directives. These are legal documents specific to the state in which a person lives that detail preferences for the health care they would like to receive or not receive at the end of life, especially if too ill to communicate. It is typical to also include documents dealing with property and finances. Common terms include a Power of Attorney for Health Care, a Living Will, a Power of Attorney for Finances, a Revocable Living Trust, and a Last Will and Testament. Some also create a Spiritual Will, a non-legal statement of personal values and appreciations. More information about advance planning is on our Hospice Foundation of America website (https://hospicefoundation.org/Hospice-Care/Advance-Care-Planning) as well as elsewhere on the internet. Knowledge of the different forms is important but having conversations around wishes at the end of life can be difficult.

While the majority of Americans think discussing their wishes for end-of-life care is very important, two-thirds never actually have the conversation with their loved ones. Why not? It may seem emotionally overwhelming to discuss death, so the topic is avoided, which is what happened for you. But even though you did not have that discussion together, at least your husband went ahead to make his wishes clear through the advance directives he created. He wanted to prevent treatments that would not cure but might instead prolong suffering.

As your letter illustrates, having an advance directive can both relieve or complicate the grieving process. Often it does both. But it is still best to have advance directives. In fact, I encourage clergy to include this topic in premarital counseling with couples, no matter what their age.

You mention a sense of guilt (“we should have done more to keep him alive”) even though you know he did not want to be artificially kept alive. You also express a sense of shame (“I let him down by avoiding the topic”). These are not unusual grief responses but are the kind of complex and nuanced emotions that hospice bereavement counselors can help with. When you have opportunity to talk about your loss, your husband’s love and wishes, the highlights and struggles of a shared life, what you treasure and what you might regret, I am confident you will be able to put your perceptions and emotions into a fuller perspective.

While his death was ultimately not preventable, your continuing bond to him can be nurtured through compassionate reflection over time, as well as by deep conversations with a counselor and other trusted companions.

The Rev. Paul A. Metzler, DMin, an Episcopal priest and psychotherapist, is semi-retired following over 40 years of service as a clergy member, therapist, and hospice-based grief counselor.

Email your questions for the experts to askjourneys@hospicefoundation.org.
words, the blessing offered by mourning is the possibility of readjusting one's life so as to achieve solace by finding ways to live on in a healthy and constructive manner.

I realize that this is a secular and perhaps idiosyncratic interpretation of the beatitude about mourning. Many will prefer to frame this beatitude within a religious or theological framework. That's fine with me. But for now, my hope is that bereaved individuals engaging in the difficult, complex, and highly personal work of mourning will be encouraged to hope that their efforts will find some positive reward. And, in fact, many bereaved individuals whose mourning processes have enabled them to become true survivors of their losses have testified that comfort, solace, and succor were what they actually achieved.

- Charles A. Corr, PhD, formerly chaired the International Work Group on Death, Dying, and Bereavement and is recipient of the 2020 Lifetime Achievement Award from the Association for Death Education and Counseling.

Many ways we grieve
by Judy Tatelbaum

Facing the loss of a loved one can be a painful process. But we don’t all have the same responses to loss, and we don’t all grieve alike. What makes grieving feel complicated is that we are apt to have many unfamiliar and uncomfortable reactions all at the same time. Some of us are very emotional and some are not.

A friend called me in agony several days after her husband’s sudden death from a heart attack. “Help me!” she shouted into the phone. “Take a breath,” I said, “and tell me what’s going on.” Then the floodgates opened. She shared all the details surrounding the death and her history with her beloved husband. Sharing gave her some relief and helped her move forward.

Like many of us, she needed help sorting out her feelings, and she needed someone to listen and care. Expressing ourselves and being heard helps us deal with loss.

Not everyone is sad about a death. After a grief lecture a woman told me her brother just died. She felt guilty about not loving him and not wanting to be with others grieving his loss. Then she shared the painful secret that her brother had sexually abused her. I thanked her for telling me and assured her she did not have to pretend to feel grief or grieve like her family. I encouraged her to find a therapist now that she acknowledged this distressing memory.

Not everyone wants to talk about how they feel. Sometimes people need a physical outlet to release the pain of loss. One man told me what helped him face the loss of his wife was going outside and chopping wood. When he had no more wood to chop, he helped neighbors with their woodpiles. Afterward he began doing volunteer work driving seniors who needed transportation. Being useful and keeping busy helped him cope.

A client whose husband was incapacitated for many years before he died admitted her deep resentment that her life was curtailed because of his illness. She felt guilty harboring anger and for sometimes wishing him dead. This was a man she loved. Her solution was writing a journal where she could freely express all she felt and swallowed through the long process of his illness and death.

In contrast, sometimes people we loved and lost became saint-like to us after they die. Idealizing a loved one can trap us into long-term sorrow. That was a pitfall I fell into after my brother died at 20 when I was 17. Good therapy years later helped me have a more balanced view of my brother and helped me remember him without pain.

Facing loss is part of everyone’s life. Finding our way through this challenge can make us stronger and more compassionate. We need not grieve forever. We can always remember with love.

- Judy Tatelbaum, MSW, LCSW, is a psychotherapist, public speaker, and author.
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while others seek to avert. Grief can challenge our spiritual beliefs, giving some new insights and depth to their beliefs, while others find themselves struggling with their faith.

Most importantly, we learned that grief is individual. We all come from different backgrounds, different faiths, and different cultures. We all have distinct relationships with the person who died. Over the years, we have learned to cope in our own way. It seems naïve to think that, when experiencing the crisis of loss, we would all react the same. Our grief is as unique and individual as we are.

Much as it is comforting to believe that there is a clear pathway as we cope with a loss, we may find comfort that we may one day “accept” our loss. Yet, we now know grief is not that predictable. Instead we may find that over time our pain eases. We can function in the world again—sometimes even better with the new skills and insights we have learned on our journey. Because we always continue our bonds with those we love, we may, perhaps on anniversaries or special occasions, have surges of grief. We also learn that we have our own unique strengths that help us find our own ways to live with our loss on the journey of grief.

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