



the *Sharing*
End-of-Life
Sojourn

*A profound call on
body and spirit*





BY TRACY HILTS

SIX WEEKS AFTER MY MOTHER died from abdominal cancer I looked at a picture of a woman standing at a church podium. Clothes several sizes too big hung off a tall, gaunt woman whose tear-streaked face and reddened eyes overflowed with yet more tears. For a moment I wondered who I was looking at.

Have you ever failed to recognize a picture of yourself?

If it weren't for the clothes she wore, I would have doubted the woman in the picture could be me. I turned to my husband on the couch and asked, "Is this what I looked like? Is this what I still look like? Why didn't anyone tell me?" I went directly to the bathroom scale to weigh myself. I was nearly 45 pounds lighter than I had been seven months before when these clothes fit.

Seven months and 45 pounds earlier, I'd received a phone call from an emergency room doctor who told me that an ultrasound she'd performed on my mother's pain-stricken abdomen revealed only tumor where her stomach was supposed to be. It had been seven months since I quit my job, moved from Minnesota to California, and began to care for my mother as stage four cancer took over her 55-year-old body and eventually her life. I was not intending to lose weight, nor did I need to. But clearly, caring for my mother through the end of her life had shrunk my body and left me oblivious to the physical effects of prolonged caregiving.

Now, 20 years later, with eight years working as a hospital and hospice chaplain, I

have a deeper understanding about the hard work of caring for a loved one through the final days of life. I can tell you that being a caregiver to such a loved one is a profound experience of the whole person, body and spirit. I can tell you that the kindest care you can give yourself as you navigate this path is to adjust your expectations daily. I can tell you that the journey of grief begins the moment you hear, "There is nothing else we can do for your loved one" and extends until the end of your own life. I can tell you that this journey is not one we were meant to walk alone.

A Profound Call

As partners in hospice ministry, chaplains, counselors and nurses often hear caregivers say, "I can't understand why I'm so tired." These caring helpers describe their days as if they are filled with passive, nearly do-nothing tasks. In reality, caring for a dying loved one activates the deepest reserves of your body and spirit—the innermost core of your being. You are preparing your loved one for death. You are watching your loved one die. In my experience, you are responding to the most profound call on your body and spirit.

A person with a life-limiting illness is

bound in a body with systems that are actively shutting down. That dying frame generates less energy, and the dying mind loses interest in the normal activities of daily living. As a caregiver, you compensate for the decline by first supporting and then performing ever-increasing tasks to secure your loved one's comfort and safety. As the body weakens and mind grows weary, you love the person through feeding, bathing, toileting, changing, turning and administering medicine and comfort.

As the disease progresses, your loved one will sleep more but you will sleep less. You sleep less because your worry keeps you awake. You sleep less because the couch or chair near your loved one's bed isn't very comfortable. You sleep less because you have to be awake to offer comfort medication around the clock. You sleep less because you are watching every breath—wondering which will be the last. And with little to no rest you must keep track of medications with names that seem to be a foreign language. “What is this pill for? When am I supposed to give it? What is the right dosage? What if he can't swallow? How will I know if it's working?”

You are also preparing for the final separation from someone you love. “Who will I be when she is gone? What will I do without her? How does life become normal again? Will I ever feel like myself again?” Caregivers often struggle with the same questions a dying person asks. “What has my life meant? What have I done with my life? What do I regret? How will I be remembered?”

You may wrestle with your sense of God. “What is God's place in this journey? God can heal, so why doesn't God heal now? How can I lean into a God who is not doing the one thing I want God to do—heal my loved one?” This is why you are so tired. Your body and spirit are worn and weary. It's not uncommon for caregivers to minimize or even forget

to care for themselves, but with a task so all-encompassing as sojourning with a loved one to the end of this life, self-care is crucial. To give your body and spirit the best chance at maintaining along the journey, practical steps may help see you through.

1. **Eat.** Caregivers will sometimes feed their loved ones but forget to eat a meal themselves. As their loved ones begin to eat less and less, caregivers find their appetites waning too. Care for yourself by making sure some quick but healthy snacks are available.
2. **Ask for specific help.** People want to know how they can help. Let them bring food and water. Let someone sit with your loved one so that you can go for a walk, go to the store or take a solid nap.
3. **Keep a medication log.** Invite someone else to listen in to the instructions with you to reinforce your listening and learning.
4. **Activate your support system.** Share your heart with a family member or friend. Talk through the process with a hospice chaplain or counselor. Ask people to pray for you and with you.
5. **Read the Psalms.** The psalmists often cry out to God with anger, despair, uncertainty and doubt. God included these cries as part of these songs of worship. God knows what we are thinking and feeling and is still there.

These steps are aspects of self-care that restore your capacity to offer support for as long as it is needed.

Pathways through Grief

Although these practices work for many people, every person,

every circumstance, every path, and every day is different. Even the path you are on will change from hour to hour and as the illness progresses. An important way to keep stable on a changing path is to adjust your expectations on a daily basis. Ask yourself, “What is most important to me today?” Maybe it is to make your loved one's favorite dessert—even if only to enjoy one bite. Maybe your most important task is to recharge with a much-needed nap. Maybe you need to limit the number of visitors or phone calls because your loved one would like to keep the day quiet. Maybe your act of deepest service is helping your loved one have a bowel movement to relieve severe constipation caused by medications and being confined to a bed.

The necessary emotion and activity of intimate care will change from day to day. Through seasons of uncertainty and exhaustion, your spirit will groan and your body tire. Staying flexible with changing needs, even your own, will lessen the strain



Keeping Company at the End-of-Life

Ten ways to care for your loved one and yourself.

1 | Learn the signs and symptoms of the end of life.

It's not unusual to be afraid of what this process will look like. Sometimes people worry they will walk in the door and find their loved one dead. Disease usually follows a pattern, and becoming familiar with this pattern can alleviate some of the anxiety of the process.

of unexpected developments. From the first moment you hear the devastating news, give yourself permission to grieve. Although heartache and heartbreak are profound and immeasurable after death, your grief throughout the dying process can be just as overwhelming. We don't always pay attention to it because, as I have heard people say, "I can't let myself grieve yet because she is still here." It is okay—it even honors your relationship—to recognize and express that you are already grieving even while your loved one is still alive.

From the beginning of the grand story in Genesis to the end in Revelation, Scripture makes it clear that God did not design us to go through the valley of desperate times alone. In the Garden of Gethsemane, Jesus models a perfect example of God's design that grief is meant to be a shared journey. Matthew 26 and Luke 22 show us how even God's perfect Son needed a community of care and support.

Many times, Jesus went off alone to

pray and seek fellowship with his Father. But this time, this grieving time as death approached, he called his disciples with him into the garden. He asked them to stay and pray. Then he took his three closest friends with him a little farther into the garden and asked them to keep watch over him. Luke tells us that Jesus' friends were too exhausted "because of grief" to keep their eyes open even though Jesus asked them three times to stay awake with him. Then, when his best friends and the other disciples could not sustain their support, Luke tells us how an angel from heaven appeared to strengthen Jesus. God knew that Jesus must not face his most difficult time alone. If Jesus, though fully God, needed fellowship to strengthen his humanity, then surely we who are only human will need the same support!

When I look back now on the photograph

of my grieving self, I see a different picture. I see with eyes that are opened by years of ministry. I see with a heart that is opened to once unknown depths. Now, I see those tears as liquid prayers—a gift from God who knew that words alone were not enough. Now I see that in my depleted body and my crushed spirit, I was bearing the image of Christ. I did not reflect Christ in the manger or Christ in the temple, but Christ in the garden.

Your pathway may be different, but as you stand at the side of one dearly loved, Christ is standing with you. His strength is your strength, and your strength is a ministering spirit as the one you love draws closer to eternity. May your journey together be blessed and a blessing. May you go under His mercy.

Tracy Hilts is a graduate of Biola University and Denver Seminary with an MA in counseling-chaplaincy. Permission from Church Health to reproduce this article for noncommercial ministry use.

2 | Take advantage of good days.

When your loved one seems to have more energy or is feeling "better," do something with that time—whatever she wants to do! And if she is exhausted the next day, it's okay. You have not hastened your loved one's decline. You have brought goodness or joy even into this journey.

3 | Gather important people before your loved one dies.

Celebrate or cry with your loved one. Bless your loved one with your heart words and let him bless you all in return.

4 | Record the word of blessing or the stories of your loved one.

Record her reading a book to or for her grandchild. Record him telling a story from his childhood.

5 | Plan a sentimental journey.

If physically possible, this could be a walk around a favorite park, a concert, a trip to an art museum—something for your loved one's joy.

6 | Speak your heart often.

Speak to your loved one and to your support system.

7 | Laugh without shame.

Memories will come from places deep within your heart and mind, and some will make you laugh and cry at the same time.

8 | Make funeral plans ahead of time.

Families are vulnerable at the time of death, and it is best to avoid making significant financial decisions in that period of stress if possible. This can also help avoid the "I'm not sure what he would have wanted" experience that can lead to dissension in families.

9 | Drink lots of water.

You have lots of tears to cry, so give your body what it needs to do so.

10 | Seek grief counseling or grief support.

Do this at least one time after your loved one's death. It can be a healing, affirming experience to be with others who are walking a similar grief path.