My life with ALS: Depending on the care of others

by Julie Ruth Harley in the July 24, 2013 issue

Photo from First United Church of Oak Park

When I was a 28-year-old chaplain in a nursing home, Marie was the one person I avoided. Marie was in her early fifties and was the first person I'd met who was living with amyotrophic lateral sclerosis. Her whole body was a grimace of pain, from her mournful eyes to her tightly clenched fists to her withered legs dangling from the wheelchair.

I was stunned by the cruelty of this degenerative neuromuscular disease. ALS typically strikes people between the age of 40 and 60. It leads to death within two to five years. While the body wastes away, the mind stays perfectly sound, forcing the patient to live his or her own dying with frightening clarity. No wonder Marie seemed angry and withdrawn.

I did not know how to be a pastor to Marie. Her bitterness intimidated me, and I could think of nothing that would ease her pain, nor could I offer a healing word. Though I was ashamed of my reaction, I still found reasons not to visit her.

Twenty-five years later I sat in a neurologist’s office and learned that I have ALS. I knew all too well what lay ahead for me and my family.

I knew from the start that I had to make significant choices so that I would not end up angry and isolated. I am single, both of my daughters are away at college, and I have no family living nearby. I was lead pastor of a large, vibrant church and had never been happier in my vocation. How would I deal with all these losses and who would be there for me as my physical health declined?

My first decision was to not focus totally on medical issues—to not be defined by ALS. I sought good medical care but did not seek alternative treatments that might extend my life by a few months. I accepted that I have a terminal illness, and I chose to be fully alive every day.

Then I began to call on my faith community in a new way. I asked the elders to pray for me and anoint me for healing. I asked the deacons for support, and they responded by forming Team Julie, a group of some 150 people who share meeting my needs each week through a website called Lotsa Helping Hands. Every day a member visits to share meals, do my shopping, take me to doctors’ appointments or pray with me. This nurturing quilt of love gives me a reason to wake up each morning.

My symptoms forced me to retire from ministry, and I now live in an apartment near the church with 24/7 caregivers. I am confined to a wheelchair. My speech is becoming very slurred, and soon I will no longer be able to speak. Then I will use a computerized communication device controlled by my eye gaze.

Many experiences sustain me. My friend Jackie, a massage therapist, comes each week to relax my contracted muscles. As she applies Tiger Balm, we talk about her latest hike or highlights from my recent theological reading.

Seven members of my church come to pray with me every few weeks. They let me cry, and they join me in laughter and listening for the Spirit. They created a home altar for me and decorated my walls with inspiring words and images.

Now that I can no longer turn the pages of a book, I call on Team Julie to read aloud to me. Kevin, who is fluent in Japanese, is reading to me a book that compares Buddhist and Christian mysticism. It is a delight to share great ideas with people I love.

What amazes me about all of these experiences is the joy that people feel in helping me. And I've learned to share my needs openly and to be unafraid to ask for assistance; people can then do something tangible to share their support and serve as my companions on this journey. When people ask, "What can I do for you?" I give them a specific task.

I turn to the writings of Paul for my spiritual solace. For me, Paul is a great exemplar of midlife spirituality. In his letter to the Philippians I hear him struggling with loss and his stubborn thorn in the flesh. Paul speaks to the existential conflicts of midlife and points to a path that allows us to find joy in sorrow. He calls us to rejoice in the Lord, not in our external circumstances. He encourages us to focus on virtues rather than stay stuck in despair. He shifts our attention from what is merely transitory to what is eternal.

Paul does not dwell on the unanswerable question of "Why me?" Instead, he seeks to deepen his dependence upon Christ: "I can do all things through him who strengthens me" (Phil. 4:13). This is my mantra when I am frustrated by no longer being able to move or speak and when energy is in short supply.

Because ALS has created limits that I'd never imagined would be mine, I've learned to place my trust in God's providence. My fervent prayer is that I will trust God to provide whatever I need when I need it—from the right medications to financial resources to compassionate friends. With no control over my life, I have had to surrender to God. This has deepened my awareness of God's presence and given me God's grace to help me transcend my pain.

With each loss, of course, there is lament. I felt humiliated when I had to use a cane while presiding at a wedding. I was shaken when I realized that I could not walk up the steps to the pulpit and had to preach with a walker and a worship assistant. When my physical therapist measured me for a power wheelchair, I burst into tears.

The losses mount, and each time I need to grieve.

One of the hardest losses is losing my voice. I find myself resisting the use of a computerized device. (I plan to program the device with plenty of four-letter words!) Often I need someone to simply listen and wipe away my tears and not be afraid of my suffering. Empathy is always more helpful than advice. These spiritual and emotional adjustments take more time than the pace of the physical changes allows.

In the midst of sorrow I look for reasons to celebrate. My retirement service was a celebration, not a memorial service. We laughed more than we cried, and love filled the sanctuary. We also held a celebration for members of Team Julie, acknowledging the remarkable Christian witness in their caring. We have learned that mourning can be turned into dancing, as the psalmist promises (30:11).

A major source of celebration for me is that I have come to live in a “gift economy.” Much of what I have is a sheer gift from others. The fifth-grade church school class made me a blanket. Church members created a quilt and a lap robe. Financial donations to Julie’s Fund help with my medical expenses. Don helped create a “voice quilt,” which recorded three hours of messages to my daughters. Jan is my personal shopper and finds clothes that are both stylish and wheelchair-appropriate. Bud wrote me a psalm. Kathleen transcribed the words for this article. I have become a receiver of gifts. I experience radical charity.

Ironically, before my illness struck, I had been feeling a spiritual call to live in community and had visited intentional Christian communities and cohousing models. I’ve now moved into a community, although it is hardly the one I imagined for myself. My caregivers are an extended family. One morning I apologized to Joanne for waking her up almost hourly to reposition me in bed. She responded with grace, “You didn’t hire me for the good nights.”

My illness has affected my daughters in powerful ways. One night when I was having a meltdown, they tried to cheer me up by telling me some good things that have come out of this year. Twenty-one-year-old Rachel said: “Mom, I used to hate the church, but now I love it. I see everything the church is doing for our family. I have learned to reach out to them. I’ve even started praying again.” My 19-year-old-daughter Emma said: “Yeah, Mom, I’m not a pagan either.” My hope and prayer is that they will see this experience as more than a tragedy. Young adults who would normally be totally focused on themselves, they’ve become my caregivers and can make me laugh every day.

For many years I defined myself as a devoted mother and capable pastor. Now I spend most of my time being rather than doing. Others have told me that my life is a sermon and that I continue to teach without standing in a pulpit, leading a class or engaging in acts of mission and advocacy. I believe my purpose now is to witness that it is in dying that we become fully alive to each moment.

How I would minister to Marie today, knowing what I now know? I would relate to Marie as a companion in suffering. I would allow her to be angry and bitter and would risk weeping with her. I would tell her that God’s strength is made perfect in weakness, that God participates in our suffering and is fully present in the agony of the cross we bear. When we share our vulnerability and our fears, we open ourselves to the power of the Spirit. Admitting our raw neediness enables other people to uncover their own wounds. Then together we turn to God for healing and hope.

The subject of hope is tricky, and a vision of heaven only partially satisfying. With sadness and regret, I would acknowledge, with Marie, the foreshortened future. I would also speak of what Douglas John Hall calls “costly hope”—what can be granted only by the Christ who suffered and died and then rose again in human flesh. Jesus too lived with his own death; after all, he knew exactly what was coming. I sometimes imagine myself prostrate in the Garden of Gethsemane with Jesus, feeling both unwilling to go forward and newly encouraged from a naked encounter with God.

I would ask Marie about her support network and encourage her to reach out to her faith community (or any community of compassion) so as to have a care team. The responsibility for caregiving is a huge burden to put only on family members. When caregiving is shared, no one has to get burned out.

If I sensed that Marie was ready, I’d read her Philippians 4, where Paul calls on us to focus on what is true, honorable, just, pure, pleasing and commendable. Even in the debilitating struggle of terminal illness we are surrounded by incomparable spiritual beauty.

Paul gives us a life-affirming invitation to experience what lies beyond our temporal frustrations: “Keep on doing the things that you have learned and received and heard and seen in me, and the God of peace will be with you” (Phil. 4:9). In the end, I would simply pray with Marie in silence and implore God to show her perfect peace.