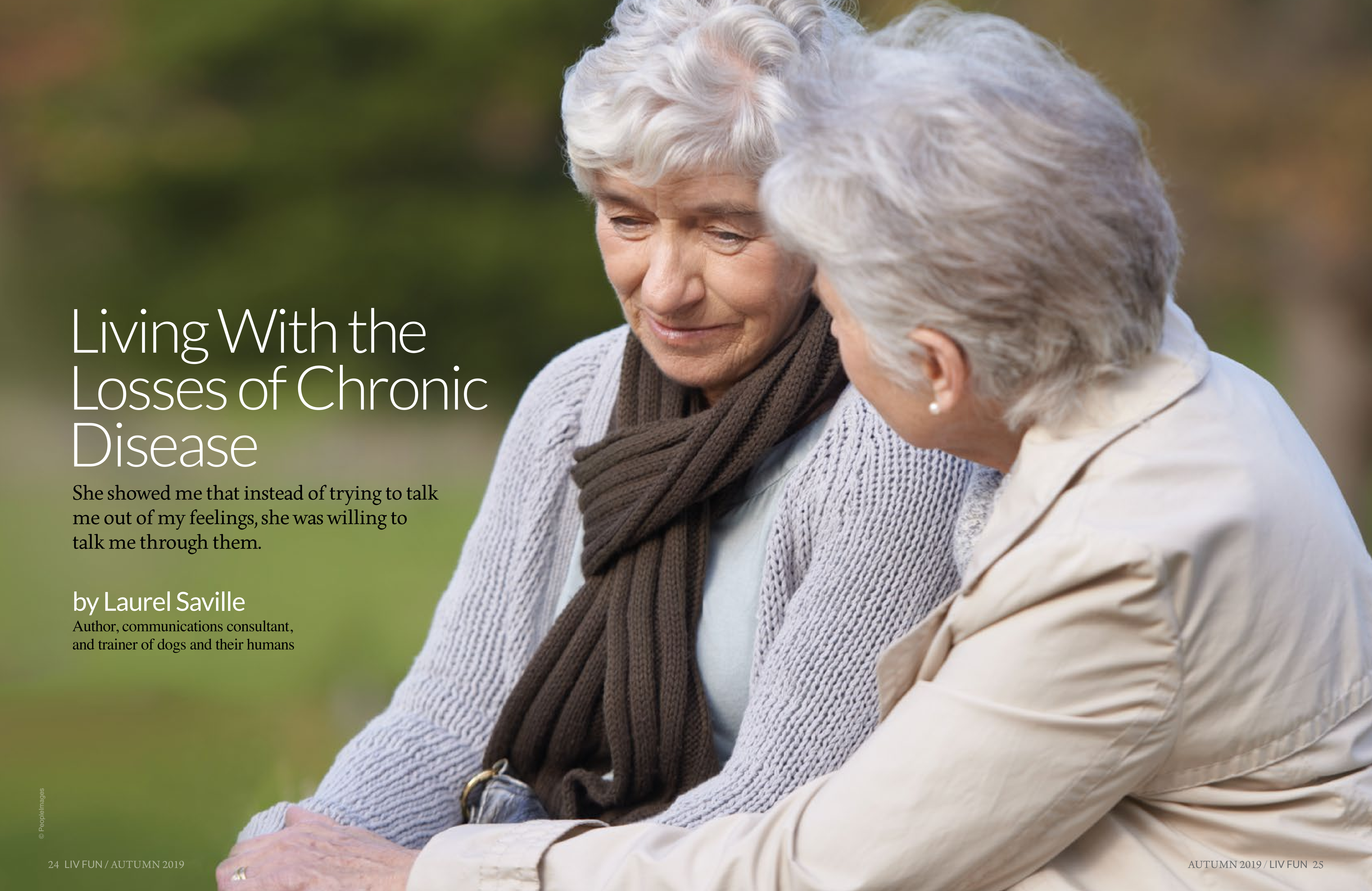

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Living With the Losses of Chronic Disease

She showed me that instead of trying to talk me out of my feelings, she was willing to talk me through them.

by Laurel Saville
Author, communications consultant, and trainer of dogs and their humans

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Advances in medical care have given each of us the promise and benefit of longer, healthier lives. But, paradoxically, because we can cure, treat and manage diseases that were, once-upon-a-time, deadly, these same advances are also giving many of us longer, *unhealthier* lives.

“Back in the day, people died of infectious diseases before they had a chance to get chronic disease,” notes Dr. Steve B. of Oklahoma, who has Parkinson’s. Statistics back this assertion: Using data from the Rand Corporation, the Centers for Disease Control and Prevention estimates that six in 10 adults in the United States have a chronic disease, while four in 10 have two or more. (Buttorff et al., 2017)

Most of us will, at some point in our lives, watch a loved one steadily diminish by illnesses like Parkinson’s, multiple sclerosis, Alzheimer’s, fibromyalgia, rheumatoid arthritis, and many others. For some of us, the process happens to the person we see every day in the mirror.

Stuck in the Sand of a Chronic Diagnosis

Ten years ago, I was successfully treated for an acute and often deadly form of breast cancer; today, I’m living with the chronic, incurable and progressive disease of Parkinson’s. The emotional journeys of the two experiences have been completely different.

Acute illness draws lines in the sand. There is the before and after of diagnosis, the before and after of either death or cure. Chronic illness, on the other hand, feels more like being stuck thigh deep at the beach, pummeled by wave upon wave of physical insults.

Kate Jackson, writing in *Social Work Today*, explains it this way: “A person with a chronic illness [is] forever walking down a dividing line between the past and the future. The experience … is invariably one of accruing myriad losses.” (Jackson, 2014)

The farewells have been numerous and wide-ranging for LaurelAnn B. of Oregon, who has multiple sclerosis. “People, friends, animals, work, abilities, adventures, and so on,” she says.

Simon W. of the United Kingdom, who has lived with chronic fatigue and other ailments for almost 30 years, laments what didn’t happen. “I feel so much sadness when I consider what I might have done in the last quarter-century,” he says.

And for those with chronic diseases, there is no pretty picture out of the windshield ahead of us to mitigate what is falling away in our rear-view mirrors.

“I feel like I’ve already lost so much, what’s the Universe going to throw at me now?” LaurelAnn says.

“That anxiety is overwhelming and exhausting,” Simon concurs. “I may well live another 25 years. The thought of what is going to happen to me in those years is horrifying.”

The Grief We Cannot See

The understandable onslaught of grief over the degradation of the self can in fact be difficult to recognize for those with incurable illnesses. Doctors focus on addressing and alleviating physical manifestations, like a mechanic fixing a broken machine. Friends and loved ones barrage us with often misguided, unhelpful and dismissive pats on the back and things to try, from the obvious to the out-there. Books and websites recycle the same generic lists of self-help pablum. Self-care. Support groups. Focus on what you can do. Get out in nature.

Much of this hopeful advice simply adds another “to-do” to a list already brimming over with tasks related to managing a disease. And plenty of it may be more difficult to implement than people realize — some days we’re too tired to “keep fighting” or too sad to “focus on the positive” — giving the ill yet another reason to feel defeated. Even compliments can back-fire.

Jackson points out that “well-meaning individuals … may try to add a helpful perspective by saying, ‘It could be worse’ or ‘You look fine,’ statements that invalidate a person’s physical and emotional suffering.”

Difficulties with processing grief also come from inside ourselves. Dr. Steve says he rarely researches the illness he lives with every day. “I want to read about diseases other than my own.” Further, he feels a kind of ironic relief that he has no family. “It’s helpful to live alone because there is an advantage to not having someone around who is worried or depressed about me, or watching me have trouble.”

LaurelAnn says, “I focus on the positive because that’s all anyone wants to hear.”

Linda R. of New York, who has fibromyalgia, went through a deep mourning over the loss of several very valued hobbies. Yet, when she considered attending a support group, she realized, “The last thing I want to do is sit around with others and complain about my ailments.” Her observation reveals yet another common absurdity to living with chronic disease: As it takes up more and more of who you are, you may want to talk about it less and less, thereby further erasing your sense of self.

And yet, not talking about “it” has the potential to make everything worse. Jackson points out, “Many ill individuals fail to realize that the anger, denial, depression or guilt they experience may be manifestations of grief. Although the losses may be vast, the grief they arouse likely will go unrecognized or unaddressed — oversights that can have severe consequences,” including everything from depression and suicidal thoughts to an increase in symptoms or worsening of the disease.

“How does it feel to have Parkinson’s?”

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Validating the Real Journey

While we encourage grieving when someone loses a loved one to the ravages of an illness, the same mourning process, when applied inward, is often framed as self-pity, something to be avoided at all costs. Sarah W. of the United Kingdom, who is living with chronic fatigue, knows the opposite to be true.

“Having done my share of grieving for parents and others, I’m aware that it’s a process. This is exactly how one feels for the loss of parts of oneself,” she says.

Then there’s the added complication that new losses keep piling up, forcing you to confront — or avoid — the entire emotional ordeal again. And again. And again.

Jackson’s advice for social workers is equally applicable to those of us with disease and those who care about us. “Social workers must have patience and compassion, and they must be able to sit with clients through tough times to help them adapt … while validating how hard their journey is.”

So how does one validate the journey of another’s chronic illness? Simon points out how straightforward it can be. “The most helpful thing is for people to ask questions,” he says.

For myself, I regularly revisit the moment a friend looked at me, her face full of genuine concern and interest, and simply asked, “What does it *feel* like to have Parkinson’s?” And then she sat with me, listening, nodding, squeezing my hand in encouragement to continue as I told her. And kept telling her.

She showed me that instead of trying to talk me *out* of my feelings, she was willing to talk me *through* them.

Sources:

Buttorff, Christine; Ruder, Teague; and Bauman, Melissa. (2017). “Multiple Chronic Conditions in the United States.” Rand Corporation. Retrieved June 6, 2019, from www.rand.org.

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Words of Wisdom

What to say — and not to say — to someone with chronic illness.

When I posted on my Facebook page asking for anyone dealing with chronic disease to tell me the most helpful response when they tell others about their health issues, I did not expect hundreds of comments. Most came from people I had assumed were perfectly healthy. The responses, the majority of which railed against the various rude, thoughtless, clumsy and insensitive remarks they’d had to endure, creates a clear picture of how difficult it is to discuss disease.

The common denominator to all the unwelcome remarks? While perhaps well-meaning, people often say things that minimize the ill person’s experience. Telling someone they “don’t look sick,” questioning their diagnosis, or comparing their symptoms to those of great Aunt Matilda suggests they are exaggerating their suffering. Offering advice on lotions, potions or other magical cures, from bone broth to CBD oil or vegetable smoothies, shows a lack of understanding of disease itself and disrespects how much time, energy and research an ill person has undoubtedly already put into understanding their options. Asking if it runs in the family or trying to ascertain other, possibly self-inflicted causes is a none-too-subtle blame game. Demonstrations of pity, sadness or discomfort make the ill person feel they need to care for you, as well as themselves. Exhortations to “be positive,” “look on the bright side,” “remember, it could be worse” are dismissive pablum.

So what should you say? Actually, nothing. Instead of talking, listen. A simple acknowledgement and an encouraging question or two are really all anyone struggling with disease wants to hear.

“That sounds really tough.”

“I’m sorry you have to deal with this.”

“What helps you feel better?”

“Is there anything I can do to help?”

“How are things going these days?”

Make gentle queries and pay attention to the answers. Ask if it’s OK to ask questions. Show concern. Be empathetic. Don’t make too big of a deal of things. Go ahead and crack a little joke. And then, naturally move on to other subjects. At the end of the day, the rules for discussing disease are simply those of any good conversationalist: Speak less, and listen more. ◆

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