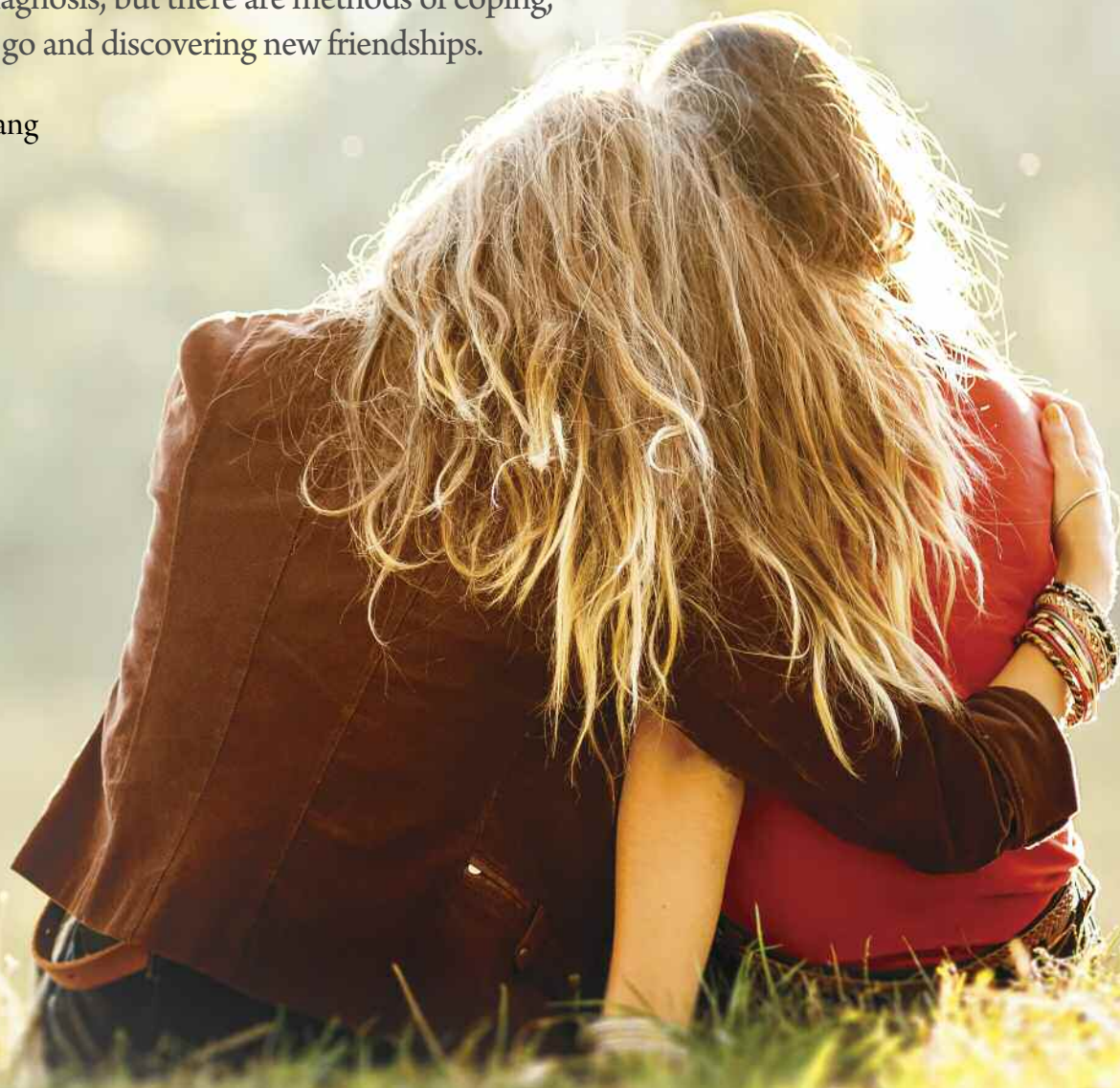


Where Did Everyone Go?

Coping with the Loss of Friendships Post-Diagnosis

There are many reasons friendships fall by the wayside after a chronic illness diagnosis, but there are methods of coping, including letting go and discovering new friendships.

By Trudie Mitschang



THE LOSS OF a friendship is rarely a clean break. Unlike the end of a romance, there are no screaming matches, slammed doors or even break-up texts. Often, there is more of a drifting away, a slow disconnect that can be more painful than a harsh goodbye. And, for a patient with chronic illness, this type of relationship unraveling tends to play itself out repeatedly, as one friend after another gradually seems to simply disappear. The fact that this occurrence is common and shared by so many does not make the pill any easier to swallow. “One of my friends — a friend I had been close with for 10 years — failed to visit, call, text or even message me on social media me when I was going through several weeks of long hospital stays,” says Ilana Jacqueline, a 27-year-old dysautonomia and primary immune deficiency disease patient from South Florida. “I was stunned, but told myself: I’m OK. I don’t need her support. She has a busy life. It’s a busy week. I can’t just expect her to drop everything and acknowledge that I’m struggling a little bit here. Can I?”

Jacqueline, like many patients, initially blamed herself for the unexplained distance in her friendship. Over time, she began to see things from a different perspective. “I tried for a long time to convince myself that it was my fault. That I was boring. That I couldn’t go out. That it was my fault I fell off her radar,” she explains. “Finally, I was just like, you know what? Even when I can’t go out and make plans, I still reach out and check in on my friends. I still offer support and comfort. I deserve people who will do the same.”

Jenni Prokopy, a Chicago-based writer and motivational speaker who was diagnosed with fibromyalgia at the age of 25, agrees: “Plenty of my friendships have changed since I was diagnosed with chronic illness, but that was nearly 20 years ago, so I have to say that most of my friendships today are with people who I’ve known since I got sick.”

It’s Not You, It’s Me

The tendency to blame oneself for relationship conflicts that arise post-diagnosis is a normal reaction, and is often coupled with feelings of grief and loss. The truth is, most people pull away during times of crises because of their own shortcomings and inability to handle the stress and limitations brought on by chronic illness and pain. In such instances, a person may hear common sentiments such as: “It was hard to see you in so much pain,” or “I didn’t know what to say, so I didn’t call you.” These excuses undoubtedly fall flat when compared to the insurmountable challenges faced by a patient with an incurable disease.

More often than not, the friend who pulls away offers no explanation at all. “I had a friend who I lost a few years ago, for

reasons unknown,” recalls Prokopy. “I was going through a really intense flare-up, and I wasn’t able to hang out as often or go on trips with her like we had in the past. I realized one day that she had just stopped reaching out. I tried to reconnect with her, but she just faded away. That was really hard to take because to this day, I do not know what precipitated that friendship breakup.”

Friends and family can be incredibly supportive, yet in many instances, they can also be extremely intimidated when it comes to helping a loved one, and may feel so overwhelmed themselves that they don’t have the strength to do so, says Beth Kane, LCSW, a private practitioner in Toms River, N.J., who specializes in working with patients coping with illness. “Very often, close family and friends can find themselves thrown into this ongoing grief process and are constantly reminded of how their own lives were before, how their own lives have changed and how the person used to be,” she explains. “They are as much in need of support and help as the individual who has the illness, sometimes more so, especially if they are the primary caregivers.”¹

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Well-meaning individuals may also make things worse in an effort to provide support by continually saying the wrong things. Some, for example, may try to be encouraging by saying things like, “It could be worse” or “You look fine” — statements that seem innocent enough but only serve to invalidate a person’s physical and emotional suffering, especially for those with invisible illness. “The notion of ‘it could be worse’ translated into ‘you could be dead’ is a big roadblock,” says Kane. “There is a lot of material out there about positive thinking, which in its own right has its own merits and can be useful. But, when statements like this are used as a viewpoint, it is very dismissive of the pain the person experiencing this type of grief is trying to manage.”¹

Finding a New Normal

Psychologically, an illness diagnosis can stir up tremendous feelings of loss. A newly diagnosed individual may struggle to accept everything from the loss of health, career, income and freedom to the loss of cognitive function, independence and certainty. Later, unexpected losses such as the dwindling circle of close personal friends can really take their toll. When it comes to developing coping skills, mental health experts suggest patients make an attempt to see things from the healthy friend's perspective. "People really don't want to be around sick people," says Steven Feinberg, MD, a past president of the American Academy of Pain Medicine. "When someone is ill, you feel sorry for them. But we're all busy. We say we care and things like that, but the reality is, except for our immediate family, we don't want to be reminded of our own mortality."

The dilemma is often compounded when, at the same time friends may be pulling away, the person who is ill may not have the energy to invest in the friendship either. "If you're in chronic pain, you don't have the physical strength," explains Dr. Feinberg. "You're irritable, and people don't want to be around you. So you start losing relationships."²

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In her book, *A Delicate Balance: Living Successfully with Chronic Illness*, author Susan Milstrey Wells explores the myriad ways a diagnosis can negatively impact relationship dynamics. "Chronic illness throws a monkey wrench into our relationships. We may seem as foreign to the people who love us as if we had begun speaking a different language," she explains. "Our family and friends still want us to be the mom who works, the dad who plays baseball in the backyard and the friend who meets them for lunch. In turn, we want to be treated as the same loving spouse, parent and friend we always have been. A large part of the responsibility for making those relationships work falls to us. We have to educate our family and friends about our disease, allow them to express their emotions openly, and clearly state our

limits and our needs. Also, we have to expect these changes to be unsettling."³

In fact, it is that sense of feeling misunderstood that can drive a wedge between current and even potential new friendships. "I don't think other parents understand my child's diagnosis," says Jessica Leigh Johnson, a mother of three sons with X-linked agammaglobulinemia (XLA) and one who passed away from XLA. "A lot of times people will say, 'Well, if you expose him to more kids, he can build up an immunity by being around more sickness.' And that's exactly what he can't do. I also don't think they understand why I am so afraid of my kids catching something like influenza that could further damage their already damaged lungs. It's a big deal, but I feel like other parents think I'm making a big deal out of nothing."

Feeling misunderstood and judged is a big reason many patients and parents of children with chronic illness tend to withdraw socially, finding it easier to spend time with close family members or others who are facing a similar diagnosis. "I don't cope very well with this challenge at all," explains Johnson. "I find myself withdrawing from other moms my age. I figure they won't understand me so I don't put myself out there, and I don't try very hard. Actually, my closest friends are my sisters-in-law. Members of our family understand because they've been with us from the beginning."

Jacqueline agrees, and says she has also relied on the support of close family members when friendships fell by the wayside: "I turned to my sister who'd recently gone through something similar after her fiancé was diagnosed with pancreatic cancer. Some of their friends just seemed to disappear in the moment. They didn't reach out at all. It was baffling."

It's important to consider that during the various stages and cycles of an illness, family and friends are also profoundly affected and may end up needing their own support. For some, there are significant changes in roles and responsibilities that can overwhelm the well person and contribute to feelings of powerlessness. For many, relationship dynamics are dramatically altered, leading to sadness and even anger over the loss of the person they knew before illness. Intimacy issues and learning how to maintain friendships as one pursues "a new normal" is possible, although it may require some ingenuity.

Some patients have coped by striving to reinvent their social time with friends and family. In an article that appeared in Health online, Shelley Kirkpatrick, 32, of Bellefontaine, Ohio, described how family and friends stuck by her once she helped them understand how fibromyalgia limited her social life.² "I can't go with a group of friends to the mall and shop all day

anymore,” she says. “I can’t spend an entire day out in the sunshine on the beach; I get fatigued.” Instead, Kirkpatrick and her friends have started planning activities around her energy levels. “I may be able to go shopping for half a day instead of a whole day. So we may plan to do shopping in the morning and see a movie in the afternoon, instead of trying to cram everything into one day. We all just kind of work together to get things done.”

Learning to Cope and Move On

There’s no question that living with a chronic illness can be difficult and lonely. While it’s not possible to control another person’s reaction to someone’s diagnosis, there are some practical steps patients can take to begin addressing their need for friendship and support:

Educate loved ones about the illness. Friends and family are able to be more supportive when they understand what the patient is going through. Share websites, books or other resources that explain the illness.

Invite a close friend to a doctor’s appointment. Getting more information about the condition can give both the patient and the friend peace of mind. Suggest the friend come along to learn more about the illness and how he or she can help.

Ask friends for what is needed, and be specific. Oftentimes, friends want to provide support but don’t know how. A patient should consider asking for help running an errand, completing chores or watching kids. Make a list of things needing to be done, and the next time someone asks if there’s anything they can do to help, tell them.

Pursue the ones who disappear. If certain friends go MIA, it’s possible they just don’t know what to say. Reaching out in a lighthearted way may take the pressure off and break the ice. Say something like: “Hey, John, I was diagnosed with primary immune deficiency not leprosy — it’s not contagious! I miss getting together.”

Reach out to new people. To extend one’s social circle, a patient might have to get out of his or her comfort zone. Try striking up a conversation with a classmate, neighbor or coworker. Join a support group either online or close to home. Getting involved in a cause related to the person’s illness can help to meet people with similar struggles.

See a therapist. A mental health professional can provide a supportive and understanding ear when a patient is feeling down. The professional can also help the patient cope with relational changes. Ask a doctor for recommendations, or run an online search for therapists who have knowledge about the condition.

Letting Go When Needed

Seeing a friend diagnosed with a chronic illness is hard for many people because it reminds them that anybody can get sick. They may disappear from their friend’s life because it makes them feel uncomfortable to think about their own health and mortality. Others may feel they have less in common with their friend now that their range of activities and interests has changed. And still others may simply be fair-weather friends who have decided to move on, requiring the patient to do the same. The bottom line is, if a friend repeatedly abandons someone when they’re needed most, perhaps the relationship isn’t worth pursuing. Letting go of a friendship is difficult, but it is sometimes the best thing to do for one’s emotional well-being.

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“I really encourage newly diagnosed people to remember that not every friend is going to be your BFF. It’s natural for friendships to change over time, and that’s not always a negative,” says Prokopy. “When it comes to making new friends, I say keep your mind open about what kinds of people might become your friends. You may not be used to thinking about meeting people in different places besides your regular social circle and work life, but there are a lot of different places for you to meet friends, and it’s important to keep your mind and heart open to possibilities.” ■

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