

Raising Kids While Coping with a Chronic Illness

Juggling family demands while navigating the unpredictable challenges of a chronic illness can feel overwhelming. The good news is support is available, and parents don't have to do it alone.

By Trudie Mitschang



SHORTLY AFTER CATHY Roll and her husband, David, adopted their young daughters, they got news that would forever alter their family dynamic: Cathy was diagnosed with multiple sclerosis (MS). “I had been struggling with pain and fatigue even before we went to Ukraine for the adoption,” she recalls, “but after we returned, it was just relentless. At first, I thought, ‘Well, maybe this is what motherhood is all about.’ But, chasing around after two children made me so incredibly tired, like I had fallen into a dark hole.”¹

Cathy’s experience mirrors that of countless other parents who suddenly find themselves faced with the unexpected challenges presented by chronic disease, the term used to describe any long-term illness that can last or recur over a lifetime. Such conditions affect tens of millions of Americans, many of them parents of young children, and they include diagnoses like MS and other autoimmune diseases, primary immune deficiencies, as well as diabetes and depression. Regardless of the specific diagnosis, parents

tasked with managing the daily demands of their medical care may be at a loss when it comes to learning how to also care for their children.

“Handling chronic illness is about learning to live in balance,” says Rosalind Dorlen, PsyD, a psychologist at Overlook Hospital in Summit, N.J., who specializes in treating the depression and anxiety that often accompany long-term health problems. “You can’t dwell on questions like, ‘Why is this happening to me?’ or ‘What if it gets worse?’ But you do have to be constantly conscious of your health status, and take the time to rest, exercise and have fun. It’s important to focus on feeling well and to maintain a positive outlook.”¹

Learning to Live with Limitations

Parents who have been diagnosed with chronic illness sometimes battle symptoms that can severely limit their ability to perform the daily physical tasks involved with raising kids. Simple things like picking up a crying child, preparing school lunches or playing a backyard game of catch are just some of the everyday activities that can become difficult or even impossible. Accompanying feelings of guilt and the concern about disappointing their children only adds to the emotional pressure.

“In the last year, I have had three surgeries, two other extended hospital stays, one ambulance ride, five emergency room visits and countless doctor visits, illnesses, injuries and bad health days. These keep me from doing my job as a college professor, from hanging out with friends, from family events and, most importantly, from taking good care of my kids all of the time,” says J. Ann Marie, a mother of three who was diagnosed with a primary immune deficiency at age 35. “Oh, I take care of them with every ounce of energy I can manage, but sometimes I physically cannot move. Those days, those days hurt me inside. I have to hear, ‘Mommy is sick again?’”²

Mental health professionals stress that as difficult as it may be, it’s vital for parents to remember that having a chronic illness isn’t their fault. Postponing or missing events and activities will be inevitable because of the unpredictability of symptoms. The truth is, parents can’t protect their children from disappointment, but it is possible to ease their feelings of being let down. Parents can let their kids know how proud they are of their accomplishments and find creative ways to share in them. For example, if they have to miss an athletic

event, another family member can record the event, and they can set aside time to view the recorded event together as a family. The key, say experts, is open and honest communication and a willingness to address children’s fears, disappointments and concerns.

In a recent study published in the peer-reviewed *Journal of Nursing*, researchers noted that with the obvious exception of infants, children share a need to understand the cause of a parent’s illness. They want to know things like whether they are responsible, whether it’s contagious and who will take care of them. The study stressed that in order for communication to be effective, it must be tailored to the children’s age and developmental level to help them develop needed coping skills.³

Additional methods for helping kids develop coping skills include establishing a fixed family schedule and routine as much as possible, and including a schedule for regular sleep times, mealtimes, quiet time and activities such as a family movie or game night. Although chronic illness is a life-altering event for a family, it is possible to turn it into an opportunity to strengthen family bonds and create resiliency. Parents can set the emotional tone of the household and help their children deal with the uncertainty of illness by being honest, setting realistic expectations and maintaining a positive attitude.

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Talking It Out

One of the most difficult skills facing anyone diagnosed with a chronic illness is learning to talk about it with others. This challenge is compounded when the proposed dialog is between parents and their children. Yet, experts agree parents shouldn’t try to shield their children by hiding the illness,

Practical Tips for Talking to Your Kids About Your Illness⁵

- Set aside as much uninterrupted time as possible. Children react in different ways, and you want ample time to deal with whatever emotions may surface. After dinner is a good time, since they are often calmer after eating and are winding down for the evening.
- Children pick up on your energy. If possible, wait until you have had time to digest and process the news so you can remain calm.
- Speak in terms they can understand. Try not to interject too much medical terminology. You can also use this time to introduce and explain some terms they may be hearing in relation to your illness.
- Allow them to ask questions. Answer with age-appropriate responses, staying focused on the specific question at hand. Including more details than necessary can be overwhelming for kids.
- Ask them questions. How do you think this will change things at home? At school? Ask for their suggestions about how to make things easier so they feel like they're part of the conversation and the process. Inclusion is important and helps keep dialog flowing.
- Don't hide your feelings. While you certainly don't want to frighten your children, you do want them to know there are times when you may feel sad or particularly tired, and there are times you may even cry. Let them comfort you. It's important for them to feel they are active participants in your life, and nothing warms a child's heart more than knowing he or she has helped you feel better.

because it is impossible to keep such a secret over time. Young children are highly perceptive and will begin to sense when something is wrong, while older children may overhear conversations or notice symptoms, and jump to the wrong conclusions.

While some parents worry that talking with their children may cause fear, honest communication actually breeds security because it builds trust. Sharing the challenge with children in age-appropriate ways has the potential to help them become more emotionally competent. But, careful planning is needed; the information must be communicated to them on their developmental level for them to properly process it.

According to Kathleen McCue, MA, LSW, child life specialist at the Cleveland Clinic Foundation, older children should be told the name and symptoms of the disease. They should be asked what they already know or what they have heard, and any wrong information they may have should be corrected. Younger children may need reassurance that their parent's illness is not a punishment for their bad behavior, it is not a "monster that comes to get them" and it is not contagious. Most important, children of all ages need to know they will still be loved and given the care they need.³

Helping Kids Cope: A Guide for the Ages

The way children respond when a parent is chronically ill is influenced by many factors, including their own developmental stage. Identifying age-appropriate ways to communi-

cate and relate as a family can ease stress for both parents and their children.

Infants. Infants whose parent has a chronic illness may experience significant changes in their routine, which in turn can cause them to become agitated or exhibit difficulty eating and sleeping. Stress may also make them more susceptible to colds or indigestion. What parents can do:

- Provide infants with extra physical contact and attention.
- Maintain a regular routine for physical needs, including feedings, sleep schedules, walks and playtime.

Toddlers. Very young children can sense feelings of frustration and fear when an illness is present, even though they may not understand what is happening. What parents can do:

- Talk to them using simple, honest words about the illness.
- Allow them to ask questions over and over.
- Let the children make choices about exposure to medical treatments such as being present during an infusion.

School-age children. The family is the basis of security for school-age children. Home is the main environment where they learn how to express their feelings. What parents can do:

- Continue to answer questions honestly and as many times as asked.
- Offer to include the children in seeing some of the medical aspects of the illness (always ask whether they want to be involved and how).
- Read books together that share stories about the illness.

- Consider peer support groups.

Tweens. Tweens alternate between their family and peer relationships for support. Their emotions are heightened by the onset of puberty. What parents can do:

- Expect children to experience emotional ups and downs. Assure them you are there for them.

- Understand their emotions may manifest in feeling physically ill (i.e., headaches, stomachaches, colds).

- Look for age-appropriate peer support groups, and encourage peer relationships and involvement.

- Answer questions honestly and thoroughly.

Teens and young adults. The primary support for teenagers is their peer group. While the family remains a significant resource, it is not uncommon for teenagers to act ambivalent about depending on their family. Having a parent diagnosed with a chronic illness can present a conflict for teens striving to assert independence. What parents can do:

- Make time for teens, even if they seem preoccupied with other priorities.

- Expect that teens may exaggerate the importance of certain aspects of this experience (strong feelings may seem out of proportion, but they must be allowed and accepted).

- Continue to encourage questions and provide honest answers.

- Encourage peer group support.

Finding Community: Parents Are Not Alone

It can be challenging for parents to help their children with their feelings when simultaneously managing their own emotions. Therefore, it is crucial for parents to find an outlet for their own evolving feelings about their illness. Just as their children look to them for help in acknowledging and processing their emotions, parents also need trusted peers to help them develop coping skills. Many of the national organizations for invisible and chronic illness offer peer support groups and hotlines. Social media groups are also popular sources of support and encouragement. “Research shows that understanding partners and peer support from similarly situated parents are particularly helpful in navigating the challenges of parenting while chronically ill,” says Katie Willard Virant, MSW, JD, LCSW, a psychotherapist practicing in St. Louis, Mo. “Friends, relatives and therapists also can help us work through our own feelings and provide the emotional fortitude to parent well in difficult circumstances.”⁴

Without question, every parent faces ups and downs while managing the daunting task of child-rearing, and for parents with chronic illness, it can be tempting to give in to hopelessness. But, by gleaning advice from others who have walked in their shoes and learning to remain optimistic when the odds seemed stacked against them, it is possible to find hope for better days ahead. “On days like today, where I was just

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released from the hospital after a long stay and I cannot go to track and field day, or the pre-k play tonight, or my son’s Boy Scout Derby, I try so hard to be thankful that I am still here, and I get to hug them when they come home and run into my room (and ask if I’m feeling better),” says J. Ann Marie. “They are too little to know this will always be this way — some good days, a lot bad, but that is fine. I want them to be too little as long as they can. I answer, ‘Yep! I am feeling better.’ Their faces light up, and they run off to play, and I take more medicine that makes me feel sick and try to rest some more and hope tomorrow I can get up and go with them.” ■

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