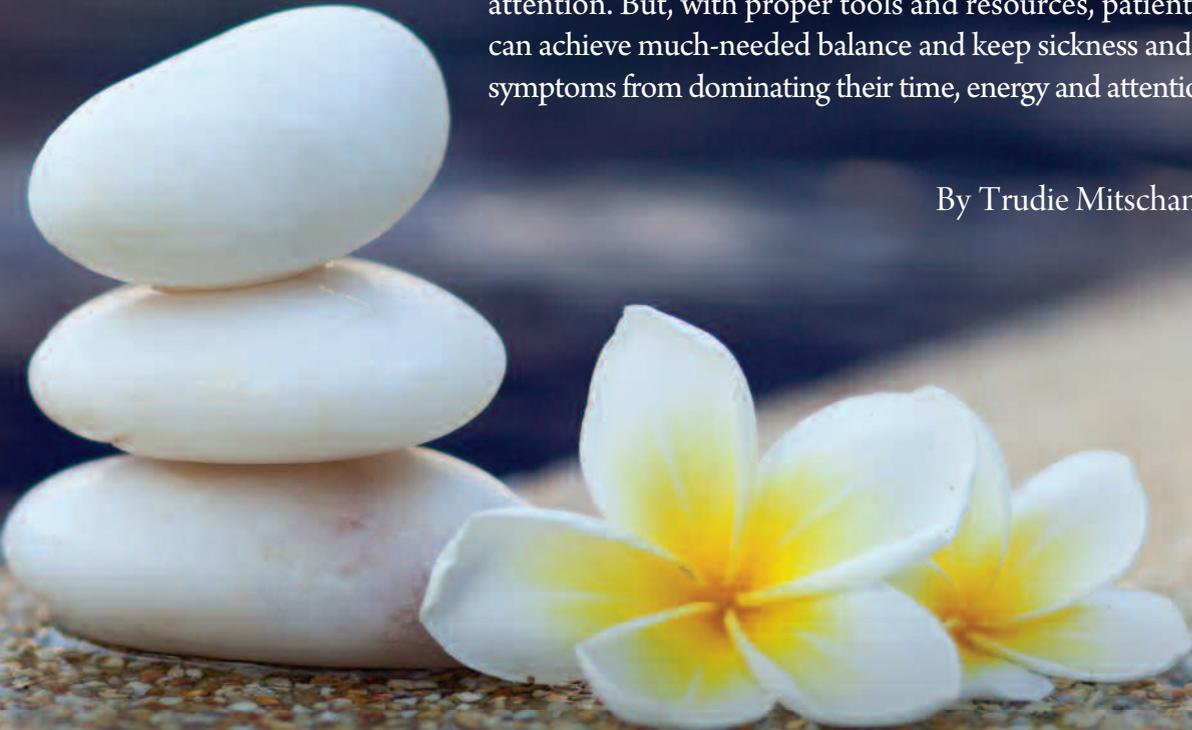


Tips for Balancing Life, Health and Finances

Not unlike a demanding toddler, chronic illness commands attention. But, with proper tools and resources, patients can achieve much-needed balance and keep sickness and its symptoms from dominating their time, energy and attention.

By Trudie Mitschang



BEING DIAGNOSED WITH a chronic illness can be both frightening and overwhelming. For many, it's as if the illness itself becomes an entity that must be managed, planned for and navigated, in addition to juggling life's everyday responsibilities such as work, relationships and finances. And, while everyone deals with varying degrees of stress, living with a long-term health condition presents a host of unique stress triggers, including:

- Coping with pain or discomfort from symptoms;
- Adjusting to new limitations the condition puts on life;
- Managing increased financial pressures and insurance questions; and
- Feelings of frustration, confusion or isolation.

The good news is, no matter where patients find themselves on their journey with chronic illness, there are steps they can take to maximize quality of life.

Balancing Energy: The Practice of Pacing

Chronic illness and fatigue go hand-in-hand, sometimes limiting life in ways most healthy people will never truly understand. There is always so much to do, but so little energy to do it. For many, it's hard to properly budget what little bit of energy they have.

In the early stages of diagnosis, patients might consider keeping a health journal to track symptoms and get a snapshot of any patterns attached to energy highs and lows. Close attention should be paid to what seems to ease symptoms or make them worse, making special note of dietary changes, activity levels and sleep patterns. A notebook or calendar can be used to record trends and other insights that might help manage symptoms. Over time, as patterns develop, patients will be able to better anticipate high energy days, putting

them in the driver's seat when it comes to making plans and social commitments.

Christine Miserandino, a writer, blogger, speaker and lupus patient advocate, perfectly describes the limited energy reserves people with chronic illness face in her popular Spoon Theory¹ object lesson. The concept was born when Miserandino was asked by a friend to describe life with lupus. Sitting in a café at the time, she reached over and gave her friend a handful of spoons, using them to illustrate finite units of energy. She then walked her friend through an average day's tasks, taking spoons (or energy) from her after each activity. Take a shower? One spoon. Cook breakfast and eat it? Two spoons. Leave the house? Three spoons. In short order, her friend was out of spoons and had a much clearer picture of what life was like for Miserandino and millions of others who live with chronic illness.

"Until Spoon Theory, no one else had explained the trials of chronic illness so simply and, yet, so effectively. It's been accepted across the world as this amazing tool to describe what life with illness is really like," says Kirstin Schultz, a blogger and patient advocate who has been living with multiple chronic illnesses since childhood. "The Spoon Theory has done some great things since its inception — one of which is providing a way for people to meet others dealing with illness. A quick search on social media will pull up hundreds of thousands of posts from people who identify as a 'Spoonie.'"²

Toni Bernhard, author of *How to Live Well with Chronic Pain and Illness: A Mindful Guide*, is no stranger to the energy depletion dilemma. Bernhard advises patients navigating recurrent exhaustion to practice a technique called "pacing," a method she says is extremely effective in helping her and others get through the day with energy to spare. "Pacing refers to spacing out your activities during the day so you're able to stay within the limits of what your body can handle without exacerbating your symptoms," she explains. "Another way to think of it is that pacing is a way to keep you inside your 'energy envelope' — the envelope that contains your energy stores for any given day."³

While the theory sounds simple enough, Bernhard is quick to admit it's a lot more difficult than it seems, since most of us have a tendency to overdo it when we feel good, only to pay the price later when energy levels crash. In her blog on the topic, she offers tips for developing a successful pacing strategy, beginning with alternating activity with rest.³

"This approach to scheduling has helped me tremendously

since becoming chronically ill," Bernhard says. "For example, if I put on the schedule for the morning, '10:00-10:30: work on article,' but then wind up working until 11:00, I revise the schedule and move on with the day. Simply having that schedule in front of me keeps me from deviating from it too much. Without set time frames, I'm likely to lose track of time and work for several hours straight; then, of course, I suffer the consequences. Some people find it helpful to set a timer; when it goes off, they know it's time to stop the activity and rest for a while." Bernhard also recommends slowing down when performing chores like folding laundry or doing dishes to keep from expending precious energy on mundane tasks.

Additionally, she advises following something she calls the 50 percent rule: "With this pacing tool, given how you feel on a particular day, you decide what you can comfortably do, and then only do 50 percent of it. One reason this is a great strategy is that I tend to overestimate what I can comfortably do, so this keeps me safely within my energy envelope. I also recommend that you think of that unexpended 50 percent as a gift you're giving yourself to help you feel less sick and in less pain."³

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Managing Money: Staying Fiscally Fit

While managing personal finances is universally challenging, people who live with a chronic illness often experience a unique set of monetary concerns, making it a wise idea to consult with a professional financial planner. Even if patients were highly adept at managing their money prior to the onset of illness, chronic conditions can be unpredictable, and investing in the help of a trained advisor can help them make sure they have all their bases covered now and in the future. For example, when it comes to developing a comprehensive plan, a professional advisor can assist in creating a budget for healthcare savings, disability coverage and long-term care

insurance. Prior to crunching the numbers, it's also a good idea for patients to research the likely progression and symptoms of their illness so they can make informed decisions. For instance, will home healthcare be required at some point? If a wheelchair will be needed, will they need to widen doorways or make additional home modifications? Additionally, retirement may come earlier than planned, or a spouse may need to leave work to become a caregiver; these are all scenarios a financial adviser can use to help prepare for projected costs.

According to Cyndi Hutchins, director of financial gerontology at Bank of America Merrill Lynch, keeping good financial records is also important, including a tracking system for medical expenses and insurance claims.⁴ She advises making a list of instructions that includes where to find important household and financial information, and providing these documents to a trusted friend or relative who can access them in an emergency. Another step to consider is streamlining finances by consolidating various accounts. Having everything in one place can make it easier and quicker to manage. Remember, when it comes to finances, knowledge is power, and staying on top of expenses, although time-consuming, can pay big dividends when it comes to peace of mind.

"The fear factor is a real factor when it comes to the financial balancing act," says patient advocate and author Ilana

need to constantly be asking questions when you're asked to pay a bill: When was the date of service? Who was the treating physician? How much of the bill did insurance cover? Why didn't insurance cover all of it? If they can't answer these questions, tell them you'll pay when they have all the data. Errors in billing are made constantly; don't be a financial victim of someone else's incompetence!"

Managing Health: Becoming an Empowered Patient

No matter the diagnosis, ignorance is not bliss when it comes to health. Learning everything one can about symptoms and treatment options is always wise. Patients should ask their doctors specific questions about their condition, and they shouldn't stop there. Online resources and patient associations for specific diagnoses are excellent places to start when it comes to increasing one's knowledge base. But, patients should be careful to get their online facts from trusted sources. With the overwhelming amount of information just a click away, it can be hard to distinguish science-backed information from sales pitches and personal opinions. To ensure information is reliable, consider limiting online research to government and nonprofit websites such as these:

- National Library of Medicine's MedlinePlus: www.nlm.nih.gov/medlineplus
- U.S. Department of Health and Human Services' Healthfinder: www.healthfinder.gov
- Centers for Disease Control and Prevention: www.cdc.gov
- American Academy of Family Physicians: familydoctor.org
- Medscape: www.medscape.com/today

When patients empower themselves as the manager of their own health, it can help them regain a sense of control at a time when things feel very chaotic. Some of that empowerment also comes from being a compliant patient. Following recommended treatment plans, taking prescribed medications as directed and attending scheduled healthcare appointments goes a long way when it comes to patients feeling their best. It may help for patients to set up a reminder system in their calendar or daily planner, or to consider any number of mobile apps⁵ that can help them juggle the tasks on their healthcare to-do lists. Here are a few apps worth checking out:

- Medisafe is an app that helps patients manage medications.

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Jacqueline. "You're getting collection letters and calls from billing departments and debt collectors constantly. Once you familiarize yourself with your insurance plan, your deductible and your co-pays, you're going to feel less intimidated. You

It helps with dosage and reminds them when they need to take their meds, increasing adherence rates. The information can also be shared with the healthcare team and pharmacy.

- Pain Diary works for anyone with a chronic illness by allowing patients to chart and score pain, as well as record and track other symptoms of the disease such as fatigue and mood swings. This app also has a feature that allows patients to connect with others living with the same chronic illness and swap best practices.

- ZocDoc is another popular app that allows patients to search for local specialists who are approved by their insurance company. The app will even tell them when the doctor is available.

- My Medical Info is a helpful app that stores all relevant health history and insurance details. This makes filling out those endless forms a little less challenging, since patients won't have to rely on their memory for all the details.

- Fooducate helps patients keep track of their diet and allows them to program how many calories they want to consume a day and then add in the food choices they make. The app will work out the nutritional values of everything they eat and tell them how many calories they've consumed. It also works in conjunction with many fitness apps to add in details of any physical activities and calories burned.

- Sleep Cycle analyzes how much sleep and the quality of sleep patients get each night. Plus, they can also have the alarm set to wake them when they're in their lightest sleep, leaving them feeling less groggy and more refreshed.

Managing Mood: Maintaining a Positive Outlook

When struggling with pain, fatigue and other chronic disease symptoms, maintaining a positive attitude is probably the last thing on patients' minds. Still, it's worth noting that mental health research indicates attitudes like optimism and hope help people recover faster from surgery and cope better with serious diseases — even diseases as serious as cancer, heart disease and AIDS. Increasingly, evidence suggests these effects may have something to do with the mind's power over the immune system. One insightful study, for example, polled healthy first-year law students at the beginning of the school year to find out how optimistic they felt about the upcoming year. By the middle of the first semester, the students who had been confident they would do well had more and better functioning immune cells than the worried students.⁶

In her new book, *Surviving and Thriving with an Invisible Chronic Illness: How to Stay Sane and Live One Step Ahead of Your Symptoms*, Jacqueline offers a wealth of tips to help patients advocate for themselves at their most vulnerable moments. She is currently working on multiple projects to help connect chronically ill patients with remote employment opportunities, financial and emotional support and

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creating new programs for patient empowerment and awareness efforts. "Managing chronic illness means developing strategies to assist you in moving forward with your life's greater focus with as minimal suffering as possible. Don't head-butt your disease, outsmart it," she says. "Life with chronic illness is just like any other — a life full of obstacles. It's easy to lie down and not get back up. But if you're not moving, you're not living. So, even when the obstacles become too great, the treatment stops working, the doctors stop telling you the good news, even when you lose support, you lose sight of what you're moving toward, you keep moving." ■

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References

1. But You Don't Look Sick. The Spoon Theory written by Christine Miserandino. Accessed at butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory.
2. Schultz, K. I'm a "Spoonie." Here's What I Wish More People Knew About Chronic Illness. Accessed at www.healthline.com/health/spoon-theory-chronic-illness-explained-like-never-before#7.
3. Bernhard, T. 5 Pacing Strategies That Help Me Manage My Chronic Illness. Accessed at themighty.com/2018/11/pacing-techniques-strategies-chronic-illness-toni-bernhard.
4. Create a Checklist to Help You Cope with Chronic Illness. Premium Health News Service, March 25, 2015. Accessed at www.tribunecontentagency.com/article/create-a-checklist-to-help-you-cope-with-chronic-illness.
5. Henderson, W. The Best Apps for Chronic Illness Management. *Fibromyalgia News Today*, July 17, 2017. Accessed at fibromyalgianewstoday.com/2017/07/17/6-best-apps-chronic-illness-management.
6. Segerstrom, SC, Taylor, SE, Kemeny, ME, and Fahey, JL. Optimism Is Associated With Mood, Coping, and Immune Change in Response to Stress. *Journal of Personality and Social Psychology*, Volume 74, Number 6, June 1998. Accessed at pdfs.semanticscholar.org/0ec4/ca4cbefa851f3d078f83ea8ef61b4a623b9.pdf.