





Grab the Reins

How to Control Your Life With Lupus

Andy Coney, M.Ed., of Tampa, FL, used to be a runner. She would arrive home from teaching elementary school, change her clothes, and hit the pavement for five or six miles. On weekends she often participated in 5K, 10K, even 15K charity runs or races, frequently winning in her age group.

Then, at age 25, Coney was diagnosed with lupus. She didn't change her busy schedule to accommodate her fatigue—not at first. She continued working full time, running long distances, and, as a true night owl, staying up late. “I didn't want to believe this was really wrong with me,” says Coney, now 55 and the new chair of the Lupus Foundation of America (LFA) Board of Directors. “I was denying the diagnosis, and I wasn't giving myself what I needed.” Coney was trying to control her illness, but she soon learned that wasn't possible. When a flare occurred or she got an infection, she couldn't dictate the outcome.

BY MELANIE PADGETT POWERS

To live a happy life with lupus, Coney says you need to embrace the “new normal.” “Lupus isn’t all of who we are. We need to continue to live our lives fully.”

Cindy Coney, M.Ed., tries to walk several miles each week, often with her dogs, Landis and Tully.



BOB CROSLIN

CONTROLLING YOUR RELATIONSHIPS

Coney now knows that people with lupus may not be able to control the disease, but she maintains they can take control of other parts of their life, from the food they eat to the people they surround themselves with. “Sometimes we will stay in a relationship that may not be good and causes us a great deal of stress. That’s something we do have control of. We can’t control other people, but we can choose who we spend time with and how we spend that time,” she says.

Taking charge of areas of your life can be empowering and offer optimism. The first question to ask yourself about a particular aspect of your life is, “Is this something I can control?” says Charles Merrill, Psy.D., a psychologist in private practice in New York City.

Educating yourself about lupus can help you answer that question. “The more you understand your condition, the better you’ll be able to evaluate what you can control and what you can’t control,” Merrill says. You’ll learn how much sleep you need, what foods you should eat, and whether that beach vacation will be doable.

Faith Dean, of Dallas, learned to accept what she could and couldn’t control after she was hospitalized in 2001 at age 24 with idiopathic thrombocytopenic purpura (ITP). ITP reduces the number of your body’s platelets, which are necessary to prevent bleeding. Dean was down to 4,000 platelets per microliter of blood—a normal count is 150,000 or more. Aiming to increase her platelet count, doctors put her on prednisone and removed her spleen. Soon after, she was diagnosed with lupus, and she spent the next seven years in and out of the hospital, sometimes for months at a time.

Although family members lived nearby, she says they didn’t visit much or provide emotional support. While initially hurt and embarrassed, Dean realized she only wanted visits from people who truly wanted to be there. “I determined that the people I needed and wanted around me were people who could handle what was going on,” she says. “I didn’t want people there just because they felt it was an obligation to visit me.”

Merrill says, “There are people who know how to be there for you, and there are people who aren’t good at it. That has nothing to do with you having lupus. There is a danger to incorrectly interpreting that the reason this person is disappointing you is because you have lupus.”



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CONTROLLING YOUR REACTIONS

When she became ill, Dean tried to keep living the life she once had. “I felt like I needed to maintain everything. It didn’t matter that I was sick, I still needed to do everything I was supposed to do.” That included keeping a clean house and not gaining weight, even though she was on prednisone. She was depressed and angry, but she eventually realized that if she continued to try to maintain a “perfect life,” she was going to drive herself crazy. Instead, she re-evaluated her life: what she wanted and who she wanted to be. Now in remission, Dean is enrolled in nursing school at the El Centro campus of Dallas County College.

And now, when she starts to become frustrated about things out of her control, she sets a time limit. “I tell myself, ‘You get 15 minutes to feel sorry for yourself and say this isn’t fair, and then you get over it.’”

“Anger in itself is not a bad thing,” Merrill says. “The challenge is to find ways to channel that anger in ways that are productive.”

Solange Garcia, 21, is another firm believer in controlling how you react to your situation. “You can definitely control your outlook every day,” she says. Although lupus comes with limiting factors, such as lack of energy and sun avoidance, she doesn’t look at the disease as a hindrance. “I don’t let lupus define me.” Instead, she recommends redefining yourself. “Become resourceful,” she suggests. “Start to enjoy other things and expand your horizon.”

She has done just that. A communications major who graduated from Boston University this spring, Garcia is on the job hunt. Meanwhile, she’s been indulging her love of theater by singing and auditioning around Boston, and volunteering for her college’s theater scene, doing hair and makeup. She enjoys more indoor activities than she once did: She cooks, she took up scrapbooking, and she reads more.

She also works out her feelings about lupus through her blog, littlivelivinglupie.blogspot.com. “I definitely have a lot to say about my lupus, what I go through every day and the thoughts that go through my head,” says Garcia, who undergoes a full day of chemotherapy every month.

Coney says controlling your negative “self-talk,” as these young women do, can be one of the best gifts you can give yourself. When her own mind starts to wander to aspects of her disease she cannot control, she says to herself over and over, “not helpful, not helpful.”

CONTROLLING YOUR LIFESTYLE

To live a happy life with lupus, Coney says you need to embrace the “new normal.” “Lupus isn’t all of who we are. We need to continue to live our lives fully.”

Part of the new normal can be taking charge of your exercise routine.

Dean is trying to live as healthy a life as possible. When she was able to walk again without a cane, her doctor told her to begin walking three days a week. Instead, she began to walk

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Solange Garcia blogs about her feelings at littlivelivinglupie.blogspot.com.



every day and, in the past two years, has lost almost all the 200 pounds she gained while she was hospitalized. She also bought a bicycle and joined a gym, receiving tips from the fitness center’s trainer on how to tone her muscles. “The attitude I have now is: I’m going to do this because I *can*,” she says. “I’m going to take the stairs because I *can* take the stairs. There are days I go to bed tired, but I realize that I’m not in as much pain, because every day I make sure to move my body.”

Such changes can do more than get your body in shape, says Jonathan Merril, M.D., CEO of Astute Technology in Reston, VA. “Exercise releases opiates in the brain,” which can improve your mood and general well-being, he says. Exercise can also boost your energy, improve your balance and flexibility, and help you get a good night’s sleep.

While no longer a runner, Coney tries to walk several miles each week. After living for 30 years with lupus, she was eager to turn 55 on October 10: 10-10-10. The milestone inspired her to set a goal to walk 1,000 miles—with her two soft-coated Wheaten terriers, Landis and Tully—and raise \$10,000 for the LFA by her birthday. A few years ago, she and Landis raised \$10,000 for LFA by walking. By September, Coney surpassed her goal, raising nearly \$12,000, and the money was still coming in. Check out her blog, landisconey.blogspot.com, for updates. “In the ’80s, I didn’t know if I’d live to this age,” she says. “So I am thrilled to be alive at 55.”

Some days, Coney doesn’t feel well enough to walk far, but she does what she can. “Some days my walk is really short, like from the bedroom to the kitchen,” she laughs, “but some days I’m good to walk four or five miles.” She encourages people to find an exercise or “movement”—because sometimes “exercise” sounds like too much to do—that they enjoy.

Merril, the physician, agrees: “What’s the best exercise you can do? The thing you can do every day. All you need to do is start moving.”

Other lifestyle changes, such as eating healthier and getting plenty of sleep, can also improve your physical and mental health. But be careful not to think that if only you could eat the right foods and get the optimum amount of sleep, you could start controlling your lupus. “It doesn’t guarantee that you’ll never have a flare,” says psychologist Merrill. “If you think, ‘I’m doing all the right things, but I still had a flare,’ you could end up feeling angry and frustrated, and perhaps depressed.”

You can also take charge of the stress in your life, although you may not realize it. Ask yourself whether there are subtle ways you can reduce your stress and whether you can change the way you react when stress does occur. “The situations we’re faced with in modern life can cause a lot of stress that can compound diseases like lupus,” says Merril, the physician, “because the immune system is very tightly coupled with stress and lifestyle.”

You may want to take up yoga or meditation. (See “Body, Mind, Soul” on page 6.) Even taking deep breaths and counting to 10 when you get stressed can help. And if certain people are stressing you out, remember what Coney says: You do have control over the people that you choose to have as part of your life.

Another way to take charge that few will argue against is to treat yourself. “We all need to give ourselves gifts,” says Merrill, the psychologist. Sign up for a painting or cooking class, save up money to spend a weekend at a bed and breakfast in the countryside, or just give yourself a quiet Friday evening with a good book. The point is to be kind to yourself and to take charge of those things you can control.

“Even though we may have to create a ‘new normal’ after a lupus diagnosis,” Coney says, “it’s important to know that life—your life—can still be fulfilling.” ■