

The Well-Planned Life

Learning to manage the fatigue of multiple sclerosis.

BY GAYLE FRANCK

My days are chopped up into evenly spaced energy events. With multiple sclerosis (MS), if you have fatigue as the primary symptom, you learn to bookend activity with rest. I liken myself to a comet: a burst of Type A activity, and then I disappear.

It took eight years to accept my diagnosis. I knew I had MS—the MRI and the neurologists said so—but pretended I didn't. Sure, there were months in bed, and I wouldn't be able to walk for periods of time, but then I would return to normal.

Plus, everyone else my age (mid-40s) seemed to be struggling to stay in shape. The sensations of numbness, muscle spasms, weird hot spots, and lightning bolts? I told myself those happened because I was “overdoing it.”

I also decided that I didn't need to work as registered nurse anyway. I had a busy life! But, gradually that familiar life morphed away. The kids began to do their own laundry; I stopped cooking and gave up lengthy social outings. I grew depressed. Eventually, friends said, “This isn't you.”

Now, 20 years after diagnosis, I have learned who I am. I've reclaimed most of what slipped away, though it's more measured and well planned—and not as boisterous—as before.

For example, when my first grandchild was born, I was so excited I nearly ended up in the hospital. So when subsequent grandkids arrived, I knew to be a calm grandma. And when my nephew died, I allowed myself only two days to cry lest my facial muscles get spazzy. When I reentered college, I rested in the car before classes, shared my dilemma with each instructor, and arranged for a place to recline after a few hours on campus.

I have also learned that I cannot pretend. I do have to pull back and rest. If I ignore the signs,

I will pay: in medications, side effects, cost, inconvenience—and despair, which is really the worst. When you are laid out, flat out, and played out, you see no end to the struggle. All is hopeless. Recovery will never happen. Of course that may not be true, but depression can push in and convince us otherwise if we aren't vigilant.

Sometimes I miss the spontaneity of the old me. But in my wiser moments, I realize that the new me is not much different. I'm still a mom, a grandma, and a wife. I can still do most of what I want, though in a different way.

In fact, these limitations have led to aspirations of another sort. Many activities, including a job, can be accomplished in a chopped-up day. I am pushed to think of creative ways to contribute to the world. If I were more able bodied, I might not discover these hidden gifts and pleasures. For example, while trudging through a touristy park with my husband, I reclined atop a picnic table, enjoying the sky. There was a huge hornets' nest far above the crowds, and I am

sure I was the only one who saw it.

I'm also getting good at finding leaky ceilings, observing fall colors from a different perspective, and noticing the nuances in other people's emotional responses. I look for ways to deal with the boredom of rest, such as reading, prayer, and planning. I hear and see things others miss because I am forced to stop and be quiet.

So if you find yourself missing what used to be you, maybe there is another side of you waiting in the background. Give it a chance for expression. Take a step in another direction. You might be surprised by what you find.

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