

With Loving Care

A CIDP Caregiver's Perspective

By Angela Macropoulos

Before I was personally confronted with being a "caregiver" for my mom, whenever I heard the word, it evoked sweet, noble thoughts. People like Florence Nightingale, generous of spirit and heart, selfless and medically knowledgeable. Or a young, working mom, sandwiched between raising her own children and managing care for an aging parent, understanding of the patient's concerns and always multitasking.

Thank God it wasn't me, I thought. I could never rise to the occasion. I was a corporate tax lawyer, single and living in New York City. While I could do the Internet medical research with my eyes closed (figuratively, of course), what about the laundry, cooking and getting someone to physical therapy?

But since February 2004, that's what I've become—a caregiver for my 77-year-old mom, who has severe chronic inflammatory demyelinating polyneuropathy (CIDP). I can now rattle off the acronym CIDP as though it's been in my life for years. Truth is, when someone you love becomes seriously ill, often the medical learning curve is dramatically shortened.

As much a journey as it has been for my mother (who until two years ago was fiercely independent), it's been a long road for me, too.

There are no travel guides for this metaphorical road trip, and, yes,



everyone's caregiver story is dependent upon such things as the nature of the disease, personality of the afflicted, siblings, spouses and outside help. But I'd like to share some things I've learned thus far. My nuggets of experiential wisdom will undoubtedly change over time, but if anything I share below resonates with one reader, then, as Martha Stewart says, "It's a good thing."

The diagnosis is the starting point; it's not the whole journey. Particularly with diseases that require immune globulin for treatment, the nature and progression of the disease is not easily mapped. In fact, most doctors (even specialists) can't tell

either you or your loved one what's going to happen, how any impairment can definitely be staved off, how the patient will feel in two years, much less five. So, you and your loved one do your reading, and ask the docs lots of questions, but get on with it. The sooner you reinforce in your loved one that there's a whole life to be lived beyond the diagnosis and if, in turn, he or she embraces a positive attitude, all the better.

Don't expect friends and employers to really understand what you're going through.

Since I'm an only child, my friends are my extended family of support. While they sympathize, unless and

until they have faced similar situations, they can't get the full picture. My advice is don't have a pity party. Just accept it, and be grateful for the love and friendship you get. As for bosses, my general advice is to be judicious in what you say about the specifics of the disease and care. You may be tempted to rattle off a litany of all the things you are doing to validate your actions or time away from work, but you may be on a slippery slope of too much disclosure for no benefit. The important thing is that your boss should know: (a) your caregiving is an important life choice that you are making for a loved one, and (b) while emergencies happen, you will do and act like a professional.

Yes, there are external sources of help, but start with good family communication. When my mom was finally diagnosed with CIDP after two months of hospitalization and rehab (ruling out lupus, polymyositis and seemingly every neurological disease imaginable), she came home to a veritable welcome wagon of support. Through the New York-New Jersey Visiting Nurse Service, social workers and home healthcare aides just showed up at the door. Mom left her house for the hospital walking but returned home in a walker and wheelchair. I went from living in my New York City brownstone apartment to returning to my childhood home. I was encouraged, however, because it seemed as though there was a great elder care social support system that was going to help me help Mom adjust to a new life at home.

But like the adage, "if it seems too good to be true, it probably is," it was. The reality was that these people came under a "plan of care," but the duration of the help was dictated by Medicare guidelines, which are limiting. There was little guidance on planning for assistance after the entourage left. Although my mom has had nursing and homecare assistance since her initial return home, we've been learning and continually adjusting to how much help she needs, such as cleaning or putting on shoes. My mom and I have always communicated directly and openly, but I'm doing my best to listen and watch carefully to see what her needs are and how much I can supply without breaking. Being back in her home has been good for her and frustrating too (since she can't navigate stairs without a "boost"), but talking—and more talking—about what is most helpful and how often she needs it is critical.

Planning for immune globulin infusions. The first time my mom got an infusion, I was so nervous because I assumed it was like a chemotherapy drip. I didn't know

what side effects, if any, to expect. Turns out I was just overly anxious. But there are small things that I make sure happen when Mom gets her biweekly infusions. For the first year, Mom got her infusions in the neurologist's office. The good news was that the infusion room was populated with only neuropathy patients. It was as much a support group as clinical treatment. The bad news was the 45-mile drive and day off from work for me.

One of the things I learned is that whether at home (where she gets infused now, still biweekly) or at a hospital or doctor's office, it's important to do a few simple things to make the infusion drama-free. First, be sensitive to whether a simple painkiller such as Tylenol might be helpful to take before the drip to ward off fever or pain. When my mother takes one Tylenol right before the treatment, she sleeps better that night and her arm doesn't swell up from the intravenous line. Second, make sure that the patient has easy access to a bathroom, particularly after the infusion is done. And most important, make sure the balance of the day is not chock-full of appointments or travel. Seeing how my mom has more vigor the day or two after an infusion, I credit the rest she gets on actual infusion days for maximizing the treatment.

Which brings me to... always remember, it's the patient's body, not yours. Time and again I have to repeat this mantra to myself. One of the first lessons of being a good caregiver or patient advocate is to acknowledge and accept that occasionally your loved one just doesn't want to go forward with certain protocols or treatments. Sometimes it's just too exhausting or frustrating for them. For example, on days when my mom tells me she's just not game for physical therapy (PT) in the rehabilitation center, I'll cajole her to go, to measure if she just wants to play hooky because she thinks she can get away with it. But like a tuning fork, I've got the ear for the truth, and I now know by looking and listening to her that there are days when spending one hour on machines exercising might tire her for days after. In those cases, PT might do more harm than good. It bears repeating that it's the patient's body and well-being—physical and mental—that's at issue. A caregiver, particularly a child or spouse, must honor that, while still trying to find the right balance of appropriate care.

I may learn new lessons in the future, but at this point, my caregiving experience has already provided me tremendous lessons in acceptance, humility and, above all, grace. 🍷