

*by Jean Mosher, R.N.*

Twenty-five years ago I was working as a private duty nurse, and it was at this time I met a family member of one of my patients. She was very energetic and involved with life and is the most creative person I know.

As I recall, she had been diagnosed with myasthenia gravis and other assorted illnesses. Nothing was clear-cut and no definitive diagnosis was made for a very long time. It took some 12 years for that to happen.

As our friendship grew and I learned more about her medical history, I heard of the disease that was then called Chronic Epstein-Barr Virus, now referred to as Chronic Fatigue Syndrome (CFS) or Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS). Although I am the nurse, I have learned a lot from my friend, now supposedly "the patient."

### **Observations About Energy: "Talking Hurts"**

CFIDS is an all-encompassing and all-consuming disease. I hear about and have seen the consequences of brain dysfunction and the inability to comprehend simple information. Ordinary tasks including walking can be very arduous for a person with CFIDS (PWC). It is not at all unusual to lose muscle strength and fall at any time. I have seen this in my friend. I hear that energy is very valuable, almost a gold standard for these patients. The energy it takes to even talk on the telephone is not easy, complicated by the persistent sore throat. Talking hurts. There are sleep disturbances. Going to bed does not mean "going to sleep." I hear of nights that no sleep was possible or, more usual, finally getting to sleep about 6 a.m. She also has times

where her sleep is disturbed and can wake every couple of hours. After sleeping 10, 12, or even 14 hours, she still is exhausted. Sleep studies seemingly have documented this disturbance but relief does not seem to be within her easy grasp.

Finding a time to visit a person with CFIDS also is difficult. If the person has some energy, it may be more important, as they prioritize their time, for them to take a shower, feed themselves, do laundry, when possible, or see doctors. Social interplay takes work. Perhaps only one or two requirements for daily living can be accomplished and the remainder put off for a later date. I have found that people who are that ill usually do not use energy to make telephone calls for help, for they are too debilitated and are in bed.

A busy week for my friend would be to have three days outside the home, perhaps taken up with medical appointments. The rest of the week she is in bed. A good day would be to have enough energy to accomplish something for a two-, three-, or (pushing) a four-hour period in one day, including eating a meal and the preparation that goes with it. There are times my friend is too ill to eat, because as she explains it, it takes too much energy to prepare meals. Money is tight—and fast or prepared foods not an option.

Times of the year are also very important for my friend. The amount of sun and the temperature of the day have significant repercussions, as do the sudden barometric pressure changes. She does better when it is warmer and there is more light; she suffers from Seasonal Affective Disorder. This seems to aggravate the CFIDS symptoms.

### **What Friends and Family Can Do**

How to help as an outsider? To help a person with CFIDS is not to say: "Call me if you need me." That call most likely won't come. No energy to reach out. To help is to enable independence, recognizing that every motion is energy and little energy is available. Doing shopping, picking up prescriptions, doing an errand, making a meal are all valuable aids for anyone with CFIDS. Even offer to change a bed or clean. Help make phone calls, mail a letter, or offer to fill in forms when necessary; Any little thing to a well person is a mountain to climb for a PWC.

It took time before I understood the brain dysfunction. At first I felt rejected, especially when my calls were not returned. I was looking at the relationship from my own perspective. I made a call; I expected a return call. I was a slow learner, but eventually, I came to understand when my friend would say she couldn't process information. Her brain had effectively shut down and she

knew what she was talking about. There have been many times she was too ill to speak on the phone. I learned to respect that and now check with her when we settle into a conversation. Sometimes it will start out fine, and a few minutes into it, she can't follow all the details and will tell me she "can't compute." I have learned this is part of the process of the illness and no longer take it personally. I have also learned to listen to her and realize that as much as I may need to talk, I will wear her out and she will not hear anything. She will call me *when* she has the energy. Our friendship is not a one-way street, but a crooked road I have learned to negotiate.

### **Navigating The Crooked Road**

Over time, I have come to understand the language of CFIDS. Everything seems to be measured in energy units. When I tell my friend of how many miles I have walked to get somewhere, she is exhausted just relating to it. I would suggest that others be sensitive to CFIDS lifestyles and the need for flexibility. PWCs do not always know when they wake up what the day will hold for them. Their lifestyle has been dramatically affected, if they have a life at all. I have worked with cancer patients, and I see them doing better than the CFIDS patients I know. Still, while this illness may put limitations on my friend, our honest communication has not diminished our friendship, or the essence of her.

To be a friend, I call regularly. I understand that if I get the answering machine, my friend can either be out, or out of it. Our mutual understanding is that she doesn't have to feel pressured into returning my calls, and I want her to know I call to check in so she knows someone cares.

Be a friend to a CFIDS patient. It is worth the work. It takes flexibility, understanding, and patience, but it is worth it. It is not enough to be willing to help, you must act on that willingness. These are not dispensable people, but rather people who cannot be dispensed with. The spirit of a person never really leaves them, whatever their physical condition, and if the friendship is built on that and on love, you've got a winner.