CFIDS Profiles: Sharon Walk

CFIDS Has Been A Challenge to Me

By Sharon Walk

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My battle with CFIDS has been a long, hard one. Looking back, I had a definite pattern of symptoms, including night time leg cramps and frequent infections, as young as age 10. My activity level was never as high as my friends', but we never suspected that I was "sick."

During my sophomore year of high school, I was exposed to mono. I got sick with a flu-like illness soon after that. Six weeks later I was still bedridden, and we had no idea what was wrong with me. I had sore throats, swollen glands, fevers, migraines and the most overwhelming fatigue I'd ever felt in my life.

The more school I missed, the worse things got. My pediatrician didn't believe that my bizarre set of symptoms was real. The school concluded that I had school phobia and insisted that my mom force me to go. Around that time I met a girl from a nearby town who came to my mom's Girl Scout meeting. She had CFIDS and her mom recognized the symptoms in me. She gave us articles and helped us find a doctor. A few weeks later I was diagnosed with CFIDS.

It was such a relief that my illness finally had a name and to know that other people were experiencing the same thing as I was. Unfortunately, the diagnosis didn't end my problems. I was put on home instruction for the rest of that school year. The next fall came and I was still unable to go back to school. The school again said I had school phobia and had me placed in a psychiatric hospital. After a week I signed myself out and tried to go back to school. With each day I went to school, even with a half-day schedule, I got sicker and sicker. A couple of months went by and finally I relapsed. I was back to being totally bedridden. I had so many symptoms, including strange new problems with my memory and concentration. I had trouble talking and thinking clearly. It was so scary.

Well, that was my first year of acute illness. I've spent five years since then learning to live with CFIDS. I struggled and finished high school by home instruction. My senior year of high school brought a severe depression. All my friends were driving and getting ready for college and it was obvious to me that I wouldn't be joining them. I felt like the world was leaving me behind.

In time, I got tired of being so isolated and I began to search for a way to meet other young persons with CFIDS (YPWCs). I couldn't find any groups for younger patients so I decided to start one myself. The YPWCs I met by starting the group have become my closest friends. I can talk to them when I can't talk to anyone else.

As the years have passed I've learned to adjust my life to CFIDS. The first and most important thing I've realized is that I am not my illness; I have to live with CFIDS but not let it control my life. I've had to find a balance between accepting my illness and fighting to get well, and a balance between resting and pushing myself. It's been hard to find a way to accept my illness and the way it limits my life, and still have the motivation to work toward the goals I have set for myself.

Unfortunately, as the years have gone by, my illness has gotten worse. I've been basically homebound, although I do push myself sometimes to go out even though I know it may mean a crash. When walking through the mall became impossible, I adapted - now a trip through the mall means getting pushed in a wheelchair. I always try to push my limits and do as much as I can. Often, it's probably not the smartest thing to do, but pushing so much is the only way I can cope.

The past few years have brought a new challenge for me. I have developed a rare illness called chronic intestinal pseudo-obstruction. CIP is basically a paralysis of the digestive system. I haven't been able to eat without vomiting since October 1994. The CIP has complicated my life. I seem to live at hospitals lately. Frequent surgeries keep setting me back.

I've had a lot of fears about what CFIDS has taken away from me. I didn't think anyone would ever love me enough to be with me through all the downs that my health brings. But last fall, I met a wonderful guy at a church meeting. I was hooked up to my IV nutrition at the time, so there was no way for me to hide that I was sick. I was very honest with Kevin about my illness. I was shocked when he asked to see me again. After our first official date, I knew that I'd found the person I was going to spend the rest of my life with. He proposed two weeks later.

I wouldn't change my life for anything because CFIDS has given me much more than it has taken away. The friends I've met through CYA are closer than any friends I had before. CFIDS has been a challenge to me, and I've accomplished more because of my illness than I ever would have if I was healthy. I'm very happy with the person I have become.

How do I cope? This quote from a book by Elizabeth Benning sums up my philosophy for living with my illness. "Try to live each day to its very fullest. Look forward with confidence and back without regret. Don't be afraid to be happy. Be the best self that you can be."