

by Priscilla Larson

In response to a questionnaire, 30 persons with the Chronic Fatigue and Immune Dysfunction Syndrome/Myalgic Encephalopathy (CFIDS/ME) or Fibromyalgia (FM) or both, shared their pain and passion, their coping skills and their hope for the future as they wait for a cure.

PWCs (Persons with Chronic Fatigue Syndrome) suffer with an extremely long list of potential symptoms, overwhelming fatigue being the bottom line. Because the symptoms vary hour to hour, patients are often misunderstood, thought to be hypochondriacs. Doctors don't like to take on patients who never get well; friends tire of someone who is always sick. Because PWCs usually look well, people frequently comment on that, giving the patient the feeling that, as several participants reported, "I feel invalidated."

When asked "What they would like well people to know", the participants in the survey expressed their need to be believed, understood, loved, and assisted in the following ways:

- *"The thought of being forgotten is almost more painful than the illness itself."*
  - *"It means a lot when you include us in your social events. Even when we can't come, it takes the sting out of being home alone because we were included."*
  - Some pleaded for patience. *"Please be patient with us—there's bound to be emotional upheavals ."*
  - Regarding assistance, the general tone was *"Treat us like you would anyone with cancer or lupus or any other long term illness ."*
  - *"Just ask me if I need help and how much. I hate to ask for fear of rejection."*
  - The longing to be understood came out in answers like, *"Sometimes I need the freedom to express honestly what I'm struggling with, without judgment and pat answers."*
- And,  
*"I wish well people understood the difference between CFIDS and temporary fatigue due to over work. So many compare their tiredness to our fatigue and think it is the same."*

In responding to the following questions, the participants have shared their creative coping skills, their heartfelt longings, and insights and suggestions on how best caring friends and family can help.

### List the most Helpful Ways that Well Persons have related to You by What They Said or Did:

- "A willingness to listen."
- "Showing interest in learning about my illness."
- "By becoming involved in the cause."
- "Friends who can accept 'maybe' commitments."
- "When friends adjust their plans so I can participate."
- "People who observe, 'I can see that this isn't one of your better days. Let's do something together on a good day for you.'"
- "Brought in a meal."
- "Telephone call that sometimes includes a prayer."
- "Believing me unconditionally."
- Regarding "maybe" commitments: A positive example is in the way a hostess graciously extended a New Year's Eve party invitation. She said \_\_\_\_\_, "Come when you can, leave when you must, and know that if you can't come at all we'll miss you but we'll understand and we'll try another time."

### What Are The Most Hurtful Ways Persons have Related To You?

- "Comparing their tiredness to CFIDS showing that they really don't get it."
- "Ignoring what I said about hurting and then going right into long descriptions of their temporary pain."
- "Saying, 'You're not sick, you're lazy. Snap out of it!'"
- "Are you sick again?"
- "The attitude that since I'm disabled I'm worthless. My accrued knowledge doesn't count."
- "Come on! You can go! Think positively!"
- "I wish I could lie around all day like you and watch TV."
- "We need an able-bodied person here."
- "You can't do anything!"
- "You should be ashamed of yourself parking in that handicap space. You don't look handicapped to me \_\_\_\_\_."

Regarding hurtful comments: Belittling the illness by the uninformed is hard on patients. Not being taken seriously can lead to several reactive attitudes that hurt. "We need compassion, not condemnation," one PWC wrote. Also, regarding the abuse some take when parking in the handicap spaces even when they have a registration to do so, the public needs to realize that all handicaps don't show. Think of persons who have heart ailments and breathing difficulties when walking. A PWC may be spending her entire energy quotient for the day to go into one store to do an errand.

### What Is the Most Difficult Aspect of being Chronically Ill?

- *"Not knowing if I'll be able to participate in an upcoming activity."*
- *"Never ending pain."*
- *"Unpredictability of a good day."*
- *"Being misunderstood."*
- *"Not having the physical capacity to follow through on my ideas."*
- *"Not having a romantic relationship."*
- *"Friends who never ask if I need help."*
- *"The financial ruin. Working brings on severe fatigue."*
- *"Not being able to work or to do something useful."*
- *"So many losses: relationships, social life, meaningful employment, my home, income."*
  
- *"Wondering if I'll ever find a partner who will understand and support me."*

In these responses we see the pangs of loneliness and the fear of further losses in relationships and property.

### **What Would You Like Well Persons To Know?**

- *"Realize that we have feelings!"*
- *"We want well people to know that we want to socialize but sometimes we can't even handle a phone call. Please don't take it personally but call again. If we don't return your call right away it's not because we don't want to but because we can't think clearly right then."*
  
- *"Give us credit for what we do."*
- *"Understand that our symptoms vary from hour to hour as different systems in our bodies become affected. What is happening today might be superseded by other symptoms tomorrow"*
  - *"When our memory shuts down it doesn't mean that what you said isn't important to us, our brains just didn't register at that moment."*
  - *"I'm still the same person—I just don't have the abilities I used to have."*
  - *"I wish that well persons understood the difference between CFIDS and temporary fatigue due to overwork. So many compare their tiredness to our fatigue and think it is the same."*
  - *"When you see us out on an errand and say, 'You look wonderful, you must be all better now,' we feel like you don't realize that we may have just used up our entire energy quotient for the day and will probably drop into bed when we get home."*
  - *"I'm able to do a lot if I can do it at my own pace. Others can't do that, so just ask."*
  - *"It means a lot when you include us in your social events and you don't get offended if we can't do it all."*

Because PWCs usually look so well, people often comment on that as if to reassure the patient.

Patients sometimes take it to mean that you don't believe that they are sick. Better to say something like, 'It must be hard for you to feel so lousy when you look so well.' That shows real sensitivity.

While a few participants in the survey have become comfortable asking for help, most find it difficult and appreciate specific offers.

Like most people, chronically ill persons would rather be the server than the servee. They would rather be involved in meaningful work than lying at home alone.

### **What Is Your Best Coping Tip To Pass On To Others?**

- *"Respect yourself enough to explore what affects you beneficially as well as adversely. Watch yourself. Analyze your needs."*
- *"Don't stop doing the things you love but do them on a different level. Have a windowsill garden instead of a yard one, listen to music instead of performing."*
- *"Read stories about overcomers and be inspired."*
- *"Develop your faith and put it to work."*
- *"Keep a list of things you like to do and do them according to your energy level."*
- *"Do what gives you satisfaction and pleasure."*
- *"Phone someone who is also suffering and offer consolation and a listening ear."*
- *"Never feel guilty about your ability level at any time."*
- *"Find something to laugh about."*
- *"Stay in touch with a support group."*
- *"Learn all you can about your illness; experiment with what you learn."*
- *"Look for alternative treatments."*
- *"Understand that you have a limited amount of energy; use it well."*

PWCs who cope best seem to be those who take control over their decisions and circumstances, stay in touch with a support system, forgive those who don't understand, learn to ask for help and give it to someone else in any way they can, build up their faith and practice it while accepting their limitations and live creatively within their imposed boundaries.

Dr. Charles Lapp of Charlotte, North Carolina cautions patients to truly grasp the concept of limited energy. "It's like money in the bank," he told the audience when speaking at Newton Wellesley Hospital. "You can take it out and use it as you wish, but when it's gone, it's gone! It takes a long time for PWCs to replenish the chemicals in their cells that make energy."

Sometimes, for a special occasion that we just have to attend, we will extend ourselves willingly and pay the price of days in bed for having gone but it was a conscious choice.

### **In What Ways Do You Help Yourself?**

- *"I listen to my body when it calls out with a need."*
- *"I've learned to rest before I'm totally drained. "*
- *"I give myself plenty of time to prepare for anything, rest time."*
- *"I gave up on trying to be perfect."*
- *"I try to learn or enjoy every moment that I can."*
- *"I don't waste energy on negative thoughts."*
- *"I've learned to let people help me."*
- *"I plan an enjoyable activity every day."*
- *"I keep a journal."*
- *"I bought an answering machine."*
- *"I stay involved in my health care seeing a doctor regularly."*
- *"I disconnect the phone whenever I need an uninterrupted nap."*
- *"I relieve my emotions by taking a walk when I can, punching a pillow to release my anger and by crying in private about my loneliness and losses."*
- *"I have simplified my life by learning to say 'No.' "*
- *"I accept myself as I am now, not as I was before."*
- *"I keep faith in a cure someday."*

**There is a ceiling on what ill persons can do for themselves. They desperately need the involvement of others in their lives.**

Joni Eareckson Tada, author, artist, and musician who is a quadriplegic and is the president of JONI AND FRIENDS, a ministry to disabled persons, says *"No one should have to suffer alone."*

### **Is There Anything Else You'd Like To Bring Up?**

- *"I wish we had a meeting place where we could go for companionship—on our bad days for comfort, on our good days to give it. We could do things together, talk, sing, do crafts, watch movies, do jobs for the organization when we could."*
  
- *"Public education is very important. We need well persons to write articles about our illness and get them in the papers."*
- *"Funds for research are desperately needed to find the cause and cure."*

- *"Most people have no idea what life with CFIDS is like. It's like a never-ending death process. I'm waiting to live!"*
- *"There's a great need for compassion. It's so important, especially when we are ill."*
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*"There is a great need for well volunteers in our organization. PWC's do what they can but it isn't enough with our limited stamina. We need willing hands and compassionate hearts to do office work, publicity, advocacy, telephone hot line volunteering, fund raising—anything that a campaign or business needs to accomplish their goals."*

To make a donation or offer your services contact the Massachusetts CFIDS/ME & FM Association.