

A Postcard from the Edge

BY GINA KERNER, CFIDS ASSOCIATION MEMBER

Chronic fatigue syndrome makes life difficult, but for people with severe symptoms, few resources and no hands-on assistance, even the barest essentials are hard to maintain. One Association member shares her front-row view of life in dire straits.

QUICK LOOK»

- Some people with CFS have so few resources and such limited assistance that they aren't able to piece together an adequate quality of life.
- These people with CFS often feel marginalized and unseen not only by society at large but even by those within the CFS community.
- By confronting the marginalization of the disabled sick, *everyone* with CFS and society as a whole will benefit.

Chronic fatigue syndrome (CFS) has been called a catastrophic illness, which it most certainly is. Yet articles and books—sometimes even ones written by people with CFS—don't always reflect just how catastrophic it can be. For the most part, published writings seem to describe the ways people manage, pace and cope. While such strategies are important and must be shared, they speak primarily to people who have enough help from friends and family, enough housing stability, enough medical care or enough physical and mental function. In short, some combination of several “enoughs” gives them the material with which to rebuild a life.

Unfortunately, not all of us struck by this illness have enough supportive factors to combine to produce a manageable life. Social and financial structures can crumble when people become disabled. This is true for everyone, but some are left with even fewer resources than others. And some people struggling with this devastating illness have next to nothing and no one to help them.

It's not my intention to imply that CFS doesn't cause great suffering for people in supportive circumstances. It's my intention to bring to light those people living in dire straits, to look beyond the “coping face” CFS that's so often presented to reveal the blemished and unsavory rawness in which some of us live.

I've encountered many people with CFS who aren't able to get by. Some don't have enough money to meet basic survival needs. Some have no spouse, family or friends providing hands-on assistance. For these people, even simple pacing and rest can be out of reach as they expend all their energy just to stay alive. The experience is grueling.

For some people with CFS, the bare bone tasks of living and self-care don't take place. They don't eat when they can't get up. They aren't able to get groceries for weeks because they have no transportation or assistance. They're

so exhausted or cognitively impaired that they can't maneuver through the steps involved in seeking medical answers, much less carry out advice given by doctors. Many of them don't have health insurance or the money to pay doctors and other health practitioners.

For some people with CFS, housing is unstable. Financially strained and without enough help, energy or mental focus to effectively seek potential sources of assistance, their precious energy is consumed by repeated relocations. Others find themselves in substandard housing, such as old spaces with mold that sickens them further or tiny living quarters that make the housebound feel as if they're in a jail cell.

I've even known people with CFS who have no housing at all—living instead in an RV or a car. Exposed to the elements, these people with CFS spend their energy trying to stay cool, or warm or dry. They exhaust their mental resources figuring out where to park, where to get cleaned up and how to avoid detection.

And there are some people with CFS who remain in dysfunctional, even abusive, relationships because they don't have the means or physical energy to venture beyond their current existence.

Again, these illness experiences are grueling. They are unmanageable. For people whose health *and* resources have been truly decimated by CFS—myself included—there simply are not enough ingredients to cobble together an adequate quality of life.

At the base of the volcano

People in this situation grapple for words to relay their experience. They resort to analogies describing their lives as a sinking ship, a toppling house of cards, a sandcastle being demolished by the incoming tide. They refer to their ability to cope as barely held together with scotch tape. They are so marginalized that some live as recluses. They feel so displaced that some call themselves refugees. The conditions of life are so precarious that one woman described it like “living at the base of an active volcano.”

So who *are* these CFS sufferers living in dire straits? They are “anybody USA.” From a variety of cultural, regional, spiritual, educational and economic backgrounds, they are former artists, cooks, med students, janitors, nurses, scientists, corporate employees, veterans and so on. They are shocked by their circumstances. They're convinced that their symptoms are made worse by the duress of their experiences. They've sought, like others, to improve their lot. Some of them make progress, and the rest con-

tinue to search for ways to reinvent their lives in the rubble. Yet many in such dire straits don't know how long they can continue this type of survival. Surrounded by able-bodied people who live comfortably—and even other CFS sufferers who manage, with sacrifice, to cope reasonably well—they sound an SOS, but feel largely unheard.

Victim as a four-letter word

Why is this happening? The dynamics between the sick and the society at large are complex. They require extensive analysis and much soul-searching to be understood. I gratefully acknowledge the help I've received along the way. Without it, I would not have survived. Still, I fall well within the category of the people I describe. This front-row seat has given me a view from which to share parts of the puzzle, as I see it.

One prevailing attitude in our culture is the unspoken acceptance of the marginalization of the ill. This societal blind spot shapes responses when the healthy world interfaces with the disabled sick. The disabled life is somehow spontaneously devalued. For those who also lack life's material basics—projecting an image even more foreign to the public at large—this attitude is compounded.

Even terminology contributes to the problem. A victim is defined as someone who has been injured by an external cause. Certainly that applies to people disabled by CFS. Yet the word *victim* has become a derogatory term. In popular culture, its meaning has been altered to refer to someone

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who is not willing to extricate himself from painful experiences or who refuses to take responsibility for his own life. It's as if our empowered culture thinks it has outgrown the possibility that there *can* be victims in need of help. Despite its spelling, victim has become a four-letter word.

People with CFS who cannot rebuild their lives are often told that we need to be more resourceful, more self-reliant and more courageous. We're admonished to cope differently, to seek psychiatric counsel and to look at the brighter side of things. We are handed society's credo: “choice determines destiny.” The fact that illness is limiting our choices is overlooked, and we're often regarded as the cause of our predicament.

HUMAN INTEREST FEATURE

Holding the disabled (of any variety) responsible for their predicament permits the able-bodied among us to walk away. And walk away they often do.

A longtime friend who has become homeless tells me he can't believe that he's received no help from those he's told about his disabling case of CFS. He repeatedly says, "They don't get it, and I guess they don't want to get it because then they'd have to leave their comfort zone." To him (and many of us), the healthy world doesn't seem to want to be disturbed. It doesn't want to be inconvenienced. It doesn't want to change. And other people with CFS, who are more likely to understand our plight, are often using the bulk of their energy holding their own lives together.

Help for those who need it

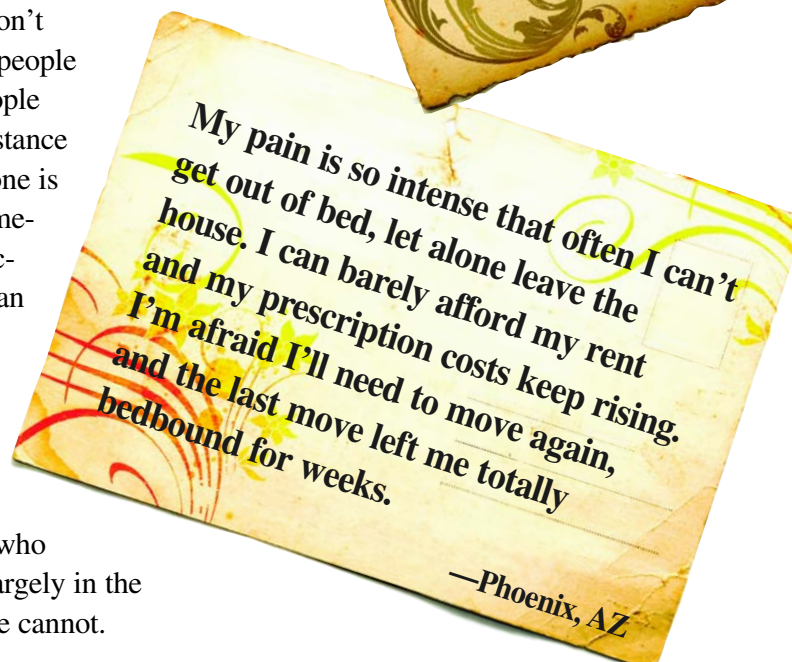
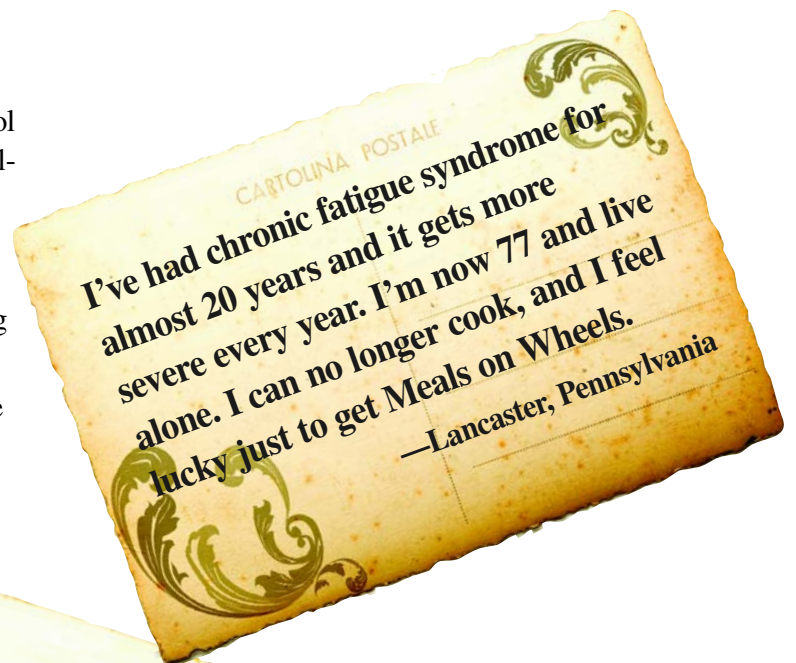
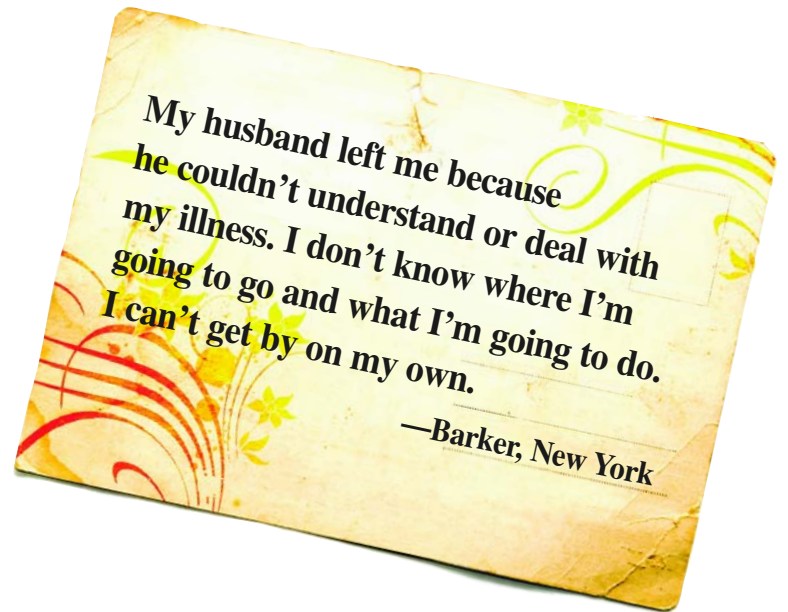
A prevalent American belief is that there's help for anyone who needs it. Along with this belief comes the apparent assumption that the obligation to help belongs to someone else. Service agencies assume that church, family and friends will help; families assume that friends and social services will help. Around and around it goes.

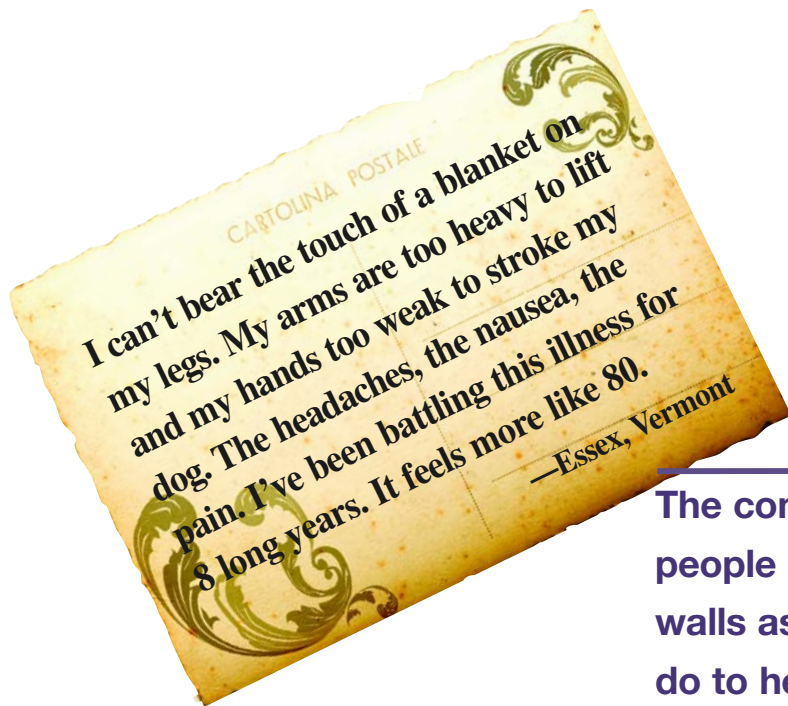
It's true that some people are already overwhelmed. They're scrambling to pay the bills and get the kids to school and, for a gamut of reasons, cannot add to their responsibilities. Yet I've encountered people capable of extending a hand who make conscious decisions to change nothing in the trajectory of their lives. No space is made to embrace the life of a disabled friend or neighbor if it means shaking up the status quo (which it often does).

The inclination to remain undisturbed is so pervasive that even well-intentioned people can sometimes get ensnared by it.

Kind people refuse to learn the facts of our disabling symptoms. Moral people don't inquire about what we need. Ethical people overlook our cries for help. Even people who claim to love us often keep a distance rather than feel grief. The comfort zone is so inviting that even good people sometimes stand together behind its protective walls as if there's nothing they can do to help.

In short, people of otherwise good character aren't immune to the unquestioned beliefs and excuses held by the society that molds them. As a result, some of us who are disabled by CFS have been left largely in the fringes to fend for ourselves when we cannot.





Yes, there are compassionate people who show concern enough to help. But others offer “random acts of kindness” and no more. The rare ones stand by consistently. And since consistency (of food, shelter, income, etc.) is in short supply for those of us in dire straits, that ongoing understanding and support alone can be an essential ingredient for survival.

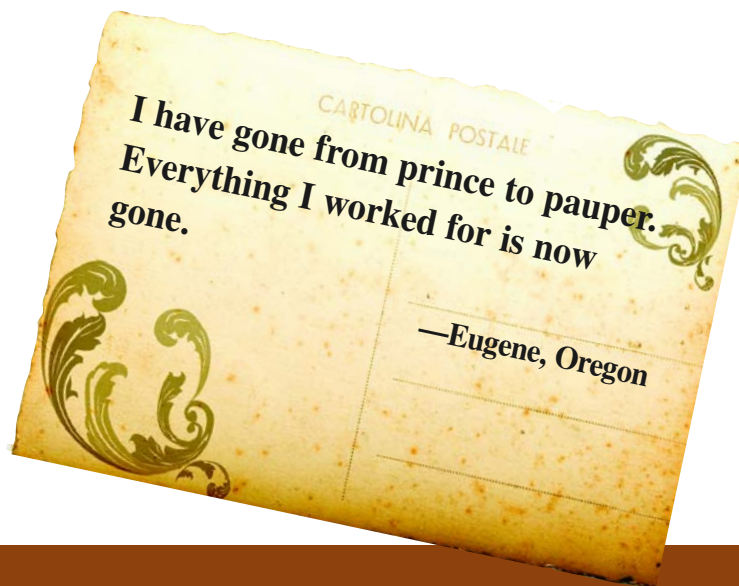
I live in a small town. Still, I've met many people with CFS surviving in extremely rough circumstances. So I conclude that there are likely people with CFS living in dire straits everywhere, in significant numbers.

The comfort zone is so inviting that even good people sometimes stand behind its protective walls as if **there's nothing** they can do to help.

If society, one person at a time, would confront the marginalization of its sick and disabled members, surely insight would shed light on the mistakes that leave some of us unseen and unattended. Then these valiant, weeping lives could be acknowledged, represented, embraced, valued and assisted.

We would appreciate that. ■

Gina Kerner lives in Arizona. She has suffered with severe CFS for years, sometimes barely able to keep a roof over her head. During this time she's taken a strong interest in the people with CFS who are similarly struggling to keep things together.



Research indicates that the symptoms of CFS can be as debilitating as multiple sclerosis or congestive heart failure. Studies also show that the negative financial impact of living with CFS can be substantial. This is a devastating combination for many people with the illness—particularly those without significant familial or community support.

The Centers for Disease Control and Prevention (CDC) estimates the annual total value of lost productivity in the United States due to CFS is \$9.1 billion—representing about \$20,000 per person with the illness. CDC research also indicates that approximately a quarter of those with CFS, who would otherwise be employed, can no longer work due their illness, and those who continue to work lose about a third of their income.

Unfortunately, many people with CFS also report obstacles to receiving Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits, and even fewer receive consistent long-term disability benefits from private insurers to help close the gap.

For this and other reasons it's important to support the fight against CFS. Support the CFIDS Association's research, education, and advocacy initiatives by visiting <http://www.cfids.org/ecommerce/donations.asp>