

by Joan S. Livingston

*"A real friend is one who walks in when the rest of the world walks out."—Walter Winchell*

There's an old saying that "friends forget those whom fortune forsakes." Before chronic illness strikes, this saying may sound nonsensical: after all, whenever you've experienced short-term crises in your life—heartbreaks and difficulties of every stripe—your friends have rallied around you.

In the case of illness, for example, friends are all too happy to bring over chicken soup or Robitussin when you have a "normal" flu (with which they can empathize, having experienced it themselves); and if you were diagnosed with terminal cancer—the other end of the spectrum—most would rally around as best they could, often reading up on what your illness entailed. In our society people seem best equipped to deal with short-term illness and, ironically, with terminal illness—after all, each will end; but many people are at a loss to react appropriately to chronic illness.

For people with CFIDS (PWCs), this is a particularly thorny and isolating problem, because ours is a chronic illness that is simply not understood (even to doctors), and about which so much misinformation has appeared in the lay press. To many—including all too many practitioners of mainstream medicine—our disease is in fact a joke.

### **The Gut-Punch**

"You're still sick?" is a question PWCs commonly have to field even after 10 or 20 years of illness. The implication—a punch to the gut—is that you're not really trying or just haven't scouted out the right doctor (yet?!), or some other gross misunderstanding between you and a non-sufferer. You can try to explain and explain again, by listing your worst symptoms or the many well-documented body-wide abnormalities, or by trying to use metaphors, but the plain fact is this: no one who hasn't personally suffered from chronic illness can ever be expected fully to understand it.

Certainly the name "CFIDS" (or worse, CFS) is no help. I once had two close friends staying with me, and I informed them at bedtime that when I woke up—"late" by their standards, early by mine—I wouldn't really be functional until I'd had not only coffee but also my morning pain

pill. They jointly said in surprise, "You have pain?" I had, needless to say, told them many times about migraines-from-hell and often-crippling joint pain, but all they'd really ever heard was the word fatigue. Sleeping late constituted the beginning, middle, and end of my "disease process," as they understood it. Similarly, I just received a note from a dearly loved cousin, who, in a four-page letter, asked in a single sentence about my illness: "Are you still having fatigue?"

### **The Redeeming Heart**

And so, many of us sadly find that the first old saw becomes true—not overnight but day by day and year by year. Friends can't comprehend why we aren't our old selves anymore. They issue invitations and we cancel, so eventually all but the most understanding (and well-informed) simply stop asking. We may not have energy to return their letters and phone calls; or we may be afraid that if we do, they'll suggest getting together, when we don't know from day to day what we'll be capable of and we're terrified of canceling again.

At the same time, people move away; they marry or divorce or remarry, have children, switch jobs as they continue on upward career paths now denied to us, and change their lifestyles in myriad ways that sever what were once-strong bonds. (This, of course, happens to everyone to a lesser extent).

Sometimes I feel like I'm outside the one-way mirror of a police station interrogation room, looking in on the members of the healthy world but not seen, beating on the glass and screaming to be heard; other times I feel that they're on the outside, with me trapped in that room unable to leave. In any event, I've seen countless friends "peel" away slowly during my 12+ years of illness, like artichoke leaves falling away one by one, leaving only a small—if sweet and solid—core (the heart).

In reaction to our losses, we often turn for friendship only to fellow PWCs (patients with CFIDS)—those we know in person (from support groups and the like), and/or those faceless, voiceless email buddies we will probably never meet in our entire lives but who are always there for us. Indeed, my closest email friends (to my mind, among the closest friends I'll ever have) include not just CFIDS victims but those with other chronic disabilities to whom I never need explain myself: people with rheumatoid arthritis, diabetes, bipolar disease, MS. These people automatically "get it," sharing the shorthand of the chronically ill everywhere. The support I have received from these "cyberfriends" is overwhelming. It demonstrates that there is something unique about all of us with chronic illness and the way we are treated by others, including doctors; we live in this world, but also in a kind of parallel universe that "normals" can never enter.

### **The Forever Friends**

There is another old saying at least as important as the first: that in your lifetime you will have scores of acquaintances, many of whom you will think of as lifelong friends (maybe for years), but in the end you will have lived a successful life if you can count on the fingers of a single hand two or three real, true "forever friends."