

Reflections on Living With Lupus

Authors share inspirations learned from those with lupus

By: *Paul J. Donoghue, Ph.D., and Mary E. Siegel, Ph.D.*

Since we first published *Sick and Tired of Feeling Sick and Tired*, we have spoken to people with lupus all over the United States. We could never have imagined how much we would be moved and taught by those special audiences. Certain themes related to living with lupus often surfaced during these talks, and we briefly reflect here on four of them.

Guilt: Feeling Bad for Being Ill

We've learned from many people who live with lupus that guilt is as much a part of the disease as are pain and fatigue. In some strange way, being chronically ill often induces feelings of being a bad person. Anxiety that the illness burdens the family and brings suffering into their lives also often generates guilt. People with lupus fear that they are depriving their partners of a companion in social activities, letting down their children for school events, and disappointing friends by canceling plans. This fear can make them overly apologetic, defensive, and even hostile. It can also cause them to deny their illness and to attempt activities that exhaust them.

Irrational guilt needs to be fought off. First, it has to be admitted and then seen to be unfair to oneself. Those with an illness did not cause their illness any more than they create the colour of their eyes. The notion that they are bad or to blame for their condition is false. Ginny Davis,* who has had lupus for nine years, says, "Fighting off this feeling of being bad at first was a losing battle—I was always apologizing for myself. But I've gotten better. To help myself, I write truthful statements in my journal and I read them when I'm tempted to give in to guilt." Here are some of the "truthful statements" that Davis reflects on daily:

- I am not responsible for being ill.
- I am totally worthwhile.
- Millions of lovely, honest, special people have been ill in the past and are ill today—I'm one of them.
- Accepting my illness takes courage and brings peace.

Davis notes realistically, "I sometimes have to force myself to read these truths daily. But, more and more, I feel peaceful."

Those living with a chronic illness can feel peaceful and live with dignity. It takes effort: mind control and good sense. Those with lupus owe it to themselves to be as truthful and as peaceful as possible.

Lupus is a Family Challenge

Some of the most inspiring experiences of our lecture events have been witnessing the loving attention of spouses and family members toward loved ones who are ill. And some of the saddest have been listening to those who are ill sitting alone and speaking of spouses who won't listen and family members who ignore them. Lupus brings out the best in families or highlights the worst. What it does *not* do is leave a family untouched.

The person with lupus and his or her family members will grow in self-knowledge and maturity, even in wisdom, or they will grow embittered by illness. We've seen both. Not sharing leads to distance, hurt, and anger. Couples who learn to share their feelings openly can deepen their trust and understanding.

Acceptance: Coping With Lupus Versus Giving Up

Accepting the fact of being ill—chronically ill—is essential to being peaceful and coping creatively. Yet, for many people with lupus, acceptance is hampered by the fear that this means giving in to illness and, therefore, giving up any attempt to live fully. True acceptance never means “giving up.” Individuals need to live as fully as possible, to stretch to the limits of their physical and mental potential. Those who learn to be creative and adaptable, who admit their limits—but never stop achieving—will live life fully with dignity and peace.

Wanda Nelson* is a marvelous example of someone who doesn't deny her illness, but who also doesn't let it define her. For 12 years she thrived as a high school mathematics teacher. Gradually her lupus sapped her energy and made teaching absolutely exhausting. Facing the truth that she would not be able to continue teaching full-time, Nelson turned to tutoring. Now from her home, on a schedule that fits her energy level, she continues to have a profound impact on young people. She says, “Sometimes I miss the excitement of the classroom and the give and take with other teachers, but I love the closeness I can have one-on-one with my kids.”

Nelson has discovered new skills within herself and established new goals. Coping with an illness can, and must, lead creatively to newness.

Meaningfulness: Finding Meaning in Illness

It is necessary to find meaning for life and meaning in its events. Those with lupus must find the hidden potential within the suffering and challenge of lupus. We were moved by Diane Moran,* who is in her 30s and a mother of two young boys. Her lupus has been particularly active with symptoms of intense pain and fatigue. Instead of giving in to self-pity and despair, she radiates serenity. When asked how she maintains such an attitude, Moran answers, “I'm not a masochist; I don't like to suffer. But I believe we all have to accept the good and bad. I have a great husband and two of the best kids in the world. My parents have been incredibly helpful. My friends are the best. It seems like we have all had to cope with lupus. My husband does so much more now with the boys...I've learned to let them all take care of me, which was very hard at first. We've all changed and I'm sure we'll keep changing. I see a lot to be thankful for.”

Moran and so many of those affected by lupus directly or indirectly whom we have met since writing *Sick and Tired of Feeling Sick and Tired* are living witnesses that lupus can bring out the very best within. Rather than being defeated, those with an illness can—one day at a time—tap into the courage, faith, and hope to live full, rich, and peaceful lives.

* *Ginny Davis, Wanda Nelson, and Diane Moran are pseudonyms.*

Paul J. Donoghue, Ph.D., and Mary E. Siegel, Ph.D., are authors of Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness. This article was adapted from the introduction to the new edition.

This article has been reprinted with permission of the Lupus Foundation of America, Inc., from Lupus Now, Summer 2005. Copyright 2005. All rights reserved.