



## What Do We Do With the Guilt?

By Linda Lang

I AM NOW WELL INTO MY SECOND DECADE of living with CRPS/RSD. Until now my coping skills and positive attitude have served me well. However, I have become more disabled and it seems that with each passing day I can accomplish less and less. What surprises me the most is my emotional reaction to all this. Rather than feeling angry or even depressed, I feel guilty.

I remember a time not so long ago that having cancer engendered the same kind of feelings. The word itself was seldom mentioned aloud; we talked about the “Big C” and people hid their disease from others because of the stigma. Rather than being treated with empathy, people were made to feel guilty for having a disease that they did nothing to bring about. It was only because of mass education that people with cancer were given the support and respect they deserved.

CRPS/RSD has not yet reached that level of awareness. Despite great strides in research, there is still a perception among

some people’s family members, friends, and healthcare professionals that CRPS/RSD is in some way psychosomatic, that the patient has control over the symptoms and with counseling or sheer determination can make them vanish. Societal pressure is very strong, and as patients we may unconsciously buy into the same prejudices.

We live in a culture that places a very high value on success and self-achievement. Just look at how we revere Lance Armstrong, not because he overcame cancer, but because he overcame cancer and went on to win the Tour de France so many times. But what kind of respect or accolades do we give to those who suffer from chronic, debilitating diseases whose accomplishments are on a much smaller scale? For some just getting out of bed in the morning and appreciating the beauty of the day may in itself be a great

achiever” at work and for being unable to put in 60 to 70 hour work weeks. I feel guilty for the days when my pain level is so high that I just cannot get out of bed. I feel guilty about every role that I can no longer fulfill the way I could when I was healthier. Telling myself that I have accomplished a great deal despite my illness does not help, because society tells me otherwise.

So no matter how much we struggle to live with CRPS/RSD, no matter how much we may actually accomplish, we are still left to look in society’s mirror that tells us we have failed. Instead of appreciating what we have done, we feel guilty for what we have not achieved. Instead of patting ourselves on the back for a job well done, we chastise ourselves for all the jobs left undone.

I’m not quite sure of how to reverse this. The pat answer would probably be to

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achievement. It does not matter that those of us with chronic, debilitating diseases such as CRPS/RSD face each day with courage and determination. It matters that we have not overcome the disease.

No wonder, then, that I feel guilty for not being able to physically help my family and friends, or for not being a “super

follow the advice of one of those self-help books, but that would only reinforce the same societal belief that we can heal ourselves. Maybe in the end, that is all we are left with. Generally, I end my columns with a tip or two to help you. This time, I’d like to hear from those of you who have managed to get beyond the guilt. ■