

dealing with guilt

People with chronic fatigue syndrome and fibromyalgia are often overwhelmed with guilt. It's important to challenge the cultural and personal belief systems that contribute to guilt because guilt won't make your illness better—and may actually make it worse!

BY LINNEA SMITH NOYES, GUEST CONTRIBUTOR

According to psychologist David Richo, guilt has two aspects—appropriate and neurotic guilt. He distinguishes between these two kinds of guilt in his book, *How to be an Adult*. Appropriate guilt, he says, comes from within and is what we refer to as conscience. It's experienced as an internal voice that arises when we have stepped out of our own truth. Neurotic guilt, in contrast, “is a learned response . . . to an external injunction or demand that we have internalized. We have stepped out of other's truth.”

Guilt is actually a belief or judgment rather than a feeling. In the case of appropriate guilt, the judgment is self-confronting and creates opportunities for resolution. Neurotic guilt, in contrast, is not impacted by acknowledgment or restitution, but hangs on as internal struggle and conflict.

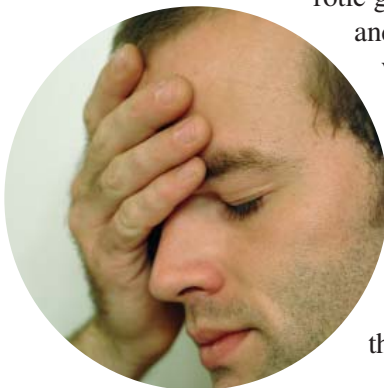
Though everyone experiences both appropriate and neurotic guilt, I believe neurotic guilt is especially challenging for people with chronic fatigue syndrome (CFS) and fibromyalgia (FM). We live in a culture and often come from families that value health, productivity and self-reliance. Being chronically ill flies in the face of these standards and invites the kind of negative self-appraisal referred to as guilt. This guilt is a result of internalizing demands to be “normal” in a culture that doesn't include chronically ill people like you in its database. Since self-confrontation is unlikely to impact the fact that you're ill, it becomes important to look for other ways to relate to this particular experience of guilt.

Let's take a look at guilt issues common in people with CFS and FM and then explore ways to minimize the influence of unproductive guilt.

Cultural sources of guilt

It's my fault. One stronghold of guilt resides in the simple fact of being ill. It's not uncommon for people to assume a direct relationship between their worth and what life delivers. You may look to your own character or lifestyle for “explanations” of why the illness arrived at your door.

Your thinking might go something like this: “I brought this on myself; if I'd think positively, I'd get over it.” Another common self-assault is this one: “I'm having these problems because I won't exercise, I'm too stressed, I'm too . . . whatever.” People with CFS or FM have no trouble filling in the blank. A more New Age version of this belief might be: “I create my own reality; if I'm not creating health



and wealth, I'm clearly doing something wrong."

Any guilt or self-blame of this type tends to hinge on the assumption that you actually have control over such matters, and that there is a relationship between "goodness" and life events.

Pace and productivity. A second kind of guilt occurs because the United States and many other Western countries put an immense value on fast pace and productivity. Because individuals with CFS and FM are often limited in these capacities, it's easy for guilt to rear its ugly head. A typical issue might involve the inability to work and contribute to the family income. Or there might be huge disappointment around difficulties starting a family, and subsequent guilt for a person who holds herself responsible. Some individuals are unable to cook, clean, shop and do what they perceive is their "fair share" of responsibilities around the home. Needing to prioritize your own needs over commitments to other people is yet another challenging area, often limiting the sense of having a satisfying social life or being dependable.

Guilt about moving at a slow pace and diminished productivity represents beliefs that are learned from role expectations and social convention.

Dependency. Finding ourselves in a receiving rather than giving role is another common source of guilt. Many individuals with CFS and FM cherish being in the role of giver and are very uncomfortable finding themselves in the position of needing to depend on others for physical or financial support.

I practice in Salt Lake City, where I work with many patients in Dr. Lucinda Bateman's Fatigue Consultation Clinic. A typical comment I hear from clients in my practice is: "I'm constantly disap-

pointing my partner, who gives, gives, gives." Or, "I feel inadequate as a girlfriend (spouse, friend, etc.) because I have to be selfish with my energy resources to survive being chronically ill." It's also common for my chronically ill patients to look back and say, "My old self would have been able to do this task and not rely on others."

Curiosity about guilt

To diminish the role of guilt in our lives, an attitude of curiosity can be very helpful. What are the beliefs and values upon which our self-judgments are based? Can they be challenged? Can we identify other beliefs and roles that are more appropriate for us and begin to think more creatively?

Challenging beliefs.

Challenging our beliefs about guilt is an important part of the work I do with patients. Linda Milne, one of my clients who has CFS and FM, told a friend she felt "spiritually embarrassed" to be chronically ill. Her friend responded, "I would never have that opinion of you. Why would you have it?" Milne realized she had equated being ill with being a "spiritual failure." She was able to recognize the faulty belief and release it.

Milne's experience isn't uncommon. Just as judgmental and negative comments can feed false beliefs, supportive friends, family and support groups can all act as positive mirrors for us and assist us in seeing through self-limiting beliefs. Surrounding yourself with these positive resources can help you navigate your way through the challenges of living with a chronic

illness that is misunderstood by so many people, including health care providers.

You can also challenge beliefs on your own. A very useful question is, "Is that really true? Can I absolutely know that what I believe is true?" For instance, if you believe you're responsible for being ill, can you actually know that's true? Not really. It's impossible to know with certainty exactly what factors coalesced to create illness. How

does it feel when you hold yourself responsible for becoming ill? Who would you be if you didn't tell yourself that story? (For more on this topic, see Byron Katie's book, *Loving What Is.*)

In a group session with other CFS and FM patients, Shawn Stupka talked about how it

can be a huge relief to let go of the thought, "I'm not supposed to be sick." Tana Howell agreed: "The

key is to ask yourself what

beliefs you're running from. They're just thoughts. You can choose not to believe them anymore."

As you let go of beliefs that are not personally supportive, the guilt associated with these beliefs will abate as well.

Another kind of personal belief you can challenge on your own are assumptions made about how others are experiencing your illness. It's easy to believe other people's feelings of disappointment or anger are worse than they actually are, and to



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feel deep despair based on these assumptions. But you have essentially made up a story about what another person is thinking or feeling, and then responded to your story as if it were true.

Guilt can be diminished and relationships strengthened when we simply begin asking people directly about their experience. By asking questions, we let others know that we are open to their truth and willing to set our projections aside.

Let's look for a moment at beliefs related to pace and productivity. The cultural expectation to move quickly and be productive is rather like the air we breathe. We are so accustomed to this cultural "press" that we don't even think to question its validity as a lifestyle.

I say question it! In a CFS/FM support group meeting, Rhonda Cassidy did just that, remarking, "We are human beings, not human doings."

In the July/August 2004 issue of *Ode*, an article titled "Going with the Slow" discussed how slowness is supportive to health, mindfulness and a sense of peace. It also described communities in Italy where entire townships are committed to creating a slower pace of life. Some of the article's recommendations for slowing down the pace make the CFS/FM lifestyle sound very reasonable.

The reality of CFS often requires people to slow down and be less productive. If you let go of the viewpoint that this is a problem, it's possible to see benefits to living life from a more tortoise-like perspective. "Who's to say this isn't a good life, or that society's pace is reasonable?" Howell asked at a recent



support group meeting. Milne responded, "Maybe we're the lucky ones. I'm kinder since I've slowed down. I notice others' needs more. I never would have discovered this pace of life if I hadn't become ill."

Thinking out of the box. In addition to challenging the beliefs that drive sensations of guilt, it's useful to notice what we value in a particular belief, and then look for new ways to express that value in our lives. When we think out of the box, we engage creativity to honor what's important to us, while at the same time respecting our physical limitations. We may find ourselves available to new interpretations of what it means to be productive, for instance.

I've noticed that as acceptance grows, clients begin to appreciate the time that's available for inner focus and personal growth, as well as their capacity to be present for others. In *Clear Mind, Wild Heart*, poet David Whyte remarks that individuals moving at rapid velocities literally cannot perceive the people who are moving slower than they are. When our own pace is slow, we can attend to people in a new, more intimate way. This is a good example of reframing and revaluing what we *can* do.

Milne has shifted her focus away from the guilt she previously felt about being dependent on other people for support. She has done this by emphasizing the concept of exchange over equitable give-and-take. Because generosity is important to her, she looks for opportunities to give to others at a level and pace that is congruent with her limitations. The contributions are usually smaller than the ones she receives and don't necessarily

involve the same people. Support from a partner or disability benefits, for example, may be "repaid" in kindnesses such as rides for ill friends or volunteering for the Organization for Fatigue and Fibromyalgia Education and Research (OFFER).

One of the ways Milne gives back has proven especially powerful—the willingness to talk about chronic fatigue syndrome and fibromyalgia to other patients, family members and anyone else who's interested. "I talk about it everywhere. It's heartwarming to help those people who haven't been diagnosed and are living secret lives. I talk about my life, OFFER and Dr. Bateman, and I let people know there's a way to have a life."

Stupka also makes the most of opportunities to talk about CFS: "I think of this as my job now."

The willingness to bring frankness and information to others is a wonderful way to open new doors and experience appreciation in areas of life that were previously shunned.

A word about therapy

Working with a licensed clinical social worker or psychologist is a very effective way to address issues such as guilt. Therapy need not be a lengthy commitment. Most therapists are happy to work with you on a particular issue like guilt or anger for a short period of time. And once you have worked with a therapist on one issue, that supportive relationship is in place for you, enabling you to return on an as-needed basis should other concerns arise.

I encourage clients to trust their own instincts in selecting a therapist who feels "right." Though the work of therapy is sometimes *uncomfortable*, the relationship with the therapist should feel *comfortable* and safe.

Individual therapy is not your

only option. Support groups and therapy groups can be very helpful in gaining insight about topics of particular concern to individuals with CFS, FM and related illnesses. While therapy groups support you to explore your personal psychology within the context of the group, support groups tend to be more topic-focused. They are generally facilitated by therapists, although some support groups are run by laypeople with group process expertise.

Either type of group has the advantage of putting you in contact with other individuals who are coping with challenges similar to your own. Sharing personal experiences and discoveries can be very empowering, especially when there's an intent to grow and be open to a more positive perspective related to being ill, instead of simply venting and complaining.

The gift of guilt

Following neurotic guilt back to its origins permits us to see more clearly the personal and cultural beliefs we hold as standards for ourselves. The opportunity then exists to challenge the appropriateness of those standards and rework them into values that are congruent with our personal ethics. As a result of this process, personal awareness will be enhanced, guilt will begin to diminish, and increasing amounts of energy will be freed for other endeavors. You may even find yourself able to feel increasing acceptance of your limitations and appreciation for experiences you would have missed had the illness not entered your life.

The struggles and imperfect qualities each of us carries through life have an essential role to play in our development. It's by working through the facets of life that are most challenging for us—whether addiction, bad relationships, poor finances or chronic illness—that we discover our true, authentic self.

This process is about being who we truly are and locating ourselves in the company of people, places and activities that call out the best in us, that inspire our grace. It's about allowing and nurturing what is heartfelt and showing kindness toward ourselves by leaving the voices of self-blame and guilt at the door. ■

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The author often shares the following poem with her patients.

Wild Geese by Mary Oliver

You do not have to be good.
You do not have to walk on your knees
for a hundred miles through the desert, repenting.
You only have to let the soft animal of your body
love what it loves.
Tell me about despair, yours, and I will tell you mine.
Meanwhile the world goes on.
Meanwhile the sun and clear pebbles of the rain
are moving across the landscapes,
over the prairies and the deep trees,
the mountains and the rivers.
Meanwhile the wild geese, high in the clean blue air,
are heading home again.
Whoever you are, no matter how lonely,
the world offers itself to your imagination,
calls to you like the wild geese, harsh and exciting —
over and over announcing your place
in the family of things.

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