

Lisa Lorden Myers

Fibromyalgia & Friendship

Seeing Through Invisible Illness

At times, one of the most difficult things about living with a poorly understood illness like fibromyalgia (FM) is figuring out how to be sick in a healthy world. In her book *You Are Not Your Illness*, Linda Noble Topf explains how illness has a way of exaggerating our sense of “being different from others, of being special or unworthy, and of ultimately being separate and alone.” Nevertheless, the experience of feeling connected to others is vital to both our physical and mental well-being.

The sense of isolation people with FM may feel is exacerbated by the fact that our illness is invisible. As FM sufferers, most of us have probably heard the phrase, “But you don’t look sick!” more times than we can count. Even when intended as a compliment, this simple statement can touch off a cascade of emotions: anger, confusion, shame, and self-doubt. It seems that no matter how long we’ve lived with FM, innocent comments like this from friends and strangers alike have the potential to touch a wound that at times feels surprisingly raw.

Often the question people with FM most dread hearing from a friend or acquaintance is “How are you?” This seemingly innocuous ritual of polite conversation can be fraught with complexity and emotion for FM sufferers. We may long for the days when we could reply, “Fine thanks,” without a second thought; but when overwhelming pain, fatigue, or other symptoms render us vulnerable and disheartened, this simple response may feel like a lie.

“You looking good,” said Sethe.

“Devil’s confusion. He lets me look good long as I feel bad,” said Paul D.

—from *Beloved*, by Toni Morrison



© Copyright 2006, Phil Date\ Agency: Dreamstime.com

Ailing Bodies, Wounded Hearts

In *Sick And Tired Of Feeling Sick And Tired*, Donoghue and Siegel point out, “where need is most pronounced, feelings are most intense.” Human beings are social creatures. Our sense of who we are and our place in the world is constantly being influenced and redefined by the nature and quality of our relationships with others. Especially at a time when chronic illness presents myriad threats to our identity and sense of self-worth, it is natural to look to others for support and validation. Never are our relationships with our friends more essential—

and more challenged—than when our lives have been transformed by illness.

However, coping with a poorly understood chronic illness can leave us feeling lonely, vulnerable, and over-sensitive. Any FM sufferer knows how difficult it can be to adjust to our own unpredictable symptoms and limitations that wax and wane over time. These symptoms may allow us to engage in an activity one day, but that same activity may be impossible to contemplate the next. Just as we struggle with an illness that is so tricky to understand, others find it even harder to comprehend because they haven’t experienced it. This problem is compounded by the fact that FM sufferers usually look healthy. “Since chronic pain and ongoing exhaustion seldom manifests outwardly, people sometimes have a

difficult time believing that a person with a healthy appearance and lively demeanor can have so many profound symptoms and limitations,” writes Carol Sveilich, author of the book, *Just Fine: Unmasking Concealed Chronic Illness and Pain*.

Assumptions are often based on physical appearance. Says Sveilich, “It’s very stressful to try to convince the world that your pain or symptoms are real.” With an invisible illness or disability, the burden typically falls upon the sufferer to explain and educate others. At first many people may respond with concern and compassion. Others may react with skepticism or ask scrutinizing questions. As time passes, even those who were originally sympathetic may question the existence of an illness that is invisible and incurable, or they may simply feel too uncomfortable to acknowledge it. Katrina Berne, CFS sufferer and author of *Running on Empty: The Complete Guide to Chronic Fatigue Syndrome*, says, “Our society encourages denial of all things unpleasant, especially those we fear or cannot readily understand.”

Without visible signs of pain and illness, we’re often left feeling the need to explain or even over-emphasize symptoms around others. We might find ourselves trying to justify our activity restrictions or insisting on the severity of our symptoms—after which we may feel guilt or anxiety about being seen as “complainers.” Desperately wishing we weren’t sick, yet wanting clear signs of illness to validate our experience, we’re left with a sense of confusion and self-doubt. It can be difficult to know how to act because we’re caught between contradictory wishes: wanting to appear normal and wanting to be understood. Fibromyalgia can often feel like the elephant in the room.

While some relationships will be deepened by the trials of chronic illness, we may have to be willing to let some friends go. In *A Delicate Balance: Living Successfully with Chronic Illness*, Susan Milstrey Wells writes, “We may lose friends because... we can no longer share a sport or hobby with them, or because we don’t seem to be as much fun as we used to be. Sometimes our friends just don’t know how to act around us when we are ill.” Still, there will be true friends to whom we can pour out our hearts, and these are friendships to be treasured.

To Tell or Not to Tell

With all its pitfalls and complexities, deciding how to communicate with others about FM can be a very thorny issue. We must choose whom to tell and how

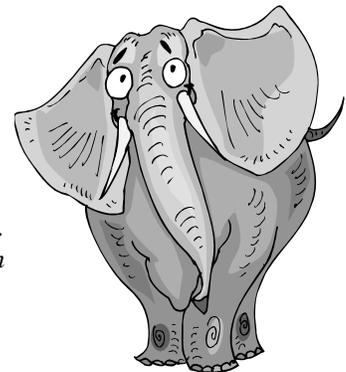
much to tell; and potentially we must make these decisions on a daily basis, with everyone we meet. Particularly with newer friends and acquaintances, it can be difficult to know when to reveal we have a chronic illness and how much detail to share.

It is often frightening to make ourselves vulnerable by disclosing our illness. We may be afraid of being rejected or of not being believed. At times we may not want to be treated differently due to our illness or want our condition to become the focus of the conversation. Perhaps we fear that someone isn’t truly interested in hearing about our symptoms or our struggles, or that our friends will grow tired of listening. I often dread questions about how I’m feeling from people I haven’t talked with in a long time. I imagine they’re thinking, “I can’t believe you’re *still* sick.”

You may be able to get a sense of how someone will react by sharing something small at first. The response you receive may help tell you how a friend might deal with more extensive details of your illness. The challenge is to find a balance between revealing too little and sharing too much. In *The Fibromyalgia Relief Book*, Miryam Williamson points out, “As hungry as you may be for support, it’s enormously important to protect those around you from being overwhelmed by your need to talk about what’s happening to you...Even the most compassionate and loving person can reach a point of boredom and fatigue if all he or she ever hears from you is about fibromyalgia.”

The circumstances of every situation and each relationship are different. Only you can decide what you want to share and how and when to reveal it. No matter what the response, do your best not to take it personally, as difficult as that may be. Says Sveilich, “It’s important to pick your own battles and believe in yourself and your reality. Don’t worry about convincing those who are fearful or can’t be convinced. It’s a waste of time and energy.”

“... we’re caught between contradictory wishes: wanting to appear normal and wanting to be understood. Fibromyalgia can often feel like the elephant in the room.”



With A Little Help From Your Friends

It is valuable to remember that—with or without FM—people will disappoint us at times, just as we will disappoint others. Realize that feelings of frustration, confusion, and sadness are natural. It is important to acknowledge the sense of pain and loss that is a part of learning to live with illness. However, there are things that you can do:

Understand and accept your changing needs, and realistically evaluate who can help you.

Chronic illness inevitably changes friendships. Some become closer, while others might fall away or become strained. Some people will surprise you by standing by you when you least expect it. Accept what people are able to give, as well as what they can't. I have a group of friends and family I privately call my "A-team." Those are the people I can truly count on to understand and support me. Others might still play a role in my life, but my expectations are different. When you reach out and ask for help, think about who among your circle of friends is most likely to be able to hear your request and want to support you. Don't expect individual relationships to meet all of your needs.

Communicate your feelings and needs honestly.

Many of us have always prided ourselves on being self-sufficient achievers. With the onset of FM, we may have to rely on others in new ways; it can be difficult to acknowledge these needs to ourselves, let alone communicate them to others. We may feel deficient, embarrassed, or frightened; perhaps we're afraid others will be resentful of our neediness or that they cannot understand. Realize that these fears are often unfounded. Sometimes we end up perceiving others as being uncaring simply because they cannot read our minds. A friend might welcome the chance to offer support but simply isn't sure what to do or say. By communicating our needs, we give others the opportunity to be of assistance (which often makes them feel good too).

Keep in mind that communicating honestly requires a willingness to risk rejection or disappointment—we may not always get the response we'd like. However, as Topf points out, "...when we stay emotionally in touch with our needs and express them clearly without all the overlays of feeling unworthy or projecting our distrust to others, support grows and expands."

Maintain a balance of friendships with other FM sufferers and those who are not sick.

Sometimes we need the comfort and understanding that only another person with FM or other chronic illness can provide. As FM sufferer and doctor Mark Pellegrino, M.D., writes in *Fibromyalgia: Up Close and Personal*, "When people with fibromyalgia first meet each other, there is almost a magical ability to immediately open the doors that lead to our... innermost sensitivities, fears, and hopes."

We can build new friendships through FM support groups and online communities. Nevertheless, sustaining relationships with "healthy" friends and loved ones is also important. At times, FM can seem to take over our worlds; but having contact with those who aren't ill helps us maintain a connection to the world *beyond* FM, allowing us to focus on other things and ease the monotony of coping with illness. Different friendships play various roles in our lives, just as they did before FM. Some are deep and intimate, while others revolve around a shared interest or activity. Remember that it may not be necessary for every friend to understand what living with FM is like for us.

Understand that others might be struggling with problems and feelings of their own.

The impact of a chronic illness like FM on our lives is so vast that at times we tend to forget that we ever had problems before we were sick! It's helpful to remember that others have challenges and worries that have nothing to do with their feelings for us. In addition, watching a loved one struggle with illness often makes people feel helpless and uncomfortable, and they may behave in awkward ways or simply have the need to create distance. They too may experience fear, disappointment, and loss; and these emotions are often complicated by feelings of guilt for being healthy or for having needs that we may not be able to meet. Keep in mind that others' reactions may have more to do with them than with us.

Resist the need to over-explain or apologize.

Living with a chronic illness involves constantly evaluating the impact that various activities might have on our pain, fatigue, and other symptoms. It often requires difficult choices about whether or not to engage in an activity that others do without a second thought. Only you can know which decisions to

make in order to best manage your symptoms. If you are unable to do something or have to change plans you've made with friends, it's important to communicate this, but don't feel obligated to provide multiple explanations or apologies. Suggest an alternative plan or invite others to go ahead without you. Try to stay positive in spite of your limitations. Avoid offering long-winded details about your illness and its constraints.

Handle unsolicited advice with as much grace and confidence as possible.

One challenging aspect of communicating about FM with friends or acquaintances is responding to others' attempts to "fix" you. For those of us with FM, at times it feels like everyone we meet has a suggestion to help our pain and fatigue or a story of someone they know who was "cured." Keep in mind that a friend may have the best intentions: it's hard to see a loved one suffering and it's natural for some people to want to fix it. However, try not to let such conversations make you doubt yourself or your treatment choices. FM sufferer and author, Lisa Copen, points out that while we may not be able to make everyone understand our illness, we can choose how we respond. Copen suggests responding with kindness—yet firmness—to those who offer unwanted advice or suggest remedies. She recommends acknowledging a friend's concern, but saying something like, "I have really jumped in and done all sorts of research on treatments and the good and the bad and the side effects and consequences. I feel like I've made a very educated choice that I can live with for now."

Provide positive feedback about things that are helpful.

Chronic illness can be devastating in so many ways, and sometimes there is nothing anyone *can* do to take the physical and emotional pain away. At times we may feel overwhelmed with needs that cannot possibly be met; but we should realize that sometimes we can turn to others for support.

Our friends may have a genuine desire to be helpful but simply not know how. Good intentions sometimes backfire, and those who care about us may be left feeling uncertain and afraid to make things worse. It's vital to appreciate the things our loved ones can do that are helpful. Let people know when they are doing something right. Communicate how much you love them and appreciate their support.

Most of all, remember that you are never alone. There are always people to whom you can reach out, whether they are somewhere in cyberspace or right next door. It may be someone you've known your whole life, or another FM sufferer you have yet to meet. While relationships might become a bit trickier, the capacity for human connection and friendship is one thing that illness simply cannot take away. It is ultimately worth the extra effort. As Joseph Addison wrote, "Friendship improves happiness, and abates misery, by doubling our joy, and dividing our grief."



Resources

A Delicate Balance: Living Successfully with Chronic Illness, by Susan Milstrey Wells (HarperCollins, 2000)

The Fibromyalgia Relief Book, by Miryam Ehrlich Williamson (Walker & Company, 1998)

Fibromyalgia: Up Close and Personal, by Mark Pellegrino, M.D. (Anadem Publishing, 2005)

Just Fine: Unmasking Concealed Chronic Illness And Pain, by Carol Sveilich (Avid Reader Press, 2004)

Running on Empty: The Complete Guide to Chronic Fatigue Syndrome, by Katrina H. Berne, Ph.D. (Hunter House, 1992)

Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness, by Paul J. Donoghue, Mary Elizabeth Siegel (W. W. Norton & Company, 2000)

"Why Can't I Make People Understand" by Lisa Copen, Rest Ministries website: <http://www.restministries.org/ARTICLES/art-makepeopleunderstand.htm>

You Are Not Your Illness: Seven Principles for Meeting the Challenge, by Linda Noble Topf (Fireside, 1995)