

By Ginny Maril, Ph.D.

Q: What are some of the emotional effects of scleroderma?

A: Just as the physical manifestations of scleroderma vary from person to person, so do the psychological effects. Not everyone will experience all or any of these symptoms, but it's important to know what is out there and how to react.

We know that scleroderma patients are about 4.5 times more likely than the general population to receive a psychiatric diagnosis. Patients often must learn to cope with increased stress, anxiety and depression. When you think about the experience of living with this disease, these reactions make sense.

There also is a good deal to feel anxious or sad about: What's going to happen to me? Can I keep working? When do I tell a date that I'm sick? What do I tell a classmate when they ask what is wrong with my hands? Sadness makes sense, too: Maybe you can't do the things you love as frequently any more. Maybe you had to stop working or cannot care for your family as you would like. All these feelings are normal reactions to an unexpected and challenging situation.

Q: I feel like my relationships are different than before. Is that normal?

A: Absolutely. A scleroderma diagnosis can impact relationships with friends, family and partners. Maybe you feel like you cannot commit to plans. If others don't understand the disease and what it means to your daily life, they may react insensitively: they may think you are unreliable or doubt your illness. Sometimes "friend thinning" happens after diagnosis. People have shared that while they lost some friends as a result of the diagnosis, they learned who their real friends were and even gained new ones through involvement with local support groups. This is very important: having supportive and caring people in your life is one of the best things you can do to combat the negative emotional effects of living with scleroderma.

Scleroderma also can impact partnered relationships physically and emotionally. It is easy to be cranky when you don't feel well. The people who absorb your crankiness are usually those who are around you the most. This can unwittingly push loved ones away when you need them most. It's definitely okay to be cranky; just be aware of how it comes out and impacts those around you. Relationships might also start feeling out of balance if one person is the primary caregiver. It's important to acknowledge what changes are happening and how they are impacting the relationship. Work together to figure out how to cope with them.

Q: How do I know if my crankiness or depression is more than a normal reaction? What should I do about it?

A: If you find yourself feeling down more days than not, or if your sadness or worry keeps you from engaging with others, you may want to consider speaking with your physician or a mental health professional, such as a psychologist. Physicians are trained to help you manage your medical symptoms, while psychologists are trained to

help you learn coping strategies. Each can help you navigate what you are going through.

Q: What are some things I can do on my own to feel better?

A: It is important to start thinking about things you can control versus those you cannot. Once you do this, you can let go of those things out of your control and focus on what is in your control. For example, you can choose to take medication as directed, avoid caffeine or other foods that might not help you feel well, and exercise as you can. These things are in your control. You also can control how you treat yourself. Practice being kind to yourself. Practice forgiving yourself. People are much more forgiving to others than to themselves. Extend yourself the same kindness you would extend to a loved one. You also can practice not judging your emotions. It can be easy to criticize ourselves because we feel sad and we tell ourselves that there are others who have it worse. While that is generally true, it also is important to just let your emotions be. If you feel sad, feel sad. It will pass. There is no need to beat yourself up because you are feeling an emotion that is perfectly normal. Beating yourself up can actually prolong your experience of feeling sad. Let yourself move through the emotions you experience.

Share your thoughts and feelings. Let those who are there to support you do so. In return, be there when they need you. Practicing this can help you feel more balanced in relationships. Make time to do things you enjoy. Sometimes this is hard to do, but it is critical for your mental and physical well-being. Identify what helps you feel recharged and schedule it into your week. This doesn't have to be a day's worth of volunteering, though it could be. It could also be 10 minutes in a quiet room reading something inspirational. Work in what will fit; just make sure you are working something in.

Q: If I went to therapy, what would I do?

A: In therapy, we talk a lot about what you are going through – from the disappointment and frustration that comes with the diagnosis to how to respond when someone asks why you're wearing mittens in the grocery store. Your therapist will listen, ask questions and provide insight or training to deal with different situations. A therapist might help you learn to build resilience by identifying your strengths and applying them to your current situation. They might help you learn to manage awkward social interactions that can occur when you live with visible signs of illness. If you are diagnosed with something like depression or anxiety, a therapist can help you learn to manage your symptoms. And perhaps the best thing a therapist can do is to provide you with an hour of non-judgmental attention. You can just be yourself and get whatever you need off of your chest. It can be a wonderful form of self-care.

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