

The Scleroderma Foundation's mission is three-fold:

☛ To help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals, and educational information.

☛ To promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns.

☛ To stimulate and support research to improve treatment and ultimately find the cause and cure of scleroderma and related diseases.

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Coping with Scleroderma



**SCLERODERMA
FOUNDATION**

SUPPORT • EDUCATION • RESEARCH

Coping with Scleroderma

Any chronic disease is life changing. Symptoms demand your attention. You have to adjust your schedule to accommodate pills, doctor appointments, and treatments of various kinds. You need to arrange for rest and relaxation as well as for doing things more slowly than you used to. You need to balance work and leisure. You will have to confront changes in your body and the way you see yourself as well as the way others are used to seeing you. The people around you need to adjust as well. They live with the changes of your disease too, even though they don't experience your symptoms. Finally, and perhaps the biggest adjustment, is for you to accept and work with and through the changes in order to cope with daily life. This pamphlet is about how you might change and grow because of, and in spite of, scleroderma. It contains a section about the emotional stages that people often go through in order to reach an acknowledgment of their changed lives. There are practical suggestions on how to cope with these stages.

The Beginning

Because scleroderma can present itself in so many different ways, diagnosing it can be difficult for physicians. That means many tests and many trips to the doctor's office before a definitive answer can be found. For the patient and family/loved ones, the waiting means lots of "what ifs" and anxiety can result from anticipating the worst. Sleeplessness, irritability, and the tendency to be distracted are usual at this point. Also common is the tendency to "mis-hear" what the doctors say because of the worry about what they are saying. Finally, people report that any aches and pains they have may be made worse by the increased anxiety of this phase.

Four

- *Take notes about what you are told. If you have any questions later when you have the time to absorb the information, you can refer to those notes and ask questions that are important to you. Some patients take a friend, a family member, and/or a tape recorder along so that the information can be reviewed later. This reduces the chance that worry will inhibit hearing the information.*
- *Share your worry with people you trust and care about, if this method of reducing anxiety works for you. Spouses and partners can be especially eager to know how you are being affected since they are closest to you.*
- *Recognize that this can be a difficult time for you. Just knowing that fact might help you to get some objectivity going. What have been your resources in the past: Your ability to go after and find information? Your ability to ask good questions? Relaxation techniques? Getting away for a day or weekend alone or with someone? Exercise? Use these to help you cope at this time, too.*
- *It has been reported that people who are struggling with a set of problems new to them often drop the fun activities in their lives in order to have the energy to keep up their responsibilities. Remember to retain the activities you enjoy and are capable of and get help with your everyday chores. Learn to delegate to those who care. They won't mind, especially if it helps you to manage better.*

The Diagnosis

The second part of your journey starts after you have actually been diagnosed with scleroderma. The beginning of the diagnosis might be characterized by fits and starts: one doctor will say you have it, another might say you don't; they both might disagree about

what form of it you have or its severity. Or, you might get a definite diagnosis of scleroderma and then have a physician say that it is terminal, untreatable, or that the treatments are all experimental. These are all situations that people with scleroderma have reported and they have also reported being angry and discouraged. You are not alone in your frustration.

Hint

- *Keeping notes and lists of questions is doubly important in order to try to maintain your objectivity in the face of the worry you will probably experience.*
- *Express your concerns to your physician and, if he/she can't help you, ask to be referred to someone who can.*
- *Remember to take a friend or tape recorder along.*

You may also experience a smoother course, where the tests all point to the same diagnosis and you have a physician who knows what the diagnosis means and can either treat you or refer you to someone else. People who have smoother experiences report that it was still a difficult time because they knew nothing about the disease. Patients report that having a healthcare provider who listens and works with them as partners in their care makes it much easier to adjust.

The Emotions

Denial

So, you have been through all the testing, you have a diagnosis, and you are mulling over what you know about it. Now what? One of the things that often happens to people when they get threatening news is that they feel disbelief and refuse to acknowledge that anything is seriously wrong with them. This can be a useful defense, similar to the body's instant numbing

of your skin when you smack against a table. But the pain does appear eventually, and to deny it is not helpful. Eventually, you have to do something about it: rub the sore spot, put on heat, whatever helps. When you keep denying that something is wrong, you cannot move forward into helpful activity. One way to absorb and deal with the news of your diagnosis is to give yourself some time to think. Listen to your favorite music, watch movie videos that make you feel good, sit in the sun in a garden, lie in a warm tub and think.

Hint

- *Think about your resources: people who care about you; your talents and abilities; information that's available that can help you understand what is happening to you; crises you've confronted in the past and conquered.*
- *Think about your options: learn about your illness and how you can live and function with it; meet others with scleroderma who are functioning well; talk to someone who can help you confront your illness and support you while you do it; call the local chapter or support group of the Scleroderma Foundation.*
- *Think about the consequences of not tending to yourself: increasing worry and pain, increasing disability, increasing depression.*

Anger and Depression

After the implications of the diagnosis dawn on you, you could get angry. Really angry. And depressed at the same time. Some people report alternating between the two feelings, a very confusing situation. This is the next phase of moving toward an acknowledgment that changes are occurring, and it isn't an easy phase to move through, not for you and not for those close to you. But it is necessary, and as long as you know you're going through it, go through it with your eyes open. Anger can be a very energizing

emotion. It's during this time that patients report they:

- Find and join support groups;
- "Shop" for a physician who knows how to treat scleroderma;
- Search libraries and the internet for information they feel might be helpful.

Depression can, on the other hand, slow people down. Patients describe feeling negative about everything, an increase in physical symptoms, and helpless/hopeless feelings as well as a decrease in energy. Fearfulness is also common. This is the phase during which a counselor (preferably someone who has experience helping people deal with chronic disease) could be helpful since he/she can be objective and help you to get angry/depressed feelings out in the open in a safe place, not on the job, or directed at your loved ones, or yourself.

Bargaining and Acceptance

While trying to cope with anger and depression, some people find themselves bargaining. This stage may take the form of praying, "God, if you'll only take this from me, I promise..." Or, being willing to take medicine with uncomfortable side effects if only it would "cure" them. Or going to herbalists, chiropractors and acupuncturists in hopes of a "cure." These are all ways of bargaining and another way of denying the reality of the disease.

So how does a person come to accept scleroderma? Patience, support, and strategies that serve people's need to function seem to work best. There isn't any one way that patients reach that stage; some never do and some do so in part. Each patient who learns to cope well with his/her disease:

- Has discovered the hope and strength he/she has inside;
- Has found people to help him/her along the way; friends, relatives, loved ones, healthcare providers, scleroderma support groups, counselors, church groups;
- Has learned to help others by getting involved in scleroderma organizations, educating his/her friends and the public, and helping other patients through the difficult times.

The most important underlying factor seems to be that patients who successfully cope with scleroderma have discovered that their lives are worth the fight.

(The Scleroderma Foundation thanks Elaine Furst, R.N., B.S.N., M.A., of Los Angeles, CA for her assistance in the preparation of this pamphlet.)

Disclaimer: The information provided is for educational purposes only. Any drugs or treatments mentioned should be discussed with your own physician(s).