

COPING WITH SCLERODERMA



**SCLERODERMA
FOUNDATION**

SUPPORT • EDUCATION • RESEARCH

Any chronic disease is life changing. Symptoms demand your attention. You have to adjust your schedule to accommodate medications, doctors appointments and treatments of various kinds. You need to arrange for rest and relaxation and do things more slowly than you used to. You need to balance work and rest. 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.

Perhaps the biggest adjustment is learning to work with and through the changes in order to cope with daily life. We hope this pamphlet will help you learn to live well with scleroderma.

THE BEGINNING

Because scleroderma can present itself in so many different ways, diagnosing it can be difficult. That means many tests and many trips to the doctor's office may be necessary before a definitive answer can be found. Finding the right physician who has experience treating scleroderma is important and can result in a quicker diagnosis and faster treatment. Contact the Scleroderma Foundation or your local chapter for names of scleroderma doctors.

For the patient, family and 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 common at this point. The tendency to mis-hear what doctors say because of worry is also common.

People sometimes report that any aches and pains they have may be made worse by the increased anxiety during this phase.

HINTS

- Take notes about what your doctor tells you. If you have any questions later after you have absorbed the

information, you can refer to those notes and ask questions. If you can, take a friend, a family member and/or a tape recorder along so the information can be reviewed later. This reduces the chance that worry will inhibit hearing the information. It may also help your family member understand the disease.

- Share your worry with people you trust, if this method of reducing anxiety works for you. Spouses and partners can be especially eager to know how you are being affected.
- Recognize that this can be a difficult time. Just knowing that fact might help you balance some of the challenges. Being proactive in doing things can channel stress and anxiety into positive action. Examples include going after and finding information; asking questions of medical professionals; partaking in relaxation techniques and/or exercise; getting away for a day or a weekend either with someone or alone. All of these can help you reduce stress and can help you cope during this difficult time.
- 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 because they don't have the energy. Remember to retain the activities you enjoy and are capable of doing. Learn to delegate other activities to those who care. They won't mind, especially if it helps you manage things better.

THE DIAGNOSIS

The second part of your journey starts after you have 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 scleroderma you have, or its severity.

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.

HINTS

- Keeping notes and lists of questions are important. Start a workbook: keep your lab work reports, medication lists, important phone numbers, reports of appointments, and lists of questions in one loose leaf notebook that you can add to or subtract from as necessary.
- Express your concerns to your physician; if he/she can't help you, ask to be referred to someone who can.
- Remember to take a friend or a tape recorder along.

Many people with scleroderma experience a smoother course. For example, you might have tests that all point to the same diagnosis and you also have a physician who knows what the diagnosis means and can either treat you or refer you to someone who can.

People who have smoother experiences often report that it was still a difficult time because they initially knew nothing about the disease. Patients say having a healthcare provider who listens and works with them as partners in their care makes it much easier to adjust.

THE EMOTIONS

DENIAL, ANGER AND DEPRESSION

Once testing has occurred and a diagnosis is made the next step is to determine what you want to do about it. Sometimes when people get upsetting news they feel disbelief and refuse to acknowledge that anything is seriously wrong. This can make people feel better for a short time, but the reality of the situation will eventually become undeniable.

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 and accept what has happened. Listen to your favorite music, watch videos that make you feel good, bask in the sun in a garden, or lie in a warm tub and think.

HINTS

- Think about your resources—people who care about you, your talents and abilities, available information 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 join a support group of the Scleroderma Foundation.
- Think about the possible consequences of not tending to yourself—increasing worry, pain, disability, and depression.

ANGER AND DEPRESSION

After you've had time to understand the implications of the diagnosis, you may get angry and depressed at the same time. This is the next phase of moving toward an acknowledgment that changes are occurring. This 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 typically do the following:

- Find and join support groups
- Seek out a physician who knows how to treat scleroderma
- Search libraries and the Internet for information they feel might be helpful

Depression can 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, directed at your loved ones or yourself. Your physician might also prescribe a medication that will help your energy level and even treat the physical pain.

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 might "cure" the disease. Some go 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.

ACCEPTANCE

So, how does a person come to accept scleroderma? There isn't any one way that patients reach that stage; some never do and some do so in part. Patients who cope well with their disease have these things in common:

- They have discovered the hope and strengths they have inside
- Have found people to help them along their way (friends, relatives, loved ones, healthcare providers, scleroderma support groups, counselors, or faith groups)
- Have learned to help others by getting involved in scleroderma organizations, educating their friends and the public and helping other patients through difficult times

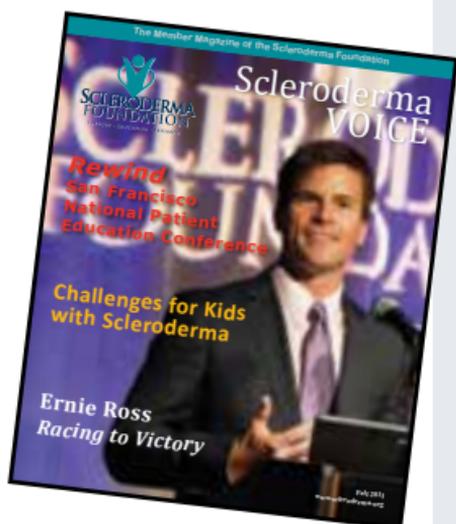
The most important underlying factor seems to be that patients who successfully cope with scleroderma have discovered that their lives are worth the fight.

Please note that this pamphlet is provided for educational purposes only. It is not intended to substitute for informed medical advice.

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

BECOME A MEMBER OF THE SCLERODERMA FOUNDATION

When you become a member of the Scleroderma Foundation, you support the organization's mission of support, education and research. Your donation helps pay for programs in each of those three areas, including:



- We budget at least \$1 million annually for research.
- Helping patients and their families cope with scleroderma through mutual support groups, physician referrals and the National Patient Education Conference.
- Promoting public education of the disease through publications, seminars, patient education events and awareness activities.

As a member of the Scleroderma Foundation, you will receive:

- Our quarterly magazine, the "Scleroderma VOICE." The magazine includes updates on the latest scleroderma research and treatments, positive and uplifting stories from patients living with the disease; and tips about how to manage living with scleroderma.
- Information and educational offerings from your local chapter.
- Discounted registration fees to the annual National Patient Education Conference.

Please consider joining the Scleroderma Foundation today. A membership form is attached on the reverse side of this panel.

To become a member of the Scleroderma Foundation, fill out this form, tear at perforation and send with your check or credit card information to:

Scleroderma Foundation
Attn: Donations
300 Rosewood Drive, Suite 105
Danvers, MA 01923

I would like to become a member and help support the Scleroderma Foundation's efforts to improve the lives of those with scleroderma, and to assist in the search for a cause and cure. Enclosed please find my check (or credit card information) in the amount of \$_____.

Donations of \$25 or more can be acknowledged as members (\$35 or more for international members).

- I am not interested in members benefits.
- However, I would like to make a contribution in the amount of \$_____.

Name: _____

Address: _____

City: _____

State/ZIP: _____

Country: _____

Telephone: _____

Email: _____

Credit Card: _____

Credit Card No.: _____

(Circle One:    )

Exp. Date: _____ CVV Code: _____

Name on Card: _____

OUR THREE-FOLD MISSION IS SUPPORT, EDUCATION AND RESEARCH

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

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

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



January 2019

A publication of
Scleroderma Foundation

300 Rosewood Drive, Suite 105, Danvers, MA 01923
800-722-HOPE (4673) www.scleroderma.org

 www.facebook.com/sclerodermaUS

 www.twitter.com/scleroderma

 www.youtube.com/sclerodermaUS