



## Coping with Scleroderma

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Chronic disease changes your whole life. Suddenly, you deal with new symptoms, medications, prescription refills, tests, and doctor's appointments. You change your daily routine. Your body and self-image change.

How can you cope with your new life with scleroderma? Here are some suggestions.

### THE BEGINNING

Scleroderma can present itself in different ways, so diagnosis is challenging. You may need multiple tests and doctor's appointments to eliminate other causes of your symptoms. It's important to work with a physician who has experience treating scleroderma. This can result in a quicker diagnosis and treatment. Contact the National Scleroderma Foundation or your local chapter for names of scleroderma doctors.

For you and your loved ones, waiting for answers is hard. You may feel anxiety because you anticipate the worst. Sleeplessness, irritability and distraction are common at first. You're more likely to mis-hear what your doctor says because you're worried. If you have aches and pain, anxiety can make them feel worse.

### Hints

- When you talk with your doctor, take notes or ask your family member or friend to join you and take notes. At the end of the appointment, go through your notes and ask questions. Use your notes to go over your diagnosis and treatments with your family.
- Share worries and fears with people you trust. This may help you reduce anxiety.
- Recognize that this is a difficult time for you. Find positive ways to ease stress and anxiety, and help you cope. Try relaxation techniques

like meditation or exercise. If you can, get away for a day or a weekend with someone you enjoy being with or alone.

- Don't drop all the fun activities in your life because you don't think you have the energy. Instead, find activities you enjoy that don't tax you too much.
- Delegate stressful or exerting tasks to others who offer to help.

### DIAGNOSIS

Diagnosis of scleroderma can happen in fits and starts. You may meet with doctors who disagree about your diagnosis, what form of scleroderma you have, or its severity or your prognosis. Some physicians may diagnose scleroderma, then tell you that it is untreatable, or that current treatments are all experimental. People with scleroderma have reported these discouraging, frustrating experiences. You are not alone in your frustration.

### Hints

- Keep detailed notes and lists of questions for your doctors. Start a spreadsheet or folder of lab work reports, medication lists, important phone numbers and appointment summaries.
- Express your concerns to your doctor. If they can't help you, ask to be referred to someone who can.

You may experience a smoother course during diagnosis. You may not have confusing test results. Your physician may understand scleroderma, and either treat you or refer you to someone who can. This may still be a difficult adjustment period for you. It helps if your healthcare provider listens to you and works with you to plan your care.

## EMOTIONS

Once you are diagnosed, the next step is to think about treatment and management of your disease. It's OK to feel anger or disbelief, or to deny that anything is seriously wrong. Accepting that you have scleroderma will help you move forward. Take a little time to adjust: listen to soothing music, spend some time in the sun in your garden, or take a leisurely walk.

### Hints

- Think about your resources: people who care about you, your talents and abilities, information sources to help you understand your diagnosis
- Learn more about your illness, and how you can live and function with it.
- Call your local National Scleroderma Foundation chapter or join a support group. Talk to others with scleroderma who are functioning well. They can help you adjust to life with this illness and suggest ways to cope.

### Anger and Depression

Once you accept your diagnosis, you may still feel angry and depressed. This is part of acknowledging changes occurring in your body and life. This isn't an easy phase for you or for people close to you. But it is necessary. Anger can energize you to take actions:

- Find and join a scleroderma support group
- Seek out a physician with experience in treating scleroderma
- Look for information about your disease and treatment options

Depression can slow you down. You may feel negative about everything. Depression can worsen physical symptoms like pain and loss of energy, and make you feel helpless.

You may wish to see a counselor or therapist with experience treating people with chronic disease. Talk with them about your anger, fear or grief instead of your loved ones or coworkers. Your physician may also prescribe medicine to treat fatigue and pain related to depression.

## Bargaining and Acceptance

Some people with scleroderma then take the step of bargaining with themselves or a higher power. They may pray, "God, if you'll only take this from me, I promise..." You may think you're willing to take medicine with uncomfortable side effects if only it might "cure" your disease. Some people seek out unproven treatments or health practitioners to "bargain" with the reality of their diagnosis.

How can you move past these phases and accept that you have scleroderma? People who say they cope well with this disease often say that they:

- Tap into hope and inner strength
- Seek help and support from friends, relatives, loved ones, healthcare providers, scleroderma support groups or faith groups
- Feel stronger by helping others, like getting involved in scleroderma advocacy and awareness activities

Celebrate that you are worth the fight—your life will continue to be enjoyable and valuable as you manage your scleroderma.

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