

Scleroderma Education Program

Chapter 5

Living with Scleroderma

Chapter Highlights

1. Scleroderma changes your life.
2. Increase your activity level.
3. How Scleroderma changes your sexuality.
4. Living with uncertainty.
5. Where to get help, support and information.

This fifth chapter usually takes about 15 minutes.

Scleroderma Changes Your Life, But You Still Have Some Control

You may have faced some big changes in your life with Scleroderma. For example, some people stop working or can't do things around the house like they used to. You definitely have experienced some smaller changes in your life with Scleroderma – you may spend more time thinking about your health, you may feel uncertain about your future, or you may be less social.

It's important for people who live with chronic illnesses like Scleroderma to feel more in control by taking charge of their illness. Having a sense of control and having positive things in your life can help you to cope better with your illness and have a better quality of life.

This chapter is about **taking back some control** over your day-to-day living. We'll be talking about the following:

1. **Getting into the routine of being physically active**
2. **Scleroderma and Sexuality**
3. **Living with Uncertainty**

Remember, your illness is just one part of your life. To really take care of yourself you need to balance the more difficult parts of your life with more positive things such as fun activities and exercise. These will help you have a more positive mental outlook which may help you cope better with your illness.

Try to Be Physically Active

Many people with chronic illnesses become less active over time. Sometimes this is caused by pain or stiffness, sometimes by fatigue, sometimes by depression. This also can happen to people with Scleroderma. Joints can become stiff or painful. The skin can be sensitive. The hands can be swollen or ulcers can cause pain.



Unfortunately, the less active you are, the more your body becomes weak, stiff and out of shape. This can make pain and fatigue even worse.

What can you do?

If you haven't already done so, talk to your physician about what types of activities you should avoid. Also ask him or her about exercise – even walking regularly. Ask whether she can recommend a regular flexibility and strengthening program for you.

Even if your doctor recommends against exercise, think about how you can spend more time out of bed and doing activities you enjoy such as playing with grandchildren, working on arts and crafts or visiting friends.

People often say they can't be active or exercise because they feel fatigued. This creates a vicious cycle. You can become fatigued because of a lack of activity and then not be active because of the fatigue. Trying hard to motivate yourself to exercise the next time you are tired may be the answer. You don't have to run a marathon, do an hour of aerobics or join a gym. Just going outside and walking around the block can help. Even stretching exercises or a good laugh with a friend can help you feel less tired.

Aim for an Active Lifestyle

One way to become more physically active is to set aside special time for exercising such as walking with a friend, taking a yoga class, or working in your garden. But don't forget about the value of just being more physically active throughout the day. Just doing your regular activities in a more active way can make an important difference.

Being more physical in everyday life can pay off.

- ? Make a goal of getting out of the house everyday. Spending too much time in bed will only make you feel more tired.
- ? Take a stroll after dinner instead of watching TV.
- ? If you can take the stairs up a flight instead of waiting for the elevator.
- ? Work in the garden or play with your grandchildren.

These types of activities can add up to health benefits. Even small amounts of daily activity can increase your fitness and improve your mood.

Develop an Exercise Program, with Your Doctor's OK

Before starting any exercise program, check with your doctor. She can tell you what level of activity is right for your Scleroderma.

Exercise Regularly

For many people, setting aside time to exercise is helpful. This should be done several times a week.

Develop a Good Program

Plan your exercise program so that it includes 3 things:

1. **Flexibility.** Do gentle stretching exercises to increase your flexibility. Flexibility

relates to how well the joints move comfortably through a normal range of motion. If you are not flexible, it can cause you pain, increase your risk of injury and make your muscles not work as well.

2. **Strength.** Muscles need to be exercised to keep their strength. Muscles weaken and shrink when they aren't active. The weaker your muscles get the less you feel like using them, the more inactive you tend to become and a vicious cycle develops.
3. **Endurance.** Endurance is your ability to keep up activity for a while. Endurance exercises will help your heart and lungs to stay strong enough to distribute oxygen-rich blood to the muscles.

Start Slowly

Warm-up, then more exercise: Plan to begin your fitness program with a flexibility and strengthening **warm-up** to get ready for more **intense exercise** later on. This will help, especially if:

- ? you haven't exercised regularly in some time,
- ? you have pain, stiffness, shortness of breath
- ? you have weakness that interferes with your regular activities

Warm-up only: Plan to limit your fitness program to **warm-up exercises only** if

- ? You have severe limitations
- ? Your doctor recommends against exercise
- ? You are just starting to exercise

What stops you from exercising?



I don't have enough time.

Everyone has 24 hours in a day. But everyone chooses to use that time differently. You may need to change your priorities. It doesn't really take that much time. Even 5 minutes a day is a good start and better than nothing. Also think about combining activities. You can ride an exercise bike while watching TV. You can spend time with your spouse while going for a walk.



I'm too tired.

Inactivity makes fatigue worse. You don't exercise because you're tired and you're tired because you don't exercise. Regular physical activity can help you feel more energetic. As you exercise you will learn the difference between feeling "out of shape" and feeling physically tired.




I'm too old.

You're never too old for some type of physical activity. No matter what your level of fitness is or you age there are ways to increase activity, energy and your sense of well-being.




I'm too sick.

It may be true that you are too sick for a strenuous or intense exercise program. You can still usually find some ways to be more active. Remember that you can exercise 1 minute at a time, several times a day. Improving your physical fitness can help you better cope with your illness.



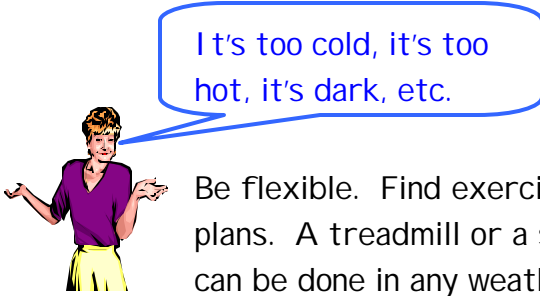
Exercise is boring

You can make it more interesting and fun. Exercise with a friend. Listen to music or watch TV while you exercise. Dance to music you like. Change your exercise activities. Take a different walking route.



Exercise is painful

You don't have to follow the old saying "No pain, no gain". There are significant health benefits from gentle, low-intensity activity. You may sweat or feel a bit short of breath. But if you are feeling more pain than before you started you are overdoing it or not exercising the right way.



It's too cold, it's too hot, it's dark, etc.

Be flexible. Find exercises that you enjoy outside, but also make back-up indoor plans. A treadmill or a stationery bike can be used at any time. Mall walking can be done in any weather.

Scleroderma and Sexuality

A chronic health problem should not re-define a person as an asexual being who has lost all interest in sex. A person facing and adapting to a chronic illness needs the love and comfort of a close, intimate relationship perhaps more than ever. But, this aspect of life is often not discussed.

One of the most difficult barriers to a satisfying sex life is the damage that illness does to your self-image and self-esteem. Many patients report that they feel unattractive as a result of Scleroderma. Changes in appearance, loss of hand function, weight loss or gain due to medications, and worries about pain, heart or lung function can interfere with your sexuality and view of yourself. This often causes some people to avoid sexual situations. They try "just not to think about it". Feelings about your appearance will be discussed more in the next chapter.

Women, Scleroderma and Sexuality

Physical problems for women with Scleroderma include:

- ? Fatigue,
- ? Vaginal dryness and,

- ? Physical discomfort during sex because of joint pain and decreased mobility.

Fatigue: Fatigue is a frequent problem in Scleroderma that can seriously alter your sexual life. See Chapter 4 for ideas on managing fatigue. Like any activity that is important to you, you may need to pace yourself and rest up to continue your sex life.

Vaginal dryness: Many patients with Scleroderma have dryness of mucous membranes. Symptoms include dry eyes and dry mouth. The vagina can also become dry, with less lubrication during arousal. This can make sex uncomfortable or even painful.

Vaginal lubricants that can be bought in most drugstores are very helpful. It's important to look at other causes of vaginal dryness before blaming Scleroderma. Menopause and the drop in female hormones that goes with it can also cause vaginal dryness. If this is the case, estrogen replacement in a pill form or in a vaginal cream can be helpful.

Physical discomfort:



Symptoms of reflux (such as heartburn) can be made worse by lying flat and by having the weight of a body on top. Some women find sex painful because they have trouble finding a comfortable position. Joints feel stiff and sore and don't move as easily as they used to.

A warm bath may help. Being open to trying new positions or activities are also important.

Men, Scleroderma and Sexuality

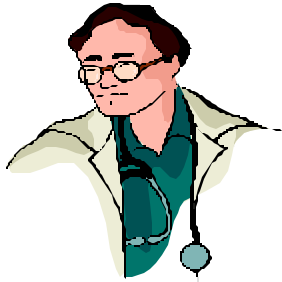
Erectile dysfunction: Erectile dysfunction, or the inability to get and maintain an erection, is the most common sexual complaint from men with Scleroderma. There are several possible causes for this.

The penis becomes erect when more blood is directed into it than is drained from it. The part of the nervous system that is responsible for this is called the parasympathetic nervous system. There is some evidence that sympathetic nervous system is damaged in Scleroderma.

Vascular problems are common in Scleroderma. Damage to the blood vessels is what causes Raynaud's phenomenon, finger ulcers and high blood pressure. The blood supply to the penis can

also be changed. Once damage to vessels or nerves happens it may not be possible to reverse it.

Problems with erections can also be caused by medication side effects. Calcium channel blockers are often used to treat Raynaud's phenomenon. These medications improve the circulation to the fingers but decrease circulation to the penis. Discuss the issue with your doctor before you stop taking medication.



Possible treatments

- ? Medications (e.g., Viagra) can improve the circulation and improve erectile dysfunction.
- ? Other treatments such as penile implants may also be helpful.

You may want to discuss the alternatives with your doctor or be referred to a urologist.

Enhancing your Sexuality

It is important to avoid any beliefs that there is only one "right way" to be sexually fulfilled. Here are some ways to help you improve sexual fulfillment.



- ? Try to set up a calm and relaxed atmosphere. Stressful or high emotional conversations may cause anxiety and are not helpful in having satisfying sexual activities.
- ? Find positions that are comfortable for both of you. There is no "right" way to have sex. Try to have open communication with your partner about what you like and want in the course of sexual activities.

? Avoid sexual activity when you feel really tired.

? Avoid sexual activity right after a big meal.

? Avoid drinking alcohol before sex.

? If you have trouble with sexual performance, check with your doctor to see if you are

taking medication which may be causing this. Changes in dosage or switching to another medication may help.

- ? If fatigue is the problem, try resting up and planning for sexual activity.
- ? Stay as active as possible. Good physical fitness enhances sexual performance.
- ? If you are having problems with arousal, or loss of interest in sex, it may be due to depression (see Chapter 9). If treatment for depression does not improve the problem, you may want to consider consulting a professional experienced in sexual counseling.

Living with Uncertainty

Being diagnosed with a rare, chronic incurable disease will likely be one of the most difficult challenges of your life. You are not in control. It is this loss of control that is at the heart of the challenge for most people. The day you are diagnosed changes your thoughts about yourself and the future. Suddenly your life goals are altered because of the uncertainty and unpredictability of living with Scleroderma.

People react in different ways to getting the diagnosis of Scleroderma.



- ? Some people want to get all the information they can.
 - ? Others are content to go to their appointments without much thought to their future.
 - ? Most people want to know what is going to happen and what they can expect from the disease.
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- ? Most people need time to gather the emotional strength to ask questions like, "Will I be able to continue working?", "Will I become disabled?", "Will I die from this?". Often these questions aren't asked because people are afraid of the answers.

Every story of Scleroderma is different

The questions you will ask about Scleroderma are simple and straightforward. Unfortunately, the answers are not. Scleroderma has such a variable course from one person to the next. This makes it very difficult to predict what will happen to you as an individual patient. The course varies from mild disease for some to severe disease for others. Sometimes people who start out with very active and progressive disease begin to slowly improve and end up doing well in the long run. Every story of Scleroderma is different. Living with this unpredictability and uncertainty can be every bit as tough as living with your symptoms. There is a future after the diagnosis. It simply may not be the one you had planned. It may be worse. In some ways it may be better.

It will take time to get used to the change

Remember that getting a diagnosis like Scleroderma changes how you think about yourself—your identity. Like any change—getting married, becoming a parent, retiring-- it will take time to get used to the change. Your family will also need time to adjust to the “new you”. They also are afraid of the unknown and what will happen. However, many patients with Scleroderma report that the illness made them reevaluate their lives and priorities. Some people find that the increased focus on friends and family is an unexpected positive side of the illness.

You can choose not to be a victim

There is a difference between being a victim suffering from an illness and being a person living with a disease. The word victim brings to mind being passive and helpless. On the other hand, the term *person living with...* brings to mind an individual who is influenced by an illness but not defined by it. It combines a sense of acceptance of the illness (because there isn't any other choice) with the idea that the person continues to be who they always have been. They aren't defined by Scleroderma. This is a hard goal to achieve but will help in coping with the unpredictable and uncertain nature of Scleroderma. Your family, your doctor, your priest, minister or rabbi, or a counselor can help you with this goal.

Where to get help

Scleroderma Foundation

89 Newbury Street, Suite 210

Danvers, MA 01923

800-722-4673 or 978-750-4499

e-mail: sclerofed@aol.com; <http://www.scleroderma.com>

The Scleroderma Foundation has local chapters and support groups throughout the United States. The foundation raises funds for research, publishes literature on Scleroderma, and holds public awareness campaigns.

Scleroderma Research Foundation

2320 Bath Street, Suite 315

Santa Barbara, CA 93105

805-563-9133 or 800-441-CURE

<http://www.scfcure.org>

This foundation also raises funds to support research.

Arthritis Foundation

National Office: 1314 Spring St. NW

Atlanta, GA 30309
404-872-7100 or 800-283-7800

The Arthritis Foundation has local chapters throughout the United States and has literature on all the connective tissue diseases, including Scleroderma. The Arthritis Foundation raises funds for research on all these diseases.

The following books are all available from the Scleroderma Foundation (address above).

Mark Flapan, Perspective on Living with Scleroderma. Scleroderma Federation, 1997.

E. Carwile LeRoy, M. D., Understanding and Managing Scleroderma. Scleroderma Federation, 1996.

Dana Lowvorn, Scleroderma: Surviving the Seventeen Year Itch. United Scleroderma Foundation, 1996.

Maureen D. Mayes, M. D., The Scleroderma Book: A Guide for Patients and Families. Oxford University Press, 1999.

Summary

Learning to live with Scleroderma can be a big challenge. There are many areas of your life that are changed by the disease. Finding ways to remain active and cope with uncertainty will lead you to feel better physically and emotionally.