

Scleroderma Education Program

Chapter 3

Pain and Fatigue

Chapter Highlights

1. I'm So Tired! -- Fatigue and Scleroderma.
-Learn to better manage your fatigue.
2. Everything hurts! Pain and Scleroderma
-Sources of pain
3. What can be done for pain in Scleroderma?
4. What makes your pain worse? What makes it better?

This third chapter usually takes about 15 minutes.

I'm so TIRED! -- Fatigue and Scleroderma



Many people feel tired.

Fatigue (feeling tired) is a common problem in the general population. It is also very common in Scleroderma. For many people with Scleroderma, doing their daily housework or putting in a full day at work is exhausting. By the end of the day there is barely enough energy left over for spending time with your family, for enjoying hobbies and activities, for exercising, or for sex.

Activities are more demanding when you have Scleroderma. The body is less capable of using energy reserved for everyday activities because some of this energy is used in the body's attempt to heal itself.

Some tiredness may not be noticed right away.

Fatigue often develops gradually in Scleroderma. You may not notice how tired you are until someone else points it out to you or you find you can't do many of your old activities.

It is wrong to think of fatigue as a personal weakness or a failing.

In our very driven society we think of fatigue as a sign of laziness or a lack of motivation to get things done. Sometimes people with Scleroderma feel bad about themselves because of their fatigue. They blame themselves for not fighting against their exhaustion. This just adds to the problem.

What's the source of your fatigue?

It is sometimes difficult to tell the difference between fatigue due to Scleroderma and that due to depression or hopelessness.

What can you do about fatigue?

Unfortunately, fatigue is hard to treat. There aren't medications that you can take that will return your old energy. But there are some things you can stop doing that might be making your fatigue worse.

✍ **Be realistic.**

Before you had Scleroderma, running a home and a full time job may not have been enough to make you tired. You may find now that balancing work and family leaves you exhausted. Even doing a couple of loads of laundry and making lunch can leave some patients very fatigued.

✍ **Know your limits and work within them.**

In this way, you can gradually increase them. You must be especially careful not to overdo it when you are beginning to feel good again. This can cause fatigue or more pain.

✍ **But be aware that TOO LITTLE activity can make fatigue worse.**

Being inactive can also make fatigue worse. A nap can help fatigue but staying in bed all day may make it worse. A physical activity program may help you feel more energized. Staying active and exercising will be discussed more in Chapter 5.

✍ **Think about your sleep habits.**

If you often feel fatigued you may want to consider your sleep habits. Not getting enough sleep or having poor quality sleep can add to your fatigue.

✍ **Improve your nutrition.**

Food is our basic source of energy. We can feel fatigued if the fuel we take in isn't top quality or in the right amount. Being overweight can add to fatigue for some people. Extra weight causes you to use more energy to do your daily tasks.

✍ **Remember that depression can cause fatigue.**

Depression and what you can do about it will be discussed in depth in Chapter 6.

Managing Your Fatigue

Figure out the Cause

If fatigue is a problem for you, the first job is to try to figure out the cause. It's important to remember that fatigue can be caused by and made worse by things other than Scleroderma. In order to have as much energy as possible, you need to change

other causes of your fatigue. Talk with your doctor about your fatigue. She may help you identify other causes and ways to best cope with it.

Think about your Diet

Improve the quality and quantity of your food if your fatigue is made worse by a poor diet. Too many empty calories in the form of junk food and alcohol will only make you feel more run down. Sometimes feeling bad causes a loss of appetite and weight loss. Make an effort to eat 3 well-balanced meals a day if you're skipping meals because you don't feel like eating.

Try to Get Some Exercise

People often say they don't exercise because they feel fatigued. This creates a vicious cycle. Fatigue gets worse because of a lack of exercise and people avoid exercise because of fatigue. Taking a short walk instead of lying down the next time you're feeling tired may actually help.

Everything Hurts!: Pain and Scleroderma

Pain, stiffness and achiness are common problems in Scleroderma. Almost all people with Scleroderma are familiar with pain due to Raynaud's or finger ulcerations. Many more experience joint, nerve, and muscle pain.

Sources of Pain in Scleroderma

We will be discussing more about different types of pain and what you can do for them later in the chapter. First, it's helpful to get background on what causes pain in Scleroderma.

Here are some of the common sources of pain in Scleroderma:

- ? Joint Stiffness Due to Fluid
- ? Arthritis
- ? Joint Contractures
- ? Tendons
- ? Nerves

Joint Stiffness

Stiffness can be caused by leaky blood vessels

Many Scleroderma patients have hand stiffness that is worse in the morning. This stiffness gets better as you move around and go through your day. The stiffness is caused by swelling.

Swelling is not just in the joints or knuckles of the hands. It may also occur in the whole finger and the back of the hand. The whole hand seems "puffy". It is impossible to make a tight fist. This is known as the *edematous phase of Scleroderma*. Edema means retaining fluid. This is not arthritis. Some patients have puffy fingers for years and never get severe skin thickening or contractures.

The puffiness is due to small blood vessels becoming leaky. The leakiness causes extra fluid to gather in the hands and fingers. It isn't usually improved with "water pills" or diuretics. This is because the problem isn't fluid retention but damaged blood vessels.

The swelling may last anywhere from weeks to years but it tends to get better on its own. It is often replaced by a more lasting phase of thickened or tightened skin that causes the fingers to curl down. This can be mild or severe.

What You Can Do

The swelling can be improved with motion during the day.

Stiffness can be caused by inflammation

Inflammation of the joints is another cause of joint stiffness. It may cause stiffness in the:

- ? hands
- ? wrists
- ? elbows
- ? shoulders
- ? knees
- ? ankles

There may or may not be noticeable swelling. This too causes stiffness in the morning or after being inactive. It tends to improve as you move around.

What You Can Do

The stiffness can be improved with motion during the day.

Arthritis

Osteoarthritis

Osteoarthritis is the most common type of arthritis. It affects almost everyone as they get older. Osteoarthritis causes morning stiffness that lasts less than 30 minutes. It often lasts less than 10 minutes.

Inflammatory arthritis

Inflammatory arthritis also causes morning stiffness but it lasts longer than 30 minutes, often lasting several hours. Inflammatory arthritis includes rheumatoid arthritis and the mildly inflammatory arthritis of Scleroderma.

What You Can Do

Arthritis can be treated with medications such as non-steroidal anti-inflammatory drugs (NSAIDs). Table 1 later in the chapter has a list of drugs used for arthritis. One of the potential side effects of these medicines is stomach irritation. This can be a problem for people who already are having GI

difficulties. Newer drugs called COX-2 Inhibitors have fewer GI side effects and only have to be taken once or twice a day.

The “arthritis” of Scleroderma

The “arthritis” of Scleroderma is different from the other types. It hurts and causes stiffness for long times without much swelling. Fibrosis of the capsule of the joint can happen and restrict motion of the finger or joint.

What You Can Do

Usual anti-inflammatory medications may not be as effective.

Joint Contractures

A contracture means a joint cannot be fully straightened out. Each joint has a normal range of motion. This means it can be flexed inward, extended outward, or rotated. Contracture of a joint means that the joint cannot be fully flexed, extended, or rotated. It has lost some of its range of motion.

In some people with Scleroderma the fingers tend to be flexed inward and the wrists do not move as freely. The elbows may not straighten out fully and the shoulder can lose motion. This causes the arms to lose some of their range of motion. This can also happen at the foot, ankle, knee and, rarely, the hip.

What You Can Do

Daily exercises can help you keep as much of your range of motion as possible.

Tendons

A tendon is a fibrous cord that attaches a muscle to the bone. Tendons are enclosed in a tendon sheath that contains a small amount of fluid. This gives it a smooth, gliding motion.

Tendonitis is a common problem in the general population. Tennis elbow is one example you may have heard of. People with Scleroderma get a type of tendonitis that is not usually seen in the general population called Tendon Rub. The term tendon rub describes a sound like two pieces of leather rubbing together. This happens when a tendon moves in an inflamed, rough tendon sheath. It happens most often at the elbows, the knees and the ankles. This condition is annoying, and sometimes crippling.

What You Can Do

Treatment includes applying heat, taking an NSAID medication or other anti-inflammatory. Sometimes analgesic pain medications are needed. Local steroid injections do not help.

Nerves

Carpal Tunnel Syndrome - Numbness and Tingling in the Hand

When there is pressure put on a nerve, it can become entrapped. This causes either pain or a tingling kind of numbness in the area that is supplied by the nerve. The most common kind of nerve entrapment in the general population and Scleroderma patients is Carpal Tunnel Syndrome.

The symptoms are numbness and tingling in the thumb, index and long fingers. It tends to be worse at night and can wake you up from sleep. Sometimes it can be hard to tell the difference between this type of pain and pain due to Raynaud's. However, Raynaud's tingling happens in response to cold exposure and carpal-tunnel tingling happens when there is no change in temperature.

What You Can Do

Wearing splints holds the hands and wrists in the best position to open the narrow tunnel. Cortisone injections are sometimes used to lower the inflammation. In more severe cases surgery is needed.

What Causes the Carpal Tunnel Syndrome of Scleroderma

One of the major nerves to the hands is the median nerve. The median nerve goes through a narrow tunnel called the carpal tunnel at the base of the wrist. This area can become narrowed by swelling. The swelling can be due to arthritis of the wrist, tendonitis or other causes. However, Scleroderma patients get Carpal Tunnel Syndrome due to the swelling from leaking blood vessels and buildup of scar tissue. This narrowing causes pain and numbness.

Other nerves can get trapped as well. For example, the ulner nerve in your elbow can get trapped due to the tightness of the skin. This causes pain down the forearm and into the little finger.

Trigeminal Neuralgia - Pain in the Face

Some people with Scleroderma develop a painful condition called trigeminal neuralgia. This is caused by inflammation of the nerves that provide sensation to the face. The nerve inflammation causes pain. The intensity of pain isn't constant. Sometimes it is sharp and other times it causes a pins-and-needle sensation.

What You Can Do

Trigeminal neuralgia sometimes responds to medication and sometimes gets better on its own. The nerve may need to be cut surgically if it doesn't get better and the pain is very bad. Unfortunately, this causes permanent facial numbness.

Other Nerve-Related Problems

Other nerves in the body can be affected by Scleroderma. Sometimes there will be weakness of a muscle leading to a foot drop. A foot drop is the inability to pick up the toes when walking. This can be caused by inflammation of a blood vessel that supplies nutrition to a nerve. This is called **vasculitis**. Vasculitis is very rare in Scleroderma. The nerve weakens and dies without the blood supply.

What You Can Do

The underlying problem is inflammation so people are treated with medications such as steroids or medications that suppress the immune system. NSAIDs are usually not strong enough to be helpful.

Managing your Pain

Your doctor will talk with you about medication that can help different painful problems related to Scleroderma. Table 1 lists the most commonly used medications. Medications don't always help and they rarely take 100% of the pain away. Other things that may be helpful are:

- ? Physical therapy
 - ? Acupuncture
 - ? Chiropractic care
 - ? Biofeedback
- } These will be discussed in Chapter 8.
- ? Tracking Your Pain Cycles to Better Control Them
 - ? Relaxation exercises
 - ? Massage
 - ? Heat
 - ? Meditation
 - ? Prayer
 - ? Talking with someone you love
 - ? Distracting yourself with fun activities

Table 1:

GOAL OF TREATMENT	MEDICATION	BASIC MECHANISM	PRINCIPAL SIDE EFFECTS
Reduce Joint and Tendon Pain	NSAIDS Flurbiprofen (Ansaid) Fenoprofen (Nalfon) Nabumetone (Relafen) Ibuprofen (Motrin, Advil, Nuprin)* Ketoprofen (Orudis) Piroxicam (Feldene) Naproxen (Naprosyn, Anaprox, Aleve)* Indomethacin (Indocin) Diclofenac-sodium (Voltaren) Sulindac (Clinoril) Tolmetin (Tolectin) Meclofenamate (Meclomen) Etodolac (Iodine) Ketorolac (Toradol) Oxaprozin (Daypro) Diclofenac (Voltaren, Cataflam)	Suppress inflammation	<ul style="list-style-type: none"> - GI upset - Stomach ulcers - Impaired Kidney function - Liver inflammation - Confusion
	COX 2 INHIBITORS Vioxx (rofecoxib) Celebrex (celecoxib) Mobic (meloxicam)	Suppress Inflammation	<ul style="list-style-type: none"> - Less severe GI upset - Headache
	ANALGESICS Acetaminophen (Tylenol)* Tramadol (Ultram)	Relieve pain	<ul style="list-style-type: none"> - No significant side effects observed - Nausea - Constipation - Drowsiness

	CORTICOSTEROIDS Prednisone (Deltasone, Cortan) Methylprednisolone (Medrol)	Suppress inflammation	<ul style="list-style-type: none"> - Fluid retention - GI irritation - May worsen vascular features
GOAL OF TREATMENT	MEDICATION	BASIC MECHANISM	PRINCIPAL SIDE EFFECTS
Reduce Joint and Tendon Pain	ANTIMETABOLITES Methotrxate	May suppress immune function	<ul style="list-style-type: none"> - Close monitoring necessary because of possible toxicity - Nausea, GI upset - Fatigue, dizziness - Reduced resistance to infection

*- Brand name drugs.

What happens when you have pain?

For many centuries, pain was thought to be due to a simple message from a part of the body – for example, your finger - to your brain. However, now we know that pain is a much more complicated signal. Sensory information comes mostly from the place where it hurts – e.g., your fingers. But the brain also can create its own idea that “my finger hurts.” Pain includes a physical feeling, your attention, and an emotion – it’s unpleasant! Pain requires each one of these:

1st: You sense a physical feeling in your finger. This feeling travels along nerves up to your brain. Many parts of your body - from the nerves in your finger through your spinal cord and up to your brain – sense the feeling.

2nd: To feel pain you must notice the sensation – you must pay attention to it.

3rd: The sensation you feel is experienced as unpleasant – this is the emotional part of pain.

Managing Long-Term Pain Needs a Special Approach

Short-term or Acute pain

Acute pain happens when you break your leg or have surgery – the pain is a signal that something is damaged and healing needs to occur. Lying down, protecting the hurt area, and using pain medications all help to heal the damage. When the pain goes away and the healing is complete, you can get on with your active life. An example of acute pain in Scleroderma is the pain from a finger ulcer.

Protecting the area and allowing the damage to heal is the priority.

Long-term or chronic pain

Long-term or chronic pain is very different from acute pain. In long-term pain, the pain usually does not signal acute damage that needs time and healing. The pain seems to take on a life of its own! Long-term pain happens in Scleroderma.

Lying down, protecting the hurt area, and even some medications can make things worse. Long-term pain requires a change in approach and challenges patients, their families, and their doctors.

A Special Approach: Learn about Your Pain Cycles to Better Control Them

1. Learn How to Track Changes - Even Small Ones

Most people find that long-term pain has cycles – pain changes during the day or across days. These cycles can be hard to identify. Sometimes only small changes may happen. But even a small change can be a big difference when you are the one with the pain!

2. Use a Scale of 0 to 10 to Describe Your Pain

Doctors and nurses usually use numbers to track changes in pain – you can also track your pain. The scale goes from 0 (no pain at all) to 10, which is used for the worst pain you can imagine ever having. Few people can live with pain of 10 all the time. You will also notice that a “10” may change as you get more experience with pain.

Some people don't like using numbers to describe pain. We prefer numbers because we know they are more sensitive than words (like none, mild, moderate) – often numbers catch small changes. Try using the numbers even though it might seem awkward at first:

After paying attention to it for one week, Yvonne noticed that her fingers hurt less in the morning when she was relaxed, after an afternoon of meetings (when she didn't have to write or type much), and in the evening when she watched television with her son.

What makes your pain BETTER?

1. _____
2. _____
3. _____

Be a Smart Consumer

Unfortunately, some pain management techniques are sold in expensive packages and are advertised as "cure-alls" for almost everything. Such expensive treatments are not necessary. Ask yourself the following questions to avoid unnecessary treatment, cost and disappointment.

1. Is the treatment offered by a reputable institution?
2. Is the cost reasonable?
3. Are claims or promises made for a cure? If so, look elsewhere.
4. Does it sound too good to be true? If so, it probably is.

Summary

Scleroderma can drain your energy and cause pain. Fatigue and pain are very real problems and not just “all in your head”. They keep you from doing the things you'd like to be doing. Worse, they can be misunderstood by people who don't have Scleroderma or other chronic illnesses. Sometimes loved ones misunderstand and think that you aren't interested in them, in activities or you just want to be alone. Medical treatment from your doctor can make these problems manageable. But you need to do your part. Changing your sleep habits, diet, activity level and trying out new pain management techniques can help improve your quality of life.