

# **Scleroderma Education Program**

## **Chapter 8**

### **Alternative/Complementary Therapies for Scleroderma**

### Chapter Highlights

1. What is alternative/complementary medicine?
2. How to be a smart consumer.
3. Picking a Complementary Medicine Provider
4. What are different types of complementary medicine?

This eighth chapter usually takes about 15 minutes.

## What is Alternative/Complementary Medicine?

American's interest in alternative medicine has grown quickly over the past 10 years.

Americans made about 425 million visits to alternative therapy providers in 1990.

More and more people are looking to alternative medicine to treat medical problems. For most people, alternative treatments are an addition to their usual medical care. This chapter will review some of the more common alternative therapies for Scleroderma.

This review is not an approval of any alternative therapy. Information is a key for feeling more in control. We'll first start by talking about alternative or complementary medicine and how to make smart choices about its use.

## What Shall We Call It: Alternative or Complementary?

### Treatment that is an ADDITION TO Conventional Medicine

There have been changes in the attitudes of patients and doctors to unconventional medicine. The term "alternative medicine" has been gradually falling out of favor but it is still widely used. Providers feel that the term wrongly reflects the idea of desperate and naive patients giving up promising mainstream treatments for unproven or "alternative" therapies offered by "quacks".

Generally, unconventional treatments in the United States are offered by licensed physicians or other credentialed health care providers. They tend to believe in the therapies they offer, are not charging excessive fees for treatment, and are treating patients of above-average education and income.

Most of these patients also choose to remain under the care of a mainstream physician. Patients who completely leave mainstream medicine

usually do so only because doctors have said there is nothing more they can do for them.

### **Complementary Medicine is a more accurate term**

More and more patients are finding that alternative medicine has a great deal to offer. This may be especially true for treating chronic conditions for which Western Medicine has little success. But, most patients do not see conventional and unconventional treatments as an either/or choice. Instead, they seek to make informed, personal choices about how to combine both. For this reason, "complementary" medicine has become the favored term for this growing field.

### **Complementary medicine includes a variety of treatments**

Some are ancient traditions used by millions of people over thousands of years (for example, acupuncture and Ayurveda--the traditional medicine of India). Most cultures have also developed herbal treatments based upon local medicinal plants.

Chiropractic and homeopathy are Western treatments that view disease processes much differently than mainstream medicine. Mind-body therapies like stress reduction techniques, biofeedback, and meditation focus on using the mind to help control symptoms in the body.

Complementary treatments often work best when used in combination with mainstream treatment. For example, chiropractic treatment or acupuncture can greatly reduce or remove the need for pain medicines.

## **How to be a Smart Consumer - Separate Hype from Help**

We've all read or seen ads on TV promising a "miracle" cure for an illness or disease. People suffering from pain and disease are always looking for news of "breakthroughs". Without a medical background it can be difficult to tell what is hype and what shows promise.

## Complementary Therapies Are Not Always Harmless

Remember that complementary therapies are not necessarily harmless. They vary in their potential for harm. If you choose to use complementary medicine, it is a good idea to consider using therapies that are basically health promoting such as diet changes and exercise.

### Spiritual/Mind-Body Approaches

#### **Promote Health**

The spiritual and mind-body approaches are health promoting or lifestyle therapies.

**Prayer, meditation, psychological therapy, imagery and support** can bring about an important change in the way you view illness and your own body. These treatments can also change the way pain is perceived. There is even some evidence they may change the course of the illness itself.

**Nutritional** approaches (if not carried to extremes) and **physical** approaches, **like massage, exercise and yoga**, are also generally health promoting.

## Drug/Herbal Approaches

### **Involve Risk**

On the other hand, some unconventional **drug, herbal and vitamin** approaches have a risk of overdose and other toxic reactions and can have dangerous interactions with prescription drugs.

**Extreme dietary** approaches can also lead to unhealthy weight loss and nutritional imbalances.

## The Research Evidence for Complementary Therapies

Generally, there is little hard research evidence for the effectiveness of complementary therapies. This does not mean that these approaches are not useful -- just that the question is still open. As these approaches are researched, they either tend to move into the mainstream, as is currently happening with a range of mind-body therapies (e.g., biofeedback) and acupuncture, or they are abandoned.

Cultural beliefs also play a role in deciding what is and what is not considered "alternative." A treatment is almost always considered "alternative" if it is not taught in medical schools, even if there is good research evidence for it working as there is for acupuncture, chiropractic and some herbal therapies.

## Choosing a Complementary Therapy

Most mainstream physicians aren't very helpful when it comes to guiding patients in the area of complementary medicine. At the same time, there is an explosion of media "hype" and commercials promoting "cures" for illnesses ranging from acne to cancer.

How does a person interested in trying complementary therapies make sense of it all?

## 1. Get a Medical Diagnosis



Always begin by getting a medical diagnosis for your condition from a doctor. Never chose an unproven complementary therapy over a promising mainstream treatment.

## 2. Educate Yourself



### **Find your own information**

Once you have a diagnosis and broad information on mainstream treatments for the condition, it is well worth your time to educate yourself about complementary medicine for your condition.

### **Go beyond what you "hear" from others**

It is very common for a patient to hear about a complementary therapy that has been helpful for someone else and to try to use that therapy for themselves. While it's useful to hear from people who have been helped by a given therapy, keep in mind that people who were not helped are less likely to talk about it. The person you heard about may be the one out of a hundred who actually got better from the treatment!

### **What made someone get better? Learn to look for the truth.**

Most medical conditions are self-limiting -- they get better eventually even without treatment. Other conditions, including some serious diseases like Scleroderma, have periods of getting better and worse regardless of treatment. In these cases knowing that someone improved when using an alternative remedy tells you nothing, because it could have happened even without the remedy.

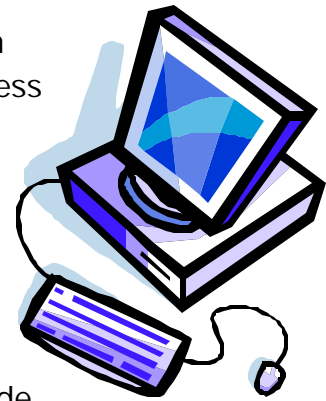
Also remember that people who use these therapies often use a number of them at once in addition to Western medicine. Therefore, it is often impossible to know exactly which therapy or combination of therapies actually helped.

### 3. Check Resources

#### Check the Internet

The Internet can be a valuable tool for finding information about different complementary therapies. If you have access to a computer:

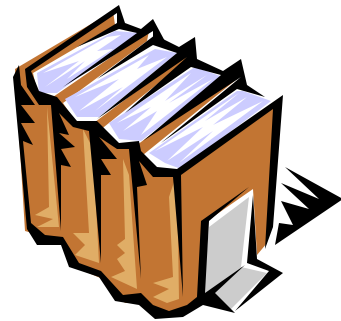
- ? Look at the Internet sites that provide information about Scleroderma, chronic pain, reflux or Raynaud's.
- ? But be aware that the web is full of unreliable information. Remember -- just because it appears on the web doesn't mean it's true!
- ? Look for medically oriented sites. They generally provide the most reliable information but they often give little information on complementary therapies.
- ? Also be aware that if a medically oriented site says a given complementary therapy is unproven, it means only that -- it's unproven. It isn't necessarily ineffective or harmful.
- ? Also look for Internet sites established by patient advocacy or support groups. They are often very good sources of information about complementary therapies.
- ? Consider joining a discussion or support group. They can give you a sense of which therapies people are finding helpful. Hearing from many people who have tried a certain therapy is a good sign that you should investigate that therapy more closely.
- ? Be suspicious of web sites that have been set up by promoters of a particular treatment, especially if a product line is being pushed.
- ? Be skeptical of any information, on the web or in print, which describes "miraculous" outcomes or "cures" for conditions that mainstream medicine considers incurable, or encourages patients to leave mainstream medicine for their alternative treatment.
- ? Look for references to research studies, when evaluating information on the web or in print. Be careful, because it is fairly common for whole books to be based on one small study. Look for references to different studies. It is the nature of research that studies contradict one another and that only a large body of research can give more definite answers. Studies in human subjects are much more important than studies in animals or in test tubes.





### Look for Resource Books

There are a number of useful resource books that can be helpful in understanding the field of complementary medicine and in choosing specific therapies. Ask the reference librarian at your local library for help.



### 4. Choose a Practitioner



Once you have settled on a therapy that you would like to try, the next step is finding a practitioner.

- ? **Treating yourself:** For some therapies, finding a practitioner may not be necessary. You can make modest changes in your diet or begin a moderate exercise regimen on your own.
- ? **Getting some help:** But if your condition is serious, the therapy is complex or if the lifestyle change is a major one, it's wise to seek out some help.

### Proceed with caution. A trained practitioner can help.

The advice of a properly trained practitioner is important in making decisions. It's tempting to simply go to the natural foods store and pick up some supplements or herbs, BUT:

- ? **Consider drug interactions.** Remember these can have serious interactions with drugs you may be taking. These "formulas" may also be very different to what a practitioner would give you since treatment should depend on the individual.

- ? **Question recommendations.** Never rely on "recommendations" by employees of health food stores -- their training in the use of herbs and supplements usually comes from sales representatives not from schools.

**When seeking a practitioner, here is what to do:**

- ? **Try to get a personal referral.** A personal referral is best, but it is also wise to talk to many people with the same condition until one name comes up two or three times.
- ? **Check with support groups.** Support groups and local branches of support organizations are good places to find this kind of information.
- ? **Ask another practitioner.** Referrals can also be obtained from another practitioner whose opinion you trust.
- ? **Check with a credentialing organization.** If these kinds of direct referrals are not available, the state or national credentialing organization for that discipline will often provide referrals.

**Before you actually begin the therapy, [tell your physician.](#)**

- ? **If your physician agrees**  
If the physician is knowledgeable and open minded, he or she may agree to work with you to coordinate care from different sources.
- ? **If your physician does not agree**  
Be prepared, however, for the possibility that you will not be supported in your decision to use complementary medicine.

If this happens, try to determine whether or not your doctor's concern is based upon an accurate understanding of the complementary therapy. If you have been able to locate research studies on the complementary therapy, show these to your doctor.

For some people, the support of their physician in this area is important enough that they will decide to seek out a doctor who will be supportive.

## Putting the Pieces Together May Be Up to You

Increasing numbers of open minded practitioners on both sides of the alternative-conventional medicine divide are coming to understand that the future of medicine clearly lies in some form of integrated healthcare, where traditional, mind-body and lifestyle approaches take a place alongside Western medicine. But until that time arrives, it is up to the patient to put these pieces together.

### Ask Your Practitioner Questions

Once you have located a candidate, don't be shy about interviewing him or her.

- ✍ Find out what their training is and how long they've been in practice.
- ✍ Ask if they are licensed and credentialed.
- ✍ Determine if they have worked with many people with your condition.
- ✍ Get a sense of their attitude concerning mainstream medicine and if they would be willing to work with your doctor.
- ✍ If for some reason you decide not to work with that practitioner, ask for a referral to another.

## Types of Complementary Medicines

The rest of this chapter will review different types of complementary medicine that you may hear about. If you are interested in learning more, go through the steps outlined in the first part of the chapter.

### Acupuncture

**GOAL:** Pain relief, relaxation, and relief of other ailments



Traditional Chinese medicine has practiced acupuncture for more than 2,500 years. Western scientists agree that acupuncture can work, but they don't know why it works.

Acupuncturists see the body as a system of energy pathways. They believe there are 14 meridians, or energy channels, running through the body. Along those meridians are

361 acupuncture points. Some practitioners also identify 48 more points, with additional energy channels along the scalp. Others identify a set of points in the ear.

It is believed that pain and illness happen when energy is interrupted along the meridians. Needles are used to stimulate points along meridians. It is thought that this stimulation balances the flow and restores health. There is some skepticism regarding the claims of acupuncture. However, respected medical journals have reported that these treatments may work well for certain patients with chronic back pain or painful joints. There is less proof for treating other ailments.

Cleanliness should always be a concern. The needles pierce the skin and only disposable needles should be used in acupuncture. Hepatitis has been transmitted in a few rare cases by improperly sterilized acupuncture needles. As with all types of treatments, beware if there are exaggerated

claims of "instant cures." All your questions should be answered clearly, and you should understand what will be done and what the treatment offers.

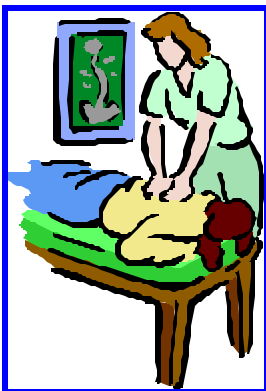
## Acupressure

**GOAL:** Pain relief, relaxation, and relief of other ailments.

This technique is similar to acupuncture, but it uses fingertip pressure rather than needles. Acupuncture actually grew out of acupressure. The pressure of fingertips on tender areas may help relieve pain. It is generally a safe technique that you can teach yourself. But patients with Scleroderma may have difficulty putting pressure on their fingertips and may need to rely on the help of others.

## Chiropractic

**GOAL:** Pain relief and relief of other ailments



A chiropractor treats diseases by manipulating the spine and other body structures. This is based on the belief that many diseases are caused by pressure, especially of the vertebrae on nerves.

Many people believe very strongly in this therapy because they get relief from pain by the manipulations. Again, check the credentials of anyone administering this therapy. Make sure they are certified, and as always, beware of claims of instant cures.

Doctors of Chiropractic medicine (D.C.) manipulate or adjust the spinal column with easy, manual thrusts to move the spinal vertebrae back to their normal positions. A chiropractor will sometimes also manipulate the joints of the neck, arms, and legs. Chiropractors also are concerned with a patient's overall well-being and recognize that many factors affect health, including stress, exercise, diet, rest, environment, and heredity.

## Massage Therapy

GOAL: Pain management and stress relief

Massage is an ancient form of pain management and stress relief. The Chinese practiced it more than 3,000 years ago and it has been used since that time. Massage is a way to relax muscles and feel refreshed. Muscular tension can make pain worse. The types of massage range from stroking, either lightly or firmly, to compression, which is kneading or squeezing. There is also percussion, which is using the hands to strike the muscles. Some physical therapists use electric vibrators to massage the muscles.

## Reflexology

GOAL: Pain relief and relaxation

This treatment is based on the belief that the muscles and organs of the body are affected by specific areas of the feet. When pressure is applied to these areas of the soles of the feet, other locations of the body are affected.

## Alexander Technique

GOAL: Stress relief

Poor posture, it is believed, is partly a reaction to stress, which can have a negative impact on the body. The Alexander technique retrains the body to eliminate unhealthy postures. The head is positioned so that it can properly balance and allow the neck muscles to relax. Bad postural habits are hard to change, so it takes time and practice to retrain your body.

## Flotation Therapy

**GOAL:** Partial relief of pain, reduce anxiety, treat addictive behaviors, and relaxation.

Flotation therapy involves floating in a pool filled with Epsom salts in a room with restricted light and sound. It can feel relaxing and therapeutic. The combination of relaxation, weightlessness, and the Epsom salts has been documented to relieve pain partly by stimulating endorphin production. Flotation tanks are used in clinics to treat persons with chronic pain, to reduce anxiety, and to treat addictive behaviors like cigarette smoking.

## TENS

**GOAL:** Relief of pain.

Transcutaneous electrical nerve stimulation (TENS) electrically stimulates the nerves to block the pain signals to the brain. It is performed by a professional and is usually done after other methods have been tried and failed. It seems to work best when the pain is in a specific area, such as the lower back. Electrodes are placed on the skin with some gel in the area to be treated. The electrical current is low level and produces a slight, tingling sensation.

## Visualization

**GOAL:** Eliminate or reduce pain.

Visualization has been shown to eliminate or reduce pain. Hypnotherapists use it to help patients come up with healing images. For example, they may have a patient imagine that the right nutrients are flowing through the blood to a particular part of the body that is diseased, thus healing it. Visualization can help pain become more tolerable or take attention away from it.

## Biofeedback

**GOAL:** Learn to control bodily functions such as blood pressure, and skin temperature.

Biofeedback gives you “feedback” about some part of your body that you usually aren't aware of. Biofeedback is being taught today by physicians, psychologists, and many types of therapists.

You may first learn different types of relaxation techniques. Sensitive monitors are attached to your body so that you can see immediately how your body is reacting to your efforts to raise your skin temperature, lower your blood pressure, lower your pulse rate, or relax your muscles.

Biofeedback reinforces your efforts to control your involuntary reflexes. The monitors let you know if your attempts to “tell your body” what to do are working. Eventually people are able to control these bodily processes without the use of the machine.

In Raynaud's phenomenon, getting feedback on temperature may help you to increase blood flow to your hands or feet. This may shorten, or even prevent a Raynaud's attack. By reducing stress and relaxing tight muscles you may reduce the level of pain and the need for medications.

## Meditation

**GOAL:** Relaxation and stress reduction.

Like visualization, this method can bring about relaxation and reduction of stress. It can slow the heart rate and breathing which reduce stress. Those who practice meditation regularly report decreased anxiety, depression, and tension, and increased concentration and resilience.





## Deep Breathing/Imagery

GOAL: Relaxation

Deep breathing is an effective way to relax. Try to find a time when you will not be disturbed. Find a comfortable, quiet place with as few distractions as possible.

1. Lie down, letting your body be as limp as possible, and close your eyes.
2. Begin breathing very deeply, slowly, and rhythmically.
3. Clear your mind of all your problems and distractions.

Try it for five or ten minutes at first and work up to twenty or thirty minutes.



Positive imagery is another variation of deep breathing. The idea is to put yourself in a quiet place with minimal disturbances, close your eyes, relax, and breathe deeply several times.

Then imagine that you are in a place where you are happy and relaxed such as the beach, the mountains, a boat in calm waters, or whatever place makes you happy. In your mind look carefully at the entire scene.

Imagine the smells, the temperature, the sounds, anything you can observe about this happy place.

## Self-Hypnosis

GOAL: Relaxation

Like other relaxation exercises, self-hypnosis focuses on the connection between the mind and the body. You may need to be taught this technique by a therapist. It is a way to put yourself into a state of deep relaxation. There are audiotapes available in most bookstores to help you with most of these types of deep relaxation. After you have practiced them for awhile you will not need the tape.

## Herbal/Nutritional Therapies

GOAL: Treatment of different ailments and promotion of good health.

Herbal therapies use individual or mixtures of herbs to treat illness or disease. An herb is a plant or plant part that produces and contains chemicals that act upon the body.

Special diet therapies, such as those proposed by Drs. Atkins, Ornish, Pritikin, and Weil, are believed to prevent and or control illness as well as promote health. Orthomolecular therapies try to treat disease with different concentrations of chemicals, such as, magnesium, melatonin, and very high doses of vitamins.

## Energy Therapies

GOAL: Improve blood circulation and immune function.

Energy therapies focus either on energy fields within the body (biofields) or those from other sources (electromagnetic fields).

### **Biofield Therapies**

Biofield therapies try to change the energy fields that surround and go through the human body. The existence of these biofields has not been

experimentally proven. Some forms of energy therapy alter biofields by applying pressure and/or manipulating the body by placing the hands in, or through, these fields. Qi gong, Reiki and Therapeutic Touch are types of biofield therapy.

**Qi gong** is a part of a traditional oriental medicine that combines movement, meditation, and regulation of breathing to enhance the flow of vital energy (qi) in the body. It is believed that improving this flow will improve blood circulation and immune function.

**Reiki**, the Japanese word representing Universal Life Energy, is based on the belief that by channeling spiritual energy through the practitioner the spirit is healed. The healed spirit then heals the physical body.

**Therapeutic Touch** is derived from the ancient technique of "laying-on of hands" and is based on the premise that it is the healing force of the therapist that affects the patient's recovery and that healing is promoted when the body's energies are in balance. By passing their hands over the patient, these healers identify energy imbalances.

### **Bioelectromagnetic-based therapies**

Bioelectromagnetic-based therapies involve the unconventional use of electromagnetic fields, such as pulsed fields, magnetic fields, or alternating current or direct current fields to treat disease or manage pain.

## Summary

More and more people are adding complementary medicine to traditional treatments. Many find these helpful, but an active role by the patient is needed. Get a medical diagnosis, do your research and never give up proven traditional therapies for unproven alternative ones. The greatest benefit will likely come from focusing on living a healthier lifestyle and feeling in greater control over your health.