



# Scleroderma Foundation Michigan Chapter's Guide for Family and Friends of Scleroderma Patients

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**No Known Cause.  
No Known CURE.  
Together, WE CAN Change That!  
It All Begins With You!**

## Someone I Love Just Told Me They Have Scleroderma.

### I Do Not Even Know What It Is!

Today may be the day you just learned that someone you love has scleroderma. You want to be empathetic and most of all, compassionate, but first you need to be knowledgeable. You need to find out what exactly your loved one has and how it will affect his or her life.



At the Scleroderma Foundation, we understand that learning someone you love has scleroderma can be overwhelming, frightening and very disruptive to your life.

The first thing we want you to know is that the Scleroderma Foundation is here for YOU! That is why we exist, to help you and your loved one along on this journey, to provide you with resources, emotional support and education.

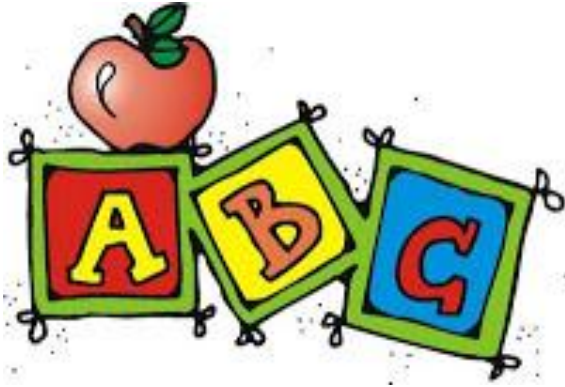
Right now you might be thinking you do not want or need these things and that is fine, but the day may come when you do and remember, on that day, we will be there.

Scleroderma does not define anyone, it is not who an individual is, it is simply a disease that someone has and this is very important that you as a loved one remember this moving forward.

The goal of this manual is help you to see that your loved one can manage their scleroderma and live a full life, filled with positive and incredible experiences. It is up to each individual what he or she chooses to do once a diagnosis is received, every day, every minute, and every second. This journey is in a patient's hands. With the right attitude, a patient can change the way he or she views a diagnosis and how they live with scleroderma. Your role during this journey will be to stand by your loved one and supply unconditional love and support.

The medical information in this manual is provided as an informational resource only, and is not to be used or relied on for any diagnostic or treatment purposes. Please consult your health care provider, or contact a licensed therapist if you have any specific questions regarding your feelings, concerns toward your loved one, or if you think you are having trouble coping.

The Scleroderma Foundation expressly disclaims responsibility, and shall have no liability, for any damages, loss, injury, or liability whatsoever suffered as a result of your reliance on the information contained in this manual. The Scleroderma Foundation does not endorse specifically any test, treatment, or procedure mentioned in this manual.



## Definition of Scleroderma. Let's Start With the Basics.

### Introduction

Scleroderma or systemic sclerosis, is a chronic, autoimmune connective tissue disease, generally classified as one of the autoimmune rheumatic diseases.

Autoimmune diseases, affect more than 50 million Americans, 30 million are woman. Autoimmune diseases are in the top ten leading causes of death in the United States.

The word “scleroderma” comes from the Greek word “sclera” meaning hard, and the Latin word “derma” meaning skin, Hardening of the skin is one of the most visible manifestations of the disease.<sup>1</sup>

The disease has been called “progressive systemic sclerosis,” but the use of that term has been discouraged since it has been found that scleroderma is not necessarily progressive. The disease may take several forms. There is much variability among patients.<sup>2</sup>

Scleroderma is a disease whose symptoms may be visible, as is the case when the skin is affected, or the symptoms may be invisible, as when internal organs are affected.<sup>3</sup>

Scleroderma is a condition in which the body's immune system attacks its own tissues. The normal role of the immune system is to provide protection from invaders such as viruses. In autoimmune disorders, this ability to distinguish foreign from self is compromised. As immune cells attack the body's own tissue, inflammation and damage result. <sup>4</sup>

### **What scleroderma is not**

- It is not contagious.
- It is not infectious
- It is not cancerous
- It is not malignant
- It is not usually hereditary<sup>5</sup>

Scleroderma can vary a great deal in terms of severity. For some it is a mild condition; for others it can be life threatening.<sup>6</sup>

Currently there are no medications to slow down the progression of scleroderma, or to help with the many symptoms that scleroderma patients face on a daily basis but research is being done and with your help can continue to be done. Scleroderma patients face a bright future with your continued support to the Scleroderma Foundation Michigan Chapter.

We know that there is no cure for scleroderma today but we are so thankful to the many excellent researchers who benefit from the funding that the Scleroderma Foundation provides. Your contributions every year go to assure that these researchers can continue to do this all important work. We look to the future and the day when we can say that scleroderma has a cure! Together, we know we can find a CURE to scleroderma!

### **How serious is scleroderma?**

We know that all chronic disease can be serious and life threatening. Since scleroderma symptoms can vary from one patient to another and the effects can range greatly, it is difficult to determine how scleroderma will affect your loved one. It is always best to seek the medical advice of a physician as to the servility of your loved one's scleroderma.

The best action is to seek treatment immediately upon learning of the diagnosis by a licensed and qualified physician. If you do not have the proper resources, the Michigan Chapter can assist you in locating physicians in your area for your loved one that are familiar with the treatment of scleroderma. These services are free

to you and your loved one and we encourage you to take advantage of contacting the Chapter as soon as you can to learn of other programs and services that we offer. Education and support are critical to both of you in being successful during this journey.

### **What Causes Scleroderma?**

The cause of scleroderma and systemic sclerosis is unknown. However, we do understand a great deal about the biological processes involved. In localized scleroderma, the underlying problem is the overproduction of collagen (scar tissue) in the involved areas of skin. In systemic sclerosis, there are three processes at work: blood vessel abnormalities, fibrosis (which is overproduction of collagen) and immune system dysfunction, or autoimmunity.<sup>7</sup>

In systemic sclerosis, the small blood vessels are damaged and become narrowed; this is what is responsible for Raynaud's phenomenon and the painful ulcers that can occur on the fingers. This vascular damage also occurs in the internal organs and is responsible for scleroderma renal crisis and PH. The small arteries are normally capable of constricting (narrowing) or dilating (relaxing) to adjust blood flow to the needs of the body. The vessels become overly sensitive to cold temperatures and other stimuli like emotional stress which results in Raynaud's attacks. <sup>8</sup>

What is known about the disease process in scleroderma is that it involves three features:

- an overproduction of collagen
- an autoimmune process
- blood vessel damage <sup>9</sup>

### **Overproduction of Collagen**

The thickened skin in scleroderma is caused by overproduction of collagen, which is the basic component of scar tissue. Abnormal accumulation of collagen is called fibrosis.

Collagen is a normal part of skin and many organs. However, in scleroderma, the

balance of collagen formation and collagen breakdown is altered so that too much collagen builds up. In systemic sclerosis, excess collagen causes fibrosis in the heart, lungs and the muscles that line the GI tract. <sup>10</sup>

### **Who Gets Scleroderma**

There are many clues that define susceptibility to develop scleroderma. A genetic basis for the disease has been suggested by the fact that systemic scleroderma is more common among patients whose family members have other autoimmune disease (such as lupus).

In rare cases systemic scleroderma runs in families, although for the vast majority of patients there is no other family member afflicted.

People of African descent and ethnic groups, including but not limited to those of Middle Eastern and Mediterranean descent, tend to experience more severe/aggressive disease.

Women are more likely to get scleroderma. Eighty percent of scleroderma patients are women.

Scleroderma is found in every age group from infants to the elderly but its onset is most frequent between 25 and 55.

Factors other than sex, such as race and ethnic background, may influence the risk of getting scleroderma, the age of onset and the pattern or severity of internal organ involvement. The reasons for this are not clear. Although scleroderma is not directly inherited, some scientists feel there is a slight predisposition to it in families with a history of rheumatic diseases. This suggests that there are some genes that can predispose toward getting scleroderma. In addition, some genes may influence the type and severity of this disease.

Environmental factors may trigger the disease in the susceptible host. For example, silica exposure has been associated with scleroderma and certain drugs can cause scleroderma like reactions. Localized scleroderma is more common in children, whereas systemic scleroderma is more common in adults. However, both can occur at any age. <sup>11</sup>

## **What types of scleroderma are there?**

There are two major classifications of scleroderma: localized scleroderma and systemic sclerosis (SSc).

### **Localized scleroderma**

Localized scleroderma is characterized by thickening of the skin from excessive collagen deposits. Collagen is a protein normally present in our skin that provides structural support. However, when too much collagen is made, the skin becomes stiff and hard.

The cause of localized scleroderma is unknown. It is not infectious. It is not hereditary, though rarely, similar problems may be present in relatives in some families. It is thought to be an autoimmune disease, but patient have no other known defect in the immune system. <sup>12</sup>

### **Types of localized scleroderma**

- **Morphea**
- **Generalized Morphea**
- **Linear Scleroderma**
- **En Coup de Sabre**

### **Morphea**

This is the most common form and presents as one or more patches of skin thickening with varying degrees of pigment changes. A violet-colored border may be seen when the lesions are still very active and extending. <sup>13</sup>

### **Generalized Morphea**

Generalized morphea has larger patches than morphea, often involving more of the body surface. Some patients with generalized morphea may also have a band of thickening on an arm or leg as seen in linear scleroderma. Patients may have a combination of different types of skin involvement. <sup>14</sup>

### **Linear Scleroderma**

Linear scleroderma shows a band or line of skin thickening. It may extend deep into the skin and even involve the underlying muscle. The bands of skin thickening are more common on the legs and arms and, when crossing the joints may prevent proper joint motion. <sup>15</sup>

### **En Coup de Sabre**

Linear scleroderma on the face or scalp may appear as a white line referred to as “en coup de sabre.” This is a French term meaning “cut from a sword,” because of the way it looks. En coup de sabre can be very destructive, as when it results in atrophy. Atrophy is the loss of tissue of the face which may involve the tongue and mouth. On the scalp it can cause some hair loss. <sup>16</sup>

### **My loved has morphea-now what?**

If your loved one has been diagnosis with scleroderma you may be wondering what will happen next. This is certainly a good question. Morphea can occur in age groups but tends to be more common with women.

Most patients develop only one or two patches of thickening that are frequently darker or lighter than the surrounding skin. You may also notice a yellow discoloration occurring. The changes to their skin can last for years even when there are improvements to their skin. In general, morphea tends to involve only the superficial layers of the skin. Patients with morphea do quite well but require follow up by a qualified physician. Rarely, patients will continue to develop new spots and essentially go on to generalized morphea. <sup>17</sup>

Generalized morphea also occurs in all age groups, and patients with this type are expected to have more extensive and prolonged periods when the disease is active. Generalized morphea represents more than just a greater number of morphea lesions, but rather a greater tendency for the condition to spread to more areas of the skin.

The areas of the skin thickening in generalized morphea tend to become confluent or joined together, occasionally involving most of the body surface and the involvement is generally greater than in morphea. It is always suggested that your loved one be followed by a qualified physician.



Depending on the degree of skin involvement, patients with generalized morphea may have severe disfigurement from the changes caused by extensive skin thickening. Eventually, as with morphea, softening of the skin is expected, but the skin discoloration may last for years or may be permanent. This is because the increased pigment persists in deeper portions of the skin and cannot be removed easily by bleaching agents.

Linear scleroderma is more common in children and adolescents. About eighty percent of patients diagnosed with linear scleroderma are younger than twenty.

The linear areas of skin thickening may extend to the underlying tissue and muscle in children, which may impair growth in an affected leg or arm. Extensive lesions of linear scleroderma, when present across joints can impair motion.

Many patients with linear scleroderma, especially if older at the age of onset of the disease, will have only minor skin changes and minimal thickening. Linear scleroderma remains active for two to five years, but can last longer in some cases. Sometimes patients develop recurrences after a period of seemingly inactive disease. This is more frequent in patients with “en coup de sabre.”<sup>18</sup>

### **Systemic Sclerosis**

While nearly all persons with systemic sclerosis have issues with their skin, particularly excessive scarring, and swollen, tight, or hard skin on their fingers, they also have organ system involvement. Many have tight, swollen or hard skin in other body areas as well, particularly the face and arms. The vascular and immune systems can also be involved.

#### **Types of systemic sclerosis**

- Diffuse cutaneous scleroderma
- Limited cutaneous scleroderma

#### **Diffuse cutaneous scleroderma**

This subgroup is characterized by thick or tight skin on the arms, above and below

the elbows, and frequently the legs, above and below the knees, with or without involvements of the face. The skin on the chest and abdomen is frequently tight, thick, or hard. The thickening often progresses rapidly and is very bothersome, leading to thickening all over the body in a short period of time. It is not uncommon for the thickening process in the skin in diffuse cutaneous scleroderma to continue for one to three years before the thickening process slows down and levels off. After one to two years of stability in the thickening usually begins to recede and the skin begins to thin or soften. <sup>18</sup>

### **Limited cutaneous scleroderma**

Patients with this form of the disease have thick, tight, or hard skin on areas below, but not above, the elbows and knees, with or without involvement of the face. Thickening of skin frequently develops gradually and is relatively unobtrusive. When measured repeatedly over time, the skin score in patients with limited cutaneous scleroderma is usually small and changes very little, even over many years.

Both subgroups are part of a more general disorder called systemic sclerosis and share the following:

- Raynaud's Phenomenon – sensitivity to cold in the fingers and toes and occurs in 90% of patients with SSc
- Heartburn and other esophagus problems
- Skin sores (primarily on fingers)
- Sores on wrists, elbows or ankles
- Abdominal grumblings and feeling full after eating only small amounts
- Bloating of the belly after eating
- Swelling of the abdomen particularly after eating
- Constipation or diarrhea
- 10-15 percent of patients may develop severe lung fibrosis leading to shortness of breathe

- 10-20 percent of patients may develop pulmonary hypertension

### **Features seen more in diffuse cutaneous systemic sclerosis**

- Kidney failure in about 15-20 percent of patients but there are excellent treatments that can preserve kidney function and prolong life to many, if treated early.
- Approximately 10 percent of patients will experience some level of heart involvement.
- Musculoskeletal aches and pains, decreased motion of some joints and declines in hand function that can result in disability are fairly frequent.

### **Typical organ involvement**

- Skin
- Lungs
- Kidneys
- Heart
- Gastrointestinal
- Musculoskeletal Pain

### **CREST Syndrome**

Limited scleroderma is sometimes called CREST syndrome. CREST stands for the initial letters of five common features:

- Calcinosis
- Raynaud Phenomenon
- Esophageal dysfunction
- Sclerodactyly
- 
- Telangiectasia <sup>19</sup>



## OK, What Do I Do Next?

### First Knowledge, Now Some Tips!

More than likely, you just finished reading all about scleroderma, who can get it, what it is, what it is not, and what the different forms are. You are now ready for the next step in helping your loved one. Question is, "What is the next step?"

Well, the next step is very easy. You become a support system to your loved one and someone that your loved one can depend on and grow to trust on good days and especially on those bad days when he or she is not feeling the best.

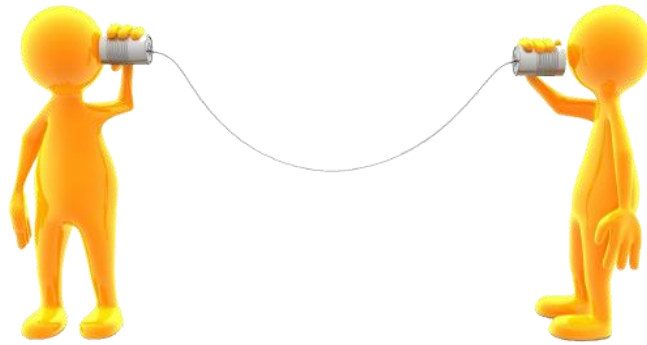
It may sound like common sense but for some, this may be a brand new role since your loved one may be the one who in your relationship who always took control of everything in your lives. Now, you suddenly may find yourself being the one who needs to step up and be strong when this is not your nature. Rest assured, you can do it, you have the ability and your loved one is in excellent hands! Together, you will make a great team!

#### **Here a few tips to help you and your loved one:**

- Remember that you and your loved one are a team and you do not need to take control over your loved one's life.
- You want to help your loved one, not take over their life or control them.
- Ask your loved one what you can do to help.
- Leave notes on the mirror for your loved one reminding them how special they are to you.



- Plan special evenings for your loved one, remembering simple is best and things that do not cost extra money can be fabulous choices. Try an inside picnic in front of the fireplace or in the basement. Combine that with her or his favorite board game for a fun evening filled with laughter and smiles.
- Fold that load of laundry without being asked so that the two of you can spend more time together just enjoying the things you like in life.
- When you see that the dishwasher needs to be unloaded, do not close it and pretend you did not see it, empty it for your loved one before being asked to or before your loved one has to do the task. Consider your loved one's face when he or she opens the dishwasher and it is already unloaded! Smiles are worth that two minutes it took you to complete that task.
- In the morning, offer to make the bed yourself so your loved one can enjoy a longer time in a hot shower. Making beds can be difficult for some scleroderma patients if their hands are compromised. While you never want to take tasks away from your loved one, it is always so nice to help them conserve their energy so they can enjoy the tasks that they loved to do.
- Park closer to the door at malls, grocery stores and even when appropriate, drop off your loved at the door of the doctor's office to save that extra couple steps. Exercise and movement is good for some scleroderma patients but for others, it can be a struggle to walk distances. Maintaining a routine and staying active can help scleroderma patients keep a positive outlook and avoid depression.



- Don't focus on the scleroderma every day; focus on your loved one. Scleroderma does not define your loved one and do not allow it to define your relationship. If your loved one desires to discuss scleroderma with you, that is a choice that they are making, if they prefer to not talk about scleroderma respect that choice and share the good and bad facts about your day with your loved one. It is important that you allow your loved one to stay active both physically and mentally.
- Be honest with your loved one at all times. If you have concern about something, compassionately voice it. Always think first before speaking, asking yourself, "If it were me, how would I react to someone telling me this?" This is an excellent way to gauge whether what you want to say is appropriate or not and if your loved one will appreciate what you are saying.
- Talk to your loved one about who needs to know about your loved one's diagnosis and who does not. Allow your love one to make the choice, not you. Never tell someone without your love one's approval and knowledge.
- Be available physically and emotionally. There will be days when your loved one just needs you to sit and listen and other days when your loved one requires nothing more than a shoulder to cry on. You will need to be able to be flexible as to the role you play in the life of your loved one.
- Keep the lines of communication open and flowing. Do not allow your feelings to bottle up or you may end up with feelings of resentment, anger and frustration. This can lead to you saying and doing things you will later regret.



## Resources for You and Your Loved One

Scleroderma Foundation Michigan Chapter (Southfield, MI)

[www.scleroderma.org/michigan](http://www.scleroderma.org/michigan)

Scleroderma Foundation (Danvers, MA)

[www.scleroderma.org](http://www.scleroderma.org)

International Scleroderma Network

[www.sclero.org](http://www.sclero.org)

University of Michigan Scleroderma Program

<http://www.med.umich.edu/scleroderma/>

National Institute of Arthritis & Musculoskeletal & Skin Diseases (NIAMS)

[www.niams.nih.gov](http://www.niams.nih.gov)

NeedyMeds

<http://www.scleroderma.org/site/News2?page=NewsArticle&id=7197>

Housing

[www.Seniorliving.org](http://www.Seniorliving.org)

The National Association of Hospital Hospitality Houses, Inc.

<http://www.nahhh.org/>

Families USE-The Voice for Health Care Consumers

<http://www.familiesusa.org/>

# HELP



## Resources Continued

Assisted Living

<http://www.nlm.nih.gov/medlineplus/assistedliving.html>

Home Care Services

<http://www.nlm.nih.gov/medlineplus/homecareservices.html>

Long Term Care Information

<http://longtermcare.gov/>

National Respite Care Locator

<http://archrespice.org/respitelocator>

Nursing Home Comparison

<http://www.medicare.gov/NursingHomeCompare/search.aspx?AspxAutoDetectCookieSupport=1>

Hospice Care

<http://www.nlm.nih.gov/medlineplus/hospicecare.html>

Hospital Compare

<http://www.medicare.gov/hospitalcompare/>

Programs that Help You Pay for Medical Expenses

<http://www.medicare.gov/Publications/Pubs/pdf/11445.pdf>

Benefits for People with Disabilities

<https://www.disability.gov/benefits>

Government Benefits-Check Your Eligibility

[http://www.benefits.gov/benefits/benefit-finder#benefits&qc=cat\\_1](http://www.benefits.gov/benefits/benefit-finder#benefits&qc=cat_1)





## Resources Continued

American Chronic Pain Association

[www.theacpa.org](http://www.theacpa.org)

Pain.Com

[www.pain.com](http://www.pain.com)

American Pain Foundation

[www.painfoundation.org](http://www.painfoundation.org)

Pain Management

[www.painmanagementweb.com](http://www.painmanagementweb.com)

American Pain Society

[www.ampainsoc.org](http://www.ampainsoc.org)

National Center for Alternative and Complementary Medicine

[www.nccam.nih.gov](http://www.nccam.nih.gov)

American Academy of Dermatology

[www.aad.org](http://www.aad.org)

American College of Rheumatology

[www.rheumatology.org](http://www.rheumatology.org)

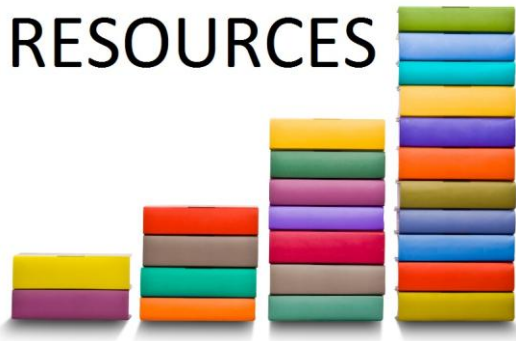
International Foundation for Functional Gastrointestinal Disorders

[www.iffgd.org](http://www.iffgd.org)

AboutGerd.org

[www.aboutgerd.org](http://www.aboutgerd.org)

# RESOURCES



## Resources Continued

American College of Gastroenterology  
[www.acg.gi.org/patients](http://www.acg.gi.org/patients)

Gastroparesis and Dymotilities Association  
[www.gpda.net](http://www.gpda.net)

Exercise Programs  
Arthritis Foundation  
[www.arthritis.org/conditions/AltTherapies/default.asp](http://www.arthritis.org/conditions/AltTherapies/default.asp)

Michigan Donated Dental Services  
[www.nfdh.org](http://www.nfdh.org)

Association of Community Psychiatrists  
[www.comm.psych.pitt.edu](http://www.comm.psych.pitt.edu)

American Academy of Family Physicians  
[www.aafp.org](http://www.aafp.org)

American Society of Pain Educators  
[www.paineducators.org](http://www.paineducators.org)

American Autoimmune Related Disease Association  
[www.aarda.org](http://www.aarda.org)



## Resources Continued

### RESOURCES

Clinical Trials for Nationwide Scleroderma Trials

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

Raynaud's Association

[www.raynauds.org](http://www.raynauds.org)

Sjogren's Syndrome Foundation

[www.sjogrens.org](http://www.sjogrens.org)

Digestive Disease National Coalition

[www.ddnc.org](http://www.ddnc.org)

Men's Health Network

[www.menshealthnetwork.org](http://www.menshealthnetwork.org)

Pulmonary Hypertension Association

[www.phassociation.org](http://www.phassociation.org)

National Organization of Rare Disorders

[www.rarediseases.org](http://www.rarediseases.org)

Disease Management Association of America

[www.dmaa.org](http://www.dmaa.org)

Association for Community Health Improvement

[www.communityhlth.org](http://www.communityhlth.org)



# LAUGHTER IS THE BEST MEDICINE

## Wrapping It All Up!

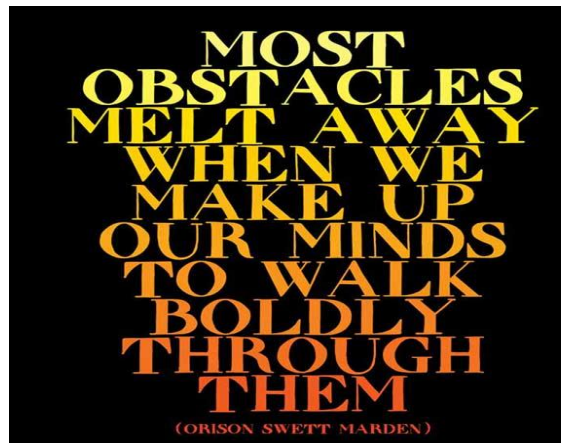
Laughter is truly the best medicine you can provide your loved one and yourself with. In fact, laughter is the medicine you will want to start every day off with and end every evening without certainly. By adopting this philosophy in life, one can be certain of several things:

1. Your outlook on life will be more positive.
2. Others around you will begin to see you as a positive person and desire to be around you more.
3. Your mental state will improve which in turn will help your overall physical health.



Having a chronic medical condition does not mean life has to stop for your loved one or for you. It simply means you need to make adaptations and changes to your life. Together with your loved one, these changes can be made lovingly and with compassion. In the end your relationship can be strengthened and enriched when you approach this with a positive attitude.

By accepting a life filled with a positive attitude and waking each day seeking to find even the smallest of gifts that life has to offer, you will soon find that not only will both your loved one and your mental health improve, but your physical well being will follow.



There will certainly be obstacles that you need to overcome, possibly these obstacles will be faced on a daily weekly or even monthly basis. These cannot be avoided. Look at these as challenges and do not fear them. You cannot control every situation for your loved one or for yourself. By controlling everything you will miss so many special moments because your energy will be going in directions it need not be. Mistakes will be made and this again is part of human nature. If you make a mistake, forgive yourself and move on, do not waste precious time worrying about things you cannot control.

Allow yourself to feel and experience life on a daily basis with your loved one. If one day your loved one is struggling with their scleroderma, not feeling well and is difficult to be around, do something extra special for he or she. Try to make your loved one's life more positive even on the days when fatigue and pain are present. Even running a hot bath, making a hot cup of tea or covering your loved one with a blanket can be those gestures that show your loved one you are there for them and that you understand this journey with scleroderma is difficult.

Remember to laugh EVERY day! Laughter is so critical to living a healthier life. You may ask, "What is possibly funny about watching my loved one being sick, being so tired and struggling with scleroderma?" Well, that is the part you will need to search for. You need to do that every day. That is the challenge you will present to yourself, to seek out the good and let go of the bad. You can journal this to remind yourself how far you have come in the weeks and months ahead. Have faith that together with your loved one, you will get through even the roughest of days with laughter, love and the bond that brought you together in a relationship in the first place.



Look for laughter in your routine, your tasks and your life. When your loved one can't do things he or she once did, help to find creative ways to assure that those tasks are not removed from your loved ones life. Having scleroderma does not mean your loved one cannot live a full and rich life, it only means that together you may need to find new ways to approach some tasks. If you cannot figure out how to help your loved one do something that is important to them, pick up the phone and call the Michigan Chapter and we can help find a solution. There are many scleroderma patients who have found excellent adaptations to doing the laundry, making the bed, cooking, cleaning the house, applying make-up, caring for children, gardening, and many other day to day activities. Just ask us, we can help you find a solution that will be tailored to your loved ones needs.

Find reasons to smile and to be thankful for. This healthy and positive attitude will keep your mind and spirit stronger and in turn you will be stronger emotionally.

The struggles that you and your loved one are facing today may not be the ones you face tomorrow. We never know what life will bring us. Everyone faces challenges and it is what we do with them that counts.

You have taken the first step toward being successful by educating yourself about scleroderma. Education you will find is critical to you accepting your loved one having a chronic illness. The more you know about scleroderma, the less fearful you will be about the future.

Also, getting involved with the Chapter can help empower you as you meet other scleroderma patients and their families. You will be taking control of scleroderma and what you do with it, rather than the other way around.



By staying home and not participating in the Chapter's educational experiences and events you are losing precious opportunities to not only educate yourself and your family on new medical treatments, clinical trials and other related scleroderma activities, but you will also be cheating you and your loved one out of chances to help others who have scleroderma. In volunteering and getting involved, you will soon feel as if you are being proactive and motivated. This will also help to keep you both from becoming depressed.

Being frustrated, angry, resentful and negative, takes so much energy and you won't have that much extra to give to these types of emotion when you are active and involved in helping the Chapter and others. You want to conserve all of your energy so that you can help your loved one. When you are happy you will feel more energy, more focused and more in control.

Think positively every day and strive to have a healthy and happy spirit for yourself and for your loved one!

The Scleroderma Foundation Michigan Chapter is here for you as you learn about scleroderma, seek treatment options for your loved one, and go through this journey along side your loved one. We want you to know you are not alone!

If you need someone to talk to, or resources, pick up the telephone and call our office. If we are not in the office, leave a message and someone will return your call.

Calling is the first step to knowing you need help and you have the desire to seek assistance. It means you want the best for your loved one and for you!



You can reach a caring professional at the Michigan Chapter by calling: (800) 716-6554 or at the National Office by calling: (978) 463-5843.

We Are Here For You!  
The Scleroderma Foundation Michigan Chapter



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7-8 Clements, Philip, Systemic Sclerosis: Diffuse and Limited. Scleroderma Foundation Brochure.

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