



Scleroderma Foundation Michigan Chapter's Guide for Scleroderma Patients

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

I Found Out I Have Scleroderma Now What Do I Do?



Today may be the day you just learned that you have scleroderma or you may have found out years ago.

No matter when you received your diagnosis, one thing is for sure, along with it came a flood of emotion.

At the Scleroderma Foundation, we understand that learning you have 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 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 here for you.

Scleroderma does not define you, it is not who you are, it is simply a disease that you have.

The goal of this manual is help you to see that you can manage your scleroderma and live a full life, filled with positive and incredible experiences. It is up to you what you do every day, every minute, every second. This journey is in your hands. With the right attitude, you can change the way you view your diagnosis and how you live with scleroderma.

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

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Feelings

Here are some feelings you may find yourself experiencing:



- Denial
- Fear/Anxiety
- Anger
- Resentment
- Depression
- Bargaining
- Acceptance

Denial

The first emotion you may feel when you learn you have scleroderma might be denial. It is common to hear at some point in your life that, “You are in denial.”

More than likely you heard this expression in terms of denial of a fact. In life when we do not like a situation, experience or we find our lives are in direct conflict with how we thought our life would be, it is human nature that one may deny their feelings.

Denying feelings can be caused by traditions, values, morals or the way you were raised. If you find yourself denying feelings about a specific situation you can reflect deeper into the reason you may be in denial with the assistance of a professional. Trained professionals can help you find the reason you are in denial and the best way you can move forward in life.

Being in denial is considered to be a defense mechanism and something humans often do to protect themselves from unpleasant situations or conflicts.

As a scleroderma patient you may find yourself denying the following:

- The fact that you have scleroderma, after all it may be the first time you even heard the word.
- Your doctor’s ability to properly diagnosis you, maybe he/she has the wrong diagnosis and you may have something else.



Fear/Anxiety

As a scleroderma patient, you may find yourself fearing or being anxious about many things; all the new information you just received can cause fear. If you had never heard the word scleroderma before and you went to the Internet and did a search, the information you located could have caused you to become anxious and overwhelmed. The unknowns are many and as a scleroderma patient you are wondering what type of care is available to you. It is very normal to have these feelings and concerns. There are many unknowns that have suddenly been placed into your life. In time, and with the help of a medical team, you will determine the answers to your questions. For now, your emotions of fear and anxiety are very real.

If you find yourself not being able to cope with your feelings of fear or anxiety, and they are interfering with your life, it is advisable that you seek medical advice from a professional.

Symptoms of fear:

- **Headaches**
- **Tension in muscles**
- **Stomach and intestinal disruption**
- **Being overly tired**
- **Inability to sleep**
- **Restlessness**
- **Heart palpitations**
- **Feeling dizzy**
- **Sweating**
- **Exhaustion**
- **Inability to focus or concentrate**
- **Having trouble problem solving**
- **Not being able to do normal daily tasks**
- **Body shaking**



What To Do When You Feel Anxious



- Join a support group for scleroderma patients.
- Get counseling from a licensed professional.
- Find someone you trust that you can talk to and share your feelings on a regular basis. Talking about how you feel is the first step to managing them in a healthy way.
- Exercise daily. Exercising can help your body relax and reduce the stress.
- Seek spiritual support from a church of your choice.
- Talk to your physician about your feelings and keep him/her aware of any changes in the way you feel.
- Use breathing techniques and mediation as a means of relaxing.
- Engage in hobbies you enjoy on a regular basis.
- Continue to maintain social interactions.

What Not To Do When You Feel Anxious

- Blame your loved one for the situation you are in or for your feelings.
- Yell or scream at your loved one or others because you are feeling anxious.
- Bottle up your feelings inside.
- Stop taking any physician prescribed medication without medical advice.

Anger

Finding out you have scleroderma, a chronic disease can be difficult and frustrating. Often you are not a trained professional and you do not know how to handle the emotion of anger. You may not even fully understand it as it appears in different situations. Here you were going along in your life and suddenly and unexpectedly scleroderma appeared and life changed.

Scleroderma may have forced you to leave your employment situation, you may no longer be able to enjoy activities as you did prior to having scleroderma and tasks that you use to do, you may now not be able to do.

All of these situations can cause feelings of anger to emerge. While anger is one of the most normal feelings, it can also be the hardest to experience.

Anger can be expressed toward a loved one, toward other family members and toward others. You may be questioning why you got scleroderma and someone else who took less care of themselves did not. Situations can cause anger to suddenly arise and without justification. When this occurs, you may find yourself becoming conflicted.

Often feelings of anger are irrational and not warranted but nonetheless very real. Some patients feel trapped, isolated and alone with their diagnosis. Others feel empowered, they are on a mission and they are going to remain in control of their medical course of action. They desire to become the best health care advocates for themselves. Everyone is an individual and your feelings will be different based on your given situation.

For scleroderma patients who do not properly express feelings of anger, issues can arise. It is advisable to seek medical treatment from a physician, therapist or counselor if you think you are not properly dealing with your anger. As a scleroderma patient, if you ever find yourself thinking about or acting out on feelings of doing harm to yourself, it is mandatory that you reach out for help. Call a hot line, a local crisis center, the Scleroderma Foundation Michigan Chapter (248) 595-8526 or even 911. You are never alone, and you should never feel that way. Seek help before it gets to the point where your anger controls you.

Remember, feelings of anger do not go away, so if you are simply burying them and denying them, in time they will surface. They will come up in other aspects of your life through resentment, guilt and even depression. This can affect your sleep patterns, eating habits, and in turn your health.

Ways to Avoid Anger As A Scleroderma Patient

- When someone offers to help you, accept the offer without feeling guilty.
- Stay organized, have a well-established daily plan.
- Continue to enjoy at least one of your hobbies on a regular basis.
- Take well deserved breaks away.
- Schedule in exercise time daily, even ten minutes a day will be beneficial to your overall health.
- Be honest with family members about your feelings and concerns.
- Allow family members and friends to share in the responsibilities of the household to conserve your energy.
- Continue to enjoy social situations as you are able to and maintain friendships.
- Weekly, do something special for yourself.
- Never forget the power of laughter and how it can help you to maintain a positive attitude.



Resentment



We are living in a world that is filled with so many obligations, work, family, employment, social media, entertainment and even hobbies can be demanding on our time. Now you are a scleroderma patient trying to struggle with finding the time to attend doctor appointments that end with “ologist” and juggle being a health care advocate for yourself and handle all of the other roles and responsibilities in your life. What the heck is a person to do?

Resentment comes into play easily and without notice as you struggle to find the right balance with your personal and medical needs. There will be days when you may feel like you are walking a tight rope, balancing between what they have to do and what they want to do. Time is just moving too quickly and the day suddenly does not hold enough hours to manage to get everything done.

The result can often be feelings of resentment. This is very normal and understanding given the situation. Juggling so many commitments can force these feelings to surface and if you are someone who has never felt this way before, it can be difficult to manage those feelings.

Scleroderma patients may start to resent their loved ones, other family members who are able to continue to live their lives untouched by scleroderma and illness, all the time while they tell you to remain optimistic. You in turn, wonder how this is possible that others are asking you to be optimistic.

Resentment can sometimes feel like feelings of anger or even guilt. If you have not experienced these feelings before you may be unsure why you are even feeling the way you are and you may try to dismiss your feelings as unimportant.

The best approach to take is to understand your feelings, accept them as being normal and try to manage them. If you find yourself acting out on them in unacceptable ways, seek the counselor and care of a licensed therapist or your physician. Seeking treatment is not a sign of weakness; rather it is a sign of strength and the desire to do the best for yourself and for those you love. Talking about your feelings openly and honestly can also be a healthy approach to managing them.

Guilt

Feelings of guilt can often accompany learning you have scleroderma. One day you wake up feeling positive about your life, and the next you feel less than happy about your future and the impact your illness may play on your spouse, caregiver, family and friends.

You may begin to feel resentment because you can no longer enjoy the things you use to while others around are able to. As those feelings start to linger, suddenly in comes the GUILT!

Just when you thought you were doing so well with handling the resentment, now you are feeling guilty about even that! Your emotions begin to feel as if you are on a roller coaster ride at your favorite amusement park. The only problem is, you want off, and you want to get off NOW!

The good news is you can stop feeling guilty with some tips and easy steps:

Ways to manage your guilt:

- Accept your feelings as they come and deal with them, even the ones that are difficult such as resentment and anger.
- Don't let feelings bottle up, talk about your feelings and emotions as you experience them.
- Allow yourself to have an "off day" once in a while without judging or trying to analyze everything you are feeling or doing.
- Know that sometimes the role of having a chronic illness is overwhelming and with that role will come a flood of emotions, some positive, some negative.



- Be honest with yourself about what you are feeling and do not try to be a hero. No one is asking you to do everything so accept help when it is offered, or ask for help when you need it.
- If you find yourself having a bad day, take a break, do something relaxing, something special for yourself and allow yourself to enjoy it!
- If you find yourself feeling guilty day after day, stop and try to determine where the guilt is coming from.
- Journal daily or even once a week to help you release your feelings and put them down on paper. This is also a great way to make a memory log for yourself later in life to reflect back on what an amazing job you really did in this medical journey.
- If you feel guilty because you had to miss your friend's birthday party due to not feeling well then simply pick up the phone and make plans with your friend to take her/him to a special lunch when you have the opportunity. If you are house bound because you are not feeling well, then invite your friend over for a lunch. You will find that friends understand and will be more than supportive.
- Know that nine out of ten times, it is solely our expectations that are not met in life, not those of other's thus the guilt we often feel is not real. Review your expectations of the situation and make sure they are truly realistic.
- Laugh every day, smile every hour and remember that whatever challenge you are facing, it will pass!



Grief

As a scleroderma patient you can experience grief. Since having a chronic illness can place so many extra demands on you, along with those demands will come many emotions.

In the beginning when you first learn you have scleroderma, you may grieve the loss of your previous life, the freedoms you have lost or even the control over your life that you had prior to finding out about the diagnosis. Suddenly you are making medical and health decisions you never thought you would have to make. You do not have time to enjoy the things you enjoyed in life. It is normal to experience grief and loss of these elements of your life.

As a scleroderma patient you may be going along with a routine and then suddenly experience grief when you least expect it. This is also very normal and can be caused by the realization that your health condition is worsening, that you may not ever get better or you perceive your role in your family is changing and this fact frightens you. To grieve all of this loss is normal and understandable.

These feelings of grief will come and if appropriately dealt with will leave just as quickly as they appeared.

Here are some tips to help you manage your feelings of grief:

- Join a support group (www.scleroderma.org/michigan)
- Take the time to identify and determine specifically what you are grieving and address the loss.
- Discuss your feelings with someone close to you.
- Seek professional help if your feelings of grief do not subside over time or become overwhelming and prohibit you from living a well balanced life, eating, sleeping or enjoying hobbies you like to do in your free time.
- Exercise daily in some form, even chair yoga, Tai Chi or stress relief breathing techniques can be helpful in reducing grief.

- Do not isolate yourself or stay home alone. Get out and enjoy social situations. Staying active will help to keep you in a positive frame of mind.
- Establish a routine so you do not have lapses in the day when you are just bored. It is during these times that grief can become overwhelming and depression can set in.
- Make appointments, arrange outings with friends and make sure that you are engaging with others and doing something daily.
- Know that there are no time lines for how long you will grieve, everyone is different. A good guide is that if your grief is stopping you from enjoying life, you want to seek professional assistance from a medical professional. The amount of time it will take to significantly grieve will depend how many changes have been made to your life because of your scleroderma. If you have had a history of depression, it may take longer.



Acceptance

Acceptance, what an amazing word! Except for many scleroderma patients, it can be like climbing up a very large mountain to get to this point. Patients must travel through so many other emotions that often once they come to acceptance, they are not sure they are even there!

Acceptance can be a peaceful place or somewhere you have arrived at because you are too tired to fight all the other emotions and you simply want to find comfort. However you have found your way to this emotion, welcome!

Acceptance means you have learned to weather the other emotions. You are finding balance and you are ready to tackle the obstacles ahead of you. It does not mean you like all of this, it just means you are doing your very best to cope. Be proud of yourself, pat yourself on the back, look at yourself in the mirror every morning and remind yourself just how incredible you are. Someone needs to, and why shouldn't it be you?

Ways to find acceptance:

- Let go of what you cannot control. Stop trying to do everything yourself, ask for help, accept help when it is offered and don't try to be more than you can be.
- Look for the good in situations rather than always seeing the bad. Every situation has good and bad in it. Since it is just as easy to find the bad as it is to see the good, why not spend the small amount of time you have in life looking for good things to focus on.
- Surround yourself with positive people. Positive people will help you feel good about yourself and thus you will feel less anger, less frustration and less resentment.
- Make sure you are caring for your own needs both physically and emotionally.

- Find a good support system early on and maintain that relationship on a regular basis.
- Don't judge yourself or your actions so harshly, reflect daily on even the smallest of tasks that turned out favorably. Journal daily so you can keep track of the triumphs and the challenges that come.
- Determine a reward system for yourself and regularly treat yourself to something special that you enjoy, possibly a special dinner out, an extra hour of reading, going to the gym even though there is laundry piled up or picking up a pizza one evening a week instead of cooking. Small rewards will add up and serve to remind you of just how incredible you truly are!
- Write yourself a thank you note and place it on your mirror or somewhere you will see every morning when you get up and every evening when you go to sleep. This will also serve as a reminder of what a great job you are doing.
- Set daily goals and if you are unable to accomplish them, forgive yourself!



Tips on How to Cope with Feelings

1. Accept your feelings as they come.
2. Understand that you may suddenly have very strong reactions to situations.
3. Find a good support system in your life, a friend, a church, a support group, someone who will be there to listen to you when you need to vent.
4. Realize that sometimes your feelings may not be positive and accept this.
5. As someone with a chronic illness you may find yourself being fearful of the future, situations that you cannot control and the unknown. Know that this is normal!
6. There will be times when you may feel anxiety about your health, you may doubt your medical options and you may even question whether you are doing enough for yourself. Know this is normal!
7. There will be days when you may feel frustrated because you do not feel well, you are tired or you lack energy. You may also feel this same emotion when you see relatives living their lives more carefree as you did before getting scleroderma. Know this is normal!
8. Sometimes as a scleroderma patient, you may feel angry. Anger can be directed toward your loved one, toward the situation you have suddenly been placed in, or in others you encounter. Often people with a chronic illness feel that they are alone and that there are so many unknowns. This can also cause people to feel anger. These are all normal feelings!
9. Enjoy the good times and focus less on the bad ones. If you find yourself always thinking negatively, work hard to find the positive aspects that surround your life. They are there, just keep looking! Some days it may be a challenge to locate them, but there will be small gifts you will find along this journey if you open your mind and heart to your illness you will find it comes with some surprises!
10. Love yourself enough to forgive yourself for not being perfect! Your illness does not have a manual that the doctor gave you. You are not trained and no one asked you if you wanted to become a scleroderma patient. All of these changes in your life can be difficult and just know that you will not make all the right decisions. Be willing to ask for help, seek resources and again, love yourself unconditionally!

Taking a Break from Being a Patient

As a scleroderma patient it becomes too easy to allow the disease to control one's life. It is so critical that you remember to take frequent breaks away from your illness, not allowing it to take control of your life or giving it permission to define who you are.



Getting Away From You Illness Tips:

- Stop worrying about having a perfectly clean home and enjoy spending more time caring for your own needs.
- Ask a trustworthy family member, friend or home healthcare aide to come on a regular basis to care for your needs.
- Take a vacation without feeling guilty.
- Make the most of every day and plan fun things into every day in an effort to keep a positive attitude.
- Schedule spa days for yourself.
- Go to a swim class.
- Take a chair yoga class.
- Have your hair done.
- Try a new make-up.
- Go shopping and pick out a new outfit.
- Go to a comedy club and remember how to laugh!
- Volunteer, this will help keep your mind on other things.
- Enjoy long weekends with family and friends.
- Start your own group with a hobby you enjoy.
- Spend 30 seconds every day dancing when no one else is watching!
- Journal – remember to include the things you are thankful for daily.
- Do not allow yourself to go to bed at night without spending at least five minutes a day laughing.

I Can Do Everything!



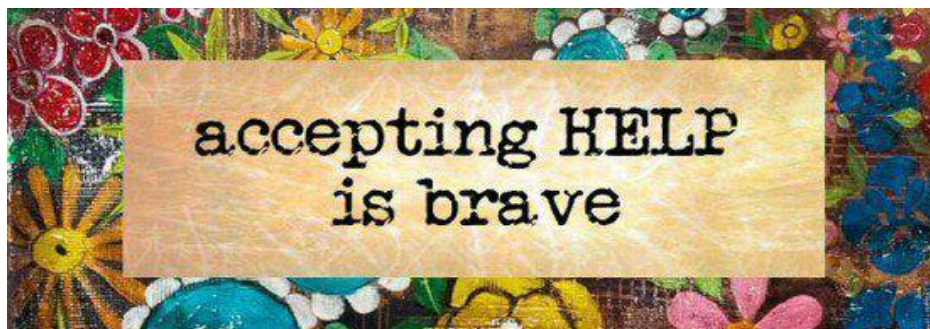
So many patients who have a chronic illness think they can do everything. It is a great way to maintain control over something in one's life, since you can't control your health. You begin to think you can tend to the housework, manage the financial responsibilities, cook, and even be a health care advocate to yourself. You shut out everyone around you who wants to help or offer assistance. For some patients, they believe this is all they can control so they refuse to allow anyone to help them with anything. The problem is, it becomes difficult as your health issues become more demanding and by not allowing others to help, and you are only hurting yourself.

Asking for help and accepting the help of others is actually a very smart and wise decision. As a patient, you will need to wear so many hats that when the opportunity appears for you to share some of the roles you have, it is advisable that you take it.

Here is a short list of some of the responsibilities you can seek assistance with:

- Ask a family member or friend to help with the grocery shopping.
- Allow others to assist with lawn care and yard maintenance.
- Assign a family member or trustworthy friend banking tasks.

- Hire a high school or college student to come weekly to clean the house. This can be a less expensive alternative to hiring a cleaning service.
- Make an arrangement with a neighbor to have them take out your trash and recyclables weekly.
- Call a local college and ask if a student in the nursing program would be interested in coming over daily for an hour or two to assist you with additional tasks.
- Request that family members prepare one meal a week for your family in an effort to assist you in having more to do the things you love.
- When appropriate, alternate who takes you to your medical appointments so this task will become a necessary task and a social one also for you.
- Accept offers from family, friends and neighbors when they offer help of time, services or emotional support. If you say no, let them know it is only a no for today and that you will need their help another day. Allowing others to provide help is not a sign of weakness, rather it is a sign of strength and courage. Know you cannot deal with a chronic illness effectively without emotional and physical support of others.





Am I Depressed? What Are The Signs?

As an individual with a chronic illness, the demands of tending to your own health needs, possibly working outside of the home, caring for a family and household responsibilities can often lead one to become depressed and overwhelmed.

This list shows some signs and symptoms of depression and feelings of being overwhelmed that you may begin to notice. If you are noticing these signs and symptoms, it is advisable that you seek medical and professional treatment.

- Feeling of being sad all the time
- Inability to sleep or sleeping too much
- Stomach and GI Issues
- Chronic headaches
- Lack of empathy for loved one, situations or self
- Sudden weight gain or loss
- Chronic illness, viral or bacterial
- Frequent fighting and arguing with friends, family members and co-workers
- Tardiness for appointments, work schedules or scheduled tasks
- Continued frustration and the inability to manage it
- Unrealistic anger and inability to properly direct anger
- Trouble with maintaining relationships
- Frustration and inability to communicate in constructive manners
- Exhausted and lacking energy
- Feelings of doom and despair
- Always viewing situations with negativity and limited senses
- Stop enjoying social situations
- Wanting to stay home and not do anything
- Viewing your situation as hopeless, forced or never changing
- Inability to laugh, smile or enjoy your life
- Change in eating habits. Overeating or not wanting to eat

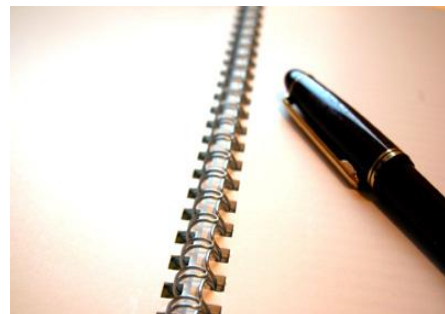


How Can I Prevent and Manage Depression?

As an individual with a chronic illness, it is important that you manage your feelings. Here is a list of ways in which you can help to manage depression and feelings of being overwhelmed. You need to take good care of yourself in order to manage your scleroderma.

- Be willing to ask for help from family and friends.
- Learn to accept help when it is offered. If the help is not something you can use today, consider what else the person could do for you to make your situation more manageable. Do not be afraid to ask someone if they are willing to do something else for you. Chances are if they were willing to offer their time to do one thing, they will be more than happy to do something else for you and your loved one.
- Do not miss any of your medical appointments or scheduled medical testing appointments. Your health is important and even if you do not like the treatment, you still need to be seen.
- Do your best to eat nutritionally. If you cannot eat then drink, ask your physician if a nutritionally balanced liquid meal replacement supplement is available for you to use.
- Get 6 to 8 hours of sleep daily.

- When appropriate, take a few moments to just lie down or sit in a chair and rest. This break can serve to relax and rest your mind, body and spirit.
- Maintain a doctor approved exercise regimen. Scleroderma patients are able to do many different type of exercise. Ask your physician what the best type of exercise regimen is for you.
- Stay properly hydrated, drink 6 to 8 glasses of water. Keeping your body hydrated will help to keep it healthy and in turn will keep you healthy.
- Journal and write daily inspirational notes to yourself about your progress in your scleroderma journey. On the days you are experiencing obstacles, journal your feelings and how you can problem solve the situation. Reward yourself for making it through a difficult day by doing something special for yourself. Be sure to include the things you are thankful for every day.
- Set routines that are attainable and realistic. Routines can help you stay organized. When you are forced to go off of your schedule be flexible and know that you will return to the schedule soon.
- Allow yourself to go on a vacation so you can relax and enjoy the time away.
- Maintain contact with friends and continue to go out in social situations. This will help to keep you from feeling isolated.





Learning to Adapt Your Life

As a scleroderma patient you will find that you may struggle to do some of the things you use to do prior to getting scleroderma. At first, your instinct may be to just give up, stop doing those things and avoid certain situations completely. This is a normal reaction to the changes that you are facing but the good news, is have options!

Just because you have scleroderma does not mean you can no longer cook, clean your own home, dress yourself, enjoy your favorite hobbies or do the same things you did before you received your diagnosis. What this all means is you need to learn to determine what adaptations you need to make so you can still do those things.

Adapting is part of everyone's life and something we all have to do whether we have scleroderma or not. For a scleroderma patient, the challenge becomes how to make those adaptations. That is where the Scleroderma Foundation Michigan Chapter can become a great resource for you! We are here to help you as you are wading through these new waters. We can partner you up with another scleroderma patient who will help to be a resource for you as you try to learn the best way to make the adaptations to your daily life. If you are someone who is shy by nature and it is not easy for you to seek out help, don't worry, just pick up the phone and call the Chapter, the rest will be done for you and within days you will be connected to a new support system. By talking to another scleroderma patient, you can learn so much and after all, why do this on your own? You do not have to go through this experience trying to make all these decisions without the emotional and educational support that you need. That is why the Scleroderma Foundation Michigan Chapter exists, for you! We want to make your life easier, and helping you to stay active and continuing to enjoy your life with family and friends is our primary goal. Call us today to learn more about how

you can be connected to another scleroderma patient. It will be a decision that will help you not only today but for many tomorrows.

You can reach someone at the Michigan Chapter by calling the office at (800) 716-6554 or by sending an e-mail to MIchapter@scleroderma.org.

Another good way to seek out support and to learn about adaptive ways is to attend a support group meeting. These state wide meetings are attended by other scleroderma patients and patients with overlapping related autoimmune conditions who are experiencing similar things as you are in their lives. You can learn from each other and grow in that knowledge. Support groups are not a depressing place, they are a place where speakers come and patients gain knowledge. We all know that education is so powerful and important.

Don't stop living just because you have been told you have scleroderma. Keep active, keep smiling, and keep laughing! Believe in yourself and do not give up. You can do whatever you set your mind on; it just sometimes will take some creativity as to how you do those things.

Also remember that you will want to conserve your energy so that you can still enjoy your favorite things in life, your hobbies and being with family and friends. Take breaks if needed and do not feel bad about resting when you need to. If your body is telling you it is tired, listen to it and do not push yourself too far. When you push beyond your limits, you can do more harm than good.

Scheduling around your health is important and knowing what your body is telling you is also valuable information to have. Listen to the clues your body gives off and do not ignore them, they just might be asking you to slow down or rest. If you pay attention to those cues and follow them, you will have more time for your favorite things in life.



Resources for Scleroderma Patients

Scleroderma Foundation Michigan Chapter (Southfield, MI)

www.scleroderma.org/michigan

Scleroderma Foundation (Danvers, MA)

www.scleroderma.org

International Scleroderma Network

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

NeedyMeds

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

Housing

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



Resources Continued

American Chronic Pain Association

www.theacpa.org

Pain.Com

www.pain.com

American Pain Foundation

www.painfoundation.org

Pain Management

www.painmanagementweb.com

American Pain Society

www.ampainsoc.org

National Center for Alternative and Complementary Medicine

www.nccam.nih.gov

American Academy of Dermatology

www.aad.org

American College of Rheumatology

www.rheumatology.org

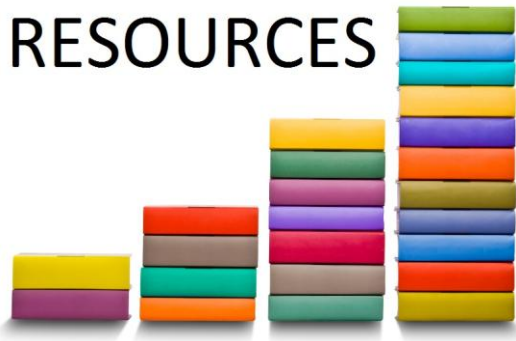
International Foundation for Functional Gastrointestinal Disorders

www.iffgd.org

AboutGerd.org

www.aboutgerd.org

RESOURCES



Resources Continued

American College of Gastroenterology
www.acg.gi.org/patients

Gastroparesis and Dymotilities Association
www.gpda.net

Exercise Programs
Arthritis Foundation
www.arthritis.org/conditions/AltTherapies/default.asp

Michigan Donated Dental Services
www.nfdh.org

Association of Community Psychiatrists
www.comm.psych.pitt.edu

American Academy of Family Physicians
www.aafp.org

American Society of Pain Educators
www.paineducators.org

American Autoimmune Related Disease Association
www.aarda.org



Resources Continued

RESOURCES

Clinical Trials for Nationwide Scleroderma Trials

www.clinicaltrials.gov

Raynaud's Association

www.raynauds.org

Sjogren's Syndrome Foundation

www.sjogrens.org

Digestive Disease National Coalition

www.ddnc.org

Men's Health Network

www.menshealthnetwork.org

Pulmonary Hypertension Association

www.phassociation.org

National Organization of Rare Disorders

www.rarediseases.org

Disease Management Association of America

www.dmaa.org

Association for Community Health Improvement

www.communityhlth.org

Final Thoughts



Maya Angelou was quoted as saying, “I can be changed by what happens to me, but I refuse to be reduced by it.” This is the resilient type of attitude that individuals with a chronic medical condition such as scleroderma need to embrace. 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 your mental health improve, but your physical well being will follow.

There will certainly be obstacles that you will need to overcome, possibly you will be faced with them daily, weekly or even monthly. These cannot be avoided. Look at these as challenges and do not fear them. You cannot control the situation you have been placed into nor should you. By controlling everything you will miss so many special moments because your energy will be going in directions it need not be.

Allow yourself to feel and experience life on a daily basis. If one day you are finding it difficult to live with scleroderma, know that tomorrow is a new day. Go to bed, forgiving yourself and wake up the next day celebrating the fact that you have a new day filled with new possibilities.

Remember to laugh EVERY day! Laughter is so critical to living a healthier life. You may ask, “what is possibly funny about sickness, all of this upheaval and all of the changes my life is facing?” 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.

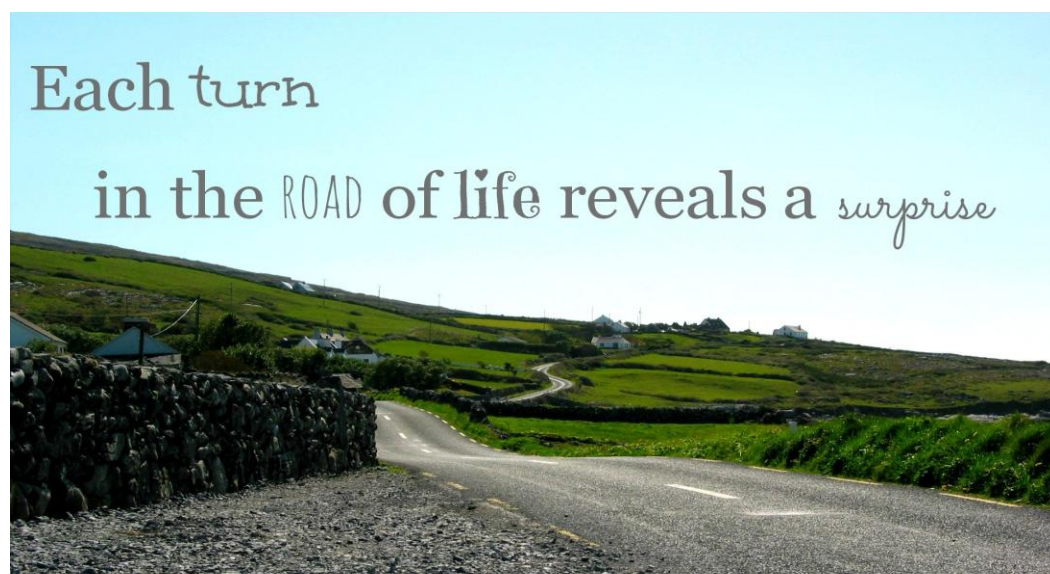
Look for laughter in your routine, your tasks and your life. Find reasons to smile and to be thankful for. This healthy and positive attitude will keep your mind and spirit stronger and in turn you will be stronger emotionally.

Life is a long journey and what you are facing today is only part of that incredible experience. Embrace this experience because truly you do not know what it will hold for you, who you will meet along the way or the lives you will change because of the courage you show.

Make a pact with yourself to learn everything you can about scleroderma. Education, you will find, is critical to you accepting that you have a chronic illness.

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 the disease 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 yourself 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 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. 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!

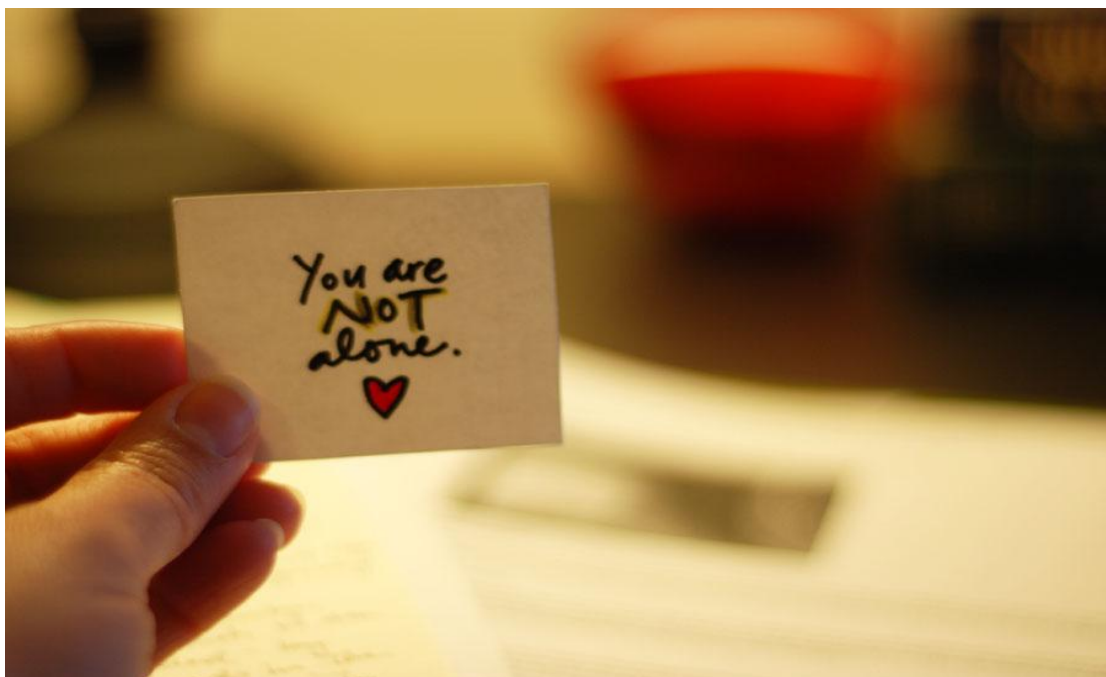
The Scleroderma Foundation Michigan Chapter is here for you as you learn about scleroderma, seek treatment, and go through this journey in your life. We want you to know you are not alone!

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 yourself.

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





Inspirational Quotes

“Turn your wounds into wisdom.”

Oprah

“Not everything that is faced can be changed, but nothing can be changed until it is faced.”

James A. Baldwin

Today is your day! Your mountain is waiting. So, get on your way.”

Dr. Seuss

“We have two options, medically & emotionally: give up, or fight like hell.”

Lance Armstrong

“One of the things I learned the hard way was that it doesn't pay to get discouraged.”

Lucille Ball

“You can't put a limit on anything. The more you dream, the farther you get.”

Michael Phelps

Although the world is full of suffering, it is full also of the overcoming of it.”

Helen Keller

“Attitude is a little thing that makes a big difference.”

Sir Winston Churchill

Inspirational Quotes

You were given
THIS LIFE
because you're
strong enough
to live it.

“Do what you can, with what you have, where you are.”

Theodore Roosevelt

“Don't wait for extraordinary opportunities. Seize common occasions and make them great.”

Orison Swett Marden

“It is the trouble that never comes that causes the loss of sleep.”

Chas. Austin Bates

“I never think of the future, it comes soon enough”

Albert Einstein

“Life is 10% what happens to me and 90% of how I react to it.”

John Maxwell

“I am not a product of my circumstances. I am a product of my decisions.”

Stephen Covey

<http://www.inspirational-quotes.info/inspirational-quotes-1.html>
<http://www.forbes.com/sites/kevinkruse/2013/05/28/inspirational-quotes/>