

Scleroderma Education Program

Chapter 6

Psychological Impact of Scleroderma

Chapter Highlights

1. Depression: Managing Intense Negative Feelings
2. What can be done about Depression.
3. Body Image: Dealing with Changes in Your Appearance
4. Scleroderma and the People in your Life.
5. So my spouse has Scleroderma.

This sixth chapter usually takes about 15 minutes.

Scleroderma and Your Relationships, Feelings and Emotions

This manual has gone over a number of ways that Scleroderma changes your health. We've discussed different organ systems that can be damaged by Scleroderma. We've also discussed many of the ways you may need to do things differently now that you have Scleroderma.

But, Scleroderma does not just affect your body. It also affects your mind. Living with a chronic, incurable condition takes its toll on your psychological health. Living with Scleroderma can have a negative influence on how you feel about yourself and your relationships. Like everything else we've covered, learning more about problems and the ways they can be managed can reduce the stress you feel from Scleroderma.

This chapter will talk about three areas that are commonly changed for people with Scleroderma:

- ? Mood - depression,
- ? body image,
- ? social relationships.

Depression: Managing Intense Negative Feelings

Negative feelings – anger, worry, and sadness – are a normal part of every day life. They make us human just like positive feelings do. They provide information. They are “natural.” But...negative feelings can be a problem if they:

- ? **Are intense**
- ? **Last too long**
- ? **Get you into trouble with others**
- ? **Change how others see you**
- ? **Get in the way of your personal goals**
- ? **Feel out of control**

For many people with Scleroderma, **depression and worry** are a problem. **Anger** can also be a problem. You can understand a feeling better if you find a word to describe it. Use this list when trying to describe a negative feeling you are having:

Negative Feelings			
Afraid	Frantic	Lonely	Terrified
Angry	Frustrated	Miserable	Threatened
Anxious	Furious	Misunderstood	Tired
Ashamed	Guilty	Muddled	Touchy
Awkward	Hateful	Needy	Trapped
Bitter	Helpless	Outraged	Troubled
Bored	Hopeless	Overwhelmed	Unappreciated
Confused	Horrified	Panicky	Unattractive
Defeated	Hostile	Pessimistic	Uncertain
Dejected	Humiliated	Phony	Uncomfortable
Dependent	Hurt	Prejudiced	Uneasy
Depressed	Ignored	Pressured	Used
Despairing	Impatient	Provoked	Useless
Desperate	Inadequate	Regretful	Uptight
Devastated	Incompetent	Rejected	Victimized
Disappointed	Indecisive	Remorseful	Violated
Discouraged	Inferior	Resentful	Vulnerable
Distrustful	Inhibited	Self-conscious	Weary
Embarrassed	Insecure	Shy	Wishy-washy
Exasperated	Irritated	Sorry	Worn-out
Fearful	Isolated	Stubborn	Worried
Foolish	Jealous	Stupid	

(from Bourne, E. J. (1995) *The Anxiety and Phobia Workbook*. New Harbinger Publications, Oakland, CA)

Depression can be a problem for people with chronic illnesses. Depression can be a scary word. Some people describe it as “having the blues” or “feeling down”. Whatever you call it, it often happens when people are ill. Unfortunately, it can make it harder to live with Scleroderma.

Sometimes it is not easy to recognize when you are depressed. Recognizing when you are becoming depressed and then catching yourself before you fall into a deep depression is even harder. Just as there are many degrees of pain, there are many degrees of depression. The next section discusses clinical depression. This is a mood disorder. However, many people will have some of these symptoms without a full disorder. Even if you have only a few of these symptoms the tips for better managing your mood should help.

What are the signs of depression?

The following signs of depression are listed separately. But, they often happen in combination. Some of the signs may also relate to your illness. This makes depression hard to recognize in people with chronic illnesses. People often do not recognize when they are depressed or do not wish to admit to themselves that they are actually depressed.

Learning to recognize the signs of depression is the first step in learning how to manage it.

Loss of interest in friends or activities

Not wanting to talk with anyone, work on hobbies, or to answer the phone or door bell. Isolating yourself is a sign of depression.

Difficulty sleeping

Changes in sleep patterns, interrupted sleep or sleeping more than usual are signs of depression. Often, depressed people can go to sleep easily but wake up and can't fall back asleep.

Changes in eating habits	This change may range from a loss of interest in food to unusually unpredictable eating or eating much more than usual.
Unplanned weight change.	This can either be a gain or a loss of more than 10 pounds in a short period of time.
Less interest in personal care and grooming.	Skipping baths. Wearing the same clothes. Not taking care of your hair or stopping shaving.
A general feeling of unhappiness.	In depression this happens every day for at least 2 weeks.
Loss of interest in sex.	This problem can also be due to medication side effects so it is important to talk with your doctor. More information on Scleroderma and Sexuality is in Chapter 5.
Low self-image.	Feeling worthless, feeling bad about yourself, or feeling like you deserve to be punished may happen with depression
Frequent arguments.	A tendency to be grumpy, grouchy or blowing up easily over minor things that never bothered you before can happen when you are depressed.
Loss of energy.	Feeling tired all the time can be a sign of depression. This is also a common symptom of Scleroderma and should be talked about with your doctor.
Inability to make decisions.	Depression can lead to feeling confused and an inability to concentrate. Every day decisions, like what to wear, can be hard to make.
Suicidal thoughts.	If your unhappiness has led you to think about hurting or killing yourself TALK

WITH YOUR DOCTOR RIGHT AWAY.
Your safety is of utmost importance.
These feelings will pass and you will feel better. Get help and don't let a tragedy happen to you and your loved ones.

Feelings That Can Lead to Depression

While these are the signs of depression, there are a number of feelings that can lead to depression in patients with Scleroderma. These include:

1. **Fear, anxiety or uncertainty about the future.**

These feelings can be due to worries about finances, the disease process or your family. Constant worry about these can lead to depression if they are not addressed by you and those involved. You and your family can worry less about these issues if you confront them early on.

2. **Frustration.**

You may find yourself thinking, "I just can't do what I want", "I feel so helpless", "I used to be able to do this by myself", or "No one understands me". Feelings like this can leave you feeling more alone the longer you hold on to them.

3. **Loss of control over your life.**

Feeling that you are losing control can make you lose faith in yourself and your abilities. Feeling that you have lost control can happen when you have to rely on medications, having to see a doctor on a regular basis or have to count on others to help you do things you used to do yourself.

Depression Can Be Managed

Having a chronic illness can be very stressful and scary and it's not unusual for people with Scleroderma to become depressed. But Scleroderma doesn't have to lead to depression. And remember that depression can be managed. In fact, there are a dozen things listed below you can do to change the situation. But if you are depressed, you may not feel like making the effort to do them. Force yourself or get someone to help you into action. Find someone to talk with. Depression feeds on depression so it is important to break the cycle.

12 Things to BREAK the Cycle

1
If you feel like hurting yourself or someone else, **CALL** your mental health center, doctor, suicide prevention center, a friend, spiritual counselor, senior center or just dial 9-1-1.

Do not delay. Do it now. Often, just talking with an understanding person or health professional will be enough to help you through this mood.

2
Be aware of tranquilizers and other medications.

Medications such as Valium, Librium, codeine, Vicodin, or sleep medication can make depression worse. Your depression may be a drug side effect. **Check with your doctor or pharmacist** if you are not sure what you are taking or are uncertain if what you're feeling could be a side effect. **Always check with the doctor that prescribed a medication before stopping it.** There may be important reasons for continuing its use or there may be **withdrawal symptoms** if you don't stop taking it in a gradual way.

3
Don't drink alcohol in order to feel better.

Alcohol is also a downer. There is no way to escape depression unless you stop adding negative influences to your brain. For most people, one or two drinks in the evening are not a problem. But even a small amount of alcohol may make you feel worse if you are depressed.

4
Continue your daily activities.



Get dressed every day, make your bed, get out of the house, go shopping, plan and cook meals. Force yourself to do these things even if you feel like spending the day in bed.

5
Visit with friends



Call them on the phone, plan to go to the movies or other outings. Depression will make you want to stay away from people. Fight against this by being around others as much as you can.

6
Join a group



Get involved in a church group, a discussion group, a class, a self-help group or other program where you will be around people. Social support is an important part of managing depression.

7
Volunteer

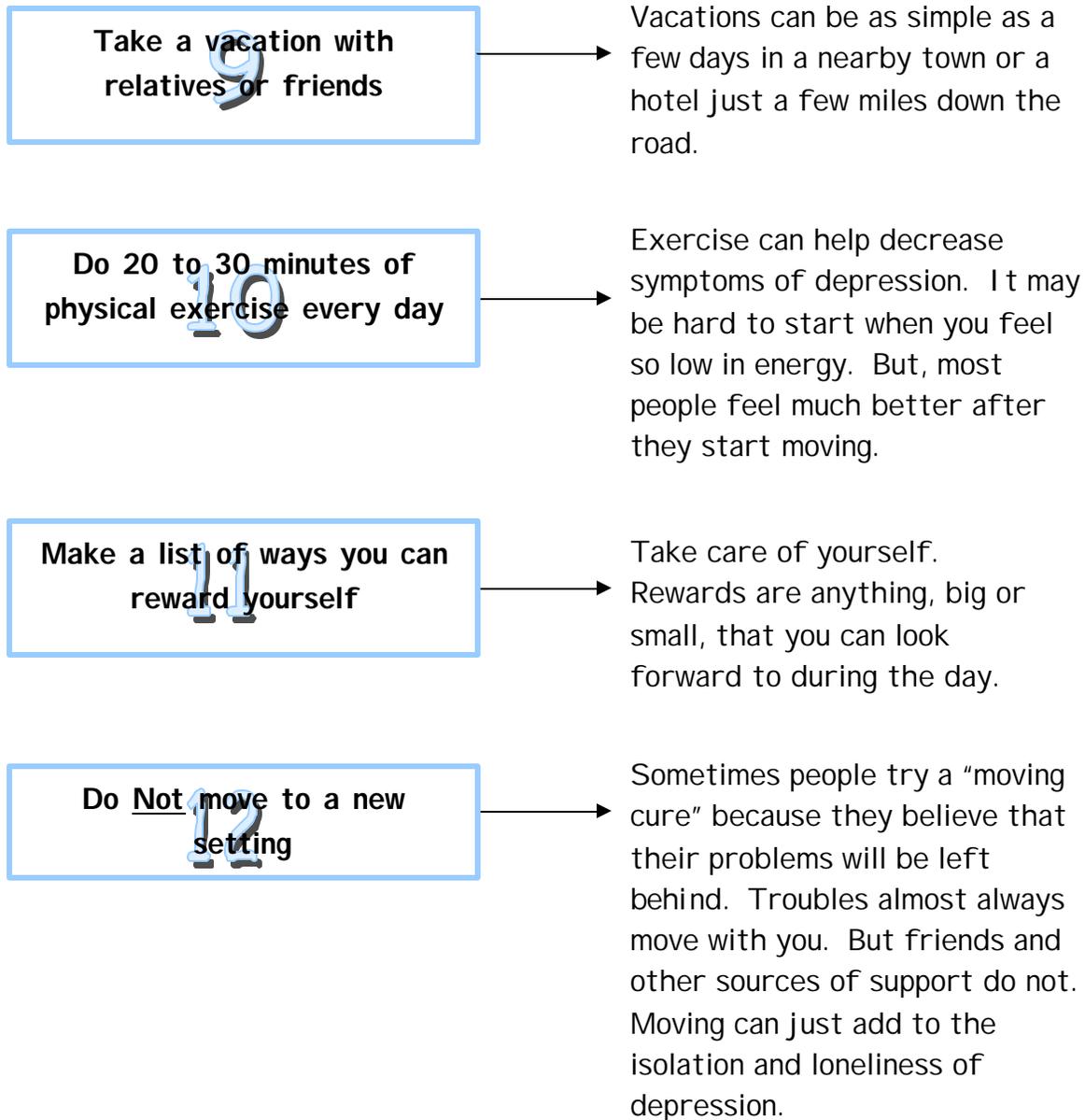


Helping other people can help you fight depression. Focusing on others helps you get your mind off your own problems.

8
Make plans and carry them out



Look to the future. Plant bulbs for next Spring. Look forward to having grandchildren even if your own children are small. If you know that one time of the year is especially difficult, such as Christmas or a birthday, make specific plans for that time. Don't wait to see what happens. Be prepared.



If You Need Help, Get It - Don't Be Embarrassed

Sometimes depression can't be managed on your own. Don't be embarrassed to talk with your doctor about depression. Your doctor may prescribe medications that can help control depression. You may also be referred to a psychiatrist, psychologist or social worker for help. Table 1 has a list of medications that are commonly used for depression. Most people with depression don't seek help. This is too bad since most cases of depression can be controlled.

Table 1:

GOAL OF TREATMENT	MEDICATION	BASIC MECHANISM	PRINCIPAL SIDE EFFECTS
TREAT REACTIVE DEPRESSION	TRICYCLIC ANTIDEPRESSANTS Amitriptyline (Elavil, Endep) Nortriptyline (Pamelor, Aventyl) Imipramine (Tofranil, Janimine) Clomipramine (Anafranil)	Improve symptoms of depression, May improve high quality (restorative) sleep May improve Raynaud's and peripheral pain	Drowsiness Dry mouth Blurred vision Orthostatic hypotension Weight gain
	SEROTONIN REUPTAKE INHIBITORS Sertraline (Zoloft) Paroxetine (Paxil) Fluoxetine (Prozac) Fluvoxamine (Luvox)	Improve symptoms of depression.	Headache Insomnia Nervousness Diarrhea Constipation (Paxil only)

Body Image: Dealing with Changes in Your Appearance

Most people with Scleroderma experience changes in their appearance. Many changes will only be noticeable to you. Other changes may be large enough that others notice them too. If Scleroderma has changed your appearance in a way that bothers you, stands out, or makes you look different from others, you may be faced with new challenges:

Your own emotions and behaviors:

- ? Negative feelings: embarrassment, anger, hurt, frustration.
- ? Feeling unattractive or even ugly.
- ? Lower self-confidence and anxiety in social situations.
- ? Avoiding certain situations (e.g., going to the pool, meeting new people).
- ? Covering up changes to appearance with make-up or clothing.

Comments and behaviors from others:

- ? staring
- ? unwelcome attention from others.
- ? questions and comments about your appearance such as:

"why does your face look so puffy?"

"what are those red spots on your hands?"

"your hands are turning blue!"

"you look really tired today"

- ? unwelcome offers for help when you don't need help.
- ? rudeness
- ? sympathy or pity
- ? others seem to be uncomfortable around you.

Understanding Your Own Reactions to Appearance Changes

Yvonne

Yvonne's face has changed due to her Scleroderma. She has red spots on her cheeks and her mouth has gotten smaller. She used to consider herself attractive but with these changes she no longer feels good about her appearance. She is often embarrassed to meet new people and she does not go out to social events as much as she used to.

Because of Scleroderma, most people will feel differently about the way they look. In Yvonne's case, not only has her appearance changed, but her body image has changed too.

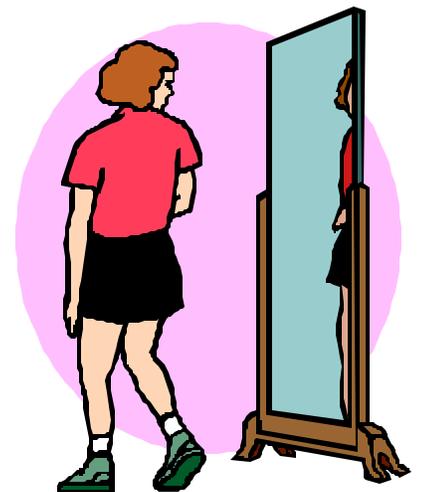
What is Body Image?

Body Image doesn't refer to what you actually look like. It refers to how you think about your body and your appearance:

- ? **How satisfied you are with it.**
- ? **How accurate you are in judging it.**
- ? **How you react to it. For example, you might stop doing things because of how you look.**

What you look like is only one part of who you are. But having difficulty accepting - and even liking - how you look can make it harder to feel good about yourself.

Scleroderma can change the way you look but it does not have to change your body image. You can learn to think differently about the changes in your appearance so that you feel better about yourself - more confident and happier.



Do YOU have a negative image of your body?

- ✍ Are you unhappy with the body you have? Do you wish you had a different body?
- ✍ Are there parts of your body you really don't like?
- ✍ When you think about the way you look do you get sad or frustrated?
- ✍ Do the same negative thoughts about your looks keep popping in your head?
- ✍ Do you spend a lot of time worrying about your looks or about changes in your appearance?
- ✍ Do you avoid certain activities or situations because you are self-conscious about how you look?
- ✍ Do you spend a lot of time and effort on changing or trying to hide your appearance?

Body Image Dissatisfaction is Very Common

Many people don't like how they look. Even people who do not have a chronic illness like Scleroderma can be unhappy with how they look. Both men and women report unhappiness with how they look in national surveys.

Why are so many people unhappy with their appearance?



?Cultural Messages: Society often gives the message that people must be good looking to be accepted, get a job, or make friends. There is too much focus on how people look, usually ignoring other parts of them. People accept this way of thinking. Over time they begin to apply this way of thinking to themselves.



?Myths of Beauty: Society teaches us that beauty is good and unattractiveness is evil. For example, in fairy tales the good characters are beautiful (Snow White) and the bad characters are usually ugly (Stepmother). We also hear the message that overweight people are lazy or lack willpower.

?Unrealistic Ideals: Over time, the ideal look has become harder to achieve. Models, Miss Americas, and Playboy Centerfolds are thinner and smaller. Men feel more pressure to be muscular and tall with a full head of hair. But in reality, the average person in the United States is getting older and heavier. This reality makes many people unhappy.

?Other Reasons: Some people may be concerned about how they look because they were teased as children. Or they generally feel bad about themselves.

REMEMBER

Your body may have changed from Scleroderma, but you are still the same person inside. Your value should not be based just on your appearance. The more you avoid situations that focus on your body concerns (for example, meeting new people), the harder it is.

Try to remember that almost everyone doesn't like some aspect of how they look. Because of this they will be less focused on your appearance. Practice what you'd say if someone asked about changes in your appearance. Knowing what you'd say ahead of time can make you feel less nervous. Most people are just curious or want to help. Rude questions say more about the other person than about you!

Scleroderma and the People in Your Life: Your Friends, Your Family, Your Spouse

The people in your life – family, friends, co-workers, neighbors – play a critical role in keeping you healthy, both mentally and physically:

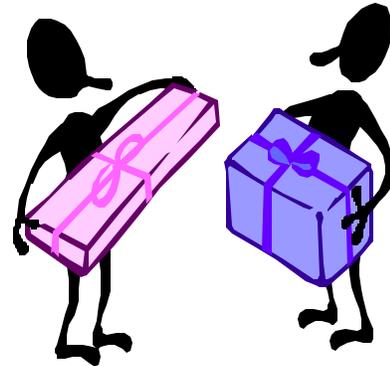


- ? They provide us with encouragement and hope.
- ? They give advice and information.
- ? Sometimes they give time, money, or other resources to help us when we need it most.

You probably already have people who are helping you deal with Scleroderma. These people may already do a lot. You may even worry that you ask too much. Or you might worry that you are a burden to these people.

How Can Scleroderma Affect My Relationships?

With only a few exceptions, most relationships involve “give and take”. Both people give to the relationship. Both people get something back in return. This is true with most relationships that are important.



Scleroderma, like other chronic illnesses, can change the give and take of relationships. See if you notice any of these changes in your own relationships:

- ✍ You find yourself thinking that you are taking too much from others and not giving enough back.
- ✍ Your daily life may become unpredictable due to Scleroderma. You hesitate to make plans to do things for fear of needing to cancel.
- ✍ You start saying no to invitations. You worry you will have to cancel if you are not feeling well enough to go.
- ✍ You need to rely more on people to take you places. Or you rely on people to help you with your daily routine.
- ✍ You start to think "I ask so much already."
- ✍ If you often feel irritable, depressed, or worried, you may also feel more comfortable being alone. Then you don't have to worry about someone else's feelings being hurt if you say the wrong thing.

Other Changes I have noticed in my relationships:

The people in your life may also struggle with your illness and the changes it causes. They see you hurting – pain, depression, the illness – and they feel helpless. They want to help and make a difference. But they don't know what to do.

How can you improve your social relationships? Communicating is the key. It's easy to get frustrated and say "You just don't understand!". It's harder to try and make sure others understand how you are feeling.



When you have a chronic illness, good communication becomes a requirement. It is in your best interest to communicate as clearly as possible. As uncomfortable as you may feel about expressing your feelings and asking for help, others feel the same way. It may be up to you to make sure the lines of communication stay open.

Improving Communication

1. Verbalize feelings with "I" messages.

"You" can be a critical word. It suggests blame. It's directed to the other person. If used, when expressing feelings, it can cause the other person to feel under attack. The other person gets defensive and discussions go nowhere. "I" is not a critical word. It doesn't blame or attack. When expressing your own feelings, it often helps to express them in terms of how YOU feel, not on how the other person makes you feel. For example, "You don't understand how I feel" versus "I'm not feeling well. I could really use your help".

2. Asking for help.

People with chronic illnesses often have a hard time asking for help or in refusing help that is not needed. It may be difficult to admit to yourself that you need help on things that used to be done independently. You may feel that you are becoming a burden. Or you may feel that if people really cared then you wouldn't need to ask. A specific request for help is the only way to be sure others understand. For example, "It would be helpful to me if you could start my car each morning before I leave for work". A well-worded "I" message may also be needed when you don't need help. For example, "Thanks for thinking about me, but I can handle it alone".

3. Practice saying "No".

You may be no longer able to do everything you once did. Not everyone will realize this and they may ask you for help. If you're working, you may not be able to stay overtime. You may not feel up to helping your friend move or carpooling in the wintertime. Recognize the importance of the request to the other person. In this way you are rejecting the request, not the person. For example, "I think this is a worthwhile project, but I think I'm not up to it this week". Again, be specific. Let the person know if you can't do it today, this week, or if you'll never be able to do it.

So My Spouse Has Scleroderma



Scleroderma changes lives

Scleroderma doesn't just change your life. It changes the lives of those you love. But sometimes it's difficult to talk about these changes or how others can help. You may want your husband or wife to read this section. It can help start a conversation about the way Scleroderma has changed things for both of you. The focus on this section is on spouses, but it may be helpful to have your adult children, siblings or others close to you read it

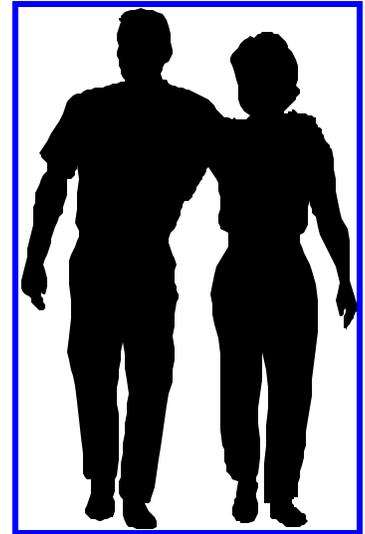
as well. Scleroderma affects all those who love you.

Remember, no one ASKS to have this illness

So your spouse has Scleroderma. What does this mean for you? It means that life will be different for you too. All things of importance that happen to your spouse will also affect you and the same is true for him or her. Being diagnosed with a rare, incurable illness is a life-changing event. Unlike other life-changing events---a move, a new career, a child---Scleroderma is unwanted and isn't voluntary. Your spouse is living with the uncertainty of the disease and you will have to as well.

Try to work out your negative feelings.

It is unfair. It would be nice if your life didn't have to change, but it will. If you are too busy, then you will have to let something else go. If you can't handle it alone you will need to get some help. Sometimes spouses become angry and feel that the patient is too demanding or really not that sick. They may communicate this anger in a punishing way. Try hard to avoid this. It is important for you to work out your feelings of disappointment, anger, even resentment. When spouses act in an angry, punishing way, patients may become more depressed.



Being helpful vs. taking over - find a balance

Sometimes the spouse develops a different attitude. They feel like being extra nice and helpful. They have an "Oh, you poor thing! Let me help you" attitude toward the spouse with Scleroderma. These spouses tend to take over all responsibilities---even the ones that the patient can still do.

Pity and over-concern may feel good in the short-term, but in the long run leave people feeling worse. Taking over makes people passive and dependent. Just because someone needs help doesn't mean they are helpless. The patient with the illness can feel resentful that they are being treated like an invalid. The spouse resents having to do everything.

Finding the right balance is very hard to do and will take time. You and your spouse will make mistakes and have conflicts as you learn to adjust. People get used to their roles and have a hard time changing them. But change can be a chance to grow, to improve and to have a better relationship.

Talk to each other - Listen to each other

This change will be much easier if you and your spouse communicate. Ask if your spouse needs help. Back off even if you could do something faster and easier. It may be important for them to feel in control or hold on to independence. Talk about how you can best be supportive.

Talk together about your feelings.

Feeling angry, sad, or afraid are all normal reactions to Scleroderma. But these feelings impact you, your spouse and your family. Feelings like, "I hate to see her suffer", "It's not fair. We can't do the things we used to", "I'm overwhelmed by doing everything", or "I can't count on him anymore" are common. Neither you nor your spouse can handle these feelings alone. Deal with them honestly. Turn to each other and to other loved ones for support.

Get support for your marriage, if you need it

Many marriages become stronger in the face of difficulty. Unfortunately, some become weaker but this is often because there were problems in the first place. Get professional help if you need it. If you can't afford it, you can turn to your church or synagogue. Most priests, ministers or rabbis can offer support or can suggest where you can go to get support.

Summary

This chapter has reviewed ways that Scleroderma can impact your psychological well-being. Feeling bad from depression, changes in your appearance or due to changes in your relationships are very real consequences of Scleroderma and shouldn't be ignored. Don't be afraid to ask your doctor for help if you need more information or guidance.