

Scleroderma and social relationships



Relationships with family members, friends, partners, and others can often be affected when having scleroderma or other chronic illnesses. You may find that some people around you will be supportive and caring, while others may react insensitively or pull away from you. Usually, people who are in our life have an important role in keeping us healthy both physically and mentally. Thus, having supportive people who can help you deal with your physical and mental symptoms is one of the best things that can help you remain positive and mindful of the good that remains in your life.

Asking for help is an important part of the scleroderma journey and will help you as you learn to accept your diagnosis. Loved ones want to help you manage your scleroderma symptoms, they want to learn about scleroderma and they want you to provide them with the information they need to help make your life easier while still giving you your independence.

Here are some common changes that can occur in relationships that are strained from a chronic illness:

- You begin to pull away from friends and family as you worry about how your illness is affecting them.
- You start to make plans in advance less, focusing on the fear and worry that your scleroderma symptoms may prohibit you from following through with your plans.
- Fatigue causes you to rest more and enjoy less of the activities you use to and your social life become restricted.
- Your scleroderma symptoms increase and you need to rely on people for doing your daily needs. This often can cause someone to feel
- You start to prefer to be lonely, and you may feel irritable, depressed, or worried.

- You start to be less caring about others' emotions even when you hurt them by saying something bad to them.

Improve your social relationships through having a good communication with others, and below are some tips to help you with that:

- Express how you feel to others.
- Ask for help. It may be difficult to admit to yourself that you need help on things that used to be done independently, but asking for what you really need is the only way that helps other understand your needs.
- Say NO to things that you cannot do anymore. Remember, you are rejecting the request, not the people.

My spouse has scleroderma

When your spouse is living with an incurable and a chronic disease like scleroderma, it is likely to have a significant impact on you as well. scleroderma can change the life of both of you and put a lot of challenges on your ways. Provided are some ways to make you a supportive partner and to help you stay well:

- **Talk about how the diagnosis makes you feel**

You and your partner may experience strong emotions and a lot of difficulties that are all due to scleroderma multiple symptoms. It is very important to share your emotions and thoughts in a constructive way so that you can begin to face them together.

- **Try not to be too much helpful**

Being helpful and caring about your spouse is a good thing in the short term, but it may leave your spouse feel worse and helpless in the long run. The spouse with scleroderma can feel resentful that they are being treated like an invalid people.

- **Try to ease the communication with your partner**

People living with scleroderma may have difficulty expressing their feelings. Most of the time, they may find it hard to find the right words to describe themselves particularly when their emotions are triggered. Understanding your spouse suffering and trying to be patient are very important to ease the communication between both of you.

- **Try to work out your negative feelings**

When your spouse has scleroderma, it seems like a full time job everyday, and it makes you very busy to take care of yourself. Definitely, This can be emotionally draining, physically exhausting, overwhelming, and monotonous for both of you, so it can impact how you feel and deal with various situations. Thus, you may feel disappointed and angry most of the time. Try to watch for signs of depression and get help if you cannot handle everything by yourself.

- Avoid any external factor that may hurt your spouse

You have to try to notice and avoid any external or environmental factor, situation, or health issue that affects your partner negatively. For example, try to avoid loud and excessively stimulating events that can cause sensory overload and being exhausting.

- Get support for your marriage

Many marriages become stronger in the face of difficulties, and some do not. Try to support and save your marriage by getting a professional help. if you cannot afford it, try to look any type of free help or counseling.



Additional ways to maintain a healthy relationship despite of chronic illness

- Create a safe environment for your partner emotionally and physically.
- Make your relationship a priority, focus on developing problem solving skills, and maintain flexibility.
- Show appreciation for each other.
- Focus on intimacy rather than sex.



Avoid saying these sentence to your ill spouse:

- You do not look sick
- Are not you worried about taking meds long term?
- You cannot be that sick if you have managed to work this whole time.
- Your situation could be worse
- You seem totally fine most of the time
- I am also really tired, so I know how you feel

<https://www.webmd.com/sex-relationships/features/chronic-illness-seven-relationship-tips#1>

<https://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-019-6800-7>

<https://www.focusonthefamily.ca/content/spousal-caregivers-when-chronic-illness-crashes-into-your-marriage>