

CARING FOR SOMEONE

WITH A CHRONIC ILLNESS

Being a Caregiver is a demonstration of love and loyalty. You may be a parent, spouse, or child, or have another special relationship with a chronic illness warrior who needs your care. Most of us never got training in being a Caregiver. You may believe a Caregiver needs to be a medical expert who knows all, a superhero who can do all, and a saint who can always be cheerful. However, Caregivers are human with all the skills, emotions, and experiences that entails. You have the ability to be the Caregiver your loved one needs. But how do you care for someone with a chronic illness and care for yourself too?

TIP 1

Learn all you can about the condition and how it presents in your loved one

This will help you learn what your chronic illness warrior is experiencing. Do they have joint problems? Do they have digestive issues? Your knowledge about their condition will help if you accompany them to doctor appointments, talk with family or friends, and research symptom treatment or management options. Learning about their condition will also help you and your loved one talk about what they are experiencing. You can learn about their condition from the condition's society, medical journal articles, from others on message boards like Inspire, and from support groups. We have virtual groups for parents and partners online as well.

TIP 2

Watch, listen and communicate.

Your loved one will likely say or show you what they need. There will be days when what they need most is simply for you to believe that they are in pain, fatigued, or experiencing symptoms making them feel awful. There will be days when your loved one needs you to encourage them to be more independent and to problem-solve ways or tools to help. There will be days when they need time completely alone, maybe in a dark room curled up in bed. And there will be days when your loved one wants to be seen as “normal” but may need your help with how to pace activities. Neither you nor your chronic illness warrior are mind readers so you both need to ask and explain. If you are uncertain about what your loved one needs — ask. If your warrior does not understand what you are doing, explain in a matter-of-fact manner. Two-way communication is crucial. If needed, a professional counselor can help you both increase your skills to have these important, honest conversations. Remember that your loved one is more than their diagnosis (separate who they are as a person from their condition) and you are more than their Caregiver (separate your role from who you are as a person). While it is necessary to talk clearly about their condition(s), it is equally necessary to set times when it is not discussed. Having open, frequent communication between you and your loved one will help you be a better Caregiver and both of you will feel better understood and supported.



TIP 3

Accept your feelings

Being a Caregiver can be hard work and it is perfectly normal for you to have feelings like anxiety, anger, grief, or guilt. Understand that your feelings are neither good nor bad; they are your feelings and need to be felt. Some find talking with other Caregivers in a support group helpful while others use journaling to express their feelings. There are family, friends, community groups, faith-based resources, professional counselors, and online forums you can use for more tips and strategies.

TIP 4

Take care of yourself

You cannot be an effective Caregiver for your loved one if you do not take care of yourself every day. This means eating healthfully, getting quality sleep, exercising regularly, and taking care of your own medical needs. But it also means nurturing more than just your body. Take time for yourself each day relaxing, doing something you enjoy, and connecting with what is important to you. Maybe you have a hobby or are part of a book club. Or perhaps a good nap or meditation restores your balance. Make this time for yourself each day. It is also important to seek social connections for both you and your loved one. These may be with your best friends, a group you belong to, cultural events in your community, the regulars at a neighborhood coffee shop, or wherever you are with others you enjoy. Being around other people can help you cope better with the responsibilities of being a Caregiver. Use community resources when needed and accept help from others. You cannot be the Caregiver you want to be if you do not take very good care of yourself physically, emotionally, and socially.

TIP 5

Remember life is more than chronic illness

You can help create opportunities for humor, adventures, problem-solving, and discussions that have nothing to do with the condition. Have conversations and show what you love about her personality, intelligence, outside interests, or passions. Have your loved one help make important decisions. Plan activities that are condition friendly so you both can have fun but not make anything worse. Allow them to help you when you need help. Celebrate what you both love about life and about each other — knowing that this condition is just one aspect of your lives.

Being a Caregiver may feel overwhelming at times. There will be good days and bad days. But if you follow these tips and work together, you will find that Caregiving can be rewarding for you both.



RESOURCE PAGE

EHLERS-DANLOS SYNDROME

[The Ehlers-Danlos Society](#)

[EDS/HSD Healthcare Professionals Directory](#)

[Inspire: EDS](#)

HYPERMOBILE SPECTRUM DISORDER

[The Hypermobile Spectrum Disorders Association](#)

[EDS/HSD Healthcare Professionals Directory](#)

[Inspire: HSD](#)

ANKYLOSING SPONDYLITIS

[The Spondylitis Association of America](#)

[National Axial Spondyloarthritis Society](#)

[Inspire: Ankylosing Spondylitis](#)

DYSAUTONOMIA

[The Dysautonomia Project](#)

[Dysautonomia Support Network](#)

[Inspire: Dysautonomia Support Network](#)

RHEUMATOID ARTHRITIS

[The Rheumatoid Arthritis Foundation](#)

[Arthritis Foundation: Rheumatoid Arthritis](#)

[Inspire: RA](#)

LUPUS

[Lupus Foundation of America](#)

[Lupus Research Alliance](#)

[Inspire: Lupus](#)

