

Caring for Your Caregiver

Many caregivers can feel so overwhelmed by caregiving and juggling the demands of day-to-day life that they forget to take care of themselves. It is important for caregivers to have time to care for themselves, which will help them recharge and provide better care for you.

Feeling overwhelmed can lead to feelings of anger and resentment and can put an emotional strain on your relationship, no matter how much you love each other. You can help your caregiver find time to recharge by coordinating and/or supporting respite care, which is when family, friends, or professional caregivers fill in to provide care or just spend time with you.

It is important to give your caregiver permission to take this personal time. It may sound like a simple thing, but many caregivers feel guilty for leaving their loved one's side and doing something for themselves.

Be Aware of How You Are Treating Others

Although you may feel angry, frustrated, and overwhelmed at times, try not to take your frustrations out on your caregiver. While it is okay to feel angry, it is not okay to be mean. Try instead to share how you're feeling and find constructive ways to communicate. Remember that this is not easy for either of you.

Joel Goldhirsh adjusted his attitude after realizing he had been making life unpleasant for those around him. "As the person living with ALS," he said, "you have to realize that it's not all about you. There are other people that are affected by the disease, especially a spouse or partner. Looking out for their well-being is just as important as thinking about your own."

Try to find ways to prioritize your relationship. How you interact and get along will be a significant factor in the quality of both of your lives. You and your partner will need to communicate your needs directly and figure out how to best address them. If you continue to struggle and feel stuck in negative patterns, you may want to talk with the social worker at your ALS clinic or ALS Arizona, or meet with a couples counselor to improve your dynamics.



Find Additional Support When You Need It

You and/or your caregiver might also benefit from attending in-person or virtual ALS support groups where you can connect with others facing similar challenges. There are support groups just for caregivers and others just for people living with ALS.

If you are struggling with overwhelming emotions or are just finding it hard to make it through each day, a skilled counselor or therapist might be able to help you develop insights, coping skills, and techniques that can help you better manage your current and future challenges.

It is not uncommon for people diagnosed with ALS to experience anxiety or depression. If you are concerned that symptoms of anxiety or depression may be affecting your quality of life and ability to handle daily activities, discuss these symptoms with your ALS care provider.

Your neurologist or mental health professional might suggest counseling and/or taking a medication that can help ease your symptoms. Many people diagnosed with ALS have found that taking medication under the guidance of a doctor or mental health professional has helped them feel more like themselves again. Accepting this help could improve your quality of life during this difficult time.

Our state of mind affects nearly every facet of our lives, including how we feel, think, act, and relate to others. When you're living with a disease like ALS, it is important to remain aware of how you're feeling and seek support when you need it. Tending to your mental health can have a positive impact on day-to-day quality of life for both you and your caregiver.

Get Local Support

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