

Finding Quality of Life

Your approach to living with ALS will play a very important role in your quality of life. It is still possible to live with purpose, meaning, and joy after your diagnosis. Staying connected with others, prioritizing important relationships, building a support team, and taking good care of yourself are a few ways you can have improved quality of life.



Finding Purpose and Meaning

Your sense of purpose may come from your family, friends, work, faith, hobbies, or other pursuits. Or, you may find deep satisfaction in something new after your diagnosis, like traveling or getting involved with the ALS community.

Knowing that your life has a sense of purpose and meaning can help you cope with your new reality. Finding something that brings you joy or satisfaction can give you something to look forward to and shift your perspective.

Staying Connected with Others

Relationships are often what bring us joy and help us through hard times. Staying connected with others can help you feel more engaged and less isolated.

This might mean seeing family and friends in person or communicating by video, phone, text, chat, or email. It might mean being active and engaged on social media. Or it could mean going out and attending events, even if you're in a power wheelchair.

Prioritizing Your Relationship

Your most important relationship will likely be the one with your spouse, partner, or whoever is your primary caregiver. 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.

It is normal to feel angry and frustrated when you lose the ability to do things that you used to do by yourself. Though it is okay to feel angry, it is not okay to be mean.

Being open and honest with your loved ones can help you feel more connected and less isolated. It's fine to say how frustrated you are. It's okay to cry. This is not easy for your caregiver, either. Your caregiver may be feeling angry and frustrated, too.

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.

Building Your Support Team

Your caregiver and loved ones may feel stressed and overwhelmed by what they have to do—and by what they don't know. That's why it is important to communicate openly and honestly with them about how they can best help you and how everyone can work together as a team.

As the disease progresses, your caregiver and inner circle will likely need additional support themselves. Even if it feels uncomfortable, it is important to ask for help from your family, friends, and the larger community so that your loved ones can have some life balance and avoid caregiver burnout.

Taking Good Care of Yourself

When you're living with ALS, it is especially important to be good to your body. Living a life of wellness can help you feel better, be more comfortable, and have more energy for the things that are most important to you. This includes getting better sleep, eating well and maintaining your weight, conserving energy, doing range of motion exercises and stretching, using assistive equipment for safety and independence, and tending to your mental and emotional health.

Get Local Support

**ALS
Arizona**

360 E. Coronado Rd Ste 140

Phoenix, AZ 85004

www.alsaz.org

602-297-3800

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