

Planning for Your Future

Planning for your future when someone you love has ALS can feel overwhelming. You may be balancing caregiving with school, work, relationships, or figuring out who you are and where you're going. Thinking ahead can bring up fear, relief, grief, pressure, or guilt. If any of that is true for you, you're not alone.

Planning does not mean having all the answers. It means giving yourself permission to ask questions and think about what you need—now and later.

Start where you are

Before making plans, pause and check in with yourself. Ask yourself:

- What feels hardest to think about right now?
- What worries keep coming up when I imagine the future?
- What feels uncertain, scary, or unfinished?

Caregiving and your own life

Many young adults feel torn between caring for their loved one and moving forward with their own goals. You may wonder:

- How do I plan for school, work, or relationships while caregiving?
- What do I want my life to look like in the next year? In five years?
- What parts of my life feel on hold?
- Which parts of my life do I want to protect?

These questions don't mean you're selfish. They mean you're human.

Thinking about roles and responsibilities

As ALS progresses, it's normal for your roles to shift. You've probably noticed changes since the person was diagnosed. That constant evolution of life and care isn't going to stop. You might consider:

- What caregiving tasks am I doing now, and how might that change?
- Who else is part of the care team and who could be?
- What support do I need that I don't currently have?

You are not meant to do this alone. Planning includes identifying help, not just responsibilities.

Making space for emotions

Planning for the future can bring up grief—sometimes even before loss happens. You might feel sadness for things that may change or anger that your life looks different than you expected.

Ask yourself:

- Who can I talk to honestly about how I'm feeling?
- What helps me release stress or reset emotionally?
- What would it look like to be kinder to myself right now?
- What feelings do I notice myself avoiding, and what might help me feel safe enough to name them?
- When things feel overwhelming, how do I usually cope—and is that still working for me?
- What kind of support do I wish I had permission to ask for right now?

It may help to write down your answers to the questions or talk about them with a trusted person. And, it's okay if you don't know how to answer any of them right away.

Be kind to yourself

Caring for someone with ALS while navigating your own young adult life is a lot to carry. There will be days when you feel strong and capable, and days when you feel exhausted, frustrated, or unsure of yourself. All of those experiences are valid.

Being kind to yourself means letting go of the idea that you have to do everything perfectly. It means noticing when you're tired and allowing yourself to rest, asking for help without guilt, and recognizing that your needs matter too. You are doing the best you can in a situation you didn't choose—and that deserves compassion, especially from yourself.



Our Mission: To unite and empower the ALS community through a collaborative approach of providing comprehensive care and support to individuals and families affected by ALS, advancing national and state advocacy, and fostering bold research initiatives.



alsrockymountain.org



info@alsrockymountain.org



(303) 832-2322

GlobalNeuroYCare.org