

MAINTAIN YOUR SENSE OF SELF

When you are caring for a person with ALS, it can feel like caregiving becomes the center of everything. Your time, energy, and attention may shift toward appointments, routines, and responsibilities. Over time, it's easy to lose sight of who you are outside of this role.

Maintaining your sense of self is not selfish—it is necessary.

You are more

Caregiving is something you do, not who you are. You are still a student, professional, artist, partner, friend, sibling, or dreamer. Those parts of you did not disappear when ALS entered your life.

Ask yourself:

- What parts of me feel most like me?
- Which interests or values do I want to protect?
- What brings me a sense of meaning or joy, even in small ways?

Staying connected to these parts helps you feel grounded during times of uncertainty.

Making room for growth

Young adulthood is a time of change, learning, trying, failing, and discovering. Caregiving may interrupt or reshape this process, but it does not stop it.

You might be asking:

- Who am I becoming through this experience?
- What have I learned about myself that I didn't know before?
- How do I want this chapter to shape me, without defining me?

There is no “right” way to grow while caregiving. Growth can be slow, uneven, and quiet—and still be real.

Spaces that are just yours

Maintaining your sense of self means allowing yourself moments that are not about ALS. This might look like:

- Spending time with friends who see you as you
- Keeping a hobby or routine that feels familiar
- Setting boundaries around when and how you talk about caregiving

These moments are not escapes—they are ways to recharge and remember who you are.

Letting go of guilt

Many young adults feel guilty for wanting a life outside caregiving. Wanting independence, connection, or joy does not mean you care any less. It means you are honoring your own humanity.

Consider asking yourself:

- Where am I holding myself to impossible standards?
- What would it sound like to speak to myself with kindness instead of criticism?

Reflecting on Who You Are

It can be helpful to pause and reconnect with yourself. Take a moment to think about who you are beyond your responsibilities and what parts of you feel most important to nurture right now. You might reflect on your values, passions, relationships, or goals—both big and small. Giving attention to these parts of yourself helps you stay grounded and reminds you that your identity continues to grow, even in challenging times.

Reflect on:

- What parts of myself feel most true or alive right now, and how can I make space for them in my life?
- What is one part of who I am that I want to protect or grow, even while caregiving?

Be kind to yourself

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 every day. 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.

You are allowed to hold multiple truths at once: love and frustration, commitment and longing, grief and hope. Maintaining your sense of self does not take away from your caregiving—it sustains you through it. **You matter. Not just for what you give, but for who you are.**

Looking for more resources?



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.



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