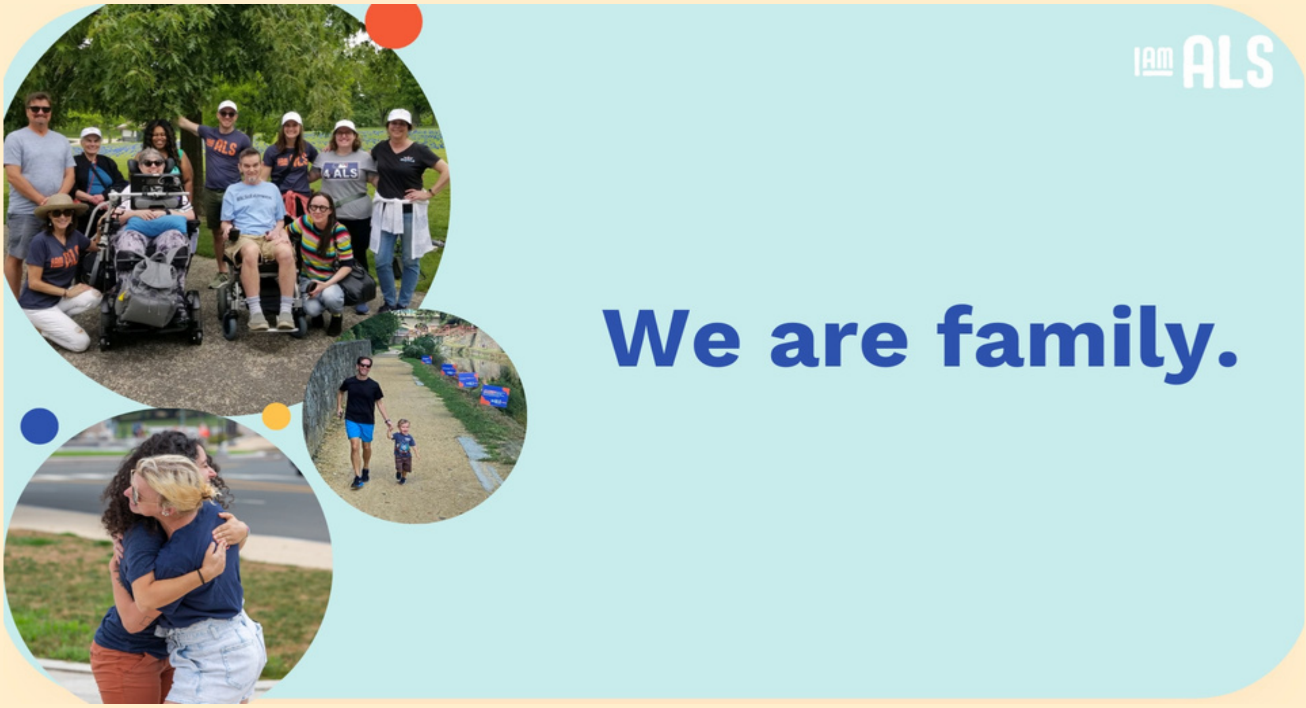

We're in this together.

ALS can feel isolating and the challenges can sometimes seem unimaginable. Remember: You are not alone in this. We are here to support you during the tough days, advocate alongside you for change and access to treatments, and celebrate the small and big wins for you and your loved ones -- now and in the future. Countless people have been impacted by ALS and we plan to stick around until we end it.

While everyone experiences ALS differently and predicting what you may eventually need is difficult, we want to help you prepare for the future, prioritize what's important to you, stay in the loop, and find what you need in this community.

Values. What are they and why do they matter?

Your values are the lenses through which you view yourself and the world. When you use your values to make decisions, you make a deliberate choice to focus on what's important to you. If you haven't already, it may be helpful to reflect on your values.

Here are some helpful questions to ask yourself to start reflecting on your values:

1. What type of activities allow you to experience a sense of joy and peace? For example: Spending time with friends and family, writing in a journal, trying different types of coffee, etc.
2. What about those activities do you enjoy? For example: I enjoy spending time with friends and family because I value connection. I enjoy writing in a journal because I value self-reflection.
3. How would you prioritize the reasons for your enjoyment of all the activities you listed? For example:
    1. Self-reflection
    2. Connection
    3. Adventure

Once you've completed this exercise, think about the following:

1. Which aspects of your health and well-being are most important to you?
2. What does quality of life while living with ALS look like for you?
3. How do you define a good quality of life for you and your family?

Have a conversation (or many) with your loved ones about your values, how they impact your decision making, and the role you want your loved ones to have in your decision making. Write a list of the goals and expectations you have for your care, and share this with your loved ones as well as your healthcare team so they can better support you in making decisions that align with how you want to live your life. When we don't think about what's important to us, the default can be to make choices that align with the values of others or make choices that we may later regret.

Redefining and maintaining independence.

Figuring out your values may play a role when it comes to redefining and maintaining your independence when living with or caring for someone living with ALS. As ALS progresses, you may need more help with doing tasks that you didn't have to think twice about before – brushing your teeth, using the bathroom, getting dressed, and making your perfect cup of coffee can all require the support of a loved one or caregiver. It's important to think about what independence means to you now. Perhaps a walker or power wheelchair will allow you to safely continue taking your daily outdoor walks, or learning how to utilize your phone's accessibility features will allow you to communicate more easily with someone you love. Exploring assistive devices and equipment can be a helpful step toward living your life with your values in mind.

Note: We know this isn't easy, and the emotional impact of just thinking about upcoming changes can sometimes feel overwhelming and discouraging. It can be helpful to process with another person – consider connecting with another person impacted by ALS through our Peer Support Initiative to talk with someone who can relate to what you're going through. Also, remember that our ALS Support Specialists are always here to support you through the emotional, physical, and other changes that accompany ALS.

Your voice matters. It can help fuel a movement for change.

Although ALS is currently classified as a rare fatal disease, we know that it impacts people everywhere and in every community. You are not alone. The Every Community map shows that ALS impacts every congressional district in the United States. Your voice and your story matters. Connect with the ALS community by adding your name to the map and sharing your story and reading about others in this community. We believe that sharing your experience through stories can be a way to process your emotions, heal, and empower yourself as well as others who may read or hear it. We know that our experiences and stories become louder when we work to end ALS together.

There's a lot to remember.

You're right about that. We know you're doing your best to remember dates, appointments, medications, symptoms, and other events. It's a lot to keep track of and it's normal to feel overwhelmed when organizing this information.

Some people find it helpful to write out a weekly routine, hang charts, or reminders in the home, or use a health journal app to stay organized. You may find the ALS Association's Key Information App, Chronically Simple or Symple make things feel more manageable. Others choose to create an ALS care binder. Care binders can help you stay organized and ensure important information is easy to find when you need it. They can be used to track symptoms, write down questions for your provider, manage medication schedules and more. Check out this guide to build your own ALS care binder, along with these medical information materials from the ALS Association.

We're here for you. Now and always.

Don't forget to stop every so often to care for yourself. Take a deep breath. Do something kind for yourself. It can be easy to go down unhelpful and time-consuming rabbit trails or prioritize another person's wellbeing over your own. Caregivers, consider creating a self-care plan and sharing it with your loved ones. And remember, our ALS Support Team is here to help anyone who's been impacted by ALS – please reach out to us. It is truly our honor to support you and your loved ones.

Meet your ALS Support Team!

McKenzie is our resident ALS Support Specialist Lead!

Allie is one of our amazing ALS Support Specialists!

Hope is one of our amazing ALS Support Specialists!

Rate the Content

Was this helpful? What else would be helpful? Please share your thoughts with us here.

In case you missed it, parts 1, 2 and 3 of this email series can be found here.

I AM ALS is a patient-led community that provides critical support and resources to patients, caregivers and loved ones. It empowers advocates to raise mainstream awareness and lead the revolution against ALS in driving the development of cures. Learn more at iamals.org.

1200 Pennsylvania Ave NW, #14135 | Washington, DC 20044
I AM ALS website