Let's get prepared.

ALS Clinic days can often be overwhelming -- you spend hours meeting with an array of care providers from a neurologist and nurse to a speech & language pathologist and occupational

therapist and more. Sometimes it's hard to know what questions to ask each person! We've got you covered -- **here** is a series of checklists with questions to ask different members of your care team. Use **this one** to help you prepare for your first visit after an ALS diagnosis.

We highly recommend getting a second opinion. If you haven't already gotten one, use this map to find an ALS specialist.

FIND YOUR CLINIC

Clinical trials = investigational treatments.

Yes, we talked about this in the previous email you received from us, but it bears enough weight to say it again: clinical trials are studies where researchers test investigational therapies to treat ALS. There are numerous clinical trials for ALS in the US right now -- you can find one by state through ALS Signal.

Pro tip: Click here for a step-by-step guide to learning about and accessing trials. Make a list of the trials you're interested in and email them to your healthcare team to learn about which ones may be appropriate for you.

Need help finding or connecting with trials? Connect with an ALS Support Specialist for help with identifying all available trials and connecting with trial site coordinators.

Learn more about your type of ALS.

Let's review the basics: sporadic ALS refers to when there are no known genetic variants causative of ALS in a person and they have no family history of ALS. Familial ALS refers to when there is a family history of ALS with a known genetic

variant causative of ALS. Genetic ALS refers to when a person has a genetic variant causative of ALS, but no family history of the disease. While the majority of ALS cases are currently sporadic, a genetic test may help you learn if you have a genetic variant known to cause ALS. This may also be helpful in finding appropriate clinical trials for you. Read more about genetics and ALS here, and connect with an ALS Support Specialist for information on how to get genetic testing and counseling.

Before you get tested: Learn how your information will be stored and used, and understand your rights.

Cognitive changes: What you need to know.

While up to 50% of people diagnosed with ALS will not experience any changes to their thinking or behavior, up to 50% of people will experience mild or significant changes in their thinking or behavior. These changes can include a perceived lack of “filter” when speaking, increased aggression, inability to remember what they were going to say or do, and more.

Researchers are still learning what causes these changes. One of the documented risk factors for changes to thinking and behavior is the presence of the C9Orf72 gene, which is associated with both ALS and fronto-temporal dementia (FTD). Check out this article for more information on cognitive changes among people living with ALS.

Building your community.

Shortly after diagnosis there is a period of disbelief where you may not want to communicate with others because you're still processing news of the diagnosis, and don't want to talk about it again. Figuring out how and when to share this with your family and friends is a very personal decision. Here are a few things to consider when preparing to share:

1. Consider finding your partner, best friend, parent, adult child, or whomever you love and trust to not go into panic mode, and share your diagnosis with them. This can help ensure you're not alone in processing the impact of this diagnosis.
2. Some people may prefer to share with as many family members and friends as possible at one time so they don't feel like they need to have the same conversation multiple times.
3. Be prepared for others' reactions. Your loved ones may express a mix of confusion, shock, and sadness over this, which can sometimes be overwhelming – for them and for you.
4. Don't rush it. Take your time to process this news and share it with others when you're ready.

Sharing an ALS diagnosis with children can be emotionally challenging. What do you tell them? And when? How much information is too much or

too little? These are difficult questions, and while the answers are not always straightforward, here are a few things to keep in mind:

1. Share honest and accurate information appropriate for each child's developmental stage.
2. If you don't know the answer to a question they ask you, don't make one up. Tell them you don't know and make sure to follow up with the information later.
3. Share your emotions. This can help normalize for them that it's okay to express theirs.
4. Check in with them frequently as they process this information.
5. Consider informing their school so that teachers know to support them.

We get it – there is no easy way to tell a child that someone they love has ALS. Read more about how to support children and teens through ALS here, and connect with an ALS Support Specialist here for personalized support.

Asking for help is a superpower.

There can be a period after diagnosis where you may hold back from asking others for help. Once you share your diagnosis with your loved ones and start asking for their help, you'll find that everyone wants to help — they just don't know how. So ask someone to start learning about the top ALS doctors and clinical trials. Ask another to help organize meals. Ask another to help with house chores like laundry, grocery shopping or lawn care. And ask another to make sure you still have fun. Remember: Asking for help is a superpower, not a weakness. You do not and should not have to go through this experience alone.

ALS can feel overwhelming and isolating. From this moment on, we are here for you — we'll be your fierce advocates, resource specialists and listening partners. In addition to providing you with helpful information, access to resources, and emotional support, we will regularly check in to make sure your wellbeing and needs are taken care of. Connect with our ALS Support Specialists today online, via email at gethelp@iamals.org or over the phone at 866-972-6257.

In case you missed it, Part I 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.

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