

# ALS 5 W's & How for Adolescents & Young Adults

ALS is a disease that impacts not just the person who has it, but also their family and friends. If you're a young person navigating this experience, you might feel overwhelmed or unsure of how to process what's happening.

It's normal to have lots of questions, and it's okay to take your time to understand what ALS means for you and your loved one. At ALS United Greater Chicago, we're here to provide the support and information you need, so you don't have to face this journey alone.

## Who?

At this point, your loved one may have opened the door in explaining that they have ALS, and at this time, there is no cure. Who has just been impacted by this? Not just them, but *you*. Understand that any of your reactions or emotions to hearing this are normal. You may have many questions and not know how to verbalize them. Go at your own pace, but most importantly, do not ignore your feelings.

Individuals with ALS will eventually need a caregiver or multiple forms of support. Here is that "who" again. You may find yourself supporting and caring for your parent or loved one more than you expected. This can be extremely difficult for someone your age. Just as you are giving support, you will need it as well.

## What?

ALS is a neurodegenerative disease that weakens voluntary muscles we use every day to breathe, move, speak, and swallow. Our bodies have nerve cells in the brain and spinal cord, and these are called motor neurons.



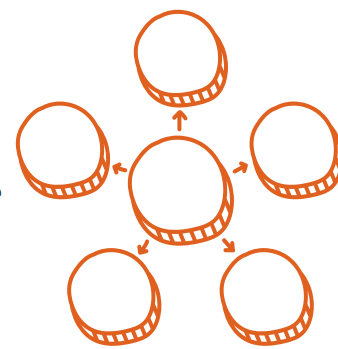
## Reflections on “Who”...

Receiving the news that a loved one has been diagnosed with ALS can bring up many emotions—shock, fear, sadness, and even confusion. It’s important to remember that these feelings are completely normal, and you are not alone.

While caregiving can be a big challenge, it can also deepen your relationship with your loved one and teach you a lot about yourself. Through these activities, you can reflect on what you’re experiencing, understand your role, and find ways to take care of yourself while also supporting those you love.

### Support Map

Create a visual support map. In the center, write your name, and then branch out with names of people or resources you can lean on—regarding this ALS diagnosis or for anything. This can include family members, friends, professionals, or even online communities. This will remind you that you don’t have to do everything alone.

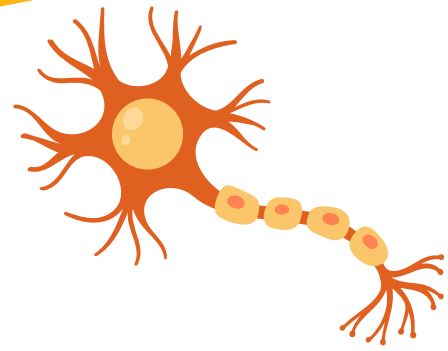


### Letter to Your Future Self

Write a letter to yourself a year from now. Describe how you’re feeling now, what you’re unsure about, and what you’re hoping for. Revisit the letter later to reflect on your growth and how you’ve managed through this challenging time.

### Reflections

- *How do you feel right now? Write about your initial reaction when you first learned about your loved one's ALS diagnosis. What emotions are you experiencing—anger, sadness, confusion, relief, or something else? Remember, all your feelings are valid.*
- *Questions on your mind: List the questions you have about ALS, your loved one's diagnosis, and how this may affect you. What do you wish you could ask, but don't know how?*
- *The role of a caregiver: Reflect on what it might mean for you to become a caregiver for your loved one. What aspects of caregiving feel overwhelming? What parts might feel rewarding? How do you think this will change your relationship with them? When you're ready, talk about this with your loved one living with ALS to learn what they might be envisioning about working together through their ALS journey.*



### What do motor neurons have to do with anything?

Well, our brain sends signals to the cells in our spinal cord to do certain things, and these cells transport the message to the muscles. If the muscles are no longer receiving the signal, they can no longer operate.

For example, when you put your popcorn in the microwave to pop, you must first press the number of minutes. If you do not do this, the popcorn will not pop. Similarly, if the nerve cells (motor neurons) can no longer send signals, our muscles become weakened.

### Famous Faces of ALS: Celebrities Stricken by ALS

- *Stephen Hawking*: World-Renowned Theoretical Physicist
- *Lou Gehrig*: New York Yankees Baseball Legend
- *Roberta Flack*: Legendary R&B Singer & Musician
- *Steve Gleason*: Former New Orleans Saints NFL Player
- *Steve "Mongo" McMichael*: Former Chicago Bears NFL Player

### When?

The onset of the diagnosis and its symptoms differ in each person. ALS is not a contagious disease. Individuals who develop ALS are typically between the ages of 40 and 70, but it can also occur in individuals in their 20s and 30s.

The life expectancy after being diagnosed with ALS is typically 2-5 years. However, half of the individuals impacted by ALS live at least three or more years after their diagnosis.

### Facts About ALS:

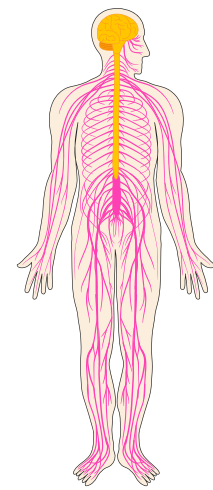
- In the United States, approximately 5,000 new cases are diagnosed annually.
- Around 30,000 people in the U.S. are estimated to live with ALS at any given time.
- ALS is 20% more common in men than women. However, with increasing age, the incidence of ALS is more equal between men and women.
- Approximately 90% of ALS cases are sporadic, with no clear underlying cause identified. About 5% to 10% of cases are familial, meaning they are inherited.
- Research is ongoing to understand genetics.
- There is no cure for ALS, but there are treatments that can help manage the symptoms of the disease.

## Where?

ALS affects the body by damaging the motor neurons, the nerve cells that control muscles. When these neurons stop working, the muscles weaken and can't perform basic tasks like moving, talking, swallowing, and eventually breathing.

While ALS impacts the body, it doesn't affect the brain. A person with ALS can still think, process information, and understand things. However, as speech muscles weaken, communication can become harder.

Your loved one may use tools like speech-generating devices or writing to express themselves. With help from their healthcare team and organizations like ALS United Greater Chicago, they can maintain their independence. Even if it's hard for them to speak, their thoughts and feelings are still there, just waiting for the right way to share them.



## Why?

The exact cause of ALS is still unknown. About 90% of ALS cases occur without any known family history or genetic link. The remaining 10% are inherited through a mutated gene that's connected to the disease.

For reasons that aren't yet understood, military veterans are more likely to develop ALS than the general public.

Researchers are working tirelessly to uncover the cause of ALS and to better understand why some people are affected by it.

## How?

While there is no cure for ALS yet, there are resources and support available to help manage the challenges that come with the disease.

Organizations like ALS United Greater Chicago offer services like care coordination, counseling, and access to clinical trials that may help improve quality of life. These resources are here to guide you and your loved one through the journey, ensuring you're not alone.

From medical support to emotional help, there are people who understand what you're going through and can provide assistance every step of the way. We are committed to supporting you and your family as you navigate this journey together.

## Reflections on “How”...

### **What Can I Control?” Chart**

On a piece of paper, draw two columns. Label one column “What I Can Control” and the other “What I Can’t Control.” Write down examples in each column (e.g., I can control how I show love to my parent, but I can’t control how ALS progresses).

Focus on the “What I Can Control” column. Highlight or circle things you can do today to make a positive difference. While there are things about ALS that are out of your hands, there are always ways to show love, kindness, and care.

### **Reflections**

- *Finding Your Tools:* What tools or resources do you think could help you and your family during this time? This could be a support group, a counselor, or even something as simple as a journal or playlist. Are there ways you feel your loved one's healthcare team or an organization like ALS United Greater Chicago can support you?
- *Staying Connected:* ALS may change how your loved one communicates or moves, but it doesn't change who they are. What are some creative ways you can stay connected, like writing notes, playing a game together, or sharing quiet moments? How might you adapt these activities if things become more challenging?
- *Building a Routine:* What are some small ways you can help support your family's routine? Whether it's helping with tasks at home, being there for your parent, or just making sure to take care of yourself, how can you balance everything while still finding time for the things that bring you joy?

Journaling is a wonderful way to keep thoughts focused on the here and now, rather than the “what ifs.” Journaling gives you a place to put your thoughts, challenge negative thoughts, and recognize opportunities to reflect on the positive in life. Our thoughts are something ALS does not control, and choosing what to give attention to while living with ALS can feel empowering.

