

Andrew Niblock's ALS Info Sheet



What is ALS?

- Motor Neurons are necessary for your brain to communicate to your body
- In ALS for some reason, they have stopped doing their job
- As a consequence, the messages don't get to where they need to go, and the body does not always do what the brain tells it to
- Like with exercise, if the messages don't get through, the body starts to lose the ability to do what the messages say when the messages do get there
- Body gets progressively weaker

Is there a cure?

- Not yet, but scientists are working on it!
 - [ALS Therapy Development Institute](#) - the largest drug discovery lab in the world focused solely on finding treatments for ALS.
- ALS is a Puzzle
- Scientists are taking four main paths
 - [Help motor neurons with stem cells](#)
 - Decrease inflammation around motor neurons
 - Hyperactive motor neurons
 - Immune system

When did you get it (Were you born with it)?

- ALS is confounding.
- Experts believe that some forms of ALS are passed on in families – I do not have this kind of ALS.

- They are not sure how most people with ALS got the disease. That is the question many of the scientists are asking every day.

How do you/doctors know you have ALS?

- There is no test for ALS.
- Doctors diagnose ALS through a process of eliminating other options.
- Because of this, it can take a year for a doctor to diagnose someone with ALS.

How common is ALS?

- It is a very rare disease.
- The CDC's Agency for Toxic Substances and Disease Registry found that about 4 in 100,000 people live with ALS in the United States.

Does it hurt?

- Only when you fall.
- Frustrating

What does it look like?

- Different for everyone
- Balance
- Strength
- Talking and Breathing
- Eating

Does ALS affect your brain function?

- Most experts believe that ALS has very limited if any affect on brain function. It primarily affects motor function.

Is it contagious?

- No
- Science thinks may be genetic in some cases
 - Not mine
 - Sporadic

Can you live for a long time with ALS?

- Yes, astrophysicist Steven Hawking was diagnosed at the age of 21 and lived into his seventies.

Have any famous people had ALS?

- Lou Gehrig, who played for the Yankees, is one of the most famous people to have had ALS. ALS is also called Lou Gehrig's disease.
- Steve Gleason, a former defensive back with the New Orleans Saints, also has ALS. He has made a movie, and his organization is [Team Gleason](#). They help people with ALS by providing them with technology that allows them to do things their body won't let them do anymore.

What can someone with ALS do to feel better?

- Be healthy – exercise and eat right
- Sleep is very important

- Be happy – it is easier to be hopeful when you are around people who make you smile
- Scientists are always looking to find medicine that will help. It is important to know about these and try to find the ones that may work for you.
 - These are usually in the form of trials, where scientists are trying to figure out whether their medicines work.

Do you take medications?

- I do, but not too many. There are only a few medicines that are prescribed to treat ALS.
- I do take some vitamins, eat a careful diet, and I make sure to sleep and exercise.

Can technology help?

- Technology can help people with ALS do many of the things their body can't do
 - Type – eye gaze technology helps me navigate my tablet with my eyes
 - Talk – synthetic voice
 - Move – super high-tech wheelchairs
 - Breathe
 - Eat
- When people can still participate with their friends and family thanks to technology, they can stay happier and live longer.

When we (adults and students) see you and think you are having difficulty with something, should we offer to help you or wait for you to ask us for assistance?

- The offer is always appreciated.
- I don't take offense, and while sometimes I may persevere with a difficult task (I can be stubborn), I may also take you up on your offer. Thank you in advance!
- I often have my aide, Yaw, with me. He is very nice and very helpful.