

# ALS Prognosis & Progression

ALS affects everyone differently and progresses at different rates for each person. Your neurologist and medical team will measure changes at each visit to get a sense of how fast or slow it is progressing for you.

On average, people diagnosed with ALS will live 3-5 years after their first symptoms appear. Keep in mind that this is just a statistical average. Some people survive less than one year while others can live multiple decades. Twenty percent of people live more than 5 years, ten percent live more than 10 years, and 5% live more than 20 years.



## How does ALS progress?

For most people, symptoms first appear in the arms or the legs. For others, ALS begins by affecting the bulbar muscles that control speech and swallowing. A small percentage of people first notice that their breathing is affected.

After initial symptoms appear, ALS gradually weakens voluntary muscles throughout the body. The disease tends to progress at a steady rate, though it can also accelerate, plateau, or slow at times. In extremely rare cases, ALS has seemed to stop or reverse. ALS does not normally affect vision, hearing, smell, taste, or touch. Nor does it tend to alter bladder, bowel, or sexual functions.

## Pain and ALS

Though symptoms like muscle twitching and cramping can be uncomfortable, ALS itself doesn't tend to be painful. However, pain can result from the muscle atrophy and immobility caused by ALS. If, for example, your arm and shoulder muscles weaken, your arms may hang down and cause pain in your shoulder joint.

## Are there stages of ALS?

Because ALS affects everyone so differently, there is no formal staging or classification system for ALS like there is for cancer. There are, however, some helpful tools that ALS medical professionals and researchers use to measure disease progression.

The ALS Functional Rating Scale (ALSFRS-R) is a questionnaire that measures a person's physical abilities to complete daily activities such as speaking, swallowing, handwriting, climbing stairs, walking, cutting food, and breathing. During clinic visits, professionals rate twelve different areas from 0-4 for an overall rating of 0-48. This scale is used to measure changes in function over time and to track drug effectiveness in clinical trials.

Forced vital capacity (FVC) is the primary test used to evaluate changes in breathing over time. It measures your current breathing level as a percentage of your initial baseline breathing ability. Forced vital capacity is one of the primary indicators that medical professionals use to determine how far a person's ALS has progressed, and it helps inform the timing of decisions, including the implementation of respiratory support and when to get a feeding tube.

## Is there anything I can do to live longer?

Yes. There are a few approved drugs that can help slow functional decline and extend life. In addition, there are non-drug interventions such as non-invasive ventilation (NIV) and nutrition that can help you live longer and have a better quality of life.

It is very important, if possible, to attend an ALS clinic with a multidisciplinary team of ALS specialists who can monitor your disease progression in order to optimize implementation of care interventions, provide support, make recommendations, and guide you every step of the way. Attending an ALS clinic once every few months has been shown to improve quality of life and extend life by one year or more.

### Get Local Support



**ALS United North Carolina**  
**4 N. Blount Street - Suite 200**  
**Raleigh, NC 27601**  
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**(919) 755-9001**

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