ALS SLA CANADA

FACT SHEET

# BULBAR ALS

## What is bulbar ALS?

Bulbar ALS is a subtype of ALS that destroys motor neurons in the corticobulbar area of the brain and brainstem. This area controls muscles in the face, head, and neck including the jaw, lips, throat, and tongue. As a result, common symptoms of bulbar dysfunction include problems with speech and swallowing, excessive saliva, and difficulty breathing.

Bulbar ALS begins by impacting a person's speech and swallowing, which is termed bulbar-onset ALS and accounts for thirty per cent of ALS cases. In contrast, spinal-onset ALS is characterized by symptoms impacting the hands, arms, legs, or feet. Eighty per cent of people with ALS will experience symptoms of bulbar dysfunction as the disease progresses over time.

## Common symptoms of speech dysfunction in bulbar ALS

- Changes in voice and speech, also known as dysarthria, which may include:
  - Changes in pitch and strength of voice, which can be strained, soft, or quieted.
  - Slurred speech, difficulty articulating specific sounds, or a slower speech rate.
  - Nasally sounding voice, as if the affected individual is talking through their nose.
  - Progressive fatigue or difficulty speaking that worsens over a typical day.

## Common symptoms of swallowing dysfunction in bulbar ALS

- Difficulties with chewing and swallowing, also known as dysphagia, which may include:
  - Coughing, gagging, and/or choking during or after swallowing.
  - Difficulty clearing food residues from the mouth, often caused by weakened muscles in the tongue, lips, or cheeks.
- Weakened cough, making it difficult for the affected individual to clear saliva and often resulting in drooling and excessive saliva.

## Other symptoms of bulbar ALS

- Involuntary spasms and/or twitching in muscles of the jaw, face, throat, and tongue.
- Spasms in the vocal cords, also known as laryngospasms, resulting in coughing fits or the sensation in affected individuals that air cannot be moved in or out.
- Sudden episodes of excessive laughing and/or crying, also known as the pseudobulbar affect.

## Bulbar ALS prognosis

Generally, bulbar-onset ALS is associated with poorer health outcomes than spinal-onset ALS because of its early impact on swallowing and breathing. On average, people diagnosed with bulbar-onset ALS live for two years from the time symptoms begin while those with spinal-onset ALS live for two to five years from the time symptoms begin.

The onset of bulbar dysfunction typically causes ALS to progress quicker, resulting in a decreased quality of life. Nearly fifty per cent of individuals affected by bulbar dysfunction symptoms may experience cognitive deficits, such as changes in their ability to think, make decisions, plan, remember words, or use complex sentences.

## Maintaining quality of life

There are ways to maintain quality of life for individuals affected by bulbar ALS, including but not limited to:

- Communication devices or applications installed on personal devices to support communication as symptoms progress (e.g., voice banking).
- Dietary changes and swallowing strategies to support chewing and swallowing (e.g., changes in posture, a feeding tube can help maintain proper nutrition).
- Assistive devices are available to help control excessive saliva and oral secretions.

For more information, affected individuals and families are encouraged to contact their local ALS Society or ALS clinical care team for complete information specific to their individual needs.

### KNOW THAT WE ARE HERE TO HELP

The ALS Society of Canada can assist in connecting people and families living with ALS in Ontario to support services, equipment, and ALS clinics. We also invest in the most promising Canadian ALS research, advocate federally and provincially for the needs of people affected by ALS, and provide information to empower Canadians affected by the disease. Learn more at www.als.ca where you can also find more resources in the "What is ALS?" section.

If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region.

## Additional Resources for Patients and Families

For more information about bulbar ALS, its associated symptoms, and steps to take when seeking medical care, please explore some of the available resources listed below:

https://als.ca/what-is-als/resources/living-with-als/
https://www.als.org/navigating-als/resources
https://www.als.org/understanding-als
https://als.org/navigating-als/resources/fyi-suggestions-and-information-about-speech-changes
https://www.als.org/navigating-als/resources/fyi-managing-excessive-saliva

## References


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