



BULBAR ALS

| Fact Sheet

What is Bulbar ALS?

- Bulbar ALS destroys motor neurons in the corticobulbar area of the brainstem in the early stages of ALS.
- The corticobulbar area controls muscles of the face, head and neck.
- Bulbar ALS usually progresses faster than limb onset.

How Common is Bulbar ALS?

- Bulbar onset observed in 30 per cent of people with ALS.
- Almost all people with ALS display bulbar symptoms at later stages.

Symptoms Affecting Speech

- Changes in voice and speech.
- Harsh, hoarse or strained voice.
- Breathy speech pattern.
- Poor articulation.
- Decrease in range of pitch and loudness of voice.

Other Symptoms

- Spasms in muscles of the jaw, face, voice box, throat and tongue.
- Inappropriate excessive laughing and crying.
- Brisk jaw jerks.
- Involuntary twitching in the muscles of the tongue.
- Vocal cord spasms causing the sensation that air cannot be moved in or out.

Not All People Living with Bulbar ALS Experience the Same Symptoms

- Loss of speech occurs in 93 per cent of people with bulbar ALS.
- Difficulty swallowing occurs in 86 per cent of people with bulbar ALS.
- Involuntary tongue twitching occurs in 64 per cent of people with bulbar ALS.
- Vocal cord spasms occur in 19 per cent of people with bulbar ALS.

There Are Ways to Maintain Quality of Life

- Speak to the members of your ALS clinic team about dietary changes, communication devices, speech therapy and medications that can help maintain quality of life.

Diagnosis

- There is no bulbar ALS-specific diagnostic test. Other diseases and conditions must be ruled out first.
- Doctors use physical examination to assess swallowing, lip and tongue strength and speech.
- Electromyography (EMG) test, blood tests, MRIs, and other tests to search for diseases similar to ALS.
- Many doctors and neurologists do not have experience recognizing and treating ALS, so patients are often sent to an ALS specialist to confirm a diagnosis.
- Find an ALS doctor in your province at http://www.als.ca/if_you_have_als/health_clinics.aspx
- People diagnosed with ALS should be fully informed about the disease, treatments, current research trials and available support services by the ALS Society in their province. A list of provincial ALS societies is available at <http://www.als.ca/units>.