

# DON'T DELAY, REFER ALS.

COULD THIS BE ALS? A TOOL FOR PHYSICIANS

## REFER BEFORE YOU'RE SURE

You **DO NOT** need confirmation of an ALS diagnosis to refer. Clinicians at CALS Clinics prefer that referrals are sent while exam results are pending and before a diagnosis.

### ✘ Patients with a DELAYED referral may:

- > Circulate through the healthcare system undergoing numerous tests and specialist referrals leading to misdiagnoses
- > Receive later than recommended multi-disciplinary support
- > Not qualify for important standard of care treatments, emerging therapies and/or clinical trials due to disease progression (*Note: some treatments require initiation before 18 and 24 months of symptom onset*)



Version 1

### DIAGNOSTIC DELAY:

 up to **2 years**

This may be most of an ALS patient's remaining life.

## SIGNS/SYMPTOMS & CLINICAL FEATURES

Amyotrophic lateral sclerosis (ALS) is a heterogeneous disease that can be difficult to diagnose. It is critical to identify both the **onset AND progression** of these symptoms:

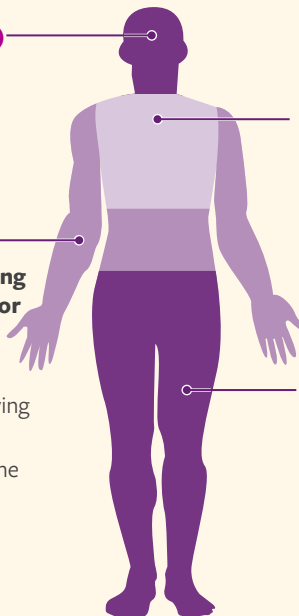
### HEAD AND NECK (BULBAR)

- > Emotional lability
- > Slurred speech
- > Difficulty swallowing
- > Excess saliva

### UPPER BODY

**Progressive weakness resulting in asymmetric decline in motor function:**

- > Impaired handwriting
- > Difficulty lifting, reaching, carrying
- > Difficulty with everyday tasks (e.g., preparing food, starting the car, using keys, opening jars or bottles, retrieving change from pockets, etc.)
- > Trouble with dressing/hygiene (e.g., doing buttons, cutting fingernails, etc.)



### RESPIRATORY

- > Shortness of breath with exertion or activities of daily living
- > Orthopnea

### LOWER BODY

**Progressive asymmetric weakness resulting in a decline in gross motor function:**

- > Frequent tripping
- > Difficulty on stairs, getting out of a chair, standing on toes, etc.
- > Foot drags when walking; cannot walk as long/far

## ! REFER IMMEDIATELY

- Asymmetry + Progression** (progression of the motor syndrome within a region or to other regions)
- Progressive Speech and/or Swallowing Difficulties**
- Pseudobulbar Affect**

### CONSIDER A REFERRAL

- Cognitive complaints/symptoms in presence of mobility impairment/weakness
- Upper/lower motor neuron signs
- Failure to thrive in elderly patient
- Patient suspects ALS

### NOTE THESE COMMON ALS MISDIAGNOSES

- **Carpal Tunnel/Sciatica/Ulnar Neuropathy** are UNLIKELY if patient exhibits hand weakness/foot drop with no pain or sensory loss
- **MSA, Parkinson's, Alzheimer's** may have SIMILAR symptoms

# DON'T DELAY, REFER ALS. RIGHT AWAY.

## WHEN TO REFER?

Referral to a specialized Canadian ALS Research Network (CALs) Clinic should occur...



...AS SOON AS ALS IS SUSPECTED



...PRIOR TO COMPLETION OF DIAGNOSTIC TESTING



...IN ABSENCE OF A DEFINITE DIAGNOSIS

## HOW TO REFER?

### 1. ORDER TESTS AND REFER

Refer to your nearest CALs Clinic, while these results are pending:

- Pulmonary Function Test (FVC)
- Electromyography (EMG)
- Imaging

#### IT IS ALSO BENEFICIAL TO:

- > Indicate if your patient is aware they are being referred to a CALs Clinic
- > Consider genetic testing when there is an indication of family history

### 2. COMMUNICATE THE REFERRAL TO YOUR PATIENT



**Share and Review the Patient Tool (page 3) with your patient.**

Discussions on prognosis DO NOT need to take place during initial diagnosis/referral stages unless specifically requested.

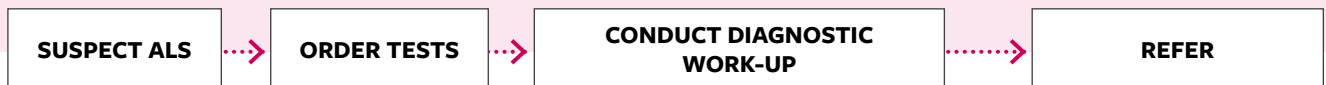
#### YOU MAY FIND IT HELPFUL TO SAY:

- "I'm concerned that there are signs that this could be a serious neurologic disease. I want to refer you to another expert — a neurologist or physiatrist — who will see you in about 2-6 weeks to assess/re-assess your symptoms."
- "This is not a diagnosis yet. The CALs clinic is best equipped to do further testing and may be able to provide you with better care supports for your symptoms."

@ QUESTIONS? [REFERRALS@ALS.CA](mailto:REFERRALS@ALS.CA)

## CONSIDER THESE REFERRAL SCENARIOS...

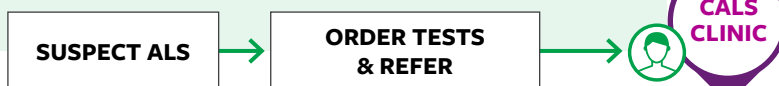
**✗ DELAYED REFERRAL/WAIT AND SEE:** Patient waits up to 2 years for diagnosis



Patient circulates through the healthcare system unnecessarily

Worsening symptoms, diminishing access to supports and emerging therapies

**✓ EARLIER REFERRAL:** Patient seen in 2-6 weeks



Patient is referred as soon as ALS is suspected and in the absence of a confirmed diagnosis

Earlier referral means faster diagnosis, timely access to critical multidisciplinary care and better quality of life.

#### WHAT IF IT'S NOT ALS?

CALs Clinics can expedite appropriate investigation and referral of other diagnoses



This document was created by the ALS Society of Canada and the CALs Network and is supported by our funding partners:



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# WHY AM I BEING REFERRED?

**COULD THIS BE ALS? A TOOL FOR PATIENTS**

## REASON FOR YOUR REFERRAL

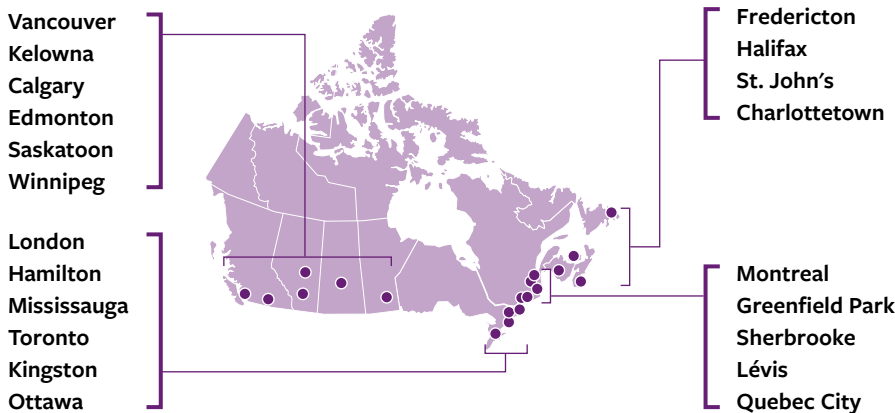


Version 1

Amyotrophic lateral sclerosis (ALS) is hard to diagnose because the symptoms can be very similar to other diseases. At a **CALS clinic**, you will be seen by a neurologist or physiatrist (an expert in physical medicine and rehab) who is trained to test for, diagnose, and support people living with ALS.

### What is a CALS Clinic?

The Canadian ALS Research Network, or CALS, is a network of 24 centres across Canada that specialise in ALS research and provide the best standard of care in a multidisciplinary (team of healthcare professionals) setting.



### Earlier diagnosis is critical

**IF you DO have ALS**, at a CALS Clinic you'll have more direct access to specialists who can help get you better access to supports, clinical trials that can slow the progression of the disease and improve your quality of life.

**IF you DO NOT have ALS**, CALS Clinicians may refer you to other specialists or for further tests.

CALS CLINIC

### Your appointment location:

## QUESTIONS ABOUT YOUR SYMPTOMS?

**If you have concerns about any of these symptoms, please bring them to your CALS Clinic appointment:**

- TROUBLE BREATHING
- SPEAKING PROBLEMS
- EXCESS SALIVA
- TROUBLE SWALLOWING
- EXCESSIVE LAUGHING & CRYING
- PAIN
- MUSCLE TWITCHES
- TIGHT LIMBS
- CRAMPS

**Your CALS Clinicians may also discuss these symptoms and other topics with you:**

- DEPRESSION
- ANXIETY
- INSOMNIA (TROUBLE SLEEPING)
- FATIGUE
- NUTRITION
- EXERCISE
- COGNITION (THINKING) and BEHAVIOUR

**Any or all of these tests may be used to help diagnose ALS:**

- > Blood and urine studies
- > Breathing tests
- > Magnetic Resonance Imaging (MRI)
- > Muscle and nerve function tests

ALS Society of Canada has worked closely with the CALS network and funding partners to present this important information to you. For more information visit: [als.ca/research/canadian-als-research-network](https://als.ca/research/canadian-als-research-network) or contact [referALS@als.ca](mailto:referALS@als.ca).



# WHY AM I BEING REFERRED FOR ALS?



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