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)

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:

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

Refer immediately

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

Consign the 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

The ALS Society of Canada has worked closely with the CALS Network and funding partners to present this critical referral information to you. For more information visit: als.ca/referrals or contact referALS@als.ca.
DON’T DELAY, REFER ALS. RIGHT AWAY.

WHEN TO REFER?

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

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? REFERALS@ALS.CA

CONSIDER THESE REFERRAL SCENARIOS...

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

EARLIER REFERRAL: Patient seen in 2-6 weeks

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:
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.

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

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.

Your appointment location:

Vancouver
Kelowna
Calgary
Edmonton
Saskatoon
Winnipeg

London
Hamilton
Mississauga
Toronto
Kingston
Ottawa

Fredericton
Halifax
St. John’s
Charlottetown

Montreal
Greenfield Park
Sherbrooke
Lévis
Quebec City

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 or contact referALS@als.ca.
WHY AM I BEING REferred FOR ALS?