INTERNATIONAL ALLIANCE OF ALS/MND ASSOCIATIONS | MY NAME'5 DODDIE FOUNDATION

R.A.C.E. TO DIAGNOSE ALS/MND

Recognize • Assess • Communicate • Expedite

Diagnostic delay remains one of the most significant barriers to timely, effective ALS/MND care. R.A.C.E. to Diagnose ALS/MND is a free online course that gives health professionals across diverse care settings a clear, four-step protocol for recognizing red flags and referring early — without waiting for full diagnostic confirmation.

R Recognize the early signs and symptoms of ALS/MND across diverse healthcare settings and specialties.

A Assess clinical features and initiate appropriate investigations, if warranted, without delaying referral.

C Communicate the need for an urgent onward specialist referral for suspected ALS/MND.

E Expedite referral, even without complete diagnostic confirmation, and ensure referral letters clearly communicate key clinical findings to support triage.

RED FLAGS: SIGNS, SYMPTOMS & CLINICAL FEATURES OF ALS/MND

Head & Neck Symptoms (Bulbar)

20–25% present with bulbar onset

- Slurred or impaired speech (dysarthria)
- Difficulty swallowing (dysphagia)
- Excess saliva
- Tongue twitching (fasciculations)

Upper Body Symptoms

- Progressive, asymmetric weakness
- Hand weakness; limited range of motion
- Difficulty lifting, reaching, or carrying
- Difficulty with everyday tasks (opening jars, using keys)
- Impaired handwriting
- Muscle spasms, twitching, fasciculations
- Trouble with dressing or hygiene

Lower Body Symptoms

- Progressive, asymmetric weakness
- Frequent tripping or stumbling
- Difficulty on stairs, getting out of a chair, or standing on toes
- Foot drags when walking; cannot walk as long or as far
- Muscle wasting or atrophy

Cognitive Symptoms

35% experience clinically significant cognitive changes

- Behavioural changes
- Emotional lability, unrelated to dementia
- Fronto-temporal dementia

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Respiratory Symptoms

1–3% present with respiratory onset

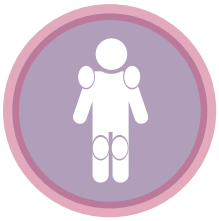
- Hard-to-explain respiratory symptoms
- Shortness of breath on exertion with daily activities
- Restricted breathing
- Excessive daytime sleepiness or difficulty sleeping
- Orthopnea

Unintentional or Unexplained Weight Loss

- Can occur alone or alongside other symptom categories
- Ask specifically when other red flags are present

CLINICAL FEATURES NOT SUPPORTIVE OF AN ALS/MND DIAGNOSIS

SENSORY SYMPTOMS OR IMPAIRMENT



SYMMETRICAL SIGNS OR SYMPTOMS

PAIN

SYMPTOM IMPROVEMENTS (WITH OR WITHOUT INTERVENTION)

KEY TAKE-HOME MESSAGES

- Early recognition and referral improves survival and quality of life. Every month counts.
- If a presentation is progressive and does not fit a typical pattern — refer.
- ALS/MND is a clinical diagnosis of exclusion. Diagnostic tests can support a referral but should not delay it.
- Multidisciplinary care improves quality of life. Early referral offers a path forward, not just a diagnosis.

ACCESS THE COURSE

Scan the QR code or visit als-mnd.org/diagnose for the full course, including video presentations and participant handouts

Questions? Contact: education@als-mnd.org

ALS, amyotrophic lateral sclerosis; MND, motor neuron disease.
Red flags adapted from: ALS Pathways (alspathways.com); ALS Canada Early Referral Tool (als.ca); Masrori P, et al. Eur J Neurol. 2020;27:1918–1929; Verma A. Amyotrophic Lateral Sclerosis. Exon Publications, 2021, Chapter 1.

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