



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

MY
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FOUNDATION

Participant Handout

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

Recognize, Assess, Communicate, Expedite

A Call to Action to Refer Early Across Diverse Healthcare Settings



R-A-C-E PROTOCOL TO AVOID DELAYING REFERRAL

R Recognize the red flags

A Assess clinical features & initiate appropriate diagnostic testing (if feasible)
Assessment & testing should not delay referral!

C Communicate the need for referral
Frame referral as a positive next step toward clarity and support

E Expedite referral —
don't wait for confirmatory testing
Emphasize “progressive, painless loss of function” on referral letters



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RED FLAGS: Key Signs, Symptoms, & Clinical Features of ALS/MND

20%–25% present with bulbar onset

Head & neck symptoms (bulbar)

- Dysarthria (slurred or impaired speech)
- Dysphagia (difficulty swallowing)
- Excessive saliva
- Tongue fasciculations

Cognitive symptoms

- Behavioural changes
- Emotional lability (not related to dementia)
- Fronto-temporal dementia

35% experience clinically significant cognitive changes

Upper body symptoms

Progressive weakness resulting in asymmetric decline in motor function:

- Hand weakness
- Limited range of motion and/or difficulty lifting, reaching, or carrying
- Difficulty with everyday tasks (e.g., preparing food, opening jars or bottles, starting car, using keys)
- Impaired handwriting
- Muscle spasms, twitching, fasciculations
- Trouble with dressing/hygiene

Respiratory symptoms

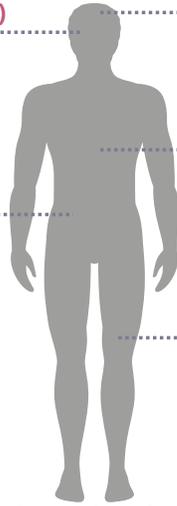
- Hard-to-explain respiratory symptoms
- Shortness of breath on exertion with daily activities
- Restricted breathing
- Excessive daytime sleepiness or difficulty sleeping
- Orthopnea

1%–3% present with respiratory onset

Lower body symptoms

Progressive asymmetric weakness resulting in decline in gross motor function:

- Frequent tripping or stumbling
- Difficulty on stairs, getting out of chair, standing on toes, etc.
- Foot drags when walking, cannot walk as long/far
- Muscle wasting/atrophy



Unintentional/
unexplained weight loss

ALS, amyotrophic lateral sclerosis; MND, motor neuron disease

Adapted from: 1. <https://www.alspathways.com/als-overview/>. 2. <https://als.ca/resource/referrals-early-referral-tool/>. 3. Masrori P, et al. Eur J Neurol. 2020;27:1918-1929. 4. Verma A, Amyotrophic Lateral Sclerosis [Internet]. Brisbane (AU): Exon Publications. 2021. Chapter 1.

Key Take-Home Messages



Early recognition and referral improves survival and quality of life

- ALS/MND is a progressive disease, where every month counts — early diagnosis enables access to multidisciplinary care, disease-modifying therapies, clinical trials, symptom management, and supportive care



If it's progressive and doesn't fit — REFER

- Progressive, painless loss of function or unexplained weight loss with breathlessness should raise red flags — timely referral to an ALS/MND specialist is essential



Don't delay referral for testing

- ALS/MND is a clinical diagnosis of exclusion; diagnostic tests can support but should not delay referral



Overcome therapeutic nihilism — there is much we can do

- While ALS/MND remains incurable, multidisciplinary clinics offer proactive, patient-centred care that supports quality of life
- Early referral offers patients and families a path forward — not just a diagnosis

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VIDEOS

Please go to the following website to access the videos below:

[https://www.als-mnd.org/
support-for-health-professionals/race-to-diagnose/](https://www.als-mnd.org/support-for-health-professionals/race-to-diagnose/)



Mr. Craig Reyenga
Ottawa, Ontario, Canada

Person with ALS/MND Sharing His Diagnostic Journey

Craig Reyenga, a person living with ALS/MND, shares his challenging diagnostic journey and the difficulties he faced throughout the process.



Prof. Orla Hardiman
Dublin, Ireland

Overcoming Therapeutic Nihilism in ALS/MND

Prof. Hardiman addresses the misconception that ALS/MND referrals are futile, stressing that multidisciplinary clinics significantly improve quality of life, offer access to research and emerging therapies, and provide meaningful hope for patients.

Faculty Members

The Cost of Delayed Diagnosis: Personal Stories from the Faculty

Members of the faculty present cases they have encountered that highlight the real-world impact of diagnostic delays in ALS/MND.



**Prof. Nortina
Shahrizaila**
Kuala Lumpur, Malaysia

RECAP: When to Suspect ALS/MND and Refer

Prof. Shahrizaila summarizes key red flags for ALS/MND, such as progressive, painless loss of motor function or unexplained weight loss with breathing difficulty, and emphasizes the need for immediate referral when symptoms do not fit typical patterns.



Prof. Orla Hardiman
Dublin, Ireland

Avoid Diagnostic Pitfalls: Prioritize Urgent Referrals

Prof. Hardiman advises non-specialists to refer suspected ALS/MND cases promptly rather than ordering exhaustive tests, noting that early referral prevents delays, reduces unnecessary costs, and ensures patients access specialized evaluation.



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Mr. Craig Reyenga
Ottawa, Ontario, Canada

Craig's MRI Maze: A Journey Through Missed Opportunities and Delayed Referral

Craig Reyenga reflects on his prolonged diagnostic process and how delays left him uncertain about how to live his life and plan for the future, wishing he had been referred to a specialist sooner.

MRI, magnetic resonance imaging



**Prof. Christopher
J. McDermott**
Sheffield, England, UK

Faculty Perspective: Frustration with Referral Delays

Prof. McDermott discusses the frustration of receiving late referrals for ALS/MND patients, emphasizing how waiting for diagnostic certainty delays care, support, and access to clinical trials. He urges clinicians to refer early if ALS/MND is even a possibility.

Ms. Leanne Sklavenitis
Australia

Mr. Bruce Virgo
Scotland

From Diagnostic Uncertainty to Clarity: Insights from the Voices of People Living with ALS/MND

Two people living with ALS/MND share their journey, describing the impact of not having a diagnosis and how they felt once it was confirmed.



Ms. Marla Calder
Fredericton,
New Brunswick, Canada

What If the Patient Asks: "Could this be ALS/MND?"

Marla Calder explains how allied health professionals should respond when patients raise concerns about serious conditions—by being honest, supportive, and ensuring prompt referral and clear documentation rather than attempting to diagnose.



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RESOURCES



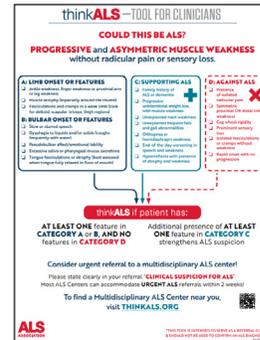
ReferALS Early Tool



<https://als.ca/resource/referals-early-referral-tool/>



ThinkALS Tool



<https://www.als.org/thinkals/thinkals-tool>



The MND Red Flag Tool



<https://www.mndassociation.org/professionals/management-of-mnd/management-by-specific-professions/information-for-gps/red-flag-diagnosis-tool>



The MND Red Flag Tool – Australia



<https://www.mndaustalia.org.au/mnd-connect/for-health-professionals-service-providers/diagnosing-mnd>



