



INTERNATIONAL ALLIANCE
OF ALS/MND ASSOCIATIONS

MY
NAME'S
DODDIE
FOUNDATION

Speaker Guide

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

Recognize, Assess, Communicate, Expedite

A Call to Action to Refer Early Across Diverse Healthcare Settings





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Program Faculty



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Person living with ALS/MND
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Program Overview

Research has shown that a diagnosis of amyotrophic lateral sclerosis/motor neuron disease (ALS/MND) is often delayed by over a year, with most studies reporting delays of 10–16 months and, in some cases, more than 24 months. Such delays significantly impact patients and their families, leading to lost opportunities for early interventions that could improve quality of life and survival.

Persons with ALS/MND are typically evaluated every three months by a multidisciplinary care team. Multidisciplinary care respects patient autonomy, facilitates shared decision-making, and provides access to therapies and supportive interventions that can meaningfully affect disease progression and quality of life.

Early diagnosis is critical because it enables individuals to:

- Make important life decisions (e.g., housing, financial planning) before significant functional decline.
- Anticipate and prepare for future needs.
- Begin disease-modifying therapies earlier, when they are most beneficial.
- Access clinical trials and experimental therapies that are only available at certain disease stages.

The committee has designed the program to help improve healthcare professional awareness, skills, and confidence in recognizing early signs and reducing time to diagnosis. The program draws upon research insights, patient and healthcare professional perspectives, and case studies.

Target Audience



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This program is designed for the following specialties involved in the treatment and management of ALS/MND:

- General neurologists
- Orthopedic surgeons
- Rheumatologists
- Physiotherapists
- Early career physicians
- Psychiatrists / rehabilitation physicians
- ENT specialists
- Occupational therapists
- Neurosurgeons
- Speech language therapists

Learning Objectives

- Recognize the early signs and symptoms of ALS/MND across diverse healthcare settings and specialties
- Assess clinical features and initiate appropriate investigations (if warranted) without delaying referral
- Communicate the need for an urgent onward specialist referral to those with suspected ALS/MND
- Expedite referrals — even in the absence of complete diagnostic confirmation — and ensure referral letters clearly communicate key clinical findings to support triage

How To Access The Program

The program is available on the International Alliance of ALS/MND Associations website:

<https://www.als-mnd.org/support-for-health-professionals/diagnostic-delay/>

Program Duration And Outline

The program is designed to be delivered in approximately 90 minutes and consists of the following key sections:

Section	Timing
An Introduction: Why Early Recognition of ALS/MND Matters	
Delays in ALS/MND diagnosis often exceed 12 months, leading to missed opportunities for early intervention, reduced survival, and diminished quality of life. This section highlights the critical importance of timely recognition and referral, explores the complex diagnostic journey across multiple specialties, and addresses the need to overcome therapeutic nihilism—a mindset that can hinder proactive care. Faculty insights and patient stories illustrate the real-world impact of these delays and reinforce the call to action for earlier clinical responses. This section also includes the following videos:	15-20 min
1. Mr. Craig Reyenga – Person with ALS/MND Sharing His Diagnostic Journey (2 min)	
2. Prof. Orla Hardiman – Overcoming Therapeutic Nihilism in ALS/MND (1 min 30)	
3. The Cost of Delayed Diagnosis: Personal Stories from the Faculty (6 min 30)	

Section	Timing
Early Symptom Roadmap: What to Look For This section explores the hallmark signs, symptoms, and clinical features that should raise suspicion for ALS/MND. It emphasizes key red flags across motor, bulbar, respiratory, and cognitive domains, and provides specialty-specific guidance to help clinicians identify early clues within their own practice. Through interactive case discussions, participants will apply these insights to determine when ALS/MND should be suspected and referral initiated. This section also includes following video: 1. Prof. Nortina Shahrizaila – RECAP: When to Suspect ALS/MND and Refer (1 min)	25-30 min
Assessment and Investigations Should Never Delay Referral When ALS/MND is Suspected This section outlines the diagnostic process for ALS/MND, which relies on thorough clinical evaluation and the exclusion of other conditions. While diagnostic tests can help rule out mimics, they should never delay referral when ALS/MND is suspected. Timely action based on clinical judgment is essential to avoid missed opportunities for early intervention and care. This section includes the following videos: 1. Prof. Orla Hardiman – Avoid Diagnostic Pitfalls: Prioritize Urgent Referrals (1 min 30) 2. Mr. Craig Reyenga – Craig's MRI Maze: A Journey Through Missed Opportunities and Delayed Referral (2 min 45) 3. Prof. Christopher J. McDermott – Faculty Perspective: Frustration with Referral Delays (1 min 15)	10 min
Initiating Timely and Effective Referrals: When, How, and Where This section provides practical guidance on initiating timely referrals for suspected ALS/MND. It outlines when to refer based on clinical suspicion, how to communicate urgency and key findings in referral letters, and where to direct patients using global clinic locators and available resources.	8 min
Communicating Diagnostic Uncertainty and the Need for Specialist Referral Clinicians are guided on how to acknowledge diagnostic uncertainty with empathy, validate patient distress, and frame referral as a positive next step. This section includes suggested language and strategies to maintain trust while emphasizing the importance of specialist evaluation. It includes the following videos: 1. Ms. Leanne Sklavenitis & Mr. Bruce Virgo – From Diagnostic Uncertainty to Clarity: Insights from the Voices of People Living with ALS/MND (2 min 30) 2. Ms. Marla Calder – What If the Patient Asks: "Could this be ALS/MND?" (1 min)	8 min
Take-Home Messages, Call to Action, Resources, and Q&A The concluding portion of the program emphasizes the critical importance of early recognition and referral in ALS/MND. It delivers a clear call to action for clinicians to act promptly on clinical suspicion. Participants are equipped with practical tools and resources to support timely decision-making and effective referrals. The session wraps up with a Q&A and reflection period, encouraging participants to share key take-aways and consider how they will integrate these insights into their clinical practice.	20 min
Although videos are presented throughout the program, the speaker may decide to skip some of them depending on the time allotted for the program and/or the program audience. The speaker can also choose to display either the video or its corresponding slide, hiding one while presenting the other. Note that participants will receive a handout that provides a link to access all videos that appear in the program. Therefore, participants will still be able to view all available videos even if they are not presented during the session.	

Virtual presentation:

- Ensure you have downloaded the PowerPoint presentation and completed the disclosure slides:
www.als-mnd.org/support-for-health-professionals/diagnostic-delay
- Your contact at the International Alliance of ALS/MND will provide you with the link to connect to the virtual session and will arrange a test session 5-7 days before the session to be sure you are familiar with the virtual platform.
- You will be asked to share the presentation from your computer.
- At the end of the session, your contact at the International Alliance of ALS/MND Associations will put an evaluation link in the chat for participants to complete.

In-person presentation:

- Ensure you have downloaded the PowerPoint presentation and completed the disclosure slides:
www.als-mnd.org/support-for-health-professionals/diagnostic-delay
- Please use your computer to present the program.

Questions?

Please contact the International Alliance of ALS/MND Associations at education@als-mnd.org.

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