

# How to Break the News in ALS/MND

A Primer for Physicians and Allied Health Professionals

## Speaker Guide



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## A Primer for Physicians and Allied Health Professionals



### Program Faculty



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### Program Overview

Research has shown that the manner in which a diagnosis of amyotrophic lateral sclerosis/motor neuron disease (ALS/MND) is delivered is a source of discontent for many people living with the disease and their caregivers.<sup>1-4</sup> This is not surprising given that conveying sensitive news to patients is an arduous and emotionally challenging task for healthcare professionals (HCPs), which many feel ill prepared for given the lack of medical training curricula devoted to this area.<sup>5,6</sup> *How to Break the News in ALS/MND: A Primer for Physicians and Allied Health Professionals* has been designed to improve HCP comfort and confidence in this task by providing them with the skills required to deliver challenging news effectively. The program centers around the A-L S-PIKES protocol which uses well-established principles of communication and counselling that are aimed at improving patient quality of life and promoting the well-being of HCPs involved in the care and management of people living with ALS/MND.

This committee has voluntarily removed the word **bad** from the communication skill of delivering **bad** news in ALS/MND. Whereas there will always be an element of suffering and challenge when speaking of an ALS diagnosis and/or disease progression, qualifying this as only "bad" news could potentially prime all parties to "only" focus on the BAD components.

#### References:

1. Shoosmith C, et al. CMAJ. 2020;192:E1453-E1468.
2. McCluskey L, et al. Amyotroph Lateral Scler Other Motor Neuron Disord. 2004;5:131-5.
3. Peters M, et al. J Health Serv Res Policy. 2013 Jan;18(1):28-33.
4. Abdulla S, et al. Amyotroph Lateral Scler Frontotemporal Degener. 2014;15:505-12.
5. Baile WF, et al. Oncologist. 2000;5:302-11.
6. Buckman R. Community Oncology 2005;2:138-42.

## Target Audience

This program is designed for physicians and allied healthcare professionals (AHPs) involved in the treatment and management of ALS/MND, including:

- Neurologists
- Psychiatrists
- Nurses
- Social workers
- Nutritionists/dietitians
- Psychologists
- Occupational therapists
- Physical therapists
- Respiratory therapists
- Speech language therapists

## Learning Objectives

- Describe the impact delivering news in ALS/MND can have on patients, caregivers and healthcare professionals
- Identify and address personal biases and perspectives on ALS/MND, death and dying
- Recognize and apply best practices in delivering news to people living with ALS and their caregivers
- Respond to patient/caregiver distress when receiving the news
- Apply the A-L S-PIKES technique in clinical practice to improve confidence and comfort in delivering news

## How To Access The Program

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

[www.als-mnd.org/support-for-health-professionals/how-to-break-the-news-in-als-mnd](http://www.als-mnd.org/support-for-health-professionals/how-to-break-the-news-in-als-mnd)

## Program Duration And Outline

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

Section	Timing
<b>An introduction to breaking sensitive news</b>	
This section provides an overview of the challenges associated with delivering sensitive news and focuses on the unique challenges in delivering this news in ALS/MND. It also includes the following three videos:	
1. "Why" this Program is Needed, by Dr. Angela Genge (≈2 min)	15-20 min
2. A Caregiver's Experience Receiving the Diagnosis (≈2 min)	
3. A Caregiver's Perspective on How Challenging Delivering a Diagnosis Must be for Clinicians (≈2 min)	

## Program Duration And Outline (continued)

Section	Timing
<b>Presentation of the A-L S-PIKES protocol</b> In this section, each step of the A-L S-PIKES protocol is reviewed in detail. The section also includes the following four videos: <ol style="list-style-type: none"><li>1. 'Know Thyself' Before the Meeting, by Dr. Melinda S. Kavanaugh (≈2 min)</li><li>2. 'Know Thyself' Mindfulness Exercise, by Dr. Melinda S. Kavanaugh (≈4 min)</li><li>3. Discuss Reasons for Hope, by Dr. Angela Genge (≈3 min)</li><li>4. What to Do When Emotions are Overwhelming, by Dr. Melinda S. Kavanaugh (≈3 min)</li></ol>	30-40 min
<b>Clinical pearls for physicians</b> This section is designed for physicians who are responsible for delivering a diagnosis of ALS/MND and consists of the following two videos: <ol style="list-style-type: none"><li>1. Clinical Pearls: How to Deliver an ALS/MND Diagnosis, by Dr. Colleen O'Connell (≈2-3min)</li><li>2. Clinical Pearls: What to Discuss When Delivering an ALS/MND Diagnosis, by Dr. Colleen O'Connell (≈3 min)</li></ol>	≈10 min
<b>Clinical pearls for AHPs</b> This section is designed for all AHPs involved in the care and management of people living with ALS/MND and consists of the following two videos: <ol style="list-style-type: none"><li>1. Clinical Pearls for AHPs in the "Aftermath" Period, by Dr. Melinda S. Kavanaugh (≈5 min)</li><li>2. A-L S-PIKES for AHPs, by Dr. Melinda S. Kavanaugh (≈6-7 min)</li></ol>	≈15 min
<b>Take-home messages, sharing experiences and learnings, and Q&amp;A</b> <ul style="list-style-type: none"><li>○ In this final section, the speaker will review the key take-home messages from the program and participants will be asked to share their experiences and learnings. They will also be asked to reflect on whether their comfort level in delivering challenging news has improved based on their participation in this program.</li><li>○ The speaker will also address any final questions from program participants in this closing section.</li></ul>	15-20 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 (i.e., physicians or AHPs). 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.

## Logistical Aspects

### Virtual presentation:

- Ensure you have downloaded the PowerPoint presentation from [www.breakthenewsinals.ca](http://www.breakthenewsinals.ca) and completed the disclosure slides.
- Your Mitsubishi representative 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.
- Polling questions will be programmed by your Mitsubishi representative directly on Zoom.
- At the end of the session, your Mitsubishi representative will put an evaluation link in the chat for participants to complete.

### Face-to-face events:

- Ensure you have downloaded the PowerPoint presentation from [www.breakthenewsinals.ca](http://www.breakthenewsinals.ca) and completed the disclosure slides.
- Please use your computer to present the program.
- For polling questions, you can ask participants to share their answers verbally.
- Your Mitsubishi representative will bring copies of the evaluation forms onsite.

## Questions?

Please contact your Mitsubishi Canada representative or email [info@agenceunik.ca](mailto:info@agenceunik.ca).

