

How to Break the News in ALS/MND

A Primer for Physicians and Allied Health Professionals

Participant Handout



A-L S-PIKES PROTOCOL FOR DELIVERING NEWS IN ALS/MND

A

ADVANCE PREPARATION

- Prepare for the discussion, both logistically and emotionally
 - Consider mentally rehearsing how you will deliver the news
- 'Know thyself' before the meeting
 - Identify your own personal perceptions/biases about the disease, death and dying that could lead to ineffective communication (see exercises on next page)
- Know the patient before the meeting (including case history, all relevant test results, clinical information, emotional and social situation and family support) and have all the information on hand for the discussion

LS

LOCATION & SETTING

- Have the conversation in a quiet, comfortable and private area
- Limit interruptions and arrange for adequate time to ensure there is no rushing
- Ensure there is a box of tissues on hand
- Make eye contact and sit close to the patient with no barriers between you
- Include caregiver/family/friends as patient desires
- Ensure other ALS/MND team members (e.g., nurse, social worker, therapist) are available if patient/family requires additional support during discussion

P

PATIENT'S PERCEPTIONS

Know where the patient is starting from:

- Assess what they already know about the condition, including their opinions, beliefs and thoughts
- Assess their current level of understanding
- Tailor delivery of information accordingly

- What do think might be wrong?
- What have you been told so far?
- When looking ahead, where do you think things are heading?

I

INVITATION

Before you tell, ask...

- Ask how much the person with ALS/MND wants to know
- Ask permission to give results or provide information so they can control the conversation
- Accept the person's right not to want to know, but offer to answer any questions they have at a later time

- How much information would you like me to give you?
- Are you someone who likes to know all the details or just the most important ones?

K

KNOWLEDGE

Sharing knowledge and information

- Present information in a step-down approach or in "chunks" based on what they want to know
- Pause often to confirm understanding and determine what else they want to know and how they're feeling
- Use the same language/terminology as your patient – avoid technical language and medical jargon
- Acknowledge that this is devastating news, but discuss reasons for hope
- Offer to provide information over time based on readiness to know more
 - Ensure appointment for next discussion is booked

- I know this is a lot of information; what questions do you have so far?
- How are you feeling about this so far? What else do you want to know right now?
- I know this is not the news you wanted to hear but there are reasons for hope...as well as support and resources available...

E

EMOTION & EMPATHY

Address emotions with empathetic responses

1. Listen for/observe and identify the emotion
 - Ask exploratory questions when emotions are not clear
 2. Identify source of emotion (most likely the news)
 3. Give them time to express their feelings then respond in a way that demonstrates you have recognized the connection between 1 and 2 (i.e., that you have identified the emotion and its origin)
 - Validate responses to help them realize their feelings are important
- See Videos section for what to do if emotions become overwhelming**

- How are you feeling right now?
- I think how you feel is a very normal response in this situation...
- How can we support you at this moment?

S

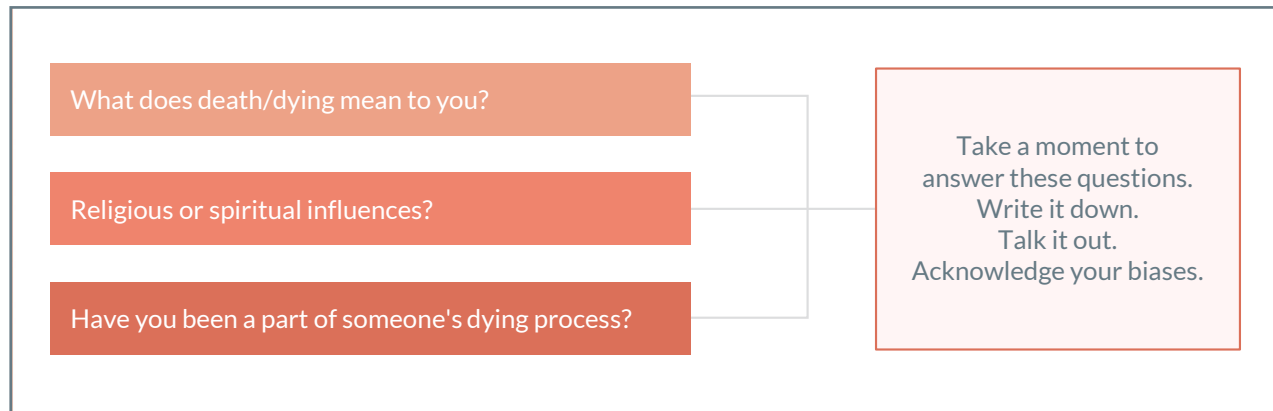
STRATEGY & SUMMARY

- Explore the patient's ideas, concerns, and expectations
- Recommend a strategy/plan for next steps based on the discussion
- Summarize the conversation
 - Consider providing a written plan or summary for them to take home
- Reassure them that the ALS/MND team will support them and they will not be 'abandoned'
- Provide reliable resources, including ALS/MND patient organizations

EXERCISES

'Know Thyself' Exercise

This exercise can help healthcare professionals identify any personal perceptions and/or biases that they may have toward death and/or dying which could impact their delivery of news to people living with ALS/MND and their caregivers. Please see the Videos section for further background and explanation of this exercise.



'Know Thyself' Mindfulness Exercise

This exercise builds on the previous "know thyself" exercise and focusses on helping healthcare professionals identify and respond to any of their own personal feelings and emotions that could affect how they communicate news to people living with ALS/MND. Please see the Videos section for further background and explanation of this exercise.

Identify

- What factors may be **influencing my emotions** affecting how I communicate news/diagnosis/progression in ALS/MND?

Monitor

- For your own **signs and feelings** – sadness, anxiety, fear, etc

Name

- Name **the emotion** – whatever it may be. It may change when repeating this exercise.

Sources

- What are the possible sources **of the emotions**?

Respond

- **Take a step back** to get perspective
- **Identify any behaviours** that may come out of the feeling (avoidance, wanting to rescue, feeling powerless or powerful)
- Think about how these **behaviours have consequences** with the diagnosis delivery
- **What alternatives exist?** Who can you add to the process?
- **Consult** with a trusted colleague or mentor

- Takes 5-7 minutes, but can be completed in small chunks throughout your day
- Find a space that is comfortable for you, but does not need to be anywhere specific
- Write out responses, or not
- Suggested for all healthcare professionals
- Suggested to think about this often. Feelings change, patients change, context changes



VIDEOS

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

www.breakthenewsinals.ca/video

Password: ALS



Dr. Angela Genge
Montreal, Quebec

Why this Program?

Dr. Genge shares her initial experiences in delivering news to people living with ALS/MND as a young Neurology Fellow, and explains how this led to the development of multidisciplinary centres of excellence in ALS/MND and the learnings shared in this educational program.



Dr. Melinda S. Kavanaugh
Milwaukee, Wisconsin

'Know Thyself' Before the Meeting Exercise

Dr. Kavanaugh explains how this exercise can help healthcare professionals identify any personal perceptions and/or biases that they may have toward death and/or dying which could impact their delivery of news to people living with ALS/MND and their caregivers.



Dr. Melinda S. Kavanaugh
Milwaukee, Wisconsin

'Know Thyself' Mindfulness Exercise

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Dr. Angela Genge
Montreal, Quebec

Reasons for Hope

Dr. Genge emphasizes the reasons for hope in ALS/MND, including current treatments that prolong survival and functioning, novel treatments under investigation, and the "army" of researchers around the globe that are working to find a cure.



Dr. Melinda S. Kavanaugh
Milwaukee, Wisconsin

What to do When Emotions are Overwhelming

Dr. Kavanaugh provides key tips to follow when emotions become overwhelming.



VIDEOS (continued)

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

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Password: ALS



Dr. Colleen O'Connell
Fredericton, New Brunswick

Clinical Pearls: How To Deliver an ALS/MND Diagnosis

Dr. O'Connell provides some of her key clinical pearls on *how to best* deliver an ALS/MND diagnosis.



Dr. Colleen O'Connell
Fredericton, New Brunswick

Clinical Pearls: What to Discuss When Delivering an ALS/MND Diagnosis

Dr. O'Connell provides some of her key clinical pearls on *what to discuss* when delivering an ALS/MND diagnosis.



Dr. Melinda S. Kavanaugh
Milwaukee, Wisconsin

Clinical Pearls for Allied Healthcare Professionals (AHPs) in the "Aftermath" Period

Dr. Kavanaugh shares some important clinical pearls for AHPs in the "aftermath" period following delivery of an ALS/MND diagnosis.



Dr. Melinda S. Kavanaugh
Milwaukee, Wisconsin

A-L S-PIKES for AHPs

Dr. Kavanaugh explains how AHPs can apply and integrate the A-L S-PIKES protocol throughout the entire disease trajectory in ALS/MND to help ensure the needs of patients and caregivers are met.



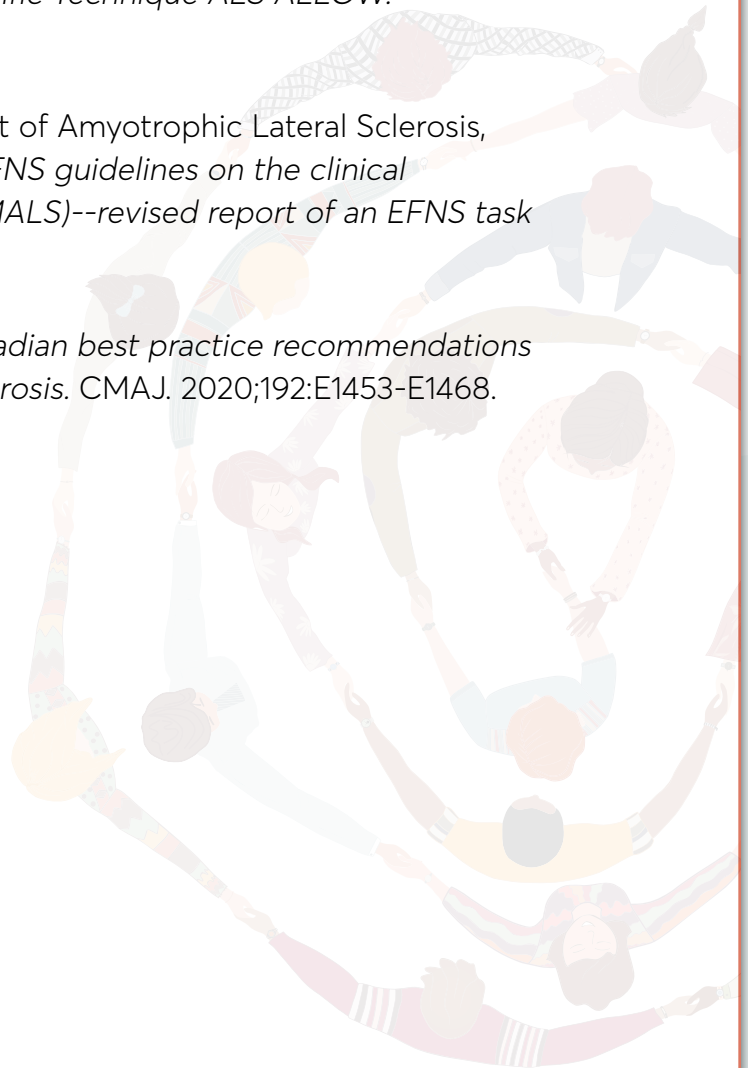
Norman MacIsaac
Montreal, Quebec

Person Living with ALS/MND Sharing His Thoughts and Experience

In this impactful video, Norman MacIsaac, a person living with ALS/MND, shares his experience when first receiving his diagnosis as well as his thoughts and comments on this program. Norman was diagnosed in 2014. Since then, he has been an active advocate for people living with ALS/MND. He collaborates with ALS Quebec, ALS Canada and the International Alliance of ALS/MND Associations.

SUGGESTED READINGS & RESOURCES

1. Buckman R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore: Johns Hopkins University Press. 1992.
2. Baile WF, Buckman R, Lenzi R, et al. *SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer*. *Oncologist*. 2000;5:302-11.
3. Buckman R. *Breaking bad news: the S-P-I-K-E-S strategy*. *Community Oncology* 2005;2:138-42.
4. Curseen K. *Implicit Bias and Its Impact on Palliative Care*. April 2021. Available at: <https://www.capc.org/blog/palliative-pulse-palliative-pulse-july-2017-overcome-implicit-bias-palliative-care/> Accessed August 16, 2022.
5. Edwards WF, Malik S, Peters J, Chippendale I, Ravits J. *Delivering Bad News in Amyotrophic Lateral Sclerosis: Proposal of Specific Technique ALS ALLOW*. *Neurol Clin Pract*. 2021;11:521-526.
6. EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis, Andersen PM, Abrahams S, Borasio GD, et al. *EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS)--revised report of an EFNS task force*. *Eur J Neurol*. 2012;19:360-75.
7. Shoesmith C, Abrahao A, Benstead T, et al. *Canadian best practice recommendations for the management of amyotrophic lateral sclerosis*. *CMAJ*. 2020;192:E1453-E1468.



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