



How to Break the News in ALS/MND

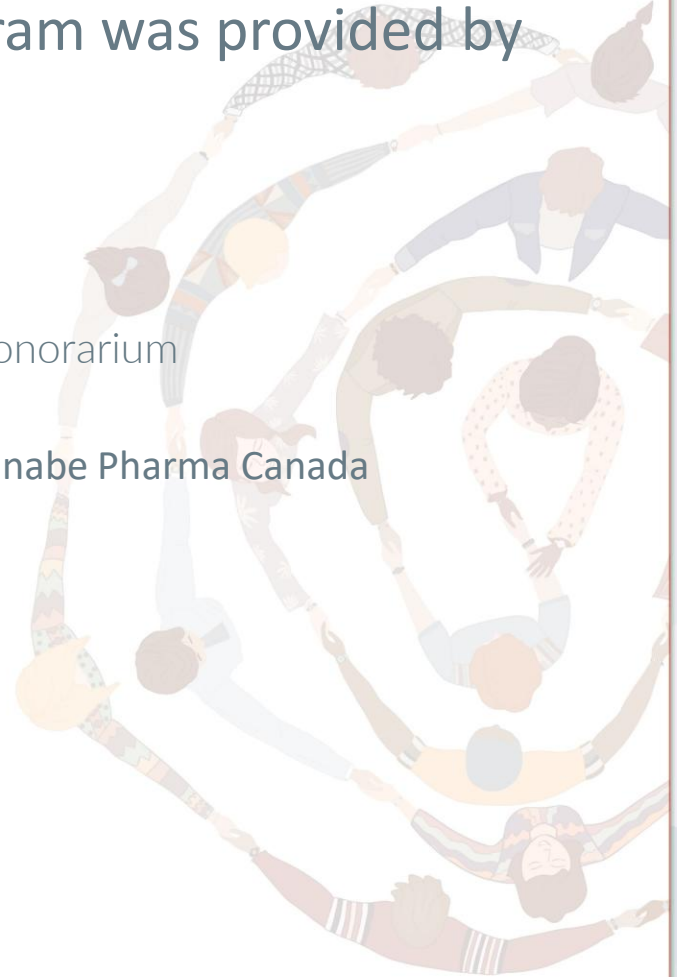
A Primer for Physicians and Allied Health Professionals

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Speaker Disclosures

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- Other:



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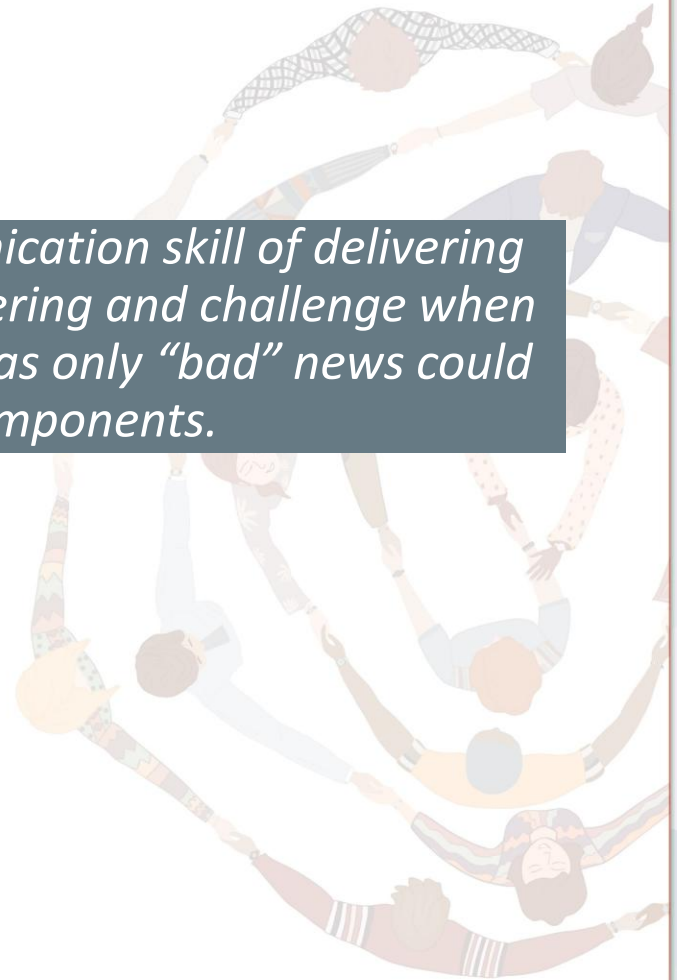


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Disclaimer

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.



Learning Objectives

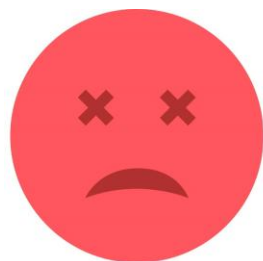
- Describe the impact delivering news in ALS/MND can have on patients, caregivers and healthcare professionals
- Identify and address personal biases and perspectives on ALS/MND, death and dying
- Recognize and apply best practices in delivering news to people living with ALS/MND and their caregivers
- 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



Question

?

How comfortable are you in delivering challenging news to people living with ALS/MND?



— Not at all comfortable

Very comfortable +

Question



Describe in a few words how you feel when delivering challenging news to people living with ALS/MND

Why was this program created?



A Caregiver's Experience Receiving the Diagnosis



The Task of Breaking Difficult or “Bad” News

“

The task of breaking “bad” news is a testing ground for the entire range of our professional skills and abilities. If we do it badly, the patients or family members many never forgive us; if we do it well, they will never forget us.

– Robert Buckman, 1992

”



What are the Barriers to Breaking News?

Healthcare professionals that deliver challenging news often experience:

Strong emotions, such as anxiety

A burden of responsibility for the news

Fear of patients'/caregivers' emotional reactions to the news

Fear of negative evaluation by the patient and family

This stress creates a reluctance to deliver the news – the “MUM” effect – and can lead to delays in delivering a diagnosis and/or follow-up care.

Unique Challenges to Delivering News in ALS/MND

Unlike oncologic diagnoses (which often have substantial treatments and often a cure), ALS/MND remains progressive and fatal even despite extensive biomedical research and availability of clinical trials

People living with ALS/MND receive challenging news at various time points throughout the disease trajectory:

Early in the disease
when they learn of their diagnosis
but are still highly functional



Ineffective communication at this stage causes emotional trauma and compromises QoL

**As the disease progresses
and function continues
to decline**



Ineffective communication at the later stages may cause unrealistic expectations, unpreparedness, and respiratory crises

Late in the disease
when palliation, dying and advanced
directives need to be discussed



All of this is further complicated by the fact that the disease manifestations of ALS/MND are markedly heterogeneous

How a Diagnosis is Delivered is a Source of Discontent for Many People Living with ALS/MND and Caregivers¹

Surveys of people living with ALS/MND and their caregivers have shown that:

50%

were dissatisfied
by the manner
in which the
diagnosis was
communicated²

41%

received
insufficient
information at
the time of
diagnosis³

33%

Were not given
a contact for
follow-up³

75%

had questions
that arose
immediately after
they received the
initial diagnosis⁴

ALS, amyotrophic lateral sclerosis; MND, motor neuron disease

1. Shoesmith 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;18:28-33. 4. Abdulla S, et al. Amyotroph Lateral Scler Frontotemporal Degener. 2014;15:505-12.

A Caregiver's Perspective on How Challenging Delivering a Diagnosis Must be for Clinicians



The Good News!

- Delivering news in ALS/MND or in any other clinical situation is a **skill that can be learned** and improved upon by:

Understanding
the process
involved

Approaching it
as a stepwise
procedure

Applying well-established
principles of communication
and counseling

- Breaking this news effectively can **improve patient well-being and QoL**
- Clinicians who are comfortable with delivering challenging news are **less subject to stress and burnout**
- Learning how to deliver the news effectively can **improve overall clinical skills and interactions with patients and families**

Practical Protocols Are Available for HCPs

SPIKES ¹	ABCDE ²	BREAKS ³	ALS ALLOW ⁴
S etting P atient perception I nvitation to give information K nowledge E xplore emotions and empathize S trategy and summarize	A dvance preparation B uild environment/relationship C ommunicate well D eal with reactions E ncourage and validate emotions	B ackground R apport E xplore A nnounce K indling S ummarize	A scertain L eave opportunity S tratify A ncor L et it be L isten in silence O ffer over time W ork together

Although each of these protocols have different acronyms, they share similar elements. Healthcare providers can choose to use whichever protocol resonates most with them (or no protocol at all) but it is important that the key elements that will be discussed in this program are followed in order to effectively deliver the news.

A-L S-PIKES Protocol for Delivering News in ALS/MND (at diagnosis and throughout the disease course)

- A** Advance Preparation
- L S** Location & Setting
- P** Patient's Perceptions
- I** Invitation
- K** Knowledge
- E** Empathy/Emotions
- S** Strategy & Summary

This program will focus on delivering news in the early stage of ALS/MND (i.e., delivery of diagnosis and “aftermath” period). However, these communication skills can be used at other time points throughout the disease trajectory by all ALS/MND team members.

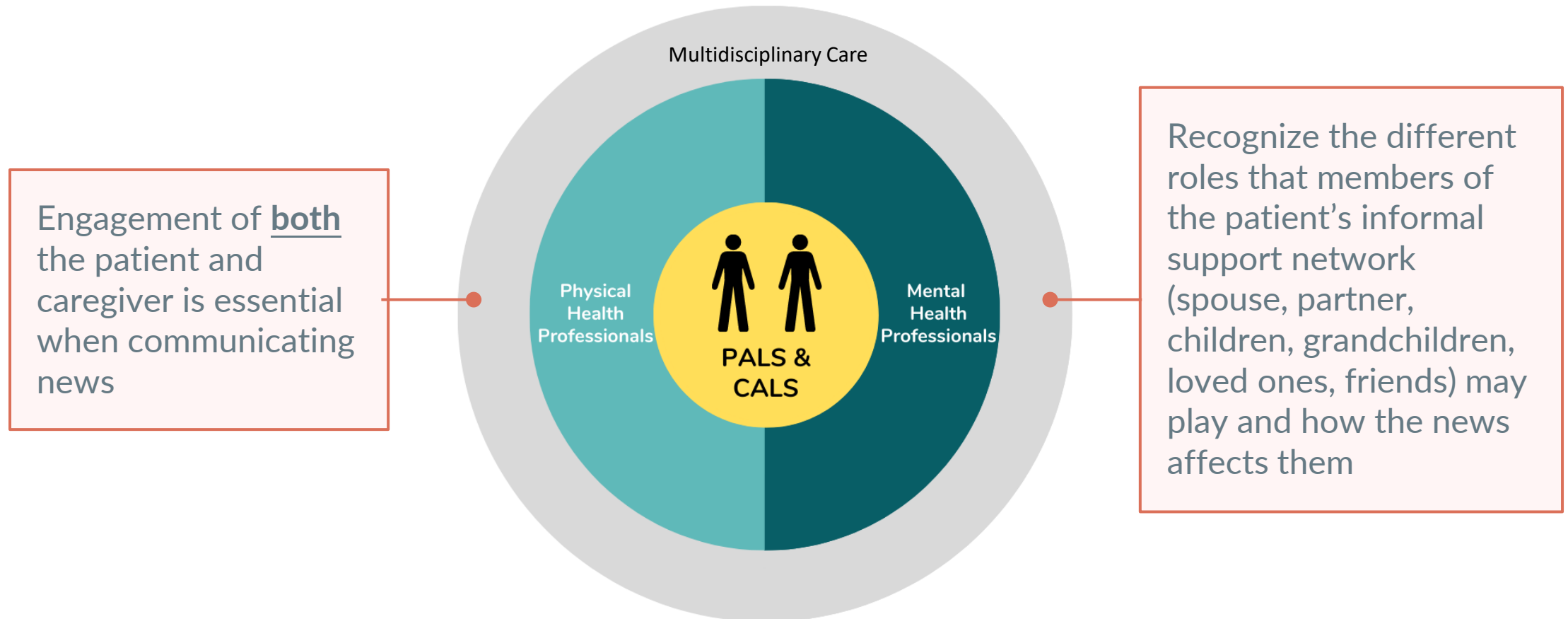
What needs to be communicated at different stages differs, but the *skills for communicating* are essentially the same.

This protocol has been adapted from the SPIKES protocol developed for delivering oncologic diagnoses.

ALS, amyotrophic lateral sclerosis; MND, motor neuron disease

Adapted from: Baile W, et al. *Oncologist* 2000;5:302-311. Buckman R. *Community Oncology* 2005;2:138-42.
EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. *Eur J Neurol*. 2012;19:360-75.

REMINDER: Both PALS & CALS are at the Centre of the Multidisciplinary Care Model in ALS/MND



A – Advance Preparation



- Prepare for the discussion, both **logistically** and **emotionally**
- **“Know thyself”** *before the meeting – but also before doing this work*
 - Identify your own personal perceptions/biases about the disease, death and dying
 - HCPs may make assumptions about what they “need to say” or “how they need to say it” without first processing their own perspectives or biases that could potentially lead to ineffective communication
- **Know the patient** *before the meeting*, including:
 - Case history, all relevant test results and clinical information
 - Emotional and social situation
 - Family support

Have all the facts on hand during the conversation

“Know Thyself” Exercise

- We all have biases about many topics, including illness, death and dying
- As professionals, we are told to leave these biases at the door, but we don't always give ourselves the time to ask What do I think? What do I believe?

What does death/dying mean to you?

Religious or spiritual influences?

Have you been a part of someone's dying process?

Take a moment to
answer these
questions.
Write it down. Talk it
out.
Acknowledge your
biases.

“Know Thyself” Before the Meeting



“Know Thyself” Mindfulness 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

“Know Thyself” Mindfulness Exercise



A – Advance Preparation (continued)



- Mentally rehearse how you will deliver the news
 - Consider practicing out loud
 - Script specific words and phrases to use or avoid
 - If you have limited experience, consider observing a more experienced colleague or role playing a variety of scenarios with colleagues beforehand
- Be prepared to provide at least basic information about prognosis and treatment options (in case the patient requests this information)

LS – Location & Setting



1

Have the conversation in a **quiet, comfortable** and **private** area

2

In-person, face-to-face

3

Arrange for **adequate time** to ensure there is no rushing

4

Limit interruptions

5

Make sure a **box of tissues** is on-hand

6

Include **caregiver/family/friends** as patient desires

7

Make **eye contact** and **sit close** to the patient with no barriers between you

8

Ensure **clinical nurse specialist** or **social worker** are available

REMINDER: An ALS/MND diagnosis should be delivered by an ALS/MND expert

ALS, amyotrophic lateral sclerosis; MND, motor neuron disease

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P – Patient's Perceptions



Know where the patient is starting from

- Assess what the patient/caregiver already knows about the condition, including their opinions, beliefs and thoughts
- Assess their current level of understanding

Tailor delivery and discussion of information accordingly

Early in the disease when delivering the diagnosis, ask:

- What do think might be wrong?
- What have you been told so far?



Later in the disease when discussing prognosis and goals of care, ask:

- When looking ahead, where do you think things are heading?
- How does this make you feel?

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**
 - If they decline, offer to meet them again in the future when they are ready
- 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 about your diagnosis?

Are you someone who likes to know all the details or would you prefer that I focus on the most important ones?

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K – Knowledge



SHARING KNOWLEDGE and Information

- Present information in a step-down approach or in “chunks” ***based on what the person living with ALS/MND wants to know***
 - This allows them to process and understand the information without becoming overwhelmed
- **Pause often to confirm understanding and determine what else they want to know and how they are feeling** about the information given
- Use the same language/terminology as your patient – avoid technical scientific language and medical jargon
- **Acknowledge** that this is devastating news, **but discuss reasons for hope**, such as research, drug trials and the variability of the disease

Here's what we know...

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...

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Discuss Reasons for Hope



K – Knowledge (continued)



Be prepared to address the most commonly asked questions when the diagnosis is given:

- How much time do I have?
- When and how am I going to die?

We really don't know... some patients survive for 5-10 years or more...

All we know is where you are at now ... and moving forward, our focus is going to be on ensuring the best possible quality of life and on what's most important to you...

Like many diseases, currently there is no cure. The symptoms will generally progress over time...

K – Knowledge (continued)



Information to be discussed early in the disease, based on the person's own timeline and level of readiness to know more

- Explain the disease (provide printed materials afterwards)
- Explain that the complications of ALS/MND are treatable
- Inform about:
 - Disease-modifying treatments (i.e., riluzole, edaravone)
 - Patient support and advocacy groups (offer contact details and leaflets)
 - Ongoing research
- Discuss opportunities to participate in research treatment protocols (if available)
- Discuss the course of the disease – be honest about the likely progression and prognosis, but give a broad time frame and recognize the limitations of any predictions
- Instruct the person living with ALS/MND and caregiver how to navigate the care system

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K – Knowledge (continued)



Offer to Provide Information Over Time... Based on Readiness to Know More

- Productive discussions need time
- Single visits are fatiguing and saturating for persons living with ALS/MND, caregivers and healthcare professionals
- A single visit often becomes ineffective after 30–60 minutes
- Discussions at different times need to occur
- Ensure follow-up appointment for next visit/discussion is booked
- Reassure that the ALS/MND team is here for them and will follow up closely

E – Emotion/Empathy



Address Emotions with Empathetic Responses

The empathetic response is a technique or skill, not a feeling

1. Listen/observe for and identify the emotion (tearfulness, sadness, shock, silence, etc.)
 - Ask exploratory questions to help understand when the emotions are not clear
2. Identify cause/source of emotion (most likely the news the person received)
3. Give the person 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

How are
you feeling
right now?

How can we
support you at
this moment?

I think how you
feel is a very
normal response
in this situation.

What to Do When Emotions are Overwhelming

- **Allowing the person with ALS/MND and caregiver to emote in the moment is extremely critical**

- Don't try to shut them down because you are uncomfortable with their emotions

- **Listen in silence**

- Trying to communicate during surges of emotion is unproductive
- When emotions are overwhelming, silence is golden
- Even stepping out of the room to allow privacy can be helpful

- **Check in – what do they need right now?**

- Be okay with what they need in the moment

- **Consider bringing in other team members**
if desired by the patient and caregiver

I'm here for you... What would be the most helpful thing for me to do?

Would you like to be alone for few minutes?
Would you like me to stay right here with you?

Would you like me to bring in some of the other ALS/MND team members?

What to Do When Emotions are Overwhelming



S – Strategy & Summary



1

Explore the **patient's agenda (ICE)**

- Ideas – what may help
- Concerns – what is worrying them the most at this time
- Expectations – what are their hopes for next steps/for the future

2

Recommend a **strategy/plan** for next steps based on the discussion

- Ask the person living with ALS/MND and caregiver to repeat to you their understanding of the plan

3

Summarize the conversation

4

Consider providing a **written plan or summary** for them to take home

5

Reassure that the ALS/MND team is available to **support** them

- Every attempt will be made to maintain their function
- Their treatment decisions will be respected
- They will continue to be cared for and will not be “abandoned”

6

Provide **reliable resources**, including ALS/MND patient organizations

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EFNS Task Force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. Eur J Neurol. 2012;19:360-75. Edwards WF, et al. Neurol Clin Pract. 2021;11:521-26.

Do NOT's in Breaking News

DO NOT

Talk in a “**non-safe**” space

Assume you **know** what they are feeling

Assume they **know** about ALS/MND

Deliver **without** emotion

Talk over the patient and caregiver

Assume they **don't** know about ALS/MND

Abandon the patient and caregiver after communicating the news

Clinical Pearls: How To Deliver an ALS/MND Diagnosis



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



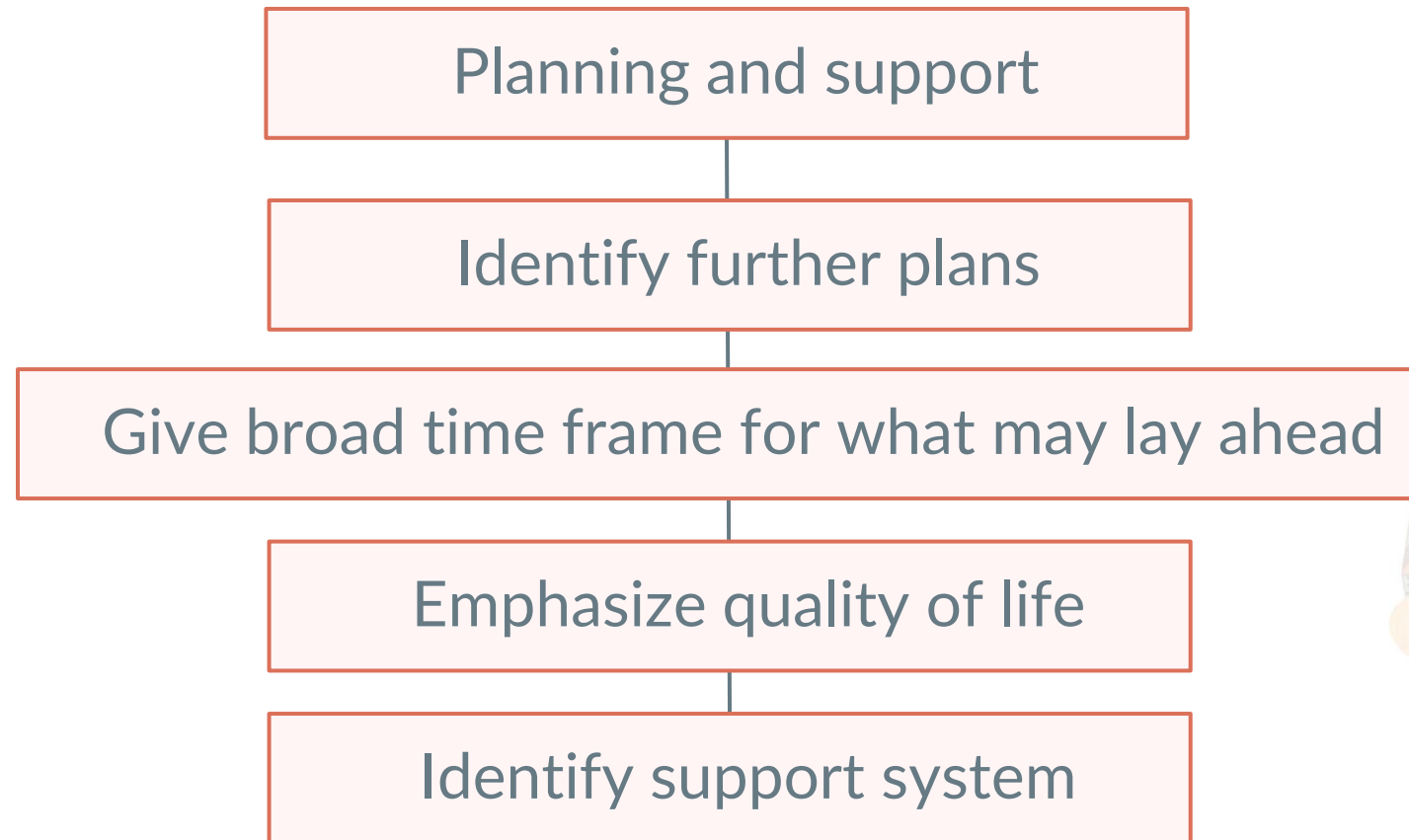
After the Diagnosis is Given

- Explain the role of the various ALS/MND team members who will be involved, and connect them with these members
 - Arrange for home visits from social work, nursing and/or therapists (ideally should occur within the week)
- Connect them with ALS/MND patient associations
- Have a clear plan for next steps and plan the next meeting
 - Provide the next clinic date where they will meet more of the team
- Offer as much reliable reading material as the family desires
- Follow up via phone within 24 hours
- Suggest that they keep track of any questions they have in a notebook so that these can be addressed at the next meeting

Supporting family after diagnosis

- Meet them “where they are at”
- Listen with empathy, and not with immediate “telling”
- Let them guide the conversation
- Be present and open to any and all emotions

Key Role of ALS/MND Team Members After the Diagnosis



Fostering the Emotional Well-being of the ALS/MND Team

Ideally, ALS/MND team should meet prior to and immediately after every clinic

ALS/MND physician has usually seen the patient prior and should prepare team members

Team building outside of the clinic is important!

Social events

Dinner outings when doing outreach

Team recognition

Have team members take on leadership roles



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



A-L S-PIKES for AHPs



Take-Home Messages

- Conveying news to people living with ALS/MND and their caregivers/families can be an arduous and emotionally challenging task
- The “good news” is that this is a skill that can be learned and improved upon
- The A–L S–PIKES technique can help:
 - Improve confidence and comfort in delivering news
 - Improve the QoL of people living with ALS/MND and their caregivers/families
 - Reduce stress and foster the well-being of healthcare professionals



Person Living with ALS/MND Sharing His Thoughts and Experience



Share Your Experience & Learnings

Please share an experience you had in delivering news to a person living with ALS/MND and their caregiver that was challenging.

- What would you have done differently based on what you learned in this program?
- What “clinical pearls” from this program do you plan to implement in your practice when delivering news?



Question

?

After participating in this program...

How comfortable are you now in delivering sensitive news to people living with ALS/MND?



— Not at all comfortable

Very comfortable +