

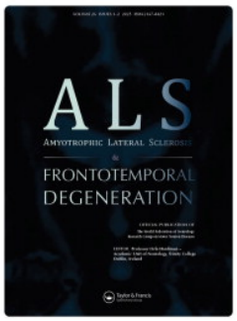
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REVIEW ARTICLE

How to break the news in amyotrophic lateral sclerosis/motor neuron disease: practical guidelines from experts

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Abstract

In amyotrophic lateral sclerosis/motor neuron disease (ALS/MND), it is necessary to communicate difficult news during the initial diagnosis and throughout the disease trajectory as the condition progresses. However, delivering difficult news to people with ALS/MND is an emotionally demanding task for healthcare and allied health professionals—one for which many feel ill-prepared because of limited training in this area. Ineffective communication of difficult news damages the patient-provider relationship and negatively impacts patient quality of life (QoL). To address this issue, we developed the A-L S-PIKES protocol based on available literature and our extensive clinical experience. It provides easy-to-follow, stepwise guidelines to effectively deliver difficult news to people with ALS/MND (PALS) that includes: *A*dvance Preparation (preparing for the discussion logistically and emotionally); *L*ocation & *S*etting (creating a comfortable setting that fosters rapport); *P*atient's Perceptions (assessing PALS' understanding and perception of their condition); *I*nvitation (seeking PALS' permission to share information); *K*nowledge (sharing information in a clear, understandable manner); *E*motion/*E*mpathy (addressing emotions with empathy and providing emotional support); and *S*trategy & *S*ummary (summarizing the discussion and collaboratively developing a plan of action). A–L S–PIKES provides practical guidelines on how to prepare for and conduct these challenging conversations. It emphasizes effective communication tailored to the individual needs of PALS and their families, empathy, sensitivity, and support for PALS' emotional well-being and autonomy. The aim of A-L S-PIKES is to both enhance skills and confidence in delivering difficult news and to improve the QoL of PALS and their families. Future studies should systematically evaluate the feasibility and effectiveness of A-L S-PIKES to establish its utility in clinical practice.

Keywords: *breaking bad news, delivering difficult news, amyotrophic lateral sclerosis, motor neuron disease, patient communication*

Introduction

Delivering difficult news to patients and caregivers is an arduous and emotionally challenging task for healthcare professionals (HCPs) and allied health professionals (AHPs). Indeed, it is one for which many feel ill-prepared given the lack of medical training curricula devoted to this area (1–9). In amyotrophic lateral sclerosis (ALS), also known as motor neuron disease (MND), difficult news needs to be conveyed not only at the time of diagnosis, but also throughout the disease trajectory as function progressively declines (4). Ineffective communication and inappropriate or insensitive delivery of difficult news—or the patient/family perception as such—damage the patient-clinician relationship, reduce patient quality of life (QoL), and hinder long-term adjustment to the consequences of the news (1–4,7). In this paper, we review the available literature on delivering difficult

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news and provide a protocol (A–L S–PIKES) for delivering such news to people with ALS/MND (PALS) and their families based on the literature and our extensive clinical experience. By providing this practical guidance, we aim to empower HCPs and AHPs to manage challenging conversations with greater confidence and compassion and, thereby, improve the QoL of PALS.

Methods

We searched PubMed for English-language studies and reviews published from 1 January 2000 to 30 April 2023, that focussed on the delivery of bad news in medical settings, particularly in the context of ALS/MND. We also manually searched the references of selected articles, as well as the grey literature for additional applicable literature and information. Guiding articles were mutually agreed upon by the authors. Content was discussed and developed via virtual meetings and email correspondence, and the proposed protocol was presented to PALS, caregivers and other members of the International Alliance of ALS/MND Associations. Final refinements to the protocol were made based on their input and feedback.

Discussion/observations

Defining "bad news" and the importance of delivering the news effectively

"Bad news" is commonly defined as "any information which adversely and seriously affects an individual's view of his or her future" (3). Dr. Robert Buckman, the late renowned oncologist and interpersonal communications expert, emphasized the importance of delivering difficult news effectively in the following quote from his book *Breaking Bad News: A Guide for Health Care Professionals:* "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 may never forgive us; if we do it well, they will never forget us" (3). If not performed appropriately, the effect of conveying difficult news can be devastating, leaving patients with a sense of abandonment, reducing their QoL, and destroying the patient-clinician relationship (10).

Barriers and challenges to breaking difficult news

HCPs and AHPs generally experience delivering difficult news to patients as an emotionally burdensome and distressing task, with the impact extending beyond the actual consultation (1, 2, 11–16). They often report experiencing strong emotions, such as anxiety and fear related to patients' emotional reactions to the news and negative evaluation by patients and their families, as well as fear of expressing and managing their own emotions during the delivery of difficult news (1, 2, 17–19). These fears can lead to a reluctance to deliver difficult news, thereby delaying a diagnosis and/or follow-up care while delivery of the news is avoided (4). In fact, some HCPs and AHPs fail to deliver difficult news altogether and refer patients to other clinicians for delivery of the news. In our practices, we have observed that some PALS have actually found out about their diagnosis by "googling" the name of the clinician to whom they were being referred.

Unique challenges to delivering news in ALS/MND

Much of the existing literature on delivering difficult news is focussed on oncologic diagnoses, which often have numerous treatment options and, for some, the potential for a cure. This is in contrast to ALS/MND, which remains progressive and fatal despite extensive biomedical research, new therapies, and the availability of clinical trials (4). Individuals with ALS/MND face a series of challenging conversations throughout the course of their disease. Early, when they learn about their diagnosis, PALS are typically still independent. Inadequate communication during this stage can lead to emotional trauma and even post-traumatic stress disorder, which can compromise QoL (4). As the disease progresses and function declines, PALS must confront their prognosis, which involves discussions around respiratory failure, assistive devices, palliative care, end-of-life decisions, and advanced directives (4). Ineffective communication during these stages can lead to unrealistic expectations, lack of preparedness, and/or respiratory emergencies. PALS may receive perceived "good news" along the way, such as normal magnetic resonance imaging or bloodwork results, which may temporarily raise hopes. Further, the great variability of ALS/MND manifestations makes it extremely challenging for even experienced ALS/MND clinicians to predict a timeline for patient prognosis (4).

PALS and caregiver perspectives on delivering difficult news in ALS/MND

The manner in which the diagnosis of ALS/MND is delivered is a source of discontent for many PALS and their caregivers (20). In one study, more than half of 50 PALS and 19 caregivers surveyed indicated that they were dissatisfied by how the diagnosis had been communicated and rated the diagnosing clinician poorly (21). In other surveys of PALS and caregivers, 40% ($n = 202/505$) indicated that they received insufficient information, almost one-third ($n = 148/505$) stated that they were not given a contact for follow-up (22), and approximately 75% ($n = 154/206$) had

questions that arose immediately after they received the initial diagnosis (23). Frequently cited reasons that contribute to suboptimal experiences include a lack of empathy or blunt manner from the diagnosing clinician, lack of information, and insufficient time to address questions and concerns during the consultation (24, 25).

The "good news" about breaking difficult news

The "good news" about the task of delivering difficult news in ALS/MND (or in any other clinical situation) is that it is a skill that can be improved upon by understanding the process involved, approaching it as a stepwise procedure, and applying well-established principles of communication and counseling (1, 2). Effective communication and appropriate delivery of bad news have been associated with improved patient well-being and functioning, as well as greater patient satisfaction with the care provided (1, 2, 4, 26, 27). Clinicians who are comfortable in delivering difficult news to patients may be less subject to stress and burnout (1). Learning to deliver difficult news effectively can improve overall clinical skills and interactions with patients and families.

Protocols for delivering difficult news

Several techniques and protocols have been developed for delivering difficult news effectively, including SPIKES, ABCDE, BREAK and ALS ALLOW (Table 1) (1, 2, 4, 28, 29). Despite the differing acronyms, all promote the importance of preparation prior to delivery of the news, establishing rapport in an appropriate setting, gaining an understanding of what patients know and how much they want to know, using clear communication techniques, addressing patient concerns and emotions with empathy, summarizing discussions, and providing an action plan and next steps.

Table 1. Protocols for delivering difficult news.

SPIKES (1, 2)	ABCDE (28)	BREAKS (29)	ALS ALLOW (4)
Setting Create a comfortable setting that can ensure privacy and help establish rapport with the patient	Advance preparation Prepare for the discussion– review the patient's history, mentally rehearse and emotionally prepare	Background Know the patient's background, clinical history and family or support person	Ascertain Ascertain participants' perceptions at the start of the appointment and use as a start point for discussions
Patient perception Use open-ended questions to determine the patient's understanding of the condition/situation	Build a therapeutic environment/ relationship Ensure adequate time and privacy	Rapport Build rapport and allow time and space to understand the patient's concerns	Leave opportunity Allow ample opportunity for interaction as the discussion proceeds
Invitation to give information Ask the patient's permission to provide information and determine how much information and detail the patient desires	Identify how the patient would like to receive the news Inform relevant staff and colleagues of the situation Maintain eye contact and sit close enough to touch the patient, if appropriate	Explore Explore the patient's understanding of the condition and start from what the patient currently knows	Stratify Stratify information using a step-down approach Prioritize and pace content
Knowledge Provide a warning statement to help lessen the shock and facilitate understanding Explain the disease and care options in plain language and pause often to confirm understanding	Communicate well Communicate results clearly—avoid medical jargon and use plain language—and move at the patient's pace	Announce Preface the bad news with a warning Announce the diagnosis after getting consent Give no more than 3 pieces of information at a time	Anchor Allow the patient to control and "pull" information—do not mechanically "push" unless deemed necessary
Explore emotions and empathize Address emotions as they arise Use empathetic statements and validate the patient's emotions	Deal with reactions Address emotions as they arise Actively listen, explore feelings and express empathy	Kindling Address emotions as they arise Ensure the patient understands what you said Be aware of denial	Let it be Recognize and accept highly variable patient responses such as denial—patient autonomy develops over time
Strategy and summarize Summarize the discussion and develop a plan for follow-up/next steps	Encourage and validate emotions Explore what the bad news means to the patient Validate emotions and offer realistic hope	Summarize Summarize the discussion and patient's concerns Provide a written summary Ensure follow-up	Listen in silence If emotions become strong or volatile, remain silent and allow waves of emotion to subside
			Offer over time Attention fatigues after 30-60 min and discussion becomes inefficient and unproductive; therefore, plan on follow-up appointments with recurrent discussions
			Work together Schedule follow-up care into an appropriate format, either individual clinic or multidisciplinary clinic

The A–L S–PIKES protocol

SPIKES, originally developed to enable physicians to deliver news about cancer in a patient-centered manner, is one of the most frequently used protocols (1, 2) and has been studied in ALS/MND (30). PALS rated their neurologist's skills and abilities in "breaking bad news" higher when the following key components of the SPIKES protocol were followed: responding empathically to the PALS' feelings and providing emotional support; sharing information and providing time to process information; exploring PALS' hopes and expectations; and making a plan and discussing next steps, including multidisciplinary care (30). We selected this technique and made small adaptations to the protocol to address the specific needs of PALS and their caregivers (Table 2). Each step of this A–L S–PIKES protocol is described herein. A-L S-PIKES also incorporates many of the European Federation of Neurological Societies' recommendations on how to communicate an ALS/MND diagnosis (10), which are also referred to in the Canadian best practice recommendations for the management of ALS/MND (20). Although the steps discussed focus on delivering news in the early stage of ALS/MND (i.e., during delivery of the diagnosis and in the immediate "aftermath" period), these communication skills can be used by all ALS/MND team members throughout the disease trajectory.

A – Advance Preparation. The first step involves preparing for delivery of the difficult news both logistically and emotionally (28) (Table 2). Before seeing PALS, HCPs and AHPs should identify their own emotions and/or personal perceptions and biases about ALS/MND, death and/or dying. Evidence suggests that HCPs'/AHPs' emotions and "inner life" can have a significant impact on the HCP-/AHP-patient interaction and the overall quality of care provided to patients (13, 15, 31, 32). Exercises to help HCPs and AHPs identify and respond to their own personal feelings and/or potential biases are provided in Table 3.

During *Advance Preparation*, HCPs and AHPs should familiarize themselves with the PALS' case history, clinical information, relevant test results as well as their emotional and social situation and available family support (10, 28, 29), and should mentally rehearse how to deliver the news (e.g., practice out loud and/or script specific words and phrases to use or avoid) (1, 2, 28). HCPs and AHPs with limited experience delivering difficult news should consider observing a more experienced colleague or role play a variety of scenarios with colleagues beforehand. Also, they should be prepared to provide at least basic information about prognosis and treatment options in case PALS and/or their family members request this information during the discussion.

L S – Location & Setting. Create a comfortable setting that can ensure privacy and fosters a connection and rapport with PALS and their families (1, 2, 10). Electronics should be silenced, safety/maintenance staff should be advised not to plan fire drills on that day, and other staff or team members should be instructed not to interrupt unless they will be involved in the discussion. Other helpful strategies for this step in the protocol, such as sitting down with PALS and maintaining eye contact, are provided in Table 2.

P – Patient's Perceptions. Before discussing the diagnosis (or other medical findings), determine where the person with ALS/MND is "starting from" (Table 2) (1, 2, 4, 10). Use open-ended questions to assess what PALS and caregivers already know about the condition and/or how they perceive the situation. Based on this information, misinformation can be corrected and delivery of the news can be tailored to what they currently understand.

I – Invitation. Obtain an invitation from PALS' to disclose or provide diagnosis information (Table 2). While many PALS express a desire for full information about their diagnosis, prognosis, and details of their illness, some do not (1). It is important to ask PALS how much they want to know at the time of diagnosis and to ask permission to give results or provide information, thereby allowing them to control the conversation (1, 2, 10). If the person with ALS/MND does not want to know details at that particular time, offer to provide information at a later date.

K – Knowledge. Information is shared with PALS and their caregivers to build their knowledge and understanding of the diagnosis (1, 2). Details should be presented in a step-down approach or in "chunks" based on what PALS want to know. This approach allows them to process and understand the information without becoming overwhelmed (4). Pause often to confirm understanding and to determine what else they want to know and how they are feeling about the information given. Acknowledge that ALS/MND is a severe diagnosis, but temper this by discussing reasons for hope, including research, trials, and the heterogeneity and variability of the disease (10).

HCPs and AHPs should be prepared to address commonly asked questions, such as: *How much time do I have? When and how am I going to die?* Be honest about the likely progression of the disease, but acknowledge that prognosis is variable and the limitations of making any predictions about an individual patient's future disease course. Focus on what can be done at present and moving

Table 2. 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 Table 3 for exercises)
	• Know the person 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
	• Be prepared to provide at least basic information about prognosis and treatment options	

L S	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 PALS with no barriers between you • Include caregiver/family/friends as the PALS desires • Ensure other ALS/MND team members (e.g., nurse, social worker, therapist) are available if the PALS /family requires additional support during discussion	
P	Patient's Perceptions *Know where the person is starting from:* • Assess what the they already know about the condition, including opinions, beliefs and thoughts • Assess their current level of understanding • Tailor delivery of information accordingly	• *What do you 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 that they can control the conversation • Accept the person's right not to want to know, but offer to answer any questions 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 the person wants to know and how the person is 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 the 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 Reponses
	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 the 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 the them realize their feelings are important
		• *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?*

(*Continued*)

Table 2. Continued.

S	Strategy & Summary • Explore the PALS' 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 to take home • Reassure PALS that the ALS/MND team will support them and they will not be "abandoned" • Provide reliable resources, including ALS/MND patient organizations

ALS/MND: amyotrophic lateral sclerosis/motor neuron disease; PALS: people with ALS/MND.
Adapted from Baile et al. (1) and Buckman et al. (2).

Table 3. Exercises to help HCPs and AHPs identify personal perceptions and potential biases that could affect how they deliver news in ALS/MND.

"Know Thyself" Exercise

This exercise can help HCPs and AHPs identify personal perceptions and/or biases about death and/or dying that could impact their delivery of news to PALS and their caregivers.

What does death/dying mean to you?	→	**Take a moment to answer these questions.**
Religious or spiritual influences?	→	**Write it down. Talk it out.**
Have you been a part of someone's dying process?	→	**Acknowledge your biases.**

"Know Thyself" Mindfulness Exercise*

This exercise builds on the previous "know thyself" exercise and focusses on helping HCPs and AHPs identify and respond to personal feelings and emotions that could affect how they communicate news to PALS.

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

Monitor
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 behaviors that may come out of the feeling (avoidance, wanting to rescue, feeling powerless or powerful)
Think about how these *behaviors 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 min, 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 HCPs and AHPs
Suggested to think about this often as feelings change, patients change, context changes

*Adapted from: Curseen (33).
AHPs: allied health professionals; ALS/MND: amyotrophic lateral sclerosis/motor neuron disease; HCPs: healthcare professionals; PALS: people with ALS/MND.

forward, which includes ensuring the best possible QoL for PALS and their families.

Table 4 lists information that should be discussed with PALS and their families early in the disease, guided by the PALS' timeline and level of readiness to know more. It is better to provide this information over time, as a single visit can be fatiguing and overwhelming for PALS, caregivers and HCPs/AHPs (4). Before the end of each visit, schedule the next appointment to ensure further discussion and knowledge-sharing.

E – Emotion/Empathy. PALS report better satisfaction with the delivery of an ALS/MND diagnosis if they believe that the clinician has expressed empathy and provided emotional support (25, 30). The *Emotion/Empathy* step outlines how HCPs and AHPs can offer support and solidarity by addressing emotions with empathetic responses (Table 2) (1, 2). Empathetic responses help validate and normalize the patient's feelings and consist of the following steps: (1) listen for/observe and identify the emotion; (2) identify the cause or source of the emotion (most likely the difficult news that the patient just heard); and (3) give the patient time to express his/her feelings then respond in a way that demonstrates the connection between the first two steps has been made (e.g., *I think how you feel is a very normal response in this situation*) (2).

When delivering difficult news, emotions can often become incredibly overwhelming, not only for PALS and caregivers, but also for HCPs and AHPs. Table 5 lists important points HCPs and AHPs can follow to be both attentive to and respectful of these overwhelming emotions. Allowing PALS and

Table 4. Information to be Discussed with PALS Early in the Course of the Disease (10).

Explain the disease (provide printed materials afterwards)
Explain that the complications of ALS/MND are treatable
Provide information about:
• Disease-modifying treatments
• Patient support and advocacy groups (offer contact details and leaflets)
• Research
Discuss opportunities to participate in research (if available)
Discuss the course of the disease—be honest about the likely progression and prognosis, but give a broad timeframe and recognize the limitations of any predictions
Instruct PALS and caregivers how to navigate the care system

ALS/MND: amyotrophic lateral sclerosis/motor neuron disease; PALS: people with ALS/MND.

Table 5. What to do when emotions become overwhelming.

Allow the person with ALS/MND and caregiver to express emotions—emoting in the moment is extremely critical • Don't try to shut them down because you are uncomfortable with their emotions	*I'm here for you … What would be the most helpful thing for me to do?* *Would you like to be alone for a 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?*
Listen in silence[4] • Trying to communicate during surges of emotion is unproductive • When emotions are overwhelming, silence is "golden" 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 PALS and caregivers	

ALS/MND: amyotrophic lateral sclerosis/motor neuron disease; PALS: people with ALS/MND.

caregivers to express and share their emotions "in the moment" is critical and may mean that HCPs and AHPs need to listen in silence. Attempting to communicate when PALS and caregivers are overwhelmed by emotions is unproductive; in these situations, silence is "golden" (4). It is also important to check in with PALS and their families to determine what would be most helpful for them. This may entail just sitting and listening, stepping outside of the room to give them space to process the information for themselves, or bringing in someone else from the ALS/MND team (e.g., social worker, therapist or nurse) to provide additional support.

S – Strategy & Summary. PALS have reported higher levels of satisfaction with how their diagnosis was delivered when their hopes and expectations were explored and when a plan of action and next steps were provided (30). Patients who have a clear plan for the future are less likely to feel anxious and uncertain (1). In this final step of the protocol, PALS' ideas, concerns, expectations and hopes for the future should be explored and, on the basis thereof, a strategy or plan for next steps should be established (Table 2). Before the end of the visit, summarize the conversation and consider providing PALS and caregivers with a written plan or summary that they can take home. It is also important to conclude the visit on a hopeful note. This can be achieved by highlighting the variability of the disease, noting that some patients can survive for decades and/or lead extraordinary lives despite their condition, and emphasizing the significant progress being made in the treatment of ALS/MND. Discuss strategies that will be explored in upcoming visits, such as new, promising medications, the potential to participate in a clinical trial or an expanded access program that PALS may qualify for.

After the ALS/MND diagnosis is given

After the diagnosis is given, explain the roles of the various ALS/MND team members who will be involved in the patient's care (i.e., nurses, social workers, respiratory therapists, occupational therapists, physiotherapists, nutritionists, speech language therapists, etc.) and put patients in touch with these members (10). These members of the ALS/MND team play a critical role in future planning and support, promoting PALS' QoL, and identifying additional support systems/networks for PALS and their families. Ideally, follow-up via phone should occur within 24 h and home visits from social workers, nurses and/or therapists should be arranged within 1 week after the diagnosis is given. PALS and family members should be connected with local, national and international ALS/MND patient organizations and provided with reliable resources, including verified and peer-reviewed websites (10). Advise them to keep track of any questions they have in a notebook so that they can be addressed at the next scheduled visit.

Finally, PALS and their families should be reassured that the ALS/MND team is available to support them and that they will continue to be cared for by this experienced team of professionals (10).

Clinical pearls for Allied Healthcare Professionals (AHPs) in the "aftermath" period

In many clinics, it is common for the physician (e.g., neurologist, physiatrist) to give the ALS/MND diagnosis to PALS and their family members alone. Afterwards, PALS are encouraged to see the social worker, therapist, nurse, or other AHP on the ALS/MND team. This visit can occur immediately, in person, or later via phone or home visit. This time period, which we have termed the "aftermath" period, is extremely critical as PALS and their families are usually still in shock and overwhelmed by the diagnosis. They often have numerous questions for the AHP during this time, such as "*When and how do we tell people/family/friends about the diagnosis? What do we need to do when we get home? How do we fight this?*" Also, AHPs often get asked "intense" questions that are not directly related to their specific area of expertise, such as *"How long am I going to live? What's going to happen to me down the road?"*. A good general response that AHPs can give to these types of questions is: *"ALS is highly variable and we have no way to predict the exact progression of the disease. But here's what we can do to help you right now…"* This type of response helps bring PALS back to the "here and now" and helps them focus on those things that can be done now and in the foreseeable future to ensure the best possible QoL. For additional clinical pearls, please see the video entitled *Clinical Pearls for AHPs in the "Aftermath" Period* available at https://www.breakthenewsinals.ca/video/en/.

A–LS–PIKES for AHPs. After the initial ALS/MND diagnosis and "aftermath" period, there will be various points throughout the disease trajectory where AHPs on the ALS/MND team will need to discuss disease progression and adaptive needs with PALS and caregivers. For example, nutritionists will need to discuss dietary changes or transitioning to a feeding tube, physiotherapists will need to discuss the need for mobility devices, and speech language pathologists may need to discuss the use of a speech-generating device or voice banking. The A–L S–PIKES protocol can be invaluable to AHPs as they plan and prepare for these discussions. For more details on how AHPs can use the protocol to enhance their current practices, please see the video entitled *A-L-S-PIKES for AHPs* available at https://www.breakthenewsinals.ca/video/en/.

Conclusions

Delivering difficult news to PALS and their families can be an arduous and emotionally challenging task, particularly given that such news needs to be conveyed not only at the time of diagnosis, but also throughout the disease trajectory as the illness progresses and function declines. A–L S–PIKES provides practical, stepwise recommendations on how to prepare for and conduct these difficult discussions and emphasizes the importance of addressing personal biases and perspectives, effective communication skills, empathy, sensitivity to the individual needs of PALS, and supporting patients' emotional well-being and autonomy. It is our aim that the use of A–L S–PIKES will not only foster HCPs' and AHPs' confidence, comfort and well-being when delivering difficult news, but also improve the QoL of PALS and their families. While A-L S-PIKES offers valuable guidance to HCPs and AHPs, it is imperative that future research systematically evaluate its feasibility and effectiveness. Our long-term goal is to generate robust evidence to support this model, ensuring its applicability and efficacy across diverse healthcare settings and healthcare professionals involved in the care and management of PALS worldwide.

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