

Articles	Y/N	Study type & AAN rating	Sample Size	Response rate	Summary
<p><b>12) Australian family carer responses when a loved one receives a diagnosis of Motor Neurone Disease—“Our life has changed forever”</b></p> <p>Abstract: While the experiences of family members supporting a person with a terminal illness are well documented, less is known about the needs of carers of people with neurological diseases, in particular, Motor Neurone Disease (MND). This paper describes the qualitative data from a large Australian survey of family carers of people with MND, to ascertain their experiences of receiving the diagnosis. The aim of the study was to describe the experiences of family carers of people with MND in receiving the diagnosis in order to inform and improve ways in which the diagnosis is communicated. Anonymous postal surveys were sent to people with MND in Australia and their family carers respectively. The perceived ability/skills of neurologists was assessed using a five-point scale from excellent to poor. Attributes of communication of bad news was measured by the SPIKES protocol. Each survey question invited further written responses. Eight hundred and sixty-four questionnaires were posted to people with MND and their family carers, with assistance from MND associations. One hundred and ninety-six family carers submitted responses, of which 171 (88%) were patient-carer dyads. Analyses were conducted on 190 family carers. Five themes emerged from reading and re-reading written responses: frustrations with the diagnosis; giving information; family carer observations of the neurologist; the setting; and what would have made the diagnosis easier? The delivery of the diagnosis is a pivotal event in the MND trajectory. Satisfaction for patients and their family carers is related to the neurologists showing empathy and responding appropriately to their emotions, exhibiting knowledge and providing longer consultations. Neurologists may benefit from education and training in communication skills to adequately respond to patients' and families' emotions and development of best practice protocols.</p> <p><i>O'Connor, Margaret; Aoun, Samar M.; Breen, Lauren J. Australian family carer responses when a loved one receives a diagnosis of Motor Neurone Disease—“Our life has changed forever” Health &amp; Social Care in the Community 2018 26 3 e415</i> Journal Article 10.1111/hsc.12541</p>	Y	survey and written questions Class IV	190	190/864	<p>Anonymous postal survey Used SPIKES protocol for assessing neurologist performance</p> <p>Satisfaction for patients and their family carers is related to the neurologists showing empathy and responding appropriately to their emotions, exhibiting knowledge and providing longer consultations. Information given at time of diagnosis was followed up in helpful ways; with family members, in writing, referral for second opinion etc.</p> <p>Cannot be certain it was actually caregivers (not patients) who responded. Unclear if responses came with higher proportion of satisfied vs unsatisfied caregivers.</p>
<p><b>31) 'The shock of diagnosis': Qualitative accounts from people with Motor Neurone Disease reflecting the need for more person-centred care.</b></p> <p>The diagnosis of Motor Neurone Disease (MND) is devastating for people with MND (PwMND) and their families. The objective of this study is to describe the experiences of PwMND in receiving the diagnosis in order to inform a more person-centred approach to communicating such bad news. The design was an</p>	Y	Survey Class IV	248 (29% response rate)	29%	<p>Anonymous postal surveys Questions based on SPIKES Additional room for written responses (Sounds like the same surveys in previous paper O'Conner – just this time they're reporting on the pwALS, not the caregivers)</p>

<p>anonymous postal survey facilitated by all MND associations across Australia (2014-15). Survey questions centred on the SPIKES protocol for communicating bad news; each question contained an area for written responses, which were thematically analysed for content. Two hundred and forty-eight responses were received from people with MND (29% response rate). Four themes emerged: challenges in being diagnosed with MND; the emotions experienced; the good and the bad; and links to further information and support. Receiving such a diagnosis requires preparation, forethought, sensitive and individualised care on the part of the neurologist, including where and how the diagnosis is given; the supports required; and timing, amounts and sources of giving information. The emotional reactions of the neurologist also caused a lasting impression on those receiving the diagnosis. This study could form the basis for best practice programs implementing a more person-centred approach to caring for PwMND right from the diagnosis stage. The focus needs to shift on the person's values, preferences, psychosocial and existential concerns in the context of the underlying disease experience and the manner clinical practice is delivered.</p> <p><i>Aoun S.M.; O'Brien M.R.; Breen L.J.; O'Connor, M. 'The shock of diagnosis': Qualitative accounts from people with Motor Neurone Disease reflecting the need for more person-centred care. Journal of the neurological sciences 2018 387 80</i> Journal Article <a href="http://dx.doi.org/10.1016/j.jns.2018.01.026">http://dx.doi.org/10.1016/j.jns.2018.01.026</a></p>					<p><b>36% dissatisfied with diagnosis delivery</b></p> <p><b>Individualized approach is important</b></p> <p><b>"Neurologists, who took time to deliver the news sensitively and deal with consequent reactions and questions were appreciated."</b></p> <p><b>Patients appreciated avenues to obtain more information</b></p>
<p><b>90) Healthcare Needs of Patients with Amyotrophic Lateral Sclerosis (ALS) in Singapore: A patient-centred qualitative study from multiple perspectives.</b> BACKGROUND: One challenge for those who manage amyotrophic lateral sclerosis (ALS) is to understand patients' needs. AIM: The aim of this study was to examine the needs of Singapore ALS patients from their perspective as well as that of their caregivers and healthcare professionals in order to develop a template for better services. METHODS: A cross-sectional qualitative study was conducted, with one-to-one interviews and focus group discussions. RESULTS: All 30 participants, key stakeholders in the field of caring for ALS patients, identified these needs categories: psychological--diagnosis must be staged and comfortably paced, and efforts must be made to encourage patients' resilience; social--positive relationships, open communication, and spiritual support must be developed; physical--attention should be paid to alleviating discomfort and disability; and environmental--appropriate services should be made available. CONCLUSION: The identified needs categories do overlap, but there are significant differences. Our findings provide a template for developing individualized patient services, which should be done within the framework of a comprehensive palliative care program.</p> <p><i>Ang, Kexin; Umapathi, Thirugnanam; Tong, Jieli; Ng, Justin; Tseng, Liang Jun; Woo, Ivan Mun Hong Healthcare Needs of Patients with Amyotrophic Lateral Sclerosis (ALS) in Singapore: A patient-centred qualitative study</i></p>	<p>N / Y</p>	<p>Interviews &amp; focus group discussion Class IV</p>	<p>30 8 pwALS 5 carers 17 health care workers</p>	<p>27 pwALS 27 carers 157 HCW initially invited to participate</p>	<p>A staged approach for diagnosis delivery was endorsed.</p>

<p>from multiple perspectives. <i>Journal of palliative care</i> 2015 31 3 150 Journal Article</p>					
<p><b>91) Breaking the news of a diagnosis of motor neurone disease: A national survey of neurologists' perspectives.</b> Communication of the diagnosis of MND is daunting for patients and neurologists. This study aimed to establish a knowledge base of current Australian practice of breaking the news of an MND diagnosis, to assess the neurologists' educational and training needs and to compare the feedback obtained from neurologists and patients to international practice guidelines. An anonymous survey of neurologists was undertaken in Australia (2014). 73 neurologists responded to this national survey (50.4% response rate). Nearly 70% of neurologists reported finding it "somewhat to very difficult" communicating the MND diagnosis, and 65% reported feeling moderate to high stress and anxiety at the delivery of diagnosis. Compared to international guidelines, areas for improvement include length of consultation, period of follow up and referral to MND associations. Two-thirds of neurologists were interested in further training to respond to patient's emotions and development of best practice guidelines. This is the first national study to provide a comprehensive insight into the process of delivering the MND diagnosis from the neurologists' perspective and to make comparisons with those of patients and the international guidelines. This study forms the basis for developing protocols to improve communication skills and alleviate the emotional burden associated with breaking bad news.</p> <p><i>Aoun, Samar M.; Breen, Lauren J.; Edis, Robert; Henderson, Robert D.; Oliver, David; Harris, Rodney; Howting, Denise; O'Connor, Margaret; Birks, Carol</i> <i>Breaking the news of a diagnosis of motor neurone disease: A national survey of neurologists' perspectives. Journal of the neurological sciences</i> 2016 367 368 Journal Article <a href="https://dx.doi.org/10.1016/j.jns.2016.06.033">https://dx.doi.org/10.1016/j.jns.2016.06.033</a></p>	Y	Survey Class IV	73	50%	<p>Nearly 70% of neurologists reported finding it "somewhat to very difficult" communicating the MND diagnosis, and 65% reported feeling moderate to high stress and anxiety at the delivery of diagnosis. Compared to international guidelines, areas for improvement include length of consultation, period of follow up and referral to MND associations. Two-thirds of neurologists were interested in further training to respond to patient's emotions and development of best practice guidelines</p> <p>The most difficult parts of discussing the news of an MND diagnosis related to: Being honest but not taking away hope (80%); dealing with the patient's emotion (38%).</p> <p><b>-Longer consults by MDC MD than non-MDC MD. cited my paper but attributed it to the US @ 78% used staged approach</b></p> <p>"The major issue is lack of access to multidisciplinary MND clinics for further management esp. in rural areas. It is very difficult as a neurologist in private practice to coordinate and access the multidisciplinary care required esp. for patients who live at a distance". (P45).</p>
<p><b>92) Receiving the news of a diagnosis of motor neuron disease: What does it take to make it better?.</b> Our objectives were to identify the experiences of people with MND in receiving the diagnosis and to determine which aspects of breaking this bad news were associated with greater satisfaction with the way the diagnosis was delivered to them. An anonymous postal survey was facilitated by all MND associations in Australia, in 2014, and centred on the SPIKES protocol for communicating bad news. Of the patients (n=248, response rate 29%), 36% were dissatisfied with the delivery of the diagnosis and gave low ratings on the ability/skills of their neurologists to deliver the diagnosis. It was evident that the longer the patients spent with their neurologists during breaking such bad news, the more they were satisfied and the higher they rated the neurologists' abilities/skills. The largest significant differences between neurologists rated as having high or low skills in delivering the diagnosis were in four domains: 1) responding empathically to the feelings of patient/family; 2) sharing the information and suggesting realistic goals;</p>	Y	Postal survey Class IV	N=248,	response rate 29%	<p><b>This is the same postal survey from Aoun 2018. They massaged the data differently to get 2 publications out of the same data.</b></p> <p><b>36% dissatisfied</b></p> <p>"The largest significant differences between neurologists rated as having high or low skills in delivering the diagnosis were in four domains: 1) responding empathically to the feelings of patient/family; 2) sharing the information and suggesting realistic goals; 3) exploring what patient/family are expecting or hoping for; and 4) making a plan and following through"</p> <p>Specific mention was made to</p>

<p>3) exploring what patient/family are expecting or hoping for; and 4) making a plan and following through. In conclusion, with over one-third of patients dissatisfied with their experience, there is room for improvement in the practice of neurologists in specified areas that could form the basis for changing practice, and the development of standards and protocols likely to have implications at the international level.</p> <p><i>Aoun, Samar M.; Breen, Lauren J.; Howting, Denise; Edis, Robert; Oliver, David; Henderson, Robert; O'Connor, Margaret; Harris, Rodney; Birks, Carol Receiving the news of a diagnosis of motor neuron disease: What does it take to make it better?. Amyotrophic Lateral sclerosis &amp; Frontotemporal Degeneration 2016 17 43193 168</i> Journal Article <a href="https://dx.doi.org/10.3109/21678421.2015.1111907">https://dx.doi.org/10.3109/21678421.2015.1111907</a></p>					<p>exploring how much detail the patient wanted to know about MND and providing written information to the patient about the diagnosis and on-line resources that are available.</p>
<p><b>93) Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey.</b> Family carers have a central role in the care and support of people with MND and face the challenges of the disease from diagnosis to progression and the multiple losses of MND, but their support needs are often neglected. This study aimed to investigate the experiences of family carers at the time of diagnosis and their satisfaction with receiving the news. An anonymous postal survey was facilitated by all MND Associations in Australia (2014) and 190 family carers completed the questionnaire. The questions centred on the SPIKES protocol for communicating bad news. Two-thirds of family carers rated the skills of their neurologists as above average and were satisfied with the delivery of the diagnosis, in terms of having a significantly longer consultation time, the neurologist being warm and caring, satisfaction with the amount and content of information they received and relevant supports, and a plan for following up support. Conversely those who rated the neurologist's skills as below average commented on the difficulties they encountered and the long term emotional stress engendered by poor communication. The study emphasises previous research that suggested that neurologists may require education and training in communicating the diagnosis and this should include family carers as a vital member in MND care.</p> <p><i>Aoun, Samar M.; Breen, Lauren J.; Oliver, David; Henderson, Robert D.; Edis, Robert; O'Connor, Margaret; Howting, Denise; Harris, Rodney; Birks, Carol Family carers' experiences of receiving the news of a diagnosis of Motor Neurone Disease: A national survey. Journal of the neurological sciences 2017 372 144</i> Journal Article <a href="https://dx.doi.org/10.1016/j.jns.2016.11.043">https://dx.doi.org/10.1016/j.jns.2016.11.043</a></p>	Y	Thematic analysis of survey questions	190	They can't calculate it	<p>This IS EXACTLY the same data as O'Conner paper.</p> <p>This is more quantitative. O'Conner is only qualitative.</p> <p>2/3 satisfied with delivery</p> <p>Better delivery assoc'd with -longer visit, warmth, received info, plan for f/u</p>
<p><b>116) Evaluation of the application of the European guidelines for the diagnosis and clinical care of amyotrophic lateral sclerosis (ALS) patients in six French ALS centres.</b> BACKGROUND AND PURPOSE: Our objective was to evaluate the extent to which the 2005 recommendations of the European Federation of Neurological Sciences</p>	N? Y?	Written survey mailed to patients (class IV)	376	300/376 (80%) 151 were prevalent cases, 149 were incident	<p>Survey of French patients to see how well their clinic had conformed to the EFNS communication guidelines: Diagnosis was (i) by the neurologist in person, in a reasonable time;</p>

<p>(EFNS) on the multidisciplinary management of amyotrophic lateral sclerosis (ALS) are followed in clinical practice. METHODS: This was a multicentre observational study involving six French ALS referral centres receiving prevalent and incident cases. Recommendations were translated into ad hoc questions referring to key aspects of management, and their application was evaluated by a clinical research assistant who independently examined the medical charts (MCs). When necessary, an independent board-certified neurologist answered the questions based on examination of the MC and interview of the caring neurologist. Questions regarding diagnosis and communication were put to patients in a self-administered questionnaire. RESULTS: In all, 376 patients [176 incident, 200 prevalent cases; median age at diagnosis 62.8 years (interquartile range 55.7-72.3); sex ratio 1.37; 27.3% bulbar onset] were included. All the topics covered in the recommendations were evaluated: diagnostic delay (e.g. mean 13.6 months, associated with age and onset); breaking the news (e.g. criteria for communication quality were satisfactory in more than 90%); multidisciplinary and sustained support (e.g. clinic visits were scheduled every 2-3 months in 90%). Also considered were whether riluzole had been offered, symptom management, genetic testing, ventilation, communication defects, enteral nutrition, palliative and end-of-life care. Characteristics associated with poor compliance with some guidelines (schedule of visits, delayed riluzole initiation) were also identified. CONCLUSION: This is the first evaluation of the application of the EFNS recommendations for the management of ALS in a nationwide sample. The results allow us to highlight areas for improvement.</p> <p><i>Marin, B.; Beghi, E.; Vial, C.; Bernard, E.; Lautrette, G.; Clavelou, P.; Guy, N.; Lemasson, G.; Debruxelles, S.; Cintas, P.; Antoine, J. C.; Camdessanche, J. P.; Logroscino, G.; Preux, P. M.; Couratier, P.; EURECALs consortium Evaluation of the application of the European guidelines for the diagnosis and clinical care of amyotrophic lateral sclerosis (ALS) patients in six French ALS centres. European Journal of Neurology 2016 23 4 787 Journal Article <a href="https://dx.doi.org/10.1111/ene.12941">https://dx.doi.org/10.1111/ene.12941</a></i></p>				cases	<p>(ii) step by step; (iii) assuring patient and family that they would not be abandoned (Fig. 3c). Nevertheless, 71.2% of incident cases versus 55.4% of prevalent cases (P = 0.005) indicated that they were given printed material on the disease, support and an informative website.</p>
<p><b>124) Communication of diagnosis in amyotrophic lateral sclerosis: stratification of patients for the estimation of the individual needs.</b></p> <p><i>Pizzimenti, Alessia; Gori, Maria Cristina; Onesti, Emanuela; John, Bev; Inghilleri, Maurizio Communication of diagnosis in amyotrophic lateral sclerosis: stratification of patients for the estimation of the individual needs. Frontiers in Psychology 2015 6 745 Journal Article <a href="https://dx.doi.org/10.3389/fpsyg.2015.00745">https://dx.doi.org/10.3389/fpsyg.2015.00745</a></i></p>	Y? No	Shouldn't be included: Review paper			<p><b>Only review paper</b></p> <p>The method of communicating a diagnosis of ALS should include:</p> <ul style="list-style-type: none"> <li>– The application of techniques of counseling, including a comfortable space, adequate time for processing information, respect for the patient and his/her reactions, acceptance of the patient's reactions.</li> <li>– The possibility of countertransference: the individual health professional should pay particular attention to his or her personal emotions, such as feelings about death.</li> <li>– Existing evidence based</li> </ul>

					<p>knowledge of methods of communication, for example the Six-Step Protocol for Delivering Bad News used in cancer care (Kaplan, 2010). This includes: setting up the interview, assessing the patient's perception, obtaining the patient's invitation, giving knowledge and information to the patient, addressing the patient's emotions with empathic responses, strategy, and summary. – The use of simple words that can be understood easily by the patient. The use of euphemisms, vague words, and not naming the disease could be a defense mechanism of the physician</p>
<p><b>128) Experiences and reflections of patients with motor neuron disease on breaking the news in a two-tiered appointment: a qualitative study.</b>  BACKGROUND: Breaking bad news should be fine-tuned to the individual patient, contain intelligible information, include emotional support and offer a tailor-made treatment plan. To achieve this goal in motor neuron disease (MND), neurologists of the amyotrophic lateral sclerosis (ALS) centre Amsterdam deliver the message on 2 separate visits within 14 days. AIM: To evaluate how patients with MND react to and view disclosure of the diagnosis, in this 2-tiered approach. METHODS: Non-participating observations and in-depth interviews with patients were conducted in 1 tertiary ALS referral centre. Qualitative analysis consisted of inductive analysis of observation reports and verbatim typed out interviews. RESULTS: 10 2-tiered appointments were observed and 21 Dutch patients with MND interviewed. They experienced the straightforward message to be suffering from a fatal disease as devastating, yet unavoidable. The prospect of a short-term second appointment offered structure for the period immediately following the diagnosis. The time between appointments provided the opportunity for a first reorientation on their changed perspective on their life. The second appointment allowed for detailed discussions about various aspects of MND and a tailor-made treatment plan. CONCLUSIONS: The 2-tiered approach fits well with the way in which Dutch patients with MND process the disclosure of their diagnosis, gather information and handle the changed perspective on their life. It may serve as a model for other life-limiting diseases.</p> <p><i>Seeber, Antje A.; Pols, A. Jeannette; Hijdra, Albert; Grupstra, Hepke F.; Willems, Dick L.; de Visser, Marianne Experiences and reflections of patients with motor neuron disease on breaking the news in a two-tiered appointment: a qualitative study. BMJ supportive &amp; palliative care 2016</i>  Journal Article  <a href="https://dx.doi.org/10.1136/bmjspcare-2015-000977">https://dx.doi.org/10.1136/bmjspcare-2015-000977</a></p>	Y	Qualitative prospective study in a single clinic	10 patients assess after initial 2 meetings, 21 patients assessed after 6 months		<p>Diagnosis at clinic in Netherlands is given in 2 steps. First visit and then another about 10-14 days later. Qualitative study to assess how patients like this approach.</p> <p>“Patients differed in their assessment of the duration of the interval between appointments. While most of them were satisfied with the 2-week interval, some patients felt that several days would have been enough. Others felt that several weeks would have been more appropriate to come to terms with their altered situation. Patients were unanimous about the intrinsic value of the ‘breathing space’. It gave them time to accommodate to their dramatically changed future in their own way, before involving a medical care team.”  “Patients mentioned various reasons why they felt the second appointment with the MND neurologist was helpful. One important reason was the opportunity to discuss facts about the disease and its course with a specialist, who is obviously better informed than a GP.”  Second appointment also served to correct misunderstandings, discuss research and alternative therapies.</p>