

**‘The shock of diagnosis’: Qualitative accounts from people with Motor Neurone Disease reflecting the need for more person-centred care.**

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## **‘The shock of diagnosis’: Qualitative accounts from people with Motor Neurone Disease reflecting the need for more person-centred care.**

### **ABSTRACT**

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 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.

## INTRODUCTION

Imparting the diagnosis of any life-limiting illness is challenging for both the clinician and the person receiving it. In MND, in particular, because of poor prognosis and levels of disability, giving the diagnosis is a significant challenge for neurologists and a devastating experience for people with MND (PwMND) and their families [1-4]. There is a lack of understanding of the transitional process, from receiving the diagnosis to living with, and adapting to, this life-limiting illness [5]. Communication deficiencies between health professionals and patients is a significant contributor to difficulties [6]; the diagnosis is described as an existential shock [7-9].

Interviews with PwMND in the UK revealed themes on aspects of the diagnosis such as communication, reactions, time before diagnosis; and coping [10]. Other interviews with PwMND, and their caregivers, showed that the delivery varied from informative and sensitive, to being abrupt and lacking empathy [11]. Additionally, a sociological-phenomenological study exploring the lived experience of 42 PwMND, in the UK, revealed that doctor-patient communication, especially at diagnosis, could be intensely distressing [12]. A recent Irish study of carers of PwMND reported communication at the time of the diagnosis to be less than optimal [13]. An Australian study of bereaved family caregivers of PwMND described an absence of compassion when delivering the diagnosis [14] while another study described negative experiences of receiving the diagnosis [15].

The manner in which the diagnosis is imparted is one of the most sensitive steps in end of life care [2]. An American survey of PwMND revealed that fewer than half were satisfied with the communication of the diagnosis [9] while an Australian survey showed that over a third were similarly dissatisfied [7].

Often, dissatisfaction is related to the information given, or the way in which it is conveyed. The traumatic effect, on PwMND, of receiving information when they are unprepared for it has been described in a Swedish study [16]. Recommendations are that information requirements are identified at diagnosis to determine which information-seeking approach the PwMND is likely to follow and whether they are Active Seekers, Selective Seekers or Information Avoiders [17]. This should be routinely checked during the course of the illness to ensure PwMND are appropriately supported [17].

Studies exploring experiences of living with MND highlight the centrality of diagnosis. How the diagnosis is communicated has implications not only for future patient-professional relationships [3], but also for the way individuals adapt to requirements for support throughout their illness [10, 12, 18]. In palliative care, individualised care in delivering diagnosis and prognosis has long been recognised, with guidelines developed in 2007 [6]; in addition the UK National Institute for Health Care Excellence has developed guidance for assessment and care of PwMND [19], which

complements International guidance to aid delivery of the diagnosis [20-23] but, to date, no similar Australian guidelines have been developed.

A number of tools assist clinicians in communicating bad news, including the SPIKES protocol (Setting, Perception, Invitation, Knowledge, Empathy, and Strategy) [24]: an appropriate setting; determining individual needs; the health professional requesting an invitation to provide diagnosis and information; the health professional exploring feelings; and together working on what to do next. However, at the heart of this clinical practice is a need to focus on the person, meaning that the disease being part of the person rather than the person being part of the disease [25], as patients present with narratives, values, preferences, psychology and emotionality, spiritual and religious concerns, cultural and social situation, fears, worries, anxieties, ambitions, goals [25,p4, 26].

To date, there have only been small samples in studies specifically investigating communicating the MND diagnosis. A recent Australian survey sought to ascertain the nature and extent of challenging experiences at the time of the diagnosis from the perspective of PwMND [7], their families [27] and also their neurologists [1]. This paper reports on the qualitative findings of that survey from the perspective of PwMND, drawn from written responses to the survey. These provide the opportunity to explore more in-depth if and how a person-centred approach to care has been adopted and inform best practice.

## **OBJECTIVE**

To describe the experiences of PwMND in receiving the MND diagnosis in order to inform a more person-centred approach to communicating such bad news.

## **METHODS**

The study was approved by Curtin University Human Research Ethics Committee (HR 188/2014).

In collaboration with all Australian MND Associations, an anonymous postal survey was sent (2014-15) to PwMND who were diagnosed in the last three years and were still alive. The survey comprised 51 questions that were grouped under 8 sections: Section 1 was *About You* (such as demographic information including age, gender, marital status, education, postcode); Section 2 was *About Your MND* (such as date of first symptoms and diagnosis, time spent by neurologist giving the diagnosis); Section 3 was about the *Setting*; Section 4 was about *Perceptions and Expectations*; Section 5 was about *Information*; Section 6 was about *Feelings*; Section 7 was about *Planning and Follow-up*; and Section 8 was about *Satisfaction*. Sections 3 to 7 addressed the attributes of communicating bad news as detailed in the SPIKES protocol [24].

Each section invited further written responses in the form of one open ended question per section, so in total 8 questions, which is the subject of this paper. The question

was in the format of “*Do you have any comments related to the questions in Section X? (If more space is required, please use the last page of the survey)*”. Given that closed survey questions are invariably driven by the researcher’s agenda, the use of open response questions in surveys is increasingly being advocated as a means of enabling respondents to voice their opinion on the topic [28].

## **Analysis**

Data were de-identified and subjected to thematic analysis [29]. Thematic analysis is a qualitative method, where themes emerge from the content of a text through listening or reading; the goal is to add to the understanding of the phenomenon under study by looking for text that has similar meanings. Thematic analysis provides a way to complement a theoretical framework (in this case the measurements from the quantitative results of the survey, using SPIKES protocol [7]). As the meaning emerges and is interpreted, the inferred meanings are illustrated through using examples from the data [29]. Qualitative responses to each question were analysed separately at first, then grouped into broader themes.

The coding schema was drawn from sections of the questionnaire that sought written responses, which were inductively and systematically coded. Emergent interpretations were refined throughout the analysis, aided by comparison between qualitative and quantitative data as well as existing literature, enabling a data-driven approach to interpretation and excerpts were chosen to illustrate themes. As the questionnaires were anonymous, identification code numbers have been applied according to the order in which the surveys were returned.

## **RESULTS**

### **Profile of respondents**

There were 248 responses received from PwMND, estimated as about 29% of those receiving care from all Australian MND Associations [7]. The mean age of respondents was 66.4 years (SD=11.0, range 30-91), 59% were male, 78% were married, and 75% were retirees. The median period from diagnosis to survey completion was 15 months (1-87); period from first symptoms to diagnosis was 10 months (range 1 to 119). Over two thirds (69%) reported having cervical/lumbar symptoms at onset, 19% had bulbar symptoms and the rest had a combination of symptoms. Thirty six percent of PwMND reported being very dissatisfied/dissatisfied with their neurologist’s delivery of the diagnosis [7].

### **Themes of experiences**

Four themes emerged: challenges in being diagnosed with MND; the emotions experienced; the good and the bad; and links to further information and support.

#### **1. Challenges in being diagnosed with MND**

Most PwMND received their diagnosis from a neurologist, having been referred by their general practitioner (GP). A number of PwMND particularly, but not exclusively, those in rural environments, noted the waiting time (two-three months) to see a neurologist. One waited eight months, eventually requesting referral to a neurologist in another state (PID307). Most described investigations to achieve a diagnosis – MRI, CT scan, spinal x-ray, ultrasound, various blood tests and nerve tests; all compounded the time to diagnosis. There were reports of being referred from one specialty to another before a diagnosis was eventually made.

*I went from GP to speech path, to GP, to orth. surgeon, to ENT specialist, then to neurologist. The neurologist did tests, EG, MRI, Electric shock and needle in muscles, so I had approx. 3 visits before the diagnosis (PID333).*

Some PwMND detailed symptoms, such as ‘muscular weakness’ (PID111), ‘floppy foot’ (PID320), ‘croaky throat’ (PID121), ‘problem with speech’ (PID296), causing them to seek further assistance and, like PID130, reported being ‘fobbed off’ by his GP, despite a ‘specific request that they be curious. I knew something was wrong’. One reported his GP had suggested symptoms were caused by too much alcohol (PID171); and another: ‘it took too many visits to the GP and then to a geriatric specialist to convince him it was not just old age’ (PID149).

By contrast, PID141 was among a number of PwMND whose physical experience led to a diagnosis: ‘I thought it was my age for the leg weakness and my new denture was the cause of my speech slurring’. PwMND described vague symptoms over time, like a ‘speech defect’ (PID256), ‘a pinched nerve’ (PID269), ‘an obvious limp’ (PID211), ‘chronic fatigue’ (PID190) or ‘related to Type 2 diabetes’ (PID224).

Most PwMND had family present when the diagnosis was given. However, 32 respondents reported no family presence, being either alone with the neurologist or with another health professional. Of those with no family member present, more than half reported their dissatisfaction either with their neurologist, their treatment or both. One person said: ‘The family should have been allocated an appointment time to receive the diagnosis in an appropriate environment’ (PID321). Respondents with family present tended to appreciate the neurologist’s invitation to involve them: ‘The whole family was invited to come to the neurologist for consultation and information re MND’ (PID143).

Overwhelmingly, the question seeking information on whether there were any positive aspects of the diagnosis, highlighted how the diagnosis was given, like: ‘It was done in a kind and caring manner’ (PID166); ‘The neurologist spoke clearly, calmly and answered my questions in ‘layman’s’ language’ (PID199); and others appreciated a straightforward approach: ‘...did not beat around the bush. He told me straight up’ (PID213). Descriptive words included the neurologist being honest, direct, responsive, caring, kind, compassionate, professional, empathetic, concerned, matter-of-fact and engaged.

PwMND made choices about how to strategically manage their care, with, one PwMND saying: *'After being treated so impassionedly (sic) by 3 different 'specialist' doctors we decided to just attend MND clinic'* (PID332). For another, *'the diagnosing neurologist did not discuss support or help...'* (PID151). The decision to *'travel for 20 weeks'*, meant that PID106 did not see the doctor in that time; *'but we were able to contact her for anything we needed i.e. prescriptions etc'*.

## **2. The emotions experienced**

Most respondents reported the diagnosis as an enormous shock. One wrote:

*'The shock of the diagnosis didn't really sink in until we left the neurologist's surgery. Lots of tears followed as the whole family tried to come to terms with it'* (PID256);

Another described being *'stunned at the time, and just wanted to get out of there'* (PID274). People variously described tears, being distressed, and too shocked to speak: *'I didn't really know what question to ask – quite a shock'* (PID286), and more intensely: *'Would gladly have driven into a pole on the way home because I was given no hope'* (PID138).

For some, the diagnosis was not a surprise, indeed a relief after uncertainty, misdiagnosis or lengthy testing. PID187 highlighted this double-edged sword: *'I was relieved to find out, what was happening to me, but devastated there was no treatment'*. Another seemed pragmatic: *'I did not, and have not, suffered any great emotion'* (PID297). Contrasting emotions were experienced within families:

*'I accepted my diagnosis with profound calmness, as I knew my fate beforehand; however my wife and daughter were very upset'* (PID238).

PwMND commented on the diagnosis being a *'death sentence with this terrible disease'* (PID116) and one person encapsulated negative feelings expressed by others: *'soon I will die'* (PID175).

PwMND spoke not just about their own feelings, but also about their awareness of clinician reactions and responses, ranging from neurologists sharing the emotions of the ill person, to being perceived as hard and lacking in empathy. There were comments like: *'how hard it must be to give people news like this'* (PID214) and describing *'feeling sorry'* (PID106) for the clinician who *'seemed to be more upset than us'* (PID111).

## **3. The good and the bad**

Several PwMND considered their neurologist's manner was 'excellent' (PID197), 'a fantastic, caring person' (PID271), 'a wonderful, caring and sympathetic person' (PID 298), and 'kind and empathetic' (PID139). Neurologists, who took time to deliver the news sensitively and deal with consequent reactions and questions were appreciated.

*He watched our shocked reactions, but gave us time to digest his information. He came around the table and offered support' (PID103).*

Alternatively, many respondents expressed dissatisfaction, describing neurologists having 'little empathy'; 'blunt', matter-of fact', 'very clinical', 'detached' and 'insensitive'. One said: 'It was just a diagnosis to the neurologist, and no emotional support or ongoing guidance given' (PID 309). Frustration was evident: 'No opportunity for discussion – 15 min appointment. I had self-diagnosed – it took 3 visits to verify' (PID139) and 'The neurologist was clinically thorough, but uncaring... left alone in city 2 hours from home after diagnosis' (PID151). Fewer PwMND appreciated their neurologist's straightforwardness:

*...it was much better to be given all the information and expectations so that we know what to expect. I much preferred to have truthfulness' (PID 256).*

Diagnosis was mostly given in a clinical setting, a hospital or consultant neurologist's rooms and most PwMND appreciated privacy and 'the way she took the time to talk with me and the kindness and empathy she showed' (PID131). Some spoke of the neurologist's availability, to answer questions without rushing, or arranging an appointment at the end of the day to allow more time, or not charging a fee for the consultation.

*I received diagnosis by neurologist and (who) then left the room so I could maintain my composure in private. Then she came back and gave me time to question her before seeing me again the next day (PID131).*

Others described a setting not conducive to hearing bad news, in a ward with the curtains drawn, or being interrupted during the consultation.

*I was not impressed by the number of interruptions during my neurologist consultations; i.e. phone calls, missing reports and copies of reports being brought in as no preparation was made prior. (PID308)*

#### **4. Links to further information and support**

Following the initial shock, PwMND appreciated other avenues for information. Several were referred to their state-based MND Association, which was 'most helpful' (PID328), or given pamphlets or a DVD. Others were specifically advised not to look at the Internet, 'as I would experience first-hand that there are no two 'same' cases'



(PID244). In contrast, PID320 sought information, *'the internet is a wonderful tool. We were well-armed with the basics of the disease at the time of diagnosis'*.

Some PwMND appreciated the staged approach to receiving information: *'needed more at the beginning – monthly for first 4-6 months, then longer interval'* (PID130); while some indicated that their initial avoidance of information changed as the illness progressed, highlighting that PwMND have different information needs: *'at initial diagnosis I did not want to know the long-term details. About 3 months later I then wanted to know'* (PID326). Another person emphasising the need for planning and prioritising care, especially where there is rapid disease progression, suggested that:

*Planning and follow-up is vital to feel like care is considered, especially with rapid progression of MND – emphasis on getting the clinic to start a program needs to be priority, so as not to feel like left on my own! Can be very disheartening'* (PID282).

Many respondents, reported that the MND Association provided a useful link, as well as for *'giving practical advice and gadgets to assist in trying to cope with the body dysfunctions such as walking and talking, swallowing'* (PID142). A number noted sourcing the MND Association through friends or the Internet: *'We had to source this ourselves – no idea there was an MND Assoc...I was poorly supported until I contacted MND Assoc'* (PID117). This created ease because the *'MND team took over and have been brilliant'* (PID214); another respondent suggested *'immediate referral to the MND Association should occur at diagnosis'* (PID222).

A few PwMND commented on the support received from referral to a specialist hospice: *'when you go to X Hospice, you are known by your name, not a number. Nothing is a problem'* (PID 210). The same hospice *'was a very important place for us to have contact with... we have had great help...'* (PID 251); and it meant they were *'seen by many specialists'* (PID294).

Another PwMND specifically outlined the need for psychological support to manage fears about the future:

*Ability to discuss fears and especially a lengthy dying process without psychological support. The devastating impact on my husband and how he would cope. I would like to discuss my longevity as my fear of life is greater than death.* (PID139).

A number of PwMND said early connection to support and information was something they would have appreciated, *'to speak to a qualified educator straight away'* (PID295). Others described how this diagnosis requires a multi-disciplinary approach:

*Having a good support team in place was a great help – MND advisor, Hospice, Home Care as well as medical professionals.* (PID316).

## DISCUSSION

The results of this study indicate that the means and content of giving an MND diagnosis can significantly impact the person with MND and their families. There are devastating consequences of this diagnosis; PwMND require sensitivity at the time of diagnosis and holistic assessment of their requirements, to ensure their needs are met. This disease has a very individual presentation and progression which consequently requires a person-focused approach to its management, especially given that PwMND respond differently to the diagnosis and have differing needs as the disease progresses. Delays in confirming the diagnosis were apparent for many respondents, with reports of being dismissed or being referred to numerous non-neurological specialties. Identifying the need for a neurological referral is known to be a key factor in reducing diagnostic delays [30].

These accounts concur with the quantitative findings from the study where 36% of PwMND were dissatisfied with the way they received their diagnosis [7]. It was evident that the longer the PwMND spent with their neurologist during the diagnosis consultation, the more they were satisfied and the higher they rated the neurologists' ability/skills [7]. The largest significant differences between neurologists rated as having high or low skills in delivering the diagnosis, by both PwMND and their family carers, were in four domains of the SPIKES protocol in the following descending order [7, 27]: 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.

Respondents indicated a number of areas where neurologists could be more effective in giving the diagnosis. Such a devastating diagnosis requires preparation and forethought from the neurologist, including where and how the diagnosis is given and ensuring the person is not alone. The presence of another person who matters was important in many responses and privacy was essential. Palliative care guidelines support the presence of a family member or friend, but emphasise individual assessment [6]. Furthermore, MND specific guidelines stress the need for the patient to be accompanied and for the diagnosis to be delivered with a step-wise approach that takes account of the information requirements of the PwMND and their family [21].

The timing of information-giving required detailed assessment. A Dutch study described the positive effects of a two-tiered appointment structure, with adherence to particular information imparted each time, alleviating the pressure to overload the PwMND with too much information [31]. Palliative care guidelines highlight that doctors tend to underestimate an individual's preferences for information [6]. Further information from the neurologist would be appreciated by most PwMND in this study, many of whom used the Internet, and contacted MND Associations. Though it is important to remember that information needs not only vary between PwMND, but also vary for individuals at different stages of disease progression [17]. Written information

could be useful, with PwMND deciding on the timing of reading which fits with the notion of Selective Seekers of information [17].

The emphasis of respondents on multidisciplinary care (MDC) is highlighted in these accounts as MDC is underpinned by service providers applying a patient- and a family-centred approach to care and sound inter-service communication, and the patient and family are considered as key stakeholders and decision makers in the multidisciplinary care network [32]. Similarly, the demonstrated relief of respondents when being connected to the MND associations is a reflection of the person-centred health and social care of these community based organisations, that are focused on supporting the physical, psychosocial and emotional wellbeing of PwMND and their family carers [33].

Because death is expected, loss and grief experiences in relation to MND have traditionally been overlooked [14]. This study demonstrates that the receipt of a serious diagnosis such as MND, can result in significant experiences of shock and aligns with 'normal' experiences of grief following an 'expected' illness [34].

Giving the diagnosis has a negative impact on the neurologists as well. The results from the neurologists' survey [1] showed that 70% of neurologists found communicating the diagnosis "very to somewhat difficult"; 43% found responding to patients' and family members' reaction to the disclosure "very to somewhat difficult"; and 65% experienced "high to moderate" stress and anxiety during the disclosure.

Educational programs in communication skills need to be emphasised in undergraduate medical education and emphasised continually throughout the curriculum, to improve this experience for both patients and neurologists [1]. Specific skills in delivering bad news need to be incorporated into post-graduate neurological education [4] and in ongoing clinical practice, utilising self-care activities like peer-support, strong collegial relationships and debriefing [6]. This study could form the basis for instigating such programs and for developing Australian best practice protocols for communicating the diagnosis of MND using a person-centred approach.

## **Limitations**

This study is one of the few qualitative studies reporting on the experiences of a large sample of respondents (n=248). With 29% response rate to the survey, we cannot be certain of the representativeness of this group of the population of PwMND in Australia, nevertheless it is the first time that the diagnostic experiences of such a large sample of PwMND in Australia have been reported in this manner. However, the profile of respondents appears similar to a comparable survey study [9]. We also cannot be certain if more satisfied or dissatisfied people made the effort to respond. In the American survey [9], a larger proportion (56%) were dissatisfied; however, this was a regional survey compared to our national coverage.

Other methods of qualitative data collection, (e.g. interviews, focus groups), usually allow the opportunity for clarification of meaning or for probing of answers to gain depth in the participant response, this was not possible here as participants provided comments on a self-completed questionnaire.

## **Conclusion**

The evocative descriptions from this large survey of experiences receiving the diagnosis should be a salient reminder of how clinical behaviours affect those receiving care. While there were positive attributes said about neurologists, even one neurologist failing to manage the delivery of bad news appropriately, is one too many.

The way forward for best practice is about 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 [25, 26]. This person-centred approach is even more vital in a disease like MND, where there is no hope for cure yet, and looking after people's personhood, in supporting and comforting rather than just treating, is what matters most in the relatively short span of this fatal disease. This study adds to the growing international calls for person-centred healthcare in general [26] and more specifically for MND.

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