

ARTICLE

The palliative approach to caring for motor neurone disease: from diagnosis to bereavement

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Abstract

... I would like to discuss my longevity as my fear of life is greater than death ... quote from a person with MND.

With no known cure and no effective treatment yet available for Motor Neurone Disease (MND), this article focusses on quality of life, quality of care and quality of death, the three outcomes of a palliative approach to caring for people with MND (PwMND) and their family carers. A palliative approach emphasizes the need for a patient and family-centred care that focuses on the person and not only on the illness, the importance of therapeutic interactions between care providers and the patient and family, a clear communication all through the illness trajectory and it stresses in particular, the importance of goals of care and advance care plans.

A palliative approach needs to be integrated into the care plan for PwMND from the time of diagnosis, aiming to optimise their quality of life by relieving symptoms, providing emotional, psychological and spiritual support pre-bereavement, minimising barriers to a good death and supporting the family post-bereavement. However, these outcomes cannot be achieved without the following cornerstones of a palliative approach to MND care which starts with an empathetic delivery of the diagnosis, the vital support of family carers, the involvement of MND Associations, the education and training of general health and community care practitioners and the connection between the informal caring networks with the formal networks, as exemplified by Compassionate Communities policies and practices.

The present article describes a number of evidence-based initiatives from diagnosis to bereavement that need to be implemented in standard practice in order to improve the health and social care of PwMND and their family carers. The drive to find a cure should not detract from the fact that PwMND and their families still need to be supported physically and psychologically until then, by all service providers using a palliative approach, through the continuum of care from start to end.

Keywords

Bereavement support, compassionate communities, family carer support, family-centred care, MND/ALS Associations, MND/ALS care, palliative approach, patient-centered care, person-centered healthcare, public health approach, quality of death

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Introduction

Motor Neurone Disease (MND), or Amyotrophic Lateral Sclerosis (ALS), is the name given to a group of diseases in which the neurons, controlling the muscles that enable us to move, speak, breathe and swallow, undergo degeneration and die. These include the muscles of the arms, legs, back and neck and of speech, swallowing and breathing. With no nerves to activate them, muscles gradually weaken and waste and paralysis ensues. The prevalence rate is 7 per 100,000 and average life

expectancy is about 2.5 years, with no known cure and no effective treatment currently available [1,2].

Until there is a cure for MND, the focus needs to be on the quality of life, the quality of care and the quality of death. Beginning with the end in mind, what are the elements of a good death that we should strive to achieve? In this context, Smith [3] has outlined twelve principles associated with a good death and these are set out in Box 1.

Box 1 12 Principles associated with a good death [3]

1. To know when death is coming and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over symptom management
5. To have choice and control over where death occurs (at home or elsewhere)
6. To have access to information and expertise of whatever kind is necessary
7. To have access to any spiritual or emotional support required
8. To have access to hospice care in any location, not only in hospital
9. To have control over who is present and who shares the end of life
10. To be able to issue advance directives which ensure wishes are respected
11. To have time to say goodbye and control over other aspects of timing
12. To be able to leave when it is time to go and not to have life prolonged pointlessly

Palliative care and the palliative approach to care

Palliative care is about achieving a good death through “an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” [4]. Its key elements are about providing relief from pain and other distressing symptoms, affirming life and to regard dying as a normal process, intending neither to hasten or postpone death and integrating the psychological and spiritual aspects of existence into patient care.

We need, however, to take a look at who and how many people who need palliative care are receiving it. In a recent Australian bereavement survey, more people with cancer (64%) had received palliative care in comparison to non-malignant illnesses (4-10%) [5]. These non-malignant diseases are still under-represented in palliative care ten years on when reported by a previous study [6]. In terms of when people are admitted to specialist palliative care in Western Australia, for example, MND patients are usually accepted into specialist palliative care only in the last 3 months of life if they need ongoing treatment for significant unrelieved symptoms such as breathlessness, secretion management, pain or non-invasive ventilation. They are discharged from palliative care if they have improved or are stable. This is comparable to the short length of stay with a palliative care service (median of one month as reported by Aoun *et al.* [5] which is not conducive to building rapport with the family in order to prepare them for the imminent death of their loved one.

In the developed world, palliative care has become synonymous with service provision, rather than with its original purpose, as an ethos and approach to care. Under this ethos, palliative care begins at the time of the

diagnosis; however in practice, care has tended to be provided only in the last months and weeks of life, due to limited resources. However, a palliative approach does not connect narrowly the provision of care with the diagnosis. More so, it supports early conversations with patients and their family carers about their needs and preferences, their wellbeing and goals of care and anticipatory planning [7] see Box 2.

Box 2 Essential Characteristics of a Palliative Approach [8]

- Upstream orientation to care: early on in the illness trajectory, even as soon as the time of diagnosis.
- Emphasis on anticipatory planning and open conversations about goals of care
- Adaptation of palliative care knowledge and expertise by primary care professionals
- Operationalization of a palliative approach through integration and contextualization within healthcare systems
- Promotion of better service planning, better care and better outcomes for patients and their family members.

We find, therefore, that a palliative approach is at the intersection of many principles related to palliative care, supportive care, end of life care and person-centered care and practices relating to terminal illnesses [8] (Figure 1). In MND, a palliative approach, incorporating these principles, needs to be manifested in all aspects of disease progression and care requirements, from diagnosis to bereavement [9] (Figure 2).

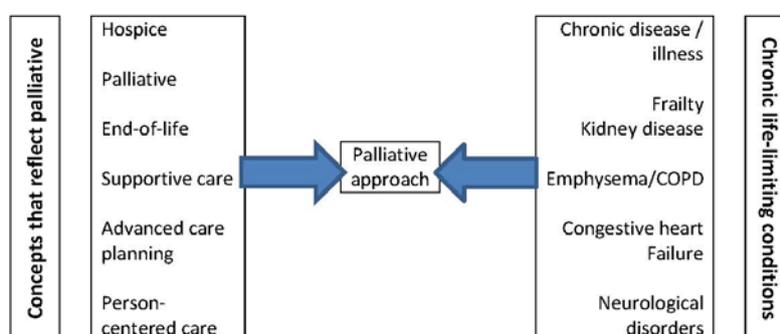
We may ask, therefore, ‘What are the cornerstones of a palliative approach in MND starting with imparting the diagnosis and ending with bereavement support?’

The cornerstones of a palliative approach to MND care

Receiving the diagnosis

As Doyle and O’Connell [10] stated: “The way the patient is told the diagnosis is now recognized to be the first and one of the most delicate steps in palliative care”. However, over twenty years later, researchers are still reporting on the negative experiences of how patients and carers received this bad news, such as those in Box 3 from a recent Australian survey of patients and their family carers [11,12].

Figure 1 The intersection of the principles of hospice, palliative and person-centered care with practices for people with chronic life-limiting conditions [8]



Modified from Sawatzky *et al.* [8]

Figure 2 A Palliative approach in MND [9]



Modified from Mitchell & Borasio [9]

Box 3 Patients' and family carers' comments on receiving the diagnosis [11,12]

"Neurologist was clinically thorough but uncaring when providing diagnosis of MND. Gave brochure for information. Told me I had 3 years left to live. Was left alone in city 2hrs from home after diagnosis"

"I was told very bluntly about my situation and how it would basically progress. He said if I had any plans do them now"

"I felt the neurologist was very insensitive. Especially saying it is "terminal" I didn't have enough time to comprehend what I had just been told."

"This diagnosis is (almost) as bad for the partner - I was hardly considered at all - little or no empathy at all. The neurologists and other doctors just don't understand the needs of the patient's partner in order that he (or she) is better able to cope and provide support!!"

In this Australian survey, 36% of patients and family carers 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 the breaking of such bad news, the more they were satisfied and the higher they rated the neurologists' ability/skills (Figure 3). The largest significant differences between neurologists rated as having high or low skills in delivering the diagnosis were in four SPIKES domains (a protocol for breaking bad news): Emotion (responding empathically to the feelings of patient/family), Knowledge (sharing the information and suggesting realistic goals), Invitation (exploring what patient/family are expecting or hoping for and Strategy (making a plan and following through) (Figure 4).

But how well are we doing against international standards? The comparison between the neurologists' experiences and those of patients and international guidelines point to areas in need of improvement (Table 1), such as longer length of consultation, more referral to MND Associations, shorter timeframe for follow-up support from diagnosis, less patients seen alone, diagnosis given with more care and empathy and with more time for patient/family to express emotions [13]. Two-thirds of responding neurologists reported feelings of stress and anxiety associated with delivering the diagnosis and two-thirds were interested in further training in responding to patients' emotions and development of best practice standards. Box 4 presents a comment reflecting the stress some neurologists experienced breaking bad news and another comment reflecting a differing view on empathy education and training [13]. The important point here is the need for peak bodies to instigate educational programs and develop standards and protocols that reflect a more person-centered approach to MND care at this critical first step of a traumatic disease journey [14].

Table 1 Neurologists' reported practice in delivering the diagnosis compared to the experience of people with MND from the parallel survey and the EFNS Guidelines [13]

	Patients N=245	Neurologists N=69	EFNS Guidelines
Diagnosis by neurologist	95%	-	always
Delivery of diagnosis (2 or more consults)	70%	78%	step-wise
Length of consultation (minutes)	30	20	45-60 mins
Private space (yes - always/frequently)	96%	97.1%	always
Avoid interruptions (yes - always/frequently)	91%	91%	always
Patient seen alone	21%	23%	never
Referral to MND Association for information and ongoing support	40%	73%	always
MND Association publications given	24%	44%	always
Diagnosis in writing	16%	22%	recommended
Asked of any previous MND knowledge	43%	-	always
Follow-up support: Neurologist	41%	75%	always
Follow-up support: MND Association	56%	35%	always
Diagnosis to follow-up (median, weeks)	7	4	2-4 weeks
Enough information given	43%	-	always
Diagnosis given with warmth, care & empathy	67%	-	always
Sufficient time to express emotions	63%	-	always
Sufficient time to have emotions responded to	62%	-	always

EFNS= European Federation of Neurological Societies

Figure 3 Ratings of neurologists' ability/skills and consultation duration [11,12]

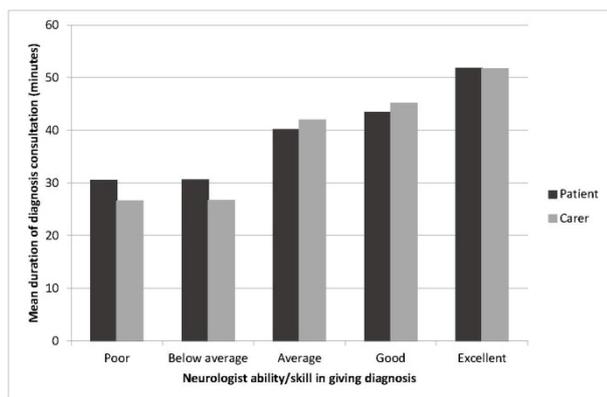
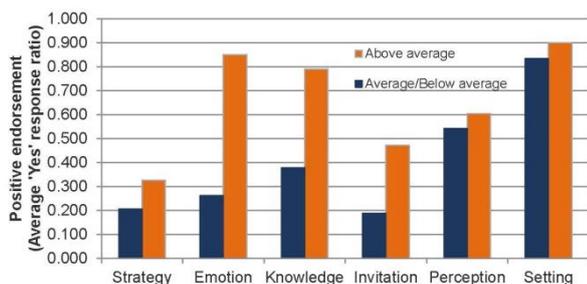


Figure 4 People living with Motor Neurone Disease ratings of neurologists' abilities/skills grouped under the 6 SPIKES domains (11)



Modified from Aoun [11]

Box 4 Comments from neurologists [13]

“Having had a migraine after each MND clinic, feeling stressed and anxious about having so little to offer, I have gradually accepted the limitations of my skills, and some confidence that assisting the patients honestly and empathetically, and not ‘abandoning’ them is of value to most patients.”

“Diagnosing MND is always unpleasant for both patient and physician ... I think many physicians don't deliver the news well but I don't believe it is something that can be taught ... Perhaps we should be selecting junior doctors to enter physician training on the basis of their communication skills? The science is easily learned. Trying to teach empathy, sincerity, and understanding is impossible. Selecting for those qualities is easy.”

Education in the palliative approach to MND care

Continuing on with the theme of education, WHO [15] called for a palliative care approach be adopted by all, not just specialist healthcare professionals and that “general palliative care” be provided by primary care professionals who have a good basic understanding of palliative care principles. Therefore, palliative care needs to be adopted by all, not just by professionals specializing in palliative care, especially considering that the MND patient and family come into contact with about 22 different medical, nursing and allied health disciplines, including neurology, general practice, palliative care, pastoral care, rehabilitation, gastroenterology, respiratory medicine, psychiatry, physiotherapy, occupational therapy, speech pathology, dietitian, complementary therapy and community support services such as the MND Associations and other government and non-government agencies.

Guidelines recommend that clinical care is delivered through specialised multi-disciplinary clinics (MDC) to ensure care is well co-ordinated between all these healthcare disciplines and support organisations. These specialised MDCs have been shown to provide effective care that can prolong patients' survival time and there is increasing evidence that palliative care integrated into MDC care leads to improved symptoms and quality of life of people with MND and their families [16-19].

Education in the palliative approach is especially pertinent when the cost of the illness is taken into consideration in addition. Although MND is relatively uncommon, the associated direct costs (e.g., healthcare, expensive equipment) and indirect costs (lost productivity and income) and intangible losses (e.g., independence, quality of life) contribute to the high cost of this illness to Society. According to an Australian report [20], the total cost of MND was estimated to be \$1.13 million per person with MND in 2015 and the per-person costs of MND are substantially higher than a number of other diseases.

An educational program to improve the knowledge of health professionals on a palliative approach in MND care has been developed, evaluated [21] and is implemented annually by the MND Association in Western Australia. The contents of this program are listed in Box 5.

Box 5 A Palliative Approach to Caring for People with MND [21]

- Overview of a palliative approach for people with MND
- Promotion of dignity and quality of life for people with MND
- Pathophysiology of MND
- Management of common symptoms experienced by people with MND
- Communication and people with MND
- Psychosocial care of people with MND
- Issues for families and caregivers
- Culturally appropriate care for people with MND
- Ethical issues associated with caring for someone with MND
- The role of health professionals in providing care for people with MND and their families

The evaluation of the program (n=78) showed that it increased the knowledge of health professionals regarding MND, increased their confidence in providing MND care and promoted more flexible approaches to MND care as described by these health professionals in Box 6.

Box 6 Comments of health professionals derived from program evaluation [21]

“Whilst recently attending a client with end-stage motor neurone I took extra special care in the way I communicated with her. I gave extra time to enable a more effective two-way conversation. I think she really appreciated that.”

“It created a positive framework for change at our workplace and a lot of in-house learning.”

Therefore, a palliative approach integrated into the care plan for people with MND from the time of diagnosis can optimise their quality of life by relieving symptoms, providing emotional, psychological and spiritual support pre-bereavement, minimising barriers to a good death and supporting the family post-bereavement. These outcomes are only attainable if the skills and knowledge in palliative care are expanded beyond the realm of specialist palliative care services to benefit the extensive range of health and community-based services providing care, mostly at home, as reiterated by WHO [15].

The role of MND Associations: Until there is a cure, there is care

In Australia (and in some other countries), MND advisory services in every state provide a range of services to People with MND (PwMND) and family carers, including information and education for PwMND, family carers and health professionals, equipment provision, fundraising, support and advocacy. MND Advisors visit PwMND in their homes to assess their current needs and to assist their connection with healthcare services. Experiences of people with PwMND and their families accessing such case management-based care from MND advisory services, have not, to date, been well investigated. However, over three years (2015-17), The MND Advisory Service in Western Australia (WA) was evaluated to identify which aspects of this service were in most need and of value to the service users, in order to improve the delivery of these services [22]. Figure 5 shows a consistent high satisfaction, at about 80%, in informational and supportive services, with comments from patients and service users reflecting these satisfaction rates (Box 7).

Table 2 highlights what was most valued by PwMND and their family carers. Approximately 90% of both groups found the MND Advisory Service of high value practically and emotionally, especially the personal contact and time dedicated to the visit, with 86-88% stating that the service had met their expectations. Two unique features of this service, not provided by other services to the same extent, were the emotional benefit to both groups and the particular focus on the family carers' needs. Therefore, until such person-centered models of care are properly investigated through the experiences of their users, erratic changes in care funding will pose a threat to their effective operation and even viability. The drive to find a cure should not detract from the fact that PwMND and their

families still need to be supported physically and psychologically until then [22].

Box 7 Comments deriving from evaluation of the MND Advisory Service in Western Australia [22]

“I was poorly supported until I contacted MND Assoc; the ‘MND team took over and have been brilliant.”

“Immediate referral to the MND Association should occur at diagnosis.”

“Prior to their contact I was ‘in the dark’ as to what do; who to contact etc.”

“The information and support they provide make all the difference.”

“They helped me with all the support and how to cope with a tragic situation.”

Box 8 Experiences of MND family carers [23,24]

“I think you’re traumatised, quite frankly. All the symptoms of trauma - numb[ness] and shock and all of those things.”

“I turned around and I said, ‘Give me a kiss’ and I thought at the time he was denying me a kiss, but I realise now he had no muscles in his face to kiss me with. I backed off and thought, it’s not that you’ve lost feelings for me; it’s just that you can’t.”

“They should bring in euthanasia - you wouldn’t put a dog through what MND does - I find it very difficult. It really rips you apart.”

“[having] ability to discuss fears and especially a lengthy dying process with 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.”

“[After the death] You go from having a whole army of people; then it is just you; You’re just left alone.”

Figure 5 Satisfaction with MND Advisory service in WA by PwMND and Family Carers (2015-17)

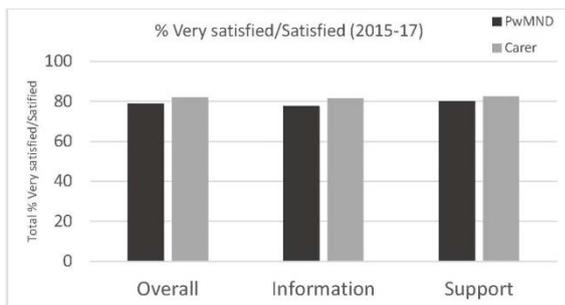


Table 2 Value of MND Advisory service (2017) [22]

(percent quite a bit/ a lot)	PwMND (%) N=52	Family Carer (%) N=43
Being visited at home	89.3	90
The personal contact	90.2	95.1
The time dedicated to the visit	91.7	95.1
The proactive approach anticipating your needs	85.7	92.3
The practical support	88.2	92.7
The emotional support	79.6	84.6

Family Carers: The vital partners in a palliative approach

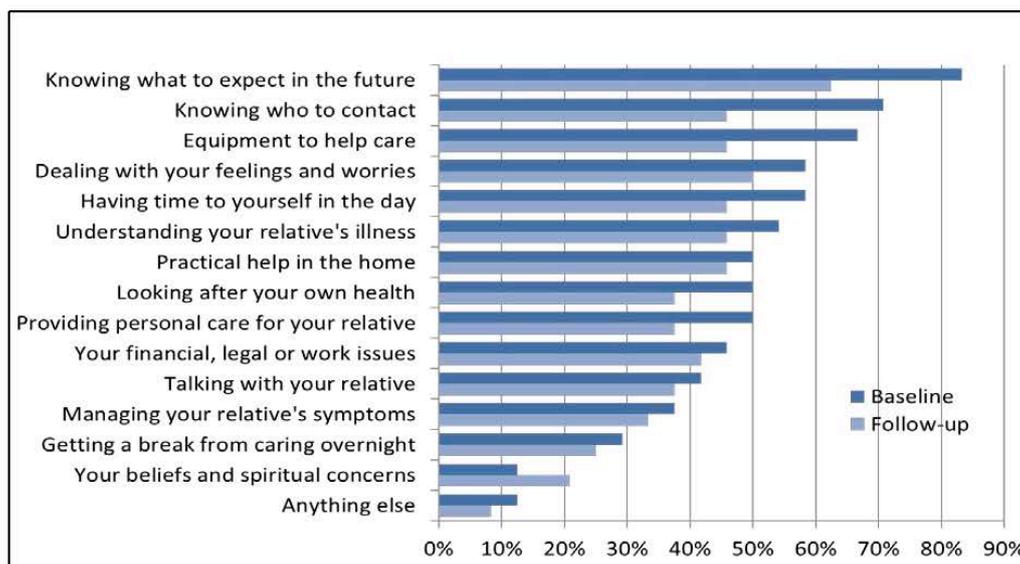
With most of the care and support occurring at home, family carers of PwMND endure adverse effects on their physical, emotional and social wellbeing and they often describe their caring experiences as unrelenting due to the progressive nature of the disease and the relative hopelessness with respect to recovery [23,24] (Box 8).

To ameliorate some of the negative effects of caregiving, family carers need support in their dual role: support to enable them to care for the patient (their ‘co-worker’ role) and also direct support for their own health and wellbeing (their ‘client’ role) [25]. As Miles and Asbridge [26] described family carers, they are vital partners in increasing the person-centeredness of health and social care systems.

To support carers in their dual role, a person-centered validated tool, the Carer Support Needs Assessment Tool (CSNAT), opens the opportunity for systematically holding conversations about the practical, psychological, spiritual and existential needs of carers in supporting their care recipients and helping themselves. An intervention using the CSNAT was trialled in Western Australia [24] and the highest support priorities reported by MND carers were: knowing what to expect in the future, knowing who to contact if concerned, equipment to help care and dealing with feelings and worries (Figure 6). For example, for the first highest priority “knowing what to expect in the future”, discussions with service providers were around end-of-life issues, advance health directives, future care and the role of palliative care. Such a seemingly difficult topic to broach can be facilitated by the CSNAT process of regular conversations. This, and other benefits from the family carer and service provider perspective, are presented in Box 9.

In general, the CSNAT had significant benefits before and after bereavement. It significantly reduced family carer strain and distress during the caregiving period and had a positive impact on perceived adequacy of support of bereaved family carers and achievement of preferred place of death according to carers [27,28]. The benefits gained by carers in being engaged in early and direct assessment of their support needs before bereavement re-inforce the need for palliative care services to effectively support carers well before the patient’s death.

Figure 6 MND Family carers expressing need for more support [24]



Reprinted with permission from CUP Aoun *et al.* [24]

Box 9 Comments from a family carer and a care advisor [24]

“One of the hardest issues to discuss is EOL issues. It, the form, focussed my mind on the need to discuss this and I ended up talking to people - I spoke to a counsellor about EOL as a direct result of going through the survey.” (MND family carer)

“I think it is interesting to see how carer needs change over time and that their needs don't always follow the same trajectory as the person with MND ... sometimes what I perceive as a very stressful time for the carer they seem to sail through, whereas something minor (for me) at another time can unleash a great emotional tide for the carer.” (MND Care advisor)

End of Life Care: Anticipatory Planning

One of the essential characteristics of a palliative approach is an emphasis on anticipatory planning and open conversations about goals of care and advance care plans. Decisions for end-of-life care, including the use, and withdrawal, of ventilation and nutrition, need to be discussed with the patient and family proactively, in advance of deterioration [29]. Around the end of life, it is common to have people with MND refuse life-sustaining treatment such as non-invasive ventilation, PEG gastrostomy feeding, medication, insulin or turning off pacemakers and implanted defibrillators. Therefore, it is important that PwMND and their family determine their preferences and record their decisions in documents such as an Advance Health Directive (AHD) or Advance Care Plan (ACP). An AHD example is presented in Box 10. Unfortunately, the uptake of such documents is still low worldwide, 10-25%, although those who received palliative care were 2-3 times more likely to have an ACP or AHD in place [5].

Box 10 Example of an AHD

1. Treatment decision

-In the following circumstances:

In the event of a cardiac arrest, stroke or respiratory arrest, or I require artificial feeding through a naso gastric tube.

-I consent/ **refuse consent** to the following treatment (cross out and initial one of these options):

Any form of active intervention this being CPR, anticoagulant therapy, artificial feeding, IV fluids or a tracheostomy.

2. Treatment decision

-in the following circumstances:

At this time in my disease if I have a chest infection, pneumonia or aspiration pneumonia or I require a PEG feeding tube, emergency surgery.

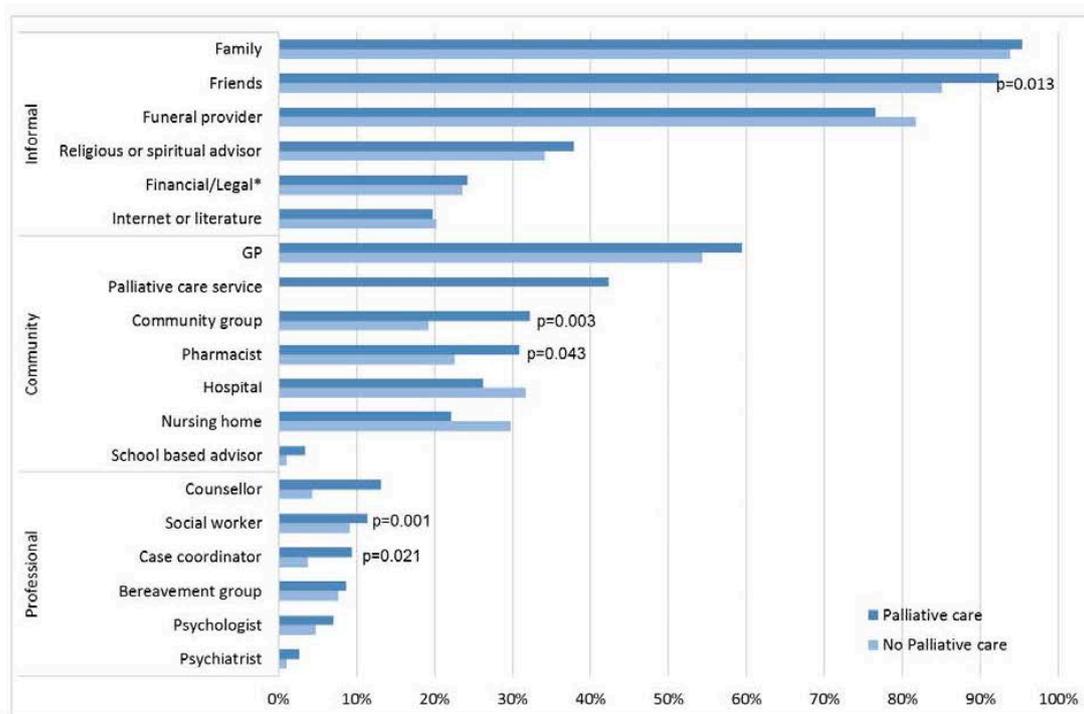
-I **consent**/ refuse consent to the following treatment (cross out and initial one of these options):

To a hospital admission for aggressive antibiotic treatment, and PEG insertion only if I'm not in the palliative or end of life stage of my disease. Emergency surgery only in consultation with my daughter.

Bereavement Support: The Poor Cousin of Palliative Care

The last cornerstone of a palliative approach is bereavement support. Nevertheless, one of the modern public health paradoxes is the neglect of the bereaved (though bereavement is a universal experience). Palliative care standards propose that bereavement support should

Figure 7 Sources of bereavement support accessed by respondents whose care recipients received or did not receive palliative care [33]



be matched to risk and need [30,31]. However, studies in many countries demonstrate that palliative care services continue to adopt a generic approach in offering support to bereaved families and therefore support is not tailored to their needs. In an Australian survey, only half of the bereaved reported they had a follow up contact from the palliative care service at 3-6 weeks and a quarter had a follow-up at 6 months. The feedback underlined the limited helpfulness of the blanket approach to bereavement support, which was often described as 'not personal' or 'just standard practice' [5]. Therefore, this support is seldom as intentional or targeted as it should be, particularly when the bereavement care phase is separated from the care and support provided prior to the death [5].

An Australian study of MND family carers reported that half of participants did not recall receiving offers of bereavement support and over one-third of the sample met criteria for prolonged grief disorder, a much higher proportion than the general population estimate of 10%. On average, palliative care services were received less than 2 months before patient death [23], confirming the before mentioned short involvement of the specialist palliative care services.

So who provides bereavement support to the bereaved? As can be seen in Figure 7, based on an Australian bereavement survey [5], the vast majority of the bereaved accessed support from family and friends, followed by funeral providers and general practitioners, whether the care recipients used or did not use palliative care services. Therefore, much of this support is provided in informal

and other community settings by a range of people already involved in the everyday lives of those recently bereaved. A public health approach to bereavement care is needed to support 'everyday assets' in the community who care for the majority of the bereaved, without the over-reach from professional services [32]. The data from this survey provided empirical evidence for building a community's capacity to provide the type of social and practical support advocated by the Compassionate Communities approach which relies on identifying and developing local caring networks around the dying person and their family [33,34].

Box 11 Compassionate Communities [34]

Publicly encourage, facilitate, support and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, death in childhood, grief and bereavement and the trials and burdens of long term care.

It is a way of thinking about how care is provided to people who are dying. It relies on the identification and development of caring networks, around the person and their carer, extending the concept of person-centred care to network focused care.

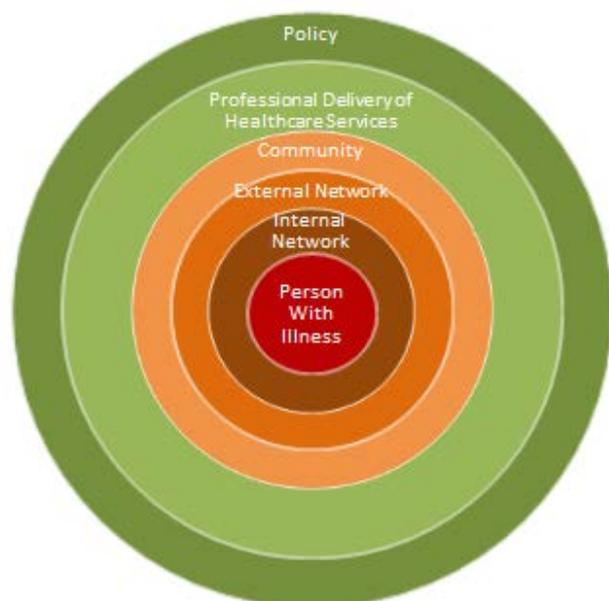
It is a natural part of life. It is about acknowledging that care for one another at times of crisis and loss is not only a task for health and social services but is everyone's responsibility.

Box 11 provides more detail on the ethos of the Compassionate Communities approach to end-of-life care and bereavement support. The caring networks consist of

both formal and informal networks working in partnership and are depicted in Figure 8 as the circles of care and described by Abel [35] (Box 11).

Such caring networks are the backbone of care outside the hospital setting, where most of the MND care takes place, in the community.

Figure 8 Circles of Care [35]



Modified from Abel [35]

Box 12 Description of 'circles of care' according to Abel [35]

"Circles of care is a way of viewing the overall networks that focuses not just on the patient, but on the main carer and the caring network. Failure to engage with and trust the caring network not only misses an important opportunity for enriching life for patient and carers, it may actually cause significant harm which can exacerbate bereavement reactions."

Conclusion

While much discourse has tended to focus on specialist palliative care, there is a limit to the resources available for providing specialist palliative care to all life-limiting illnesses. Hence, it is important to advocate for a more realistic palliative approach to care that is more achievable from diagnosis to bereavement, through better education of all service providers, improved support for family carers, better resourcing of MND Associations and consistent anticipatory planning and bereavement support. The way forward for best practice is about implementing a more person-centered approach to caring for PwMND from the start to the end of the disease trajectory as exemplified by the palliative approach. The focus needs to shift on the patients' and carers' values, preferences, psychosocial and existential concerns in the context of the underlying

disease experience and the manner clinical practice is delivered. This person-centered approach is even more vital in a disease such as MND, where there is at present no hope for a cure yet and where 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. Extending the concept of person-centered care to network-focused care is vital for the identification and development of sustainable caring networks before and after bereavement, around the person with MND and their family carer(s).

Acknowledgements and Conflicts of Interest

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