

Palliative Approach to MND

There is increasing evidence that palliative care, integrated in a multidisciplinary approach to care, leads to improved symptoms and quality of life in pwMND and their families.

These outcomes can only be achieved if palliative care knowledge and expertise is extended beyond the domain of palliative specialist services to include the full scope of health and community based services.

22 health professionals come into contact with one pwMND. Imagine if all took a palliative care approach!

The palliative approach to caring for MND: From diagnosis to bereavement

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Palliative care begins at time of diagnosis, rather than just service provision at the end of life.

Especially important to start palliative care from diagnosis in MND because of smooth downward trajectory.

Survey of bereaved families: 64% of pw cancer received palliative care. Non-malignant illnesses was 4-10%. Patients usually accepted into palliative care usually in last 3 months of life.

True palliative approach promotes early interventions aimed at having conversations with patients and family members about their goals of care, comfort measures, and needs and wishes. Should emphasise anticipatory planning, open conversations & clear communication throughout the illness, planning goals of care to reduce the effects of the disease while promoting optimal and meaningful living for the pwMND and their family.

Points of note

- “Until there is a cure there is care.”
- “My fear of life is greater than my fear of death.” A pwMND in response to his level of confidence in his care.
- A palliative approach aims at having early interventions, aimed at having meaningful conversations with patients and their families about their goals of care, comfort measures, needs and wishes.
- “Upstream orientation to care” from early on in an illness with an emphasis of anticipatory conversations about shaping the care to come from a patient – and family-centred focus, not disease focus.
- “Quality of life, quality of care, quality of death.” Begin one’s approach with the end in mind.
- The principles of a good death: Smith, 2000
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1128725/>
- WHO says palliative approach should be adopted by primary care professionals.
- Need for education/training in palliative approach to caring for pwMND.
- West Australia runs one-day training programme – very popular.

Diagnosis

- Diagnosis is one of the most sensitive steps:

- “The manner in which the diagnosis is imparted is one of the most sensitive steps in end of life-care” (Borasio et al, 1998)
- Disclosing the diagnosis questionnaire adapted by Prof Aoun for pwMND showed 36% patient dissatisfaction in how and where their diagnosis was told to them.
- National survey of all neurologists in Australia, carers. 36% of patients dissatisfied with way diagnosis delivered. Conservative estimate.
- High skills = empathy, imparting knowledge.
- “It’s up to them to learn some skills.” Powerful quotes about experiences with neurologists from patients/carers.
- This slide compares neurologist practice in delivering the diagnosis, patient experience and the European Federation of Neurological Societies guidelines:

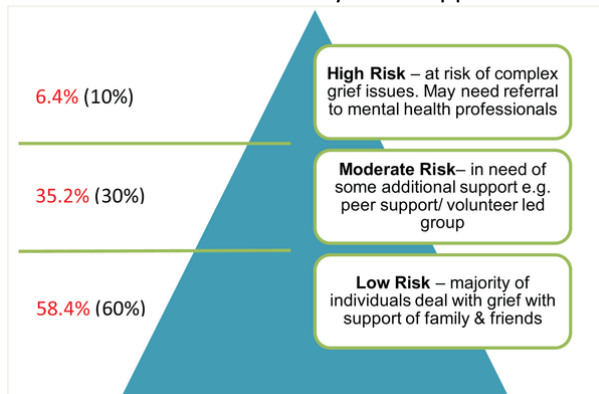
Practice/Experience	People with MND (n=245)	Neurologists (n=69)	Guidelines
Diagnosis by neurologist	95%	-	Always
Delivery of diagnosis (2 or more consults)	70%	78%	step-wise
Length of consultation (minutes)	30	20	45-60 mins
Private space (yes - always/frequently)	96%	97.1%	Always
Avoid interruptions (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
Enough information given	43%	-	Always
Follow-up support: Neurologist	41%	75%	Always
Follow-up support: MND Association	66%	35%	Always
Diagnosis to follow-up (median, weeks)	7	4	2-4 weeks
Diagnosis given with warmth, care & empathy	67%	-	Always
Sufficient time to express emotions	63%	-	Always

Carers

- Family carers: experience like PTSD, prolonged grief.
- Carer Support Needs Assessment Tool (CSNAT) is an evidence-based measure of carer support needs intended for use as a practice tool in palliative home-care. CSNAT interventions significantly reduced family carer strain, had a positive impact on perceived bereavement support and achievement of the preferred place of death.
- CSNAT opens opportunity for systematic conversations about needs of carers. Need to do early enough with carer – prepares them well to accept help.
- CSNAT intervention significantly reduced family carer strain and distress. Positive impact on perceived adequacy of support and achievement of preferred place of death. These benefits reinforce the need for early intervention of palliative care.
- Highest priorities for carers:
 - knowing what to expect
 - knowing who to contact if concerned
 - equipment to help care
 - dealing with feelings and worries

Bereavement support

- About 10% of people at high risk for complex grief issues (need professional support). 30% at moderate risk. 60% are okay with support from family and friends.



- Large amount of bereavement support comes from funeral providers. Funeral Providers were accessed more for support by people who did not receive palliative care than those that did receive it.
- Palliative care services should match their commitment to providing a good death with supporting a good grief by investing their efforts into developing community capacity for bereavement rather than delivering specialised bereavement services.
- Bereaved caregivers are willing to provide experiential knowledge and advice for others in their situation. Such knowledge can be used to develop community bereavement care strategies through information brochures, posters, and community education providers to upskill PC bereavement volunteers and the wider community so that bereaved family caregivers are best supported.

Who needs bereavement support?

- Compassionate communities – how care is delivered to those who are dying and their carers. It relies on identifying and developing care networks around the person and their carer and extending the concept of patient-centred care to network-focused care.
- “It is everyone’s responsibility to care for each other in times of crisis and loss not just those in the health and social services”.
- *NZ application – In theory compassionate communities would help support 90% of those people with healthy grief responses. Compassionate Community engagement depends on societies willingness to get comfortable with feelings about death, loss and grief.*
- “Carer as co-ordinator.”
- Value of MND Advisory service survey results. Family carer scores were higher than patient scores.