

MND- The value of early palliative care



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Objectives

In this session, we are going to talk about:

- Benefits of palliative care
- What palliative care can and cannot do
- The importance of talking about planning for care

Motor Neurone Disease

- Life limiting
- Unpredictable in its course
- Planning needed (to live, and to die)
- Looking ahead is needed, but is difficult
- Affects 'the family' ... the one you are born into, or the one that you build

Motor Neurone Disease

- Might be incurable, but it is never untreatable....
- From a palliative care perspective, "... will never give up trying to address a problem that is impacting on a person's quality of life"....

Palliative care is seen as.....

- Something that people don't want to talk about
- Care at the end of life
- Giving up?

Palliative care is not the problem



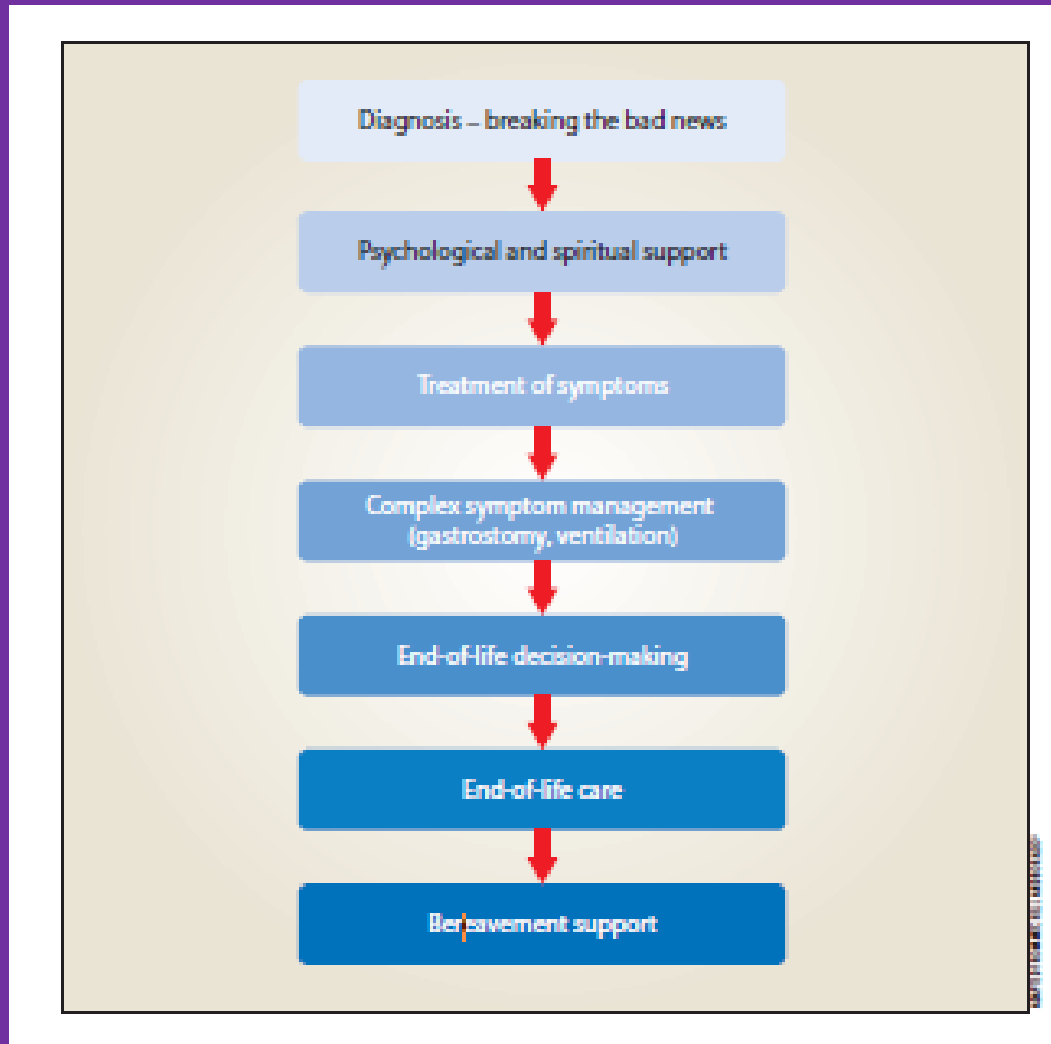
What is palliative care?

Early palliative care has benefits.

‘Care that addresses symptoms that cause suffering for people who have life limiting illness....’

Even if people are pursuing treatment, ‘fighting’, going on trials, making applications for in the background, palliative care can be there to help people to **live well** for the rest of their lives....

What sort of care is palliative care?



Oliver, D & Aoun, S. 2013

Creating a care team

- Care team members will change over time. For a person with MND - Social Work, Speech Pathology, Physio, MND advisor, Neuro Clinic/Neurologist, GP, Dietitian, faith leader, personal care workers, palliative care team
- Sometimes palliative care will be the lead in the care team, and sometimes the person with MND might even be discharged from a palliative care service, and readmitted as necessary
- Palliative care can come in and out of the team, depending on need

All palliative care services....

- Are different... different resources, team members, availability of services, different criteria for admission
- The person with MND and their 'journey' with this illness is also unique, as are symptoms and progression
- The palliative care service will usually be multidisciplinary, and work with the specialist neuro service (such as Calvary, Barwon, Northern Health MND clinics) to support the client and family

Planning for care

Palliative care is care that can run along aside other treatments. It is not a last resort, nor is it only available if no other treatment is working.

Any/all of these could be received in conjunction with palliative care

- Clinical trials
- Medications
- NIV
- PEGs
- Respite

Planning for care

- Advance care plans (ACP) are only as good as the conversations that have been had (hopefully many) to complete them
- Not only important for people with MND! Start now...
- Provide guidance for the medical treatment decision maker, if the person with MND is no longer able to make their own decisions

Planning for end of life

- Just as ACP issues are important to discuss, so is planning for care when the person comes to the end of their life, when death will come
- Plans come from conversations, and exploring what is a choice, and what is not wanted... where will the person die, who will be there, what is important, what needs to be done before.
- Plan early, discuss, and change your mind if needed
- Don't wait until these decisions have to be made with no time to consider options

Things that might happen

- Fatigue
- Pain/comfort/positioning
- Loss of weight and swallowing problems
- Breathing difficulties
- Sleep
- Constipation
- Mood changes, anxiety
- Other issues specific to the person

Supporting people experiencing grief and loss

- MND is often called a 'disease of losses', that doesn't give you time to catch up
- Palliative Care will assess and support the psychosocial and emotional wellbeing of the person with MND, and their primary carer throughout their involvement
- Will stay in contact after death (if wanted). MND Vic will also provide support in bereavement
- But support for those experiencing loss is not just for after death...

Questions- ask away.....

OR.... Other palliative care issues to discuss:

- ? Morphine
- What is dying like?

References

- Oliver, D & Aoun, S. 2013, *What palliative care can do for motor neurone disease patients and their families, European Journal of Palliative Care*, 20 (6).
- Oliver, D. 2019, “Palliative care in motor neurone disease: where are we now?” *Palliative Care: Research and Treatment*, 14 (1).

Resources

- End of life resource for people living with MND - MND Australia
https://www.mndaaustralia.org.au/getattachment/32d3a0d6-df0c-4400-ae53-482289a75758/MNDAus_EndofLifeGuide_digital-version.pdf?lang=en-AU
- Palliative Care Vic website
<https://www.pallcarevic.asn.au/page/107/useful-information>