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The Joint Select Committee on Palliative Care in WA – An inquiry into palliative care

Submission from the Motor Neurone Disease Association of Western Australia (MNDAWA)

The MNDAWA advisors and the neurologists in WA work closely with palliative care services where possible, but it is clear that these services are under-resourced to provide adequate services for neurodegenerative disorders in general. MND is a key example as the disease progresses more quickly than most other neurodegenerative disorders so it needs more input, but the gap applies more broadly. It is important that palliative care services are involved early after diagnosis for a rapidly progressive disease like MND to:

1. Enable adequate time to build a relationship
2. Manage symptoms throughout the course of the disease
3. Have conversations with the patient and family early enough about goals of care, advance care plans etc.

In many neurodegenerative diseases, specialists diagnose the disease, but are not necessarily as engaged in providing ongoing symptomatic support during their journey with the disease. Palliative care would be best placed to manage many of these patients and their symptoms and help prepare their families. However, in the current environment, palliative care services only accept referrals of “dying” patients, or when they are distressed with symptoms, then discharge them. Our experience is that the various Specialised Palliative Care Services do not seem to talk to one another and work together as well as they should.

More specifically, the following gaps have been experienced:

- Engagement of palliative care services with MND patients is often not long enough to establish a rapport before death, as the referral is accepted too late in the disease journey.
- Palliative care staff are unfamiliar with MND symptoms and its progression.
- There is no consistency with visiting nurses. Patient and carer are confused as to who will be visiting them next.
- There are no regular visits by a palliative care doctor. Many patients have only seen a doctor at initial consult.
- Resistance from palliative care staff to speak to an MND specific nurse or specialist.

- There is a regular discharge from palliative care services that then requires a new referral for re-engagement.
- Family carers are often dismissed in having an opinion on their loved ones' status.
- Recent observations of palliative care staff providing their personal views on Voluntary Assisted Dying to patients; and encouraging a hospice admission when AHD states the patient wants to be cared for at home.
- GP referral is often declined by palliative care services. No home visit for assessment takes place by the palliative team. Clarity on criteria needs to be improved.

Additional points:

-For the NMHS region, there is a desperate need for more public Hospice beds in the North at Joondalup Health Campus [not at Osborne park Hospital]. Increasing public beds in this area has been promised by the WA Labour Government.

-There is a marked inequity of access to palliative care services between metropolitan and regional areas for MND patients.

-In countries where VAD is legal, 20% of VAD deaths are for people with MND compared to 5% cancer. Having had sadly two suicides this year, we are concerned that this may be the case also in WA as of July 2021, where MND patients will be over-represented in VAD cases, if palliative care services will not improve for people with MND.

Contributors

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Kind Regards



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