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MNDAWA RESPONSE TO JOINT SELECT COMMITTEE ON END OF LIFE CHOICES

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INTRODUCTION

The difference between palliative care and the palliative approach to care

Every person in Western Australia with a life-limiting illness has a fundamental right to a palliative approach to care. To enable this right to be met, issues regarding palliative care, specifically equity, access and affordability need to be considered for both current and future populations. It is important to note, that in most instances a palliative approach to care can be provided in the community supported by knowledgeable health professionals. The community is the preferred place of care for most patients and admission to a specialised palliative care inpatient facility may only occur during brief episodes of care (i.e. respite, symptom management, terminal phase of illness). (Palliative Care Review in WA Report, DoH, 2005)

In much of the Western world, palliative care has become equated with service provision, rather than with its original intent, as a philosophy and approach to care. Instead of an upstream orientation, where palliative care begins at the time of the diagnosis, care has tended to focus on the last months and weeks of life. A palliative approach does not link care provision too closely with prognosis but, rather, promotes early interventions aimed at having conversations with patients and their family members about their goals of care, comfort measures, and needs and wishes (Stajduhar and Tayler, 2014; Kristjanson et al, 2003). The World Health Organization (2014) has also suggested that a palliative care approach be adopted by all, not just specialist health care professionals, and that “general palliative care” be provided by primary care professionals who have a good basic understanding of palliative care principles.

There is increasing evidence that palliative care integrated in a multidisciplinary approach to care leads to improved symptoms and quality of life of people with MND (PwMND) and their families (Oliver et al, 2016). It is recommended that a palliative approach is integrated into the care plan for people with MND 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. These outcomes can only be achieved if palliative care knowledge and expertise is extended beyond the domain of specialist palliative care services to include the full scope of health and community-based services providing care, mostly at home, in order to meet the extensive range

of needs of people with MND and their family carers, from diagnosis to bereavement (from Aoun's abstract for Australasian MND Symposium, March 2018).

We feel it is important to delineate the difference between palliative care and the palliative approach at the start of this document, as both are operating at different stages of the disease journey. We offer some recommendations to help achieve the palliative approach to MND care in the conclusions section.

This submission

This submission is based on the current practice as experienced by the Association's MND Advisors and two neurologists, and complemented by the latest research evidence from WA and elsewhere.

PALLIATIVE CARE

Research evidence

According to latest research by Aoun et al (2017) "From the terminal illnesses that lend themselves to palliative care, more people with cancer (64%) had received palliative care in comparison to other non-malignant illnesses (4-10%) with these non-malignant diseases are still under- represented in palliative care ten years on from an earlier study where it was reported that less than 10% of people who died of non-malignant diseases had accessed specialist palliative care services, compared with 66% of people who died of cancer". Hence cancer sufferers still have better access to palliative care compared to other non-cancer conditions.

"Yet these terminal conditions, other than cancer, have required a longer period of care, twice as long as that of malignant diseases (48 vs 24 months, $p < 0.001$), with more 'other relatives' helping the immediate family (mainly spouses and adult children) in this prolonged period of care".

There is a very short period of a median of 1 month that patients were under palliative care. Referrals are not occurring early enough for patients and families to benefit from this holistic care.

Regarding the quality of care received by palliative care services, about 90% of respondents considered the quality of palliative care in WA to be excellent/ good. This is higher than Victoria (82%) or all states combined (84%).

In terms of the settings where care was received, there were significant differences ($p = 0.001$) between the three settings: More respondents rated the quality of care in in-patient settings (hospitals and hospices) as excellent/ good (93%); followed by community settings (81%), with the least being nursing homes (73%).

Reference: Aoun SM, Rumbold B, Howting D, Bolleter A, Breen LJ (2017). Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. PLoS ONE 12(10): e0184750. <https://doi.org/10.1371/journal.pone.0184750>.

Q1. In your experience is specialist palliative care available to people with MND in Western Australia throughout the course of the disease?

There is good support from specialist palliative care (PC) services especially for PwMND at home from the Silver Chain Home hospice service, the various Hospices and Teaching Hospital PC services but usually only in the last 3 months of life due to limited funding. Patients will only be accepted if they need ongoing treatment for significant unrelieved symptoms such as breathlessness; secretion management; pain; non-invasive ventilation, but may then be discharged from PC care if improved or stable when more prolonged care is required.

Q2. Are current palliative care services in Western Australia adequate? If not, what could be improved?

The current palliative care services in Western Australia are not adequate for all people with MND in Western Australia. People with MND in nursing homes generally miss out as it depends on the skills of the visiting GP and resident staff and will usually end up at hospice to receive the palliative care, although the Metropolitan Palliative Care Consultancy Service, MPaCCs, will consult into nursing homes on request. People with MND who remain at home will receive some palliative care towards the end of the disease after this is arranged by their referring GP, neurologist or respiratory physician. The referral does not always get acted on promptly by the specialist PC services. Silver Chain Palliative services have a policy of responding to clients within 24hrs once a referral is received. This is the client's experience for initial contact. Ongoing services may vary for each individual.

There is a need for more formal regular education of PC nurses/Teams about MND and the management of the very difficult symptoms that commonly occur particularly in the home setting, especially excessive secretion management with a poor cough; breathlessness, pain; risk of falls and transfer techniques in a weak person.

There is a need for greater communication (phone/email) and more joint on-going problem-solving between the PC nurses and the other specialist groups involved in the patient's care such as the Public Hospital MND Care Team; respiratory physician; neurologist; GP. An initial meet and discuss meeting with PC soon after diagnosis would be useful. There could be a Western Australian electronic palliative care register put in place.

Q3. The Committee has received evidence that palliative care is not effective for 100% of patients at the end of life. Some individuals will continue to suffer with untreatable symptoms such as pain, distress, breathlessness, delirium and nausea.

a. Given the current state of medicine, and the available drugs and equipment, is palliative care adequate for people with MND at end of life?

The palliative care currently provided in Western Australia for people with MND is not entirely adequate. MND clients often report a breakdown in communication between the GP, neurologist, patient, carer and immediate family as to palliative care options and End of Life choices to be made by the person with MND. More effort in discussing these issues and filling out an Advanced Care Directive about the patients end-of-life wishes are needed.

People with MND can experience a lot of pain, breathlessness, distress, anxiety, delirium which will need to be managed. The specialist PC doctor can prescribe drugs to assist with these symptoms however In MNDAWA's experience the staff of specialist PC services are inexperienced in MND care in general.

b. If not, in your experience what proportion of MND patients receive inadequate symptom control?

In the terminal weeks or months, breathlessness and pain would be the main complaints reported by about 10-15% of MND clients and their carers. There are some symptoms and distress that are impossible to adequately treat such as tenacious thick mucus in the back of the throat where the PwMND cannot cough and these cannot be controlled by a cough-assist machine; breathlessness where NIV is not tolerated and morphine is insufficient; and existential mental distress caused by being totally dependent. The fear of these impossible to control symptoms leads some PwMND to request an assisted earlier death from health professionals or can lead them to commit suicide while they are still capable of doing so.

END OF LIFE – REFUSAL OF TREATMENT

Q4. In your submission you have indicated that following the decision in Rossiter (with Mr Rossiter describing himself as a “prisoner in his own body”), the law in Western Australia clearly permits a patient to refuse life-sustaining treatment.

a. In your experience do some patients with MND refuse life-sustaining treatment around the end of life?

Yes, the majority of people with MND refuse life-sustaining treatment like NIV around the end of life. They may refuse feeding. This is discussed and agreed to with the palliative care doctor or neurologist.

b. If so is this a rare or more common occurrence?

It is more common to have people with MND refuse life-sustaining treatment around the end of life. Refusal of treatment is more prevalent these days with MND people as they are more aware of symptoms and stages of the disease up to end of life.

c. What types of treatments are refused?

MND people will refuse Non-Invasive Ventilation, PEG gastrostomy feeding, medication, even insulin or turning off pacemakers and implanted defibrillators.

d. Are you aware of substitute decision makers having to refuse life-sustaining treatment on behalf of someone with MND once they have lost capacity to communicate?

Yes, MNDAWA is aware that substitute decision makers (with Medical Guardianship usually) have refused life-sustaining treatment on behalf of someone with MND, after that person was unable to speak or has an associated fronto-temporal dementia but who had communicated his/her wishes at some point after diagnosis.

e. If so, do you have any suggestions which might be able to better assist or support family members put in that position?

To better assist or support family members in that position, there should be a family (the primary carer and immediate family) meeting with the neurologist and have the case advisor and MND nurse present. The neurologist would explain the disease and choices to be made by the person with MND at the end of life stage. Hopefully this situation would be avoided by having had these discussions earlier and having made an Advanced Health Directive.

f. Have family and carers expressed any concerns to you regarding refusal of treatments at end of life?

The main expressed concern is that it may be extremely difficult for the primary carer and family to carry out the refusal of treatment request especially if there are differences in opinion within the family. More information on what will happen at the end is required and should be passed on by the medical professionals. There are guilt feelings associated with such decisions and counselling should be available.

TERMINAL SEDATION AND PALLIATED STARVATION

Q5. The Committee has received evidence regarding the practice of terminal sedation:

a. Are some sufferers of MND treated with terminal sedation?

MND AWA is aware that terminal sedation is common practice always after detailed negotiation with the patient or more likely, the carer.

b. If so, have family and carers expressed any concerns to you about this process?

MND AWA sometimes receives concerns from the primary carer and family regarding this practice. Moral dilemma for them and a huge responsibility for the carer administering the sedative drugs and if they do not like doing this at home, the patient is then admitted to hospital or hospice.

c. In your experience is the patient (or authorised decision-maker's) consent sought prior to administering terminal sedation?

People with MND and their carers always provide consent to the administration of terminal sedation. They are aware that the medications provided will keep them "comfortable" but not all of them realise these medications are assisting the end. Medications given at end of life do not hasten death.

Q6. The Committee has received evidence regarding palliated starvation:

a. In your experience do some sufferers of MND elect to die by palliated starvation?

Yes some people with MND have elected to die by palliated starvation. In starvation the client chooses to withdraw from all nutrition and fluids. Thus, a life expectancy between 8-12 days. This process would normally be monitored by health professionals in a hospital or residential facility.

b. If so, have family and carers expressed any concerns to you about this process?

Family and carers have expressed concerns about palliated starvation. Will the patient feel hungry if starved? But usually this is done with a palliative care service in attendance in a hospice, or home situation with good symptom control.

- c. In your experience do healthcare workers always follow a patient's wishes when they indicate that they will no longer accept nourishment or hydration?**

The healthcare workers will always follow the patient's wishes when they indicate that they will no longer accept nourishment and hydration, unless there is a religious prohibition on this. This request is discussed with the nursing and medical staff beforehand and agreed upon; anyone who does not wish to participate is excused from the care team (which happens rarely).

VOLUNTARY ASSISTED DYING (VAD)

- Q7. In your submission you have stated that "We believe it is time to support their right to choose". Does this mean that the MNDWA supports the introduction of a voluntary assisted dying scheme in Western Australia?**

- a. If so, what protections would you like to see built into the legislation?**

MNDWA would support the right of self-determination which is afforded by VAD. The person with MND, the primary carer and immediate family would need to be completely clear of what the stages of MND are, what choices are available and what will happen to the patient at end of life. It must be clear there is no quality of life being enjoyed by the patient, that the patient has no desire to live any longer and is at the end of life stage. The patient has to provide consent for this practice to take place, in discussion with the primary carer, immediate family, neurologist and care advisor. The process and protections provided for in the recent Victorian Parliament VAD Legislation provides a good model and template.

- b. What other features of any proposed legislation would be required to enable people dying with MND to access to VAD?**

Education and information on end of life choices must be provided to the person with MND to enable an informed choice or decision to be made which will be accepted and respected by the primary carer, immediate family, neurologist, care advisor. The pwMND who wish to access VAD must meet the eligibility criteria as set out by the state government with safeguards as outlined for instance in the Victorian legislation.

- c. Would a time limit prescribing the likely period until death be too prescriptive for people with MND?**

We think that there should be some time taken to confirm the MND diagnosis and proven inexorable progression of weakness and disability. For most PwMND, it is the fear of total dependency and loss of dignity as well as carer burden that leads to the thought of the possibility of VAD. This is most often in the last 6-12 months of probable progression of the disease in that particular person. The Victorian legislation dictates "that a person with MND may access VAD provided that the condition is expected to cause death within 12 months" which seems a sensible and

would meet the needs of the small percentage of PwMND who would be predicted to want access to VAD.

- d. In your view if VAD was introduced into Western Australia would Advance Health Directive (AHDs) be an appropriate mechanism to enable someone suffering with MND to access VAD, where that person is unable to contemporaneously communicate their wishes?

Yes a PwMND could put into an AHD that they have successfully negotiated a VAD contract (with supportive documentation) to be activated under certain circumstances such as the advent of a more severe dementia or severely disabled state of a certain degree. There should always be a separate pathway to achieve a valid VAD contract however.

MND advisors always bring to the attention of clients and families the importance of putting an AHD in place, and this is done several times during the MND journey. MNDAWA does include an AHD form in its information documents provided to every MND client at diagnosis stage.

ADVANCE CARE PLANNING

Research evidence

The following table shows the uptake of AHD, EPG and ACP of terminally-ill patients who had or did not have palliative care services, in a national bereavement survey undertaken by Aoun et al (2017). In general, the uptake is higher if people had access to palliative care. Those who received palliative care were 2-3 times more likely to have an advance care plan or advance health directive, albeit still in quite low proportions overall (12-13%). The majority of the bereaved next of kin (95%) reported that the AHDs or ACPs have been fulfilled. The uptake of EPG and ACP is much lower in WA compared to Victoria or other states such as NSW and Tasmania. Therefore, we need more education and training for the community and health professionals to improve rates of ACP in WA.

	Preparation for Dying (%)					
	WA		Vic		Rest	
Had Palliative Care	Yes	No	Yes	No	Yes	No
A Will	85.7	78.2	78.3	81.3	84.5	81.9
Enduring Power of Attorney	52.9	50.0	62.3	54.2	62.7	56.9
Enduring Power of Guardianship*	7.6	2.3	15.9	12.5	32.7	34.7
Advanced Care Plan*	9.2	3.5	24.6	8.3	22.7	5.6
Advanced Health Directive*	14.3	7.0	13.0	4.2	17.3	9.7
Funeral arrangements	32.8	27.9	46.4	25.0	27.3	26.4

Aoun SM, Rumbold B, Howting D, Bolleter A, Breen LJ (2017). Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. *PLoS ONE* 12(10): e0184750. <https://doi.org/10.1371/journal.pone.0184750>.

Q8. In your submission you have indicated that the law on AHDs and Enduring Powers of Guardianship (EPGs) is very clear.

a. Would the system operate more effectively if there was a central electronic registry in Western Australia for AHDs?

A central electronic register in Western Australia for AHDs would be highly recommended by MNDWA. Access to the register would be by health professionals and care advisors. This register would have to have strict guidelines for maintenance and currency of information.

b. Do people with MND usually make AHDs and/or EPGs?

People with MND do make AHDs and EPGs. About 50% people with MND would have AHDs, and almost all would have EPGs.

c. Do people raise concerns with you regarding whether or not their wishes are followed by healthcare professionals in accordance with their AHD?

People with MND have raised concerns regarding whether or not their wishes are followed by healthcare professionals in accordance with their AHD. Hospital staff are sometimes not aware of AHDs on admission. One case reported was a patient trying to overdose herself on medicinal patches, which were prescribed to make her comfortable. On admission to hospital, this was treated as a suicide attempt and therefore AHD was overwritten by the fact it was suicide.

It is important for the AHD to accompany the patient on a hospital admission. PwMND and their carers are instructed to always give a copy to the ambulance staff and make sure the ED staff know of its contents. MNDWA clients with AHDs have provided a copy to the GP, neurologist, case advisor and MNDWA.

d. In your experience are healthcare professionals aware of the law in relation to AHDs, EPGs and the hierarchy of substitute decision-makers?

MNDWA believes that healthcare professionals are usually aware of the law in relation to AHDs, EPGs and the hierarchy of substitute decision-makers.

e. You have indicated a view that AHDs can be very prescriptive about what a person wants (or most often, refuses) and similarly most Enduring Guardianship documents completed by people living with MND are about ensuring their life is not extended by clinical health intervention. In your view are there any changes to the law regarding AHDs and EPGs that would improve their effectiveness, in particular to ensure that the wishes of people with MND are complied with?

MNDWA would recommend that there be a current and well maintained central register of all AHDs and EPGs available at all public hospitals in Western Australia. Clients are encouraged to have this information on their fridge for ambulance workers to access.

f. In your view is there a need for more community education about AHDs and EPGs?

The view of MNDAWA is that there is definitely a need for more community education about AHDs and EPGs. MNDAWA care advisors ensure that people with MND are aware of the importance of AHDs and EPGs quite early in the “journey” and revisit the subject at various stages of the disease until end of life. MNDAWA also provides education programs to people living with MND and their family carers which specifically address AHDs and EPGs on a regular basis. Ultimately, it is up to the patient to agree to have an AHD or EPG in place. They can only do this if they are well informed and feel comfortable and confident in making the decision to have an AHD or EPG.

CONCLUSIONS

While the proposed questions of this hearing have tended to focus on specialist palliative care, there is a limit in the resources available to provide specialist palliative care to all life-limiting illnesses. VAD will be helpful for a very small group of MND sufferers and research from other countries shows that the VAD uptake is generally very low (1-2%) although it may be slightly higher for MND (Maessen et al, 2014). The essential principle is that people want to know that they have the choice of self-determination, which fits within the international emphasis on person-centred care. Professor Ian Maddocks, who is considered the ‘father’ of Palliative Care in Australia, has said: *“if compassionate and loving care towards patients and families is what palliative care is all about, then assisted dying is part of that. It is time the profession dealt with it”*.

However, this does not mean that more improvements cannot be done in the palliative care field for the vast majority of patients and the focus needs to be on a palliative approach to care, particularly for conditions like MND where there is no cure or effective treatment (Aoun, Hogden and Kho, 2018; Oliver and Aoun, 2013). This can be achieved by several strategies that have been trialed by MNDAWA, based on research evidence, but still need to be integrated in routine practice to show improvements in patient and carer outcomes:

- Education/ training in palliative care needs to be provided to all health and community service providers involved in MND care; and education/ training in the care needs of people with MND to be provided to service providers in palliative care. To this aim, MNDAWA runs an annual educational program to improve the knowledge of health professionals about a palliative approach to MND care, a program initially funded by NHMRC and developed by Aoun and colleagues (McConigley, Aoun et al, 2012).
- The family and in particular the primary family carer (who is most often the spouse and substitute decision maker) needs to be better informed about all options throughout the illness trajectory and be prepared for the impending death. This would minimize the psychological burden on them while they are asked to make existential decisions they are not well equipped to make, and as a consequence the adverse outcomes, and in particular complicated grief, linger on through to the bereavement stage (Aoun et al, 2018; Aoun, Connors et al, 2012). To this aim, MNDAWA has trialed the use of a person-centred international validated tool, the Carer Support Needs Assessment Tool (CSNAT), which 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. The highest support priorities of MND carers were “knowing what to expect in the future,” “knowing who to contact if concerned,” and “equipment to help care”, and “dealings with feelings and worries”. 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 (Aoun et al, 2017). This is exactly what a palliative approach to care is promoting as outlined in the introduction section.

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