

Comments on the Draft National Framework for Advance Care Directives

Submitted via email to:

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By:

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Background

MND Associations in Australia were formed during the 1980s to meet the complex and changing support, equipment and information needs of people living with MND, their carers and their families. MND Australia was established in 1991 as a national peak body for motor neurone disease (MND).

MND Australia and its six State Association members work together to advance, promote and influence local, state and national efforts to achieve the vision of 'a World Free from MND'.

Motor neurone disease (MND) is the name given to a group of rapidly progressive degenerative neurological diseases that cause increasing and complex levels of disability leading to death, usually within three years of diagnosis. The most common form of MND is amyotrophic lateral sclerosis (ALS). Currently around 1400 Australians are affected by MND and thousands more; family, friends and carers live daily with its effects. Each day at least one Australian dies of this cruel disease and a new person is diagnosed. Although MND was first described nearly 150 years ago there is still no known cause (in most cases), no known cure and no effective treatments. Average age of onset is 59 years; however, the age range of onset is 18 to 90 years.

The rapid progression of MND results in increasing and changing support needs and reliance on a range of aids and equipment to maintain quality of life and social inclusion. Support needs include assistance with: feeding, communication, breathing, movement, transferring, toileting and all daily activities.

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses that pose:

1. huge problems of adjustment for people who have MND;
2. an escalating and stressful burden on carers and families; and
3. a challenge to health professionals, disability services, community care, and aged care providers involved in meeting the variable and complex care needs, particularly in regional, rural and remote areas of Australia.

At present treatments for MND only offer the potential to slow the disease process. A palliative care approach is therefore required from diagnosis to ensure that early discussions around future care management and advance care planning are held and optimal symptom management for the person with MND and their family is achieved¹. Discussions around end-of-life care need to be instigated as soon as the person with MND is ready, preferably before speech is affected, to ensure optimal interaction and communication to address their more profound concerns.

¹ D Oliver, D Walsh & GD Borasio (eds) *Palliative care in amyotrophic lateral sclerosis: from diagnosis to bereavement*, 2nd edn, Oxford University Press, New York, 2006.



Comments on the draft National Framework for Advance Care Directives

MND Australia welcomes the opportunity to comment on the Draft National Framework for Advance Care Directives. The development of nationally consistent best practice guidelines for the use and application of advance care directives within the broader context of advance care planning will be welcomed by the MND community. MND is a disease of progressive loss, therefore maintaining some semblance of decision making control is an imperative for people living with MND. Early discussions around future care management and advance care planning are vital to ensure that optimal symptom management is achieved for the person with MND and their family, based on their individual needs and wishes. For people with MND advance care planning must to be easily accessible and flexible to accommodate the impact of increasing disability and loss of independence on quality of life as the disease progresses.

MND Associations provide information and advice to members regarding the benefits of advance care planning and why a person with MND should consider having an Advance Care Directive. A National Framework will encourage the Australian community to think and talk about future care preferences and the advantages of having an Advance Care Directive. However, having an Advance Care Directive must remain a choice rather than be an imperative for access to certain care options or services.

At present developing and presenting consistent national information on advance care planning for people living with MND is difficult due to the different legislative standards that exist in each state. In addition there continues to be a lack of understanding amongst many clinicians regarding advance care planning generally, the rights of patients to make decisions about future care and their right to appoint a substitute decision-maker.

The draft framework appears to meet its objectives and covers relevant aspects of the advance care planning process. We anticipate it will be a useful tool in providing guidance to legislators and policy makers that will hopefully facilitate a more national approach. The Best Practice Standards and the Code of Ethics could be used to assist health professionals improve awareness of, and respect for, a person's wishes. The framework in its entirety would be unlikely to be used by health professionals but could be used to develop shorter more easy to read information materials for busy health professionals, as well as for the general community. Consistency of information and terminology is imperative if Advance Care Directives are to be recognized and applied across jurisdictions; the framework will certainly facilitate this.

The structure of the framework is appropriate for policy makers and legislators. The information related to the need for a national framework and the context for the framework will assist with review and development of current laws and legislation to reflect the current needs of the community. The objectives outlined on page 5 clearly



outline the purpose of the framework, and MND Australia supports these objectives as being relevant to the needs of people living with MND.

It is important to also include within the objectives the need for advance care directives to be responsive to the changing needs of people with progressive conditions. This would encourage individuals and health care professionals to re-visit plans and directives regularly. People living with MND when first diagnosed will often decide that they do not want any interventions that will prolong their life. However, as the disease progresses and they adjust to the impacts of MND, many are able to maintain a quality of life that is acceptable and seek interventions that they previously would not contemplate. Advance care planning must therefore be flexible and an ongoing process for the person and the health professionals involved in their care.

The objective that *advance care directives will be readily recognized and acted upon with confidence by health care professionals and will be part of routine practice in health and aged care settings* is welcomed by MND Australia. Experience has demonstrated that health professionals sometimes struggle with the decisions made by people living with MND and their families to reject or cease interventions, particularly related to feeding and breathing. Respecting and understanding people's wishes can only be achieved through increased discussion and education on advance care planning and the rights of the individual to make decisions about their future care supported by well informed health professionals.

Although the structure is appropriate for policy makers and legislators, it is a lengthy document with some repetition. The framework does however provide information that policy makers and legislators can use to develop information resources for other stakeholders and the community.

As a set of principles the Code for Ethical Practice covers key aspects of Advance Care Planning and enshrines respect for the autonomy of the individual within the context of their culture. The principles related to the Substitute Decision Maker appear to provide appropriate guidance to support health professionals to assess the authority of that person when applicable. It is anticipated that the Code for Ethical Practice should be read in conjunction with the Best Practice Standards and if so this should be highlighted in their respective introductions. Principle 2 may be contentious in that a person can make a decision about their future care, a decision which does not need to be informed. This principle does not encourage the individual to discuss health matters and possible outcomes with a trusted health professional. The Best Practice Standards highlight the difference between an ACD and a Medical Directive, which should also be highlighted in the code to avoid confusion. The differences between ACD's and Medical Directives need to be clearly articulated from the outset of the framework.

The Best Practice Standards are comprehensive and helpful for policy makers and legislators in moving regulation and practice in each jurisdiction to a more nationally consistent approach. The development of nationally consistent advance care planning information and forms would be welcomed by the community. These Standards will be useful for those community and project groups developing ACD forms to ensure a consistent approach and a common language. The case studies in particular provide useful examples of various common scenarios.



The decision making pathway will be a useful tool for substitute decision makers (SDM). Plain English guides will need to be developed to assist SDM's to understand their role and mechanisms to support them, as required. The form checklist is also a useful tool and encourages flexibility and regular review. Opportunities for developing online forms that can be stored appropriately to maintain privacy whilst being accessible when required will need to be explored as e-health initiatives develop.

MND Australia congratulates the Working Group on its work to date. The draft guidelines are comprehensive and support a nationally consistent approach to advance care planning. MND Australia anticipates that the framework will lead to the development of information and education resources for the community to promote and encourage discussion about the advantages of talking about our future care needs with family and a nominated substitute decision maker. The draft guidelines need to acknowledge, however, that whether to have an Advance Care Directive, or not, must remain a choice for all individuals. Targeted education and information for health professionals will also be imperative to ensure that advance care planning discussions are routinely held and Advance Care Directives respected. Health care professionals need to be fully informed about advance care planning legislation and their role in supporting their patients' choices within the context of current laws without fear of litigation.

MND Australia looks forward to receiving the final National Framework and is available to provide further information if required.

A handwritten signature in black ink, appearing to read 'Carol Birks', is written over a light blue horizontal line.

Carol Birks

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