



**Submission to the
Senate Standing Committee on Community Affairs Inquiry into
Palliative Care in Australia**

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Introduction

The Inquiry into Palliative Care in Australia should lead to improved access to palliative care services and the required resources, and MS Australia welcomes the opportunity to provide this submission to the Committee.

At the most fundamental level it is essential that the provision of palliative care in Australia is founded upon and delivers outcomes based on ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual’ (World Health Organization definition).

While this definition is widely subscribed to within many Australia reports and policies, it is still largely an aspiration rather than a reality. Families and front-line staff working with people with MS report a wide range of positive and negative experiences in relation to palliative care. In general, those who have been able to access timely and responsive palliative care services have had better experiences than those that have not. This submission outlines some of the key issues.

MS is a chronic progressive and incurable disease affecting the central nervous system. There are approximately 21,000 people with MS in Australia, average age of diagnosis is between 20-40 years old, and about three-quarters of those diagnosed are women. As a progressive disease that can be life threatening and generate very significant levels of pain and other major health problems, palliative care is an important approach and set of services for people with MS.

Understanding Palliative Care

Unlike the WHO definition above, there is a persistent view at the community level that palliative care is only about end-of-life care – death and dying. Staff working in the disability sector (where most of the day-to-day assistance for people with MS and their families is provided) are often hesitant to raise the issue of accessing palliative care with clients and families because:

- a) There is no certainty that the person with MS will get access to needed services
- b) People with MS and their families perceive this as the ‘end-of-the-road’
- c) Lack of clarity about what palliative care services actually do

Palliative Care and the Disability Sector

Overall it is readily apparent that there is a need for much more work to be done at the intersection of disability services and palliative care, particularly in relation to progressive neurological illnesses. These currently operate as almost entirely separate silos at almost every level with little awareness and understanding of each other. There are notable exceptions to this, but the overall result is that few people who have most of their daily

needs for assistance met from the disability sector will get timely access to palliative care services when they are needed.

The developmental work now underway to establish a National Disability Insurance Scheme represents a major opportunity to help ensure stronger links in the future, and the palliative care sector needs to be resourced and supported to help forge these links.

Without targeted efforts to build stronger links between disability services and palliative care services, these problems will persist, and those who would benefit from palliative care will continue to miss out. There are numerous potential opportunities to do this including:

- clearer pathways between palliative care services and disability services;
- joint activities such as participating in each other's annual conferences and other key events, publications, committees, etc.
- improved education/training for disability sector staff in palliative care and visa versa
- targeted research focused on the intersection of disability, progressive neurological diseases and palliative care

Education and Training

Within the disability sector there is little education and training available regarding palliative care. There have been important efforts made at various times in various jurisdictions to address this issue. For example in 2009 the Victorian Dept of Human Services produced *Disability Residential Services Palliative Care Guide* (see [http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/\\$FILE/disability_palliative_care_guide.pdf](http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/$FILE/disability_palliative_care_guide.pdf)). While the primary purpose of this work is in relation to residential care, much of it is also of relevance and use in the community care setting. However, there are no resources to promote uptake or adherence to the guide.

Like other issues regarding the intersection of palliative care and disability services, responsibility for training and education seems to be falling between the cracks with each sector assuming the other has responsibility. No doubt much of this is a result of high demand and under-resourcing of both sectors, and a mutual avoidance of issues that fall within this intersection.

The end result is that disability staff are not equipped to identify the appropriate timing regarding when palliative care services should be introduced, and are also often unable to assist clients and families to understand the actual role of palliative care services and their value. The inevitable result is that when referrals are made, they are often much later than they should have been and the overall experience for people with MS and their families is poor.

Training and education should also include skills development regarding encouraging and supporting people to undertake end-of-life planning sooner rather than later.

End of Life Planning

MS organisations regularly run forums that introduce people to the concepts of enduring powers of attorney and advanced care directives, as well as the importance of having a will in place. However, this is rarely sufficient to ensure that everyone has the necessary conversations within their families and effective arrangements are in place. A more effective approach would be to promote these issues more extensively at a national level, and put programs in place to help ensure that all Australians do this. It is not only an issue for those with progressive illnesses, but for everyone.

National consistency in laws and policies regarding advanced care directives would make this more achievable and should be established as soon as possible, but will not be sufficient to ensure that the Australian population embraces the concept and takes the required steps for themselves. A set of pilot projects with populations such as those with MS should be established to identify the best ways to encourage and support people to get this done for themselves and other family members.

The introduction of personal electronic health records is one of the opportunities that should be utilised to both record and encourage people to undertake advanced care directives.

Research

More research evaluating specific programs and interventions related to the intersection of palliative care, progressive neurological diseases and disability would, over time, help to improve practice in this area and foster academic and service delivery partnerships.

Palliative Care Consensus Statement

Much of the work that needs to be done to improve the access, timing and quality of palliative care services are well described in the Palliative Care Consensus Statement (Palliative Care Australia 2011 – see the end of this submission for a copy). If these points are followed through, with the essential additional focus on stronger links to the disability sector, the lives of people with MS, their families and many others would be significantly improved.

Palliative Care Australia (2011)

National Palliative Care Consensus Statement and Call to Action

This National Consensus Statement is a blueprint for action spanning a range of social and health professional issues related to palliative care in Australia. It was developed following a stakeholder forum convened by Palliative Care Australia (PCA) held on 26 May 2011 at Parliament House, Canberra, and represents the forum's collective analysis, evaluation, and opinion. The National Consensus Statement complements the work undertaken by the Australian Government in developing the National Palliative Care Strategy 2010.

Why the need for a National Consensus Statement?

There is a need for clarity on four key issues identified as recurring themes in palliative care internationally and nationally:

- Where people prefer to die.
- The need for advance care planning.
- Access and equity in provision of palliative care services.
- Awareness about palliative care in the general community and in groups of healthcare professionals.

What is its Purpose?

To inform:

- Development of PCA submissions designed to influence the national health reform agenda.
- Development of national policy Position Statements by PCA on the four key issues listed above, including statements which address groups with special needs.
- Health care professionals and managers responsible for the development, implementation and review of palliative care services.
- Program planners and managers, and policy makers responsible for the development of strategic programs dealing with palliative care.

What is Palliative Care?

Palliative care is defined by the World Health Organization (WHO) as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual.'

Who is Palliative Care Australia?

PCA is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care for all at the end of life. PCA works in collaboration with its State and Territory member organisations and the Australian Government Department of Health and Ageing to implement the National Palliative Care Strategy 2010; to raise awareness of palliative and end of life care; improve community understanding about services and their availability; and encourage discussion to support improved knowledge networks.

A Call to Action

This National Consensus Statement is a call to action by PCA and its members to ensure that all Australians have access to quality palliative care and to ensure no Australian with a terminal illness will suffer from preventable discomfort and pain. Palliative care is a fundamental part of Australia's healthcare system and requires adequate resourcing for training of healthcare professionals, appropriate infrastructure and research.

The National Consensus Statement accords with the Australian Government's National Palliative Care Strategy 2010 in recognising a need for Commonwealth, State and Territories to work cooperatively and collaboratively in achieving common and agreed goals to achieve what Australians want - a system that supports all of us to live well at the end of life.

The following priorities have been identified as needing urgent action. Goal statements have been developed that will need refinement and translation into measurable indicators as part of implementing the National Consensus Statement.

1. All Australians must have reasonable access to resources to support them to die in the location of their choice.

Goal:

- That funding is in place by 2015 to ensure reasonable choices in where people want to die.

Most Australians would prefer to die in their own home. This means greater emphasis on end of life 'care in the home' however that is defined and understood by people.

2. A single common legislative requirement regarding advance care planning must be adopted throughout Australia

Goal:

- That national legislation is in place by 2015 supporting advance care planning and associated documentation without unnecessary jurisdictional variation.

Advance care planning supports patients in communicating their wishes about their end of life. An advance care plan should be linked to a personal electronic health record.

3. All Australians have a right to equitable access to quality palliative care when and where needed.

Goals:

- That palliative care services are networked through electronic and e-Health links by 2015.
- That access to specialist clinical services is available when needed in all hospitals, hospices, residential care services and homes.

The objective of 'dying well' is fundamental to palliative care and at the core of quality service provision. Issues to be addressed include access to: appropriate health care, information in a range of languages, specialist clinical care, and carers and volunteers.

4. All Australians must have access to education about dying and death

Goals:

- That information on dying, death and palliative care is available nationally in a range of languages and formats appropriate for Australia's multicultural society by 2015.
- That dying, death and the role of palliative care are integrated into the personal development syllabus of all schools and the development of the Australian Curriculum by 2015.

Talking about dying and death should be normalised and de-stigmatised. Every Australian should understand that dying is a normal part of the life continuum. Information provided should be available in plain English and translated into appropriate CALD and Indigenous languages.

5. Adequate and appropriate education in quality end of life care must be a standard provision for all health professionals.

Goals:

- That revised and updated palliative and end of life care training curriculum be in place in appropriate faculties of tertiary teaching institutions by 2015.
- That the Palliative Care Curriculum for Undergraduates (PCC4U) is in place in all appropriate faculties of tertiary teaching institutions by 2015.

Palliative care must be a core competency for all those involved in providing end of life care and a mandatory requirement in health care teaching institutions. Training in Indigenous and cultural safety must be included. Continuing professional education must be underpinned by a nationally consistent set of core competencies.

6. The Standards for Providing Quality Palliative Care for all Australians (the Standards) must be embedded in all appropriate care settings.

Goal:

- That the Standards are adapted in all services providing end of life care by 2015.
- That the National Standards Assessment Program (NSAP) is aligned with organisational accreditation cycles by 2015.

The Standards need to be universally adopted if they are to support effective, quality, palliative care. They have been designed to be used alongside other standards for health services goals.

7. Appropriate funding must be made available by all levels of government to palliative care services on an equitable population needs basis.

Goal:

- That all funding priorities identified in this Statement are addressed by the Australian Government by 2020, in collaboration with States and Territories (as outlined in the National Palliative Care Strategy 2010).

Areas of immediate concern include better resourcing of tertiary services; increased funding for medical palliative care training places; implementation of national legislation to support advance care planning; access to advance care planning and palliative care for people with dementia; a national 1800 Telephone Information and Support Service; and a national Palliative Care Volunteering Strategy.

8. Research in palliative care must be appropriately funded and targeted.

Goals:

- That palliative care and end of life issues are prominent on the national research agenda and funded for clinical, health systems and social research by 2015.
- Increased number and scope of postgraduate and post-doctoral scholarships in palliative care and end of life issues in place by 2015.
- Increased number of post clinical industry placements available by 2015.

Developing capacity within the palliative care research community must be supported. Funding and resources must be provided to ensure a balance between clinical, health systems and social research. Research must be translatable, inform policy and be communicated and disseminated to those who can make the most effective, timely use of it.