The Committee Secretary
Health and Community Services Committee
Parliament House
BRISBANE QLD 4000

Re: Inquiry into palliative care services and home and community care services in Queensland

MS Australia – QLD welcomes the opportunity to contribute to the *Inquiry into palliative care services and home and community care services in Queensland*.

MS Australia – QLD'svision is a world free from multiple sclerosis (MS) and its devastating impact. We exist to help people living with MS to get the best out of life; to advocate for changes and to search for a cure. Our mission is to be the first-choice for MS information, education, treatment, care and support across Queensland.

MS is typically a disease that is diagnosed young – between the ages of 20 and 40 –and is a progressive and unpredictable neurological disease of the central nervous system that interferes with the transmission of nerve impulses throughout the brain, spinal cord and optic nerves resulting in impairment of motor, sensory and cognitive functions. Although we do not yet fully understand why some people are susceptible and others are not, we do know that more than 21,000 Australian have MS, almost 4,000 in Queensland.

For people living with Primary Progressive MS, life expectancy is wildly unpredictable and in comparison to other forms of MS much shorter. MS Australia – QLD believes high quality, flexibleand responsive palliative care services take into account the nature of the disease, the age and needs of the person and the specialist support and care coordination required in order to best manage and care for a person through end-of life.

MS Australia – QLD operates within our own Palliative Care ethos for people living with MS accommodated both in our residences and in other community settings. We are not a direct palliative care provider as such,but we partner with other skilled and caring providers and advocate on behalf of our clients at this challenging time of life. We offer to people living with MS what no-one else can: disease-specific, age-appropriate, educated and dignified care throughout the unpredictable and variable stages of the disease.

I would welcomethe opportunity to answer questions regarding MS Australia – QLD's submission.

Yours sincerely,

[redacted]

CEO

6 August 2012

Palliative care services and home and community care services inquiry
A SUBMISSION FROM MS Australia - QLD

Introduction

Multiple Sclerosis (MS) is a progressive neurological diseaseof the central nervous system that interferes with the transmission of nerve impulses throughout the brain, spinal cord and optic nerves resulting in impairment of motor, sensory and cognitive functions. Although we do not yet fully understand why some people are susceptible and others are not, we do know that more than 21,000 Australians have MS, almost 4,000 in Queensland.The prevalence of MS has increased by approximately 4% per year since 2005.

MS is typically a disease that is diagnosed when young – between the ages of 20 and 40 – and life expectancy is in general not greatly impacted. However for people living with Primary Progressive MS (PPMS), life expectancy is wildly unpredictable and in comparison much shorter.

The nature of MS and end-of-life considerations

Research shows that people living with MS have needs similar to those with other advanced conditionsand palliative care has been demonstrated to help with symptoms such aspain, fatigue, breathlessness, spasticity and nausea. Specific issues arise however when considering palliative care for people living with MS and other progressive neurological diseases for that matter (such as Parkinson’s, Huntington’s and Motor Neurone Disease).

The unpredictable nature of MS and variability of the disease from person to person makes end-of-life considerations very difficult. For individuals with long term neurologicalconditions such as MSthere is simply no predictable patient journey or disease trajectory.End-of-life in this case may begin far beyond what normally would start no earlier than one year before death.

Challenging questions arise as a result: does it matter if palliative care for people living with MS starts early in the care pathway? When is “too early” to help someone living with MS with end-of-life care planning? Noting the potential for cognition and communication issues for people living with progressive neurological disease, these are important matters.
Ultimately what probably matters most is the recognition that any system and structure of palliative care is able to “flex” and respond according to the variable needs and speed of a

person's end-of-life situation and in the case of MS, possibly for a longer time than with other more predictable conditions.

RECOMMENDATION 1. People living with progressive neurological disease such as MS need high quality care, personalised to meet their individual and changing needs, even when by nature of the disease progression is over a longer term.

RECOMMENDATION 2. Consideration that end-of-life care planning beginearly for people living with long term progressive neurological disease such as MS, even though such planning may seem premature.

Young people living with MS

Other challenging questions also arise when considering the age of the person involved. As discussed earlier in this submission, the average age of diagnosis of MS is 30 years of age.

Nursing homes are not appropriate for young people to live as they are designed for older people and age-appropriate care is not available in these.Yet we know that over 1,000 young people in Queensland, many of whom live with MS and other progressive neurological diseases, are accommodated in nursing homes as the only available care option for them.

Just as living in a nursing home for these young people is inappropriate, so is dying.
At MS Australia – QLD our purpose is to help people living with MS to get the best out of life, one of the wayswe seek to address the issue of age-appropriate care is to prevent young people entering nursing homes by directly offering:

- Long-term residential accommodation for 16 people
- Planned or crisis respite supportfor 8 people
- Transition accommodation for 4 people
- Independent living for 8 people
- Support to remain at home with appropriate care in place

We know that many people in the end-of-life stage choose to die at home. This choice is denied to young people accommodated in nursing homes who, whilst receiving high quality palliative care are receiving this side-by-side with older people.

Through the facilitation of both appropriate care pathways and accessible housing solutions, young people will be able to be maintained in either their home or in appropriate age-appropriate accommodation through every life stage.

MS Australia - QLD has been part of the landmark 2006 *Young People in Residential Aged Care Program* (YPIRAC) which produced a Continuous Care Program and has been successfully trialed in the YPiRAC program as a proactive risk management services to keep young people out of aged care.

RECOMMENDATION 3. Deliver age-appropriate palliative care pathways and expand accessible housing solutionsto enable young people to be maintained in either their home or in age-appropriate accommodation through the end-of-life stage.

RECOMMENDATION 4. National implementation of the 2006 Young People in Residential Aged Care Program (YPIRAC) proactive risk management service to keep young people in age appropriate care.

Disease-specific specialist support and care coordination

Given the unpredictable patient journey and disease trajectory of MS and other progressive neurological disease, clearly outlined and understoodcare pathways are needed to ensure seamless integration between health, rehabilitation and age-appropriate palliative care is achieved.

Specialists in MS and other progressive neurological disease are critical to patient support but also communication with non-MS medical and care staff, particularly in hospital or general practice environments. As a specialist they are able to act as lead-agent in case coordination, knowing intimately the needs of the individual involved and what supports are best needed and when.

Matching specialist disease-specific information, coordination and hands-on support with palliative care “collaborators” (such as direct palliative service providers including hospices) gives everyone involved an effective and efficient approach to the care situation. Training provided by MS Specialist education nurses would up-skill generalist nurses delivering palliative care regarding the unpredictable nature and care for people living with progressive MS.

For example, MS Australia - QLD is not a palliative care provider as such; however we are deeply experienced with, and offer access to palliative care to people living with progressive MS in our care as well as in community settings. In such scenarios, we apply our expert specialist knowledge of MS into direct palliative care partners to give the best and most appropriate understanding and level of care to people living with MS.We focus on an individual’s needs and relief of suffering. Palliative care support is provided as part of a continuum of care that addresses the ongoing needs, values, comfort and living wishes in a person’s life and the final outcome of dying.

Impact of the proposed National Disability Insurance Scheme

The proposed National Disability Insurance Scheme is very much focused on self-management coupled with individualised funding. In this new environment, providers of palliative care services will be required to be responsive to the demandsof individuals.
As a result, palliative care will need to become even more responsive and demonstrate clear care pathways for individuals and their loved ones in the various services purchased/provided.

The care plan will require higher levels of case coordination to appropriately manage the many and varied combinations of services requested by the individual, carer and their family. For example, it is likely that people living with MS (or some other specific-disease for that matter) will seek to purchase access to specialist knowledge and expertise alongside a range of other care services within their overall palliative care plan. Demonstrating clear care pathways and high levels of coordination will be essential to high quality outcomes.

RECOMMENDATION 5. Disease-specific specialist support is incorporated into care pathway planning with a focus on specialist information, symptom management and overall care coordination.

Health system reforms and policies

The currently developing health systems reforms – particularly the Local Health & Hospital Networks and associated Medicare Locals provide for better co-ordination and collaboration of primary health needs of the community. This initiative allows for greater communication amongst health and community care providers to ensure the individual palliative care needs of people with progressive neurological conditions, such as MS are well understood and catered for within the local community setting – whether that be through age-appropriate supported accommodation, or within the person’s home environment.

The opportunity to build relationships with palliative care providers within each LHHN region will enhance understanding of the complexities surrounding care for this cohort of patients. MS Australia – Qld is most welcoming of the opportunities to build the level of understanding palliative care service providers have of these conditions and their impact on palliation, particularly for younger people.

RECOMMENDATION 6. The inclusion of palliative care needs of people with progressive neurological disease such as MSneed to be identifiedand acknowledged at the commencement of development of health system reform processes.

SUMMARY RECOMMENDATIONS

RECOMMENDATION 1. People living with progressive neurological disease such as MS need high quality care, personalised to meet their individual and changing needs, even when by nature of the disease progression is over a longer term.

RECOMMENDATION 2. Consideration that end-of-life care planning beginearly for people living with long term progressive neurological disease such as MS, even though such planning may seem premature.

RECOMMENDATION 3. Deliver age-appropriate care pathways and expand accessible housing solutionsto enable young people to be maintained in either their home or in appropriate age-appropriate accommodation through every life stage.

RECOMMENDATION 4. National implementation of the 2006 Young People in Residential Aged Care Program (YPIRAC) proactive risk management service to keep young people in age appropriate care.

RECOMMENDATION 5. Disease-specific specialist support is incorporated into care planning with a focus on specialist information, symptom management and overall care coordination.

RECOMMENDATION 6. The inclusion of palliative care needs of people with progressive neurological disease such as MSneed to be identified, and acknowledged at the commencement of development of health system reforms.