

Palliative Care and Neurological Conditions

Position Statement

This is a joint position statement from Palliative Care Australia (PCA) and the Neurological Alliance Australia (NAA)

***Palliative Care Australia** is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australia and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care for all at the end of life.*

***The Neurological Alliance Australia** is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research. Members of the Alliance include Alzheimer's Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia and Spinal Muscular Atrophy Australia.*

PCA and the Neurological Alliance Australia believe:

- Palliative care¹ should be available to all people with neurological conditions who need and want it.
- Palliative care for people living with neurological conditions should be person centred, be integrated with other services and supports, recognise people's individual needs and treat people with dignity and respect.
- Palliative care for people living with neurological conditions can improve quality of life, symptom control, end of life care, and support for the person, their family and carer/s at all stages.
- People with more rapidly progressing conditions will benefit from early referral to palliative care services so that they can express, and be engaged in discussions about their future care wishes and preferences.
- Advance care planning and advance care directives should be a standard part of the care plan for people living with neurological conditions.
- All parts of the health, disability and aged care systems that provide care to people living with neurological conditions should be informed and aware of both neurological conditions and palliative care.
- People living with neurological conditions, their family and carer/s need to be provided with accurate information about palliative care.

PCA and the Neurological Alliance Australia call for:

- Improved access to palliative care services for people living with neurological conditions, their family and carer/s based on their needs and wants.

¹ 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, psychosocial and spiritual. (World Health Organisation *WHO definition of Palliative Care*, <http://www.who.int/cancer/palliative/definition/en/>)

- Education for neurologists and health professionals involved in the care of people with neurological conditions about the benefits of palliative care to improve access and information provision to people with neurological conditions, their family and carer/s.
- Education for palliative care staff about neurological conditions to improve their knowledge and understanding of neurological conditions, and their confidence in providing care to people with neurological conditions.
- Early, comprehensive and accessible information on palliative care for people with neurological conditions, their family and carer/s, particularly for people with more rapid onset conditions such as MND.
- Neurology and palliative care teams to work together and provide coordinated care for people living with long-term neurological conditions.
- The development of a national framework for people living with neurological conditions outlining a pathway for palliative care service provision. It should adopt an interdisciplinary approach and outline triggers for when palliative care and end of life discussions should occur between people living with neurological conditions, their family and carer/s, health and community services. The framework must recognise the varied symptoms and needs of different neurological conditions.
- The high care needs associated with neurological conditions be considered in future policy decisions about funding and access to inpatient and community palliative care services.

Background

Neurological conditions are group of long term conditions resulting from injury or disease of the nervous system which will affect a person for the rest of their life. They include:

- Sudden onset conditions (e.g. acquired brain injury of any cause including stroke, and spinal cord injury)
- Intermittent conditions (e.g. epilepsy)
- Progressive conditions (e.g. motor neurone disease (MND), multiple sclerosis (MS), Parkinson's disease and other neurodegenerative disorders)
- Stable conditions with or without age related degeneration (e.g. polio or cerebral palsy)²

Neurological conditions present and progress with significant clinical variation. People living with these conditions can live for many years while developing cumulative physical and cognitive disabilities, and deal with a decreasing quality of life before reaching the terminal stage of their condition. A growing area of interest is the provision of palliative care for specific symptoms during the terminal phase of neurological conditions.³ This is particularly for more rapid onset conditions such as MND and many guidelines recommend early referral to palliative care services. The appropriate time to provide palliative care can be a challenge due to the longer and varying time course of neurological conditions and difficulties in determining when the person is approaching the terminal stage. The diversity of symptoms including cognitive, behavioural and communication problems can also be a challenge for palliative care.⁴

There has been growing support for the palliative approach to caring for people with neurological conditions to enhance symptom control when actively managing the disease, improving end of life care, and increasing both individual and family and carer support at all stages.⁵ The main focus of adopting a palliative approach to neurological conditions has been described as:

² Turner-Stokes, L. et al. "Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care" *Clinical Medicine* April 2008 8:2 pp.186-91

³ Gofton, T.E. et al. "A Palliative Approach to Neurological Care: A Literature Review" *The Canadian Journal of Neurological Sciences* 2009 36: pp.296-302

⁴ Turner-Stokes, L. et al. "Long-term neurological conditions"

⁵ Gofton, T.E. et al. "A Palliative Approach to Neurological Care"

‘...maintain dignity and increase hope through the disease process by adequately managing physical, psychological and existential suffering while assisting with decision making processes.’⁶

Managing the symptoms of neurological conditions that cause distress and pain, as with palliative care for any condition, can greatly reduce suffering and improve quality of life, while a team approach to providing palliative care will optimise the overall management of the condition.⁷ There has also been an identified need for better palliative care education for neurologists and better neurological education for palliative care specialists, so that both groups of health professionals are aware of the benefits of palliative care for neurological patients.⁸

*The National Service Framework for Long-term Conditions*⁹ developed by the Department of Health in the United Kingdom (UK) addresses the way health and social services support people with long term neurological conditions through quality requirements that cover diagnosis to end of life care.

It notes, as recognised previously, that people with more rapidly progressing conditions will benefit from early referral to palliative care services, particularly for MND where people may lose their ability to speak, so that they can be engaged in discussions about their future care plans.¹⁰ The UK Framework also provides evidence based markers of good practice:

1. Specialised neurology, rehabilitation and palliative care multidisciplinary teams and providers work together to provide care for people with advanced long-term neurological conditions.
2. People with advanced long-term neurological conditions have access to palliative care services which support them at home or in a specialised setting according to their choices and needs.
3. Staff providing care and support in the later stages of a long-term neurological condition have training so that neurological staff are trained in palliative care skills, and all staff are trained in the management of long-term neurological conditions and palliative care.¹¹

The Victorian Government established the MND Pathway Project to develop a framework for people living with MND to access palliative care services, and for palliative care services managing and supporting people with MND. This project has broader applicability for a range of neurological conditions. Amongst the project’s interim report findings were that:

- there was no existing framework to integrate palliative care for MND within the overall care,
- palliative care workers did not feel confident in their level of knowledge of MND,
- people with MND had a distorted understanding of what palliative care offered,
- both palliative care workers and people with MND stated the rarity and progression of the condition created difficulties in coordinating care between a range of agencies, and
- inpatient palliative care services reported that patients with MND had high level needs.¹²

In light of these findings, the interim report made a number of recommendations to improve access to palliative care for people with MND. PCA and the Neurological Alliance of Australia believe that these

⁶ Gofton, T.E. et al. “A Palliative Approach to Neurological Care”

⁷ The American Academy of Neurology Ethics and Humanities Subcommittees “Palliative care in neurology” *Neurology* 1996; 48: pp.870-872

⁸ Gofton, T.E. et al. “A Palliative Approach to Neurological Care”

⁹ Department of Health (2005) *The National Service Framework for Long-term Conditions* Department of Health Publications: London

¹⁰ Ibid.

¹¹ Ibid.

¹² Metropolitan Health and Aged Care Services Division, Victorian Government Department of Human Services (2008), *Motor Neurone Disease and palliative care: interim report on the MND Pathway Project* Department of Human Services: Melbourne

recommendations are applicable to neurological conditions in general. The recommendations below from the MND Pathway Project have been adapted to reflect neurological conditions as a whole:

- The development of a document for health professionals on the range and availability of palliative care and community services to assist people living with neurological conditions.
- The palliative care sector agrees on common points at where palliative care services should be involved with people living with neurological conditions.
- The development, funding and implementation of a palliative care model for those who work with people living with neurological conditions to ensure early referral, education, support and effective coordination of services.
- An education and support program for palliative care staff on neurological conditions including peer support from specialist centres and education on palliative care for people living with neurological conditions, their family and carer/s.
- Guidelines and a mechanism for supplementary funding for inpatient and community palliative care services to meet the high care needs of people living with neurological conditions.
- Recognition of the importance of timely access to respite for people with neurological conditions, their family and carer/s.
- People with neurological conditions, their family and carer/s are considered in future policy decisions about funding and access to after-hours palliative care.¹³

The UK *End of life care in long term neurological conditions: a framework for implementation*¹⁴ outlines a pathway for neurological disease including reiterating the need for regular assessment to identify triggers for when the person's condition is deteriorating, and encourages greater openness and discussions about these triggers. It provides a useful framework to consider in addressing the challenge of when to discuss and provide palliative care for long-term neurological conditions. The stages in this pathway are as follows:

Diagnosis of neurological condition – Involves palliative and supportive care, and holistic assessment

Future care discussions – Discussion of cognitive status; ethical considerations; proactive management plans; and wishes and preferences and advance decisions

Generic triggers which show a decline in physical status including swallowing difficulties, weight loss, recurring admissions and frequent infection – Considerations include identifying a key worker and contacting the relevant palliative care service; detailing a needs assessment; an assessment for continuing health care; and assessing a person's decision making/mental capacity. Clinicians also need to consider what may be the specific triggers showing that the end of life may be approaching.

End of life care discussions and care in the last days of life – These stages involve a diagnosis and reviewing existing medications, and ethical decision making, along with support for carers.

Care after death – Includes bereavement support and supporting information.¹⁵

Palliative care provides an excellent opportunity for people with life-limiting conditions, their family and carer/s to achieve the best quality of life before death. A greater recognition for the importance of access to palliative care for people with neurological conditions is essential.

¹³ Metropolitan Health and Aged Care Services Division *Motor Neurone Disease and palliative care*

¹⁴ The National Council for Palliative Care, The Neurological Alliance and National Health Service *End of life care in long term neurological conditions* 2011 NHS: UK

¹⁵ The National Council for Palliative Care, The Neurological Alliance and National Health Service *End of life care in long term neurological conditions* 2011 NHS: UK