Stop stroke. Save lives. End suffering.

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24 April 2012

Committee Secretary
Senate Standing Committees on Community Affairs
Parliament House
Canberra ACT 2600
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Dear Committee Secretary

Re: Palliative Care Inquiry

Thank you for the opportunity to provide the following submission to the Palliative Care Inquiry. The National Stroke Foundation is a member of the National Aged Care Alliance (NACA) and endorses the submission provided to the inquiry from the alliance.

We would like to draw the Committee's attention to the issue of palliative care for stroke patients in hospital under term of reference *(d): the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities.*

Stroke patients experience specific issues and have particular needs for end of life care, particularly in the hospital setting. Fourteen per cent of acute stroke patients admitted to hospital die in hospital (9% within 7 days)[1] and approximately 20% die as a result of the stroke in the first 30 days.[2]

There are a number of challenges for stroke end of life care:

- Fragmentation of care
  There can be a lack of coordination between stroke and palliative care services regarding identification of need and commencement of service. It is not always clear who raises palliation matters with carers and family. Practical end-of-life issues, such as the use of medical power of attorney and advance care directives, should be discussed. Organ donation may be sensitively raised if appropriate. Issues of bereavement may become part of the responsibility of the stroke team.

- Support for carers
  A systematic review of the palliative care needs of stroke patients identified only seven studies.[3] The review showed that carers of stroke patients have different needs to those involved in specialist palliative care in cancer. They require more support,

[1] National Stroke Foundation. National Stroke Audit Acute Services Organisational Survey Report 2009. 2009.

[2] Thrift AG, Dewey HM, Macdonell RA, McNeil JJ, Donnan GA. Stroke incidence on the east coast of Australia: the North East Melbourne Stroke Incidence Study (NEMESIS). Stroke. 2000;31(9):2087–92.

[3] Stevens T, Payne SA, Burton C, Addington-Hall J. Palliative care in stroke: a critical review of the literature. Palliat Med. 2007;21:323–31.

particularly as they are likely to be older and in poor health, and caring for their family members in difficult circumstances, often unsupported.

People with stroke who are dying and their families and carers should receive care consistent with the principles and philosophies of palliative care in accordance with the *Standards for Providing Quality Palliative Care for All Australians*.[4] This includes an integration of the physical, psychological, spiritual, cultural and social needs of all those involved. An accurate assessment of prognosis or imminent death should be made for patients with severe stroke or those who are deteriorating.

- Research regarding the palliative needs of stroke patients
  There is also a lack of evidence regarding the palliative needs of stroke patients. In the systematic review undertaken, only one observational study was identified that developed and implemented a care pathway for palliative care in acute stroke. The study reported improved processes of care based on national standards compared to care provided prior to the pathway.[5]

While there are a number of systematic reviews on palliative care (primarily for cancer), there are insufficient studies to support specific interventions.[6][7] A randomised control trial that compared an inpatient palliative care service (IPCS) with usual care demonstrated greater patient satisfaction, more advanced directives at first hospitalisation discharge, reduced intensive care unit (ICU) admissions on subsequent hospitalisation, and lower total health costs for patients in the IPCS intervention.[8] While not specific to stroke the results may be applicable to those with stroke but implementation is dependent on the availability of such services in Australia. There is evidence from systematic reviews to suggest that communication skills training can have a small beneficial effect on behaviour change in health professionals working with people with cancer.[9][10]

With respect to palliative care, The *Clinical Guidelines for Stroke Management (2010)* recommend that:

a) An accurate assessment of prognosis or imminent death should be made for patients with severe stroke or those who are deteriorating.

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[4] Palliative Care Australia. Standards for Providing Quality Palliative Care for all Australians. 2005 [cited; Available from: http://www.pallcare.org. au/Portals/9/docs/Standards%20Palliative%20Care.pdf

[5] Jack C, Jones L, Jack BA, Gambles M, Murphy D, Ellershaw JE. Towards a good death: The impact of the care of the dying pathway in an acute stroke unit. Age Ageing. 2004;33(6):625–6.

[6] Goodwin DM, Higginson IJ, Edwards AG, Finlay IG, Cook AM, Hood K, et al. An evaluation of systematic reviews of palliative care services. J Palliat Care. 2002;18(2):77–83.

[7] Forte AL, Hill M, Pazder R, Feudtner C. Bereavement care interventions: a systematic review. BMC Palliative Care. 2004; 36; 3(1):3.

[8] Gade G, Venohr I, Conner D, Mcgrady K, Beane J, Richardson, et al. Impact of an Inpatient Palliative Care Team: A Randomized Controlled Trial. J Palliat Med. 2008;11(2):180–90.

[9] Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers. Cochrane Database Syst Rev. 2004, Issue 2. CD003751.

[10] Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. Support Care Cancer. 2004;12(10):692–700.

b) Stroke patients and their families/carers should have access to specialist palliative care teams as needed and receive care consistent with the principles and philosophies of palliative care.
c) A pathway for stroke palliative care can be used to support stroke patients and their families/ carers and improve care for people dying after stroke.

We therefore recommend to the Committee that there is a need for further research of end of life care for stroke patients and support for carers. There is also a need for system development to integrate specialised stroke care with specialised end of life care.

Thank you for your consideration of the issues faced by stroke palliative care patients and their carers and families. If you require any further information please contact Rebecca Smith Government Relations Manager National Stroke Foundation on rsmith@strokefoundation.com.au .
Regards

Dr Erin Lalor
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