



Level 7  
461 Bourke Street  
MELBOURNE VIC 3000  
Australia

T +61 3 9670 1000  
F +61 3 9670 9300

admin@strokefoundation.com.au  
www.strokefoundation.com.au

ABN 42 006 173 379

*Patron in Chief:*  
Her Excellency  
Ms Quentin Bryce AC  
Governor-General of the  
Commonwealth of Australia

*Patrons:*  
David Brownbill AM  
Sir Gustav Nossal AC  
Lady Southey AM

## Introduction

The National Stroke Foundation (NSF) welcomes the opportunity to make this submission to the Productivity Commission's *Caring for Older Australians* public inquiry on behalf of stroke survivors and their carers.

We support the general direction outlined in the *Caring for Older Australians* Draft Report particularly in terms of reducing the complexity of the current aged care system for consumers and their families and service providers with the aim of providing better integration and linkages between services and agencies within the aged care sector.

Stroke survivors and carers' experience of navigating the aged care service system mirrors that of the broader community. They describe it as confusing and fragmented, requiring contact with multiple agencies, and an understanding of a system with which they have had little or no previous contact. The result is that many people do not receive the support and services they require. Survivors describe this as feeling as if they are 'falling into a black hole', often not receiving much needed services until their health has significantly deteriorated.<sup>1</sup>

Our comments and recommendations set out in this submission focus primarily on Chapter 8 Care and Support of the Draft Report.

The NSF commends the Commission on its draft recommendations to bring about real and long-lasting structural reform that will enable the aged care system to better meet future demands. We would be pleased to provide any further information on the specific needs of stroke survivors and their carers.

## Overview of Stroke

Currently, an estimated 350,000 people are living after stroke in Australia. Of those aged 16-85, 72% of stroke survivors are aged over 60, with the remainder predominantly in the 40-59 age category<sup>2</sup>. The prevalence of stroke increases markedly with age, affecting:

- 8.1% of men and 5.3% of women aged 65 – 74 years
- 14.7% of men and 11.4% of women aged 75 – 84 years and
- 15.1% of men and 17.1% of women aged 85 years and over.<sup>3</sup>

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<sup>1</sup> National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne.

<sup>2</sup> Australian Institute of Health and Welfare, *Australia's health 2010*. 2010, AIHW.



Stroke is a leading cause of death in Australia and a significant contributor to disability amongst adults. Between 20 and 30% of stroke survivors go on to develop vascular dementia suggesting that the increase in strokes over the next decade will add between 100,000 and 150,000 new cases of vascular dementia to the Australian community<sup>4</sup>.

The consequences of stroke can include paralysis, inability to speak, difficulty with memory and thinking, or problems completing everyday activities such as dressing and eating.

### **Impact of Stroke**

The impact of a stroke is profound:

- Stroke survivors are more likely to have profound limitations relating to self care, movement and communication than other people with disability<sup>5</sup>.
- Health related quality of life (HRQoL) for the majority of stroke survivors up to two years after their stroke has been rated as very poor<sup>6</sup>.
- Depression is seen in approximately a third of survivors<sup>7</sup>.

Survivors of stroke report difficulties associated with stroke that impact on many facets of their lives. These range from physical to emotional problems and impact their ability to work and participate in social and family activities.<sup>8</sup>

Nearly 90% of these stroke survivors live at home and more than 282,000 live with a permanent disability. This means that there will be many more stroke survivors living at home seeking information and services to help in their recovery journey.

Some of the common issues often faced by survivors include:

- Being discharged home and then not sure of what to expect;
- Survivors and carers need help but do not know where to find it; and

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<sup>3</sup> Australian Institute of Health and Welfare 2011, *Cardiovascular Disease: Australian Facts 2011*. AIHW

<sup>4</sup> Mackowiak-Cordoliani, M.A., et al., *Poststroke dementia in the elderly*. *Drugs Aging*, 2005. **22**(6): p. 483-93.

<sup>5</sup> Australian Institute of Health and Welfare, *Australia's health 2010*. 2010, AIHW.

<sup>6</sup> Sturm, J.W., et al., *Determinants of handicap after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS)*. *Stroke*, 2004. **35**(3): p. 715-20.

<sup>7</sup> Hackett, M.L., et al., *Frequency of depression after stroke: a systematic review of observational studies*. *Stroke*, 2005. **36**(6): p. 1330-40.

<sup>8</sup> National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne.



- Survivors and carers are unable to locate or have difficulty accessing the many existing service providers as they are hidden from the consumer view<sup>9</sup>.

The NSF supports the Commission's recommendations that support the independence and wellness of older people and enable them to remain in their own homes for longer.

### **National Stroke Foundation Response to the Caring for Older Australians Draft Report**

The NSF supports the move toward a less complex process of assessment and provision of care which provides for greater consumer choice and flexibility. We would welcome a greater integrated aged care system where stroke survivors and carers experience accurate assessment of need and appropriate community response provided in a timely manner.

We would like to draw the Commission's attention to several issues that relate primarily to implementation.

#### **1. Recommendation 8.1**

The NSF supports the move to the aged care gateway—a single, integrated model of information provision, assessment and referral.

##### **Single Information Platform**

The provision of information via a single aged care information platform is an important and urgent need. Currently there exist several ways that consumers can currently access information, many of which are not successful.

The National Stroke Foundation has concerns as to how access to the aged care gateway will be coordinated and promoted for groups such as stroke survivors and carers, including those who may not yet be in need of aged care services, but are in need of information about non-aged care services to assist them to stay in their own homes, maintain wellness and independence.

The specific challenge in providing information to stroke survivors is, unlike the general aged population, health literacy encompasses several abilities including word recognition, reading comprehension, communication skills and conceptual knowledge – approximately a third of stroke survivors will have problems with one or more of these skills.<sup>10</sup> Tailoring information to accommodate these deficits will be a critical aspect in ensuring the single information platform is successful.

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<sup>9</sup> National Stroke Foundation, *Stroke Support Strategy*. 2008, NSF: Melbourne

<sup>10</sup> Cited in Berens A, Laney G, Rose T and Howe T, *The Australian Aphasia Guide 2008*



The National Stroke Foundation has recently completed semi-structured qualitative interviews with stroke survivors, carers and health professionals working in stroke. The key factors which should be considered when making written information accessible to stroke survivors are:

- information should be written in plain English at Year 7 - 10 level of readability
- an interactive level of health literacy
- design issues such as, font size, layout, use of white space
- key words highlighted
- aphasia friendly
- design and content responding to low literacy level and the cognitively impaired.<sup>11</sup>

Staff within the aged care gateway will require access to stroke specific knowledge and skills in order to respond to the special needs of this group. They must be in a position to appropriately and comprehensively refer this large group to community- based services focused both on wellness and community engagement in addition to intervention and service provision.

**To enable stroke survivors to successfully access information through the aged care gateway, the National Stroke Foundation recommends that:**

- Information be developed and provided in a range of formats, both written and verbal, in order to respond to special needs. In the case of stroke survivors, key words need to be highlighted, content and design needs to be aphasia friendly, and be targeted to low literacy levels.
- A comprehensive education/information campaign is implemented in order to ensure that consumers are aware of the aged care gateway including stroke survivors and carers.
- A framework be developed which clearly articulates how all agencies will work together with respect to the aged care gateway.
- That the National Stroke Foundation be consulted in the development of aged care information platform to ensure that the needs of stroke survivors and their carers are considered given that 1 in 5 people will suffer a stroke over the next 10 years.
- KPIs be developed and built into the aged care gateway workplan to ensure and measure the effectiveness of the above.

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<sup>11</sup> National Stroke Foundation, *Internal report*, 2011



## Assessment and Referral

Stroke recovery is not a linear journey, but rather a complex and changing one. Many survivors (57%) will be discharged home to a carer—most often their spouse.<sup>12</sup> Fifty per cent will not have a discharge plan.<sup>13</sup> Of those that do, many will not have had their needs accurately predicated on discharge with 40% requiring more support at home than predicted by hospital staff. At six months post-discharge, 32% of these consumers will have needs that are greater than their needs at six weeks.<sup>14</sup>

In a pilot study undertaken by the National Stroke Foundation, survivors were referred to the National Stroke Foundation, at discharge by hospital staff. A health professional telephoned survivors to provide support and information. Referral to a local liaison officer was available for complex clients where support was provided either by phone or face to face. In addition, the local liaison officer accepted referrals from the community. Those accepted from the community were, on average, many years post stroke.

The pilot showed that whilst many survivors' needs could be met via the standard telephone consultation, 33% required additional information that could be provided over the telephone including a more detailed assessment and referral to services. In addition, those requiring more intensive local follow up doubled at 12 weeks.

Of greater concern where the numbers referred from the community where 36% required face-to-face follow-up by a liaison officer and double the time spent in service navigation assistance.<sup>15</sup>

Assessment of need, therefore, must be undertaken at various time points even when need for referral has not been identified initially. In the case of stroke survivors, there is a need for assessment to occur before they need aged care services and in this way, they continue to be independent members of the community. This early assessment has the potential to delay the need for aged care services. In response to this the NSF has developed a follow up service, StrokeConnect, which directly addresses this issue. The NSF would envisage referrals between the aged care gateway and StrokeConnect could provide a more holistic and preventative approach.

Carer support is also of utmost importance. As this draft report document recognizes, carers carry a significant burden, often with very little support. The burden of care of stroke survivors most often falls to family members

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<sup>12</sup> National Stroke Foundation *National Stroke Audit Rehabilitation Services* 2010 Melbourne Australia

<sup>13</sup> National Stroke Foundation *National Stroke Audit Rehabilitation Services* 2010 Melbourne Australia

<sup>14</sup> Luker, J. and K. Grimmer-Somers, *Factors influencing acute stroke guideline compliance: a peek inside the 'black box' for allied health staff*. J Eval Clin Pract, 2009. **15**(2): p. 383-9.

<sup>15</sup> National Stroke Foundation, *Internal report*, 2010



or friends with 57% of survivors receiving assistance from a family member (most often their spouse) Carers report the burden of care has a significant impact on all areas of their lives.<sup>16</sup>

The gaps in services for carers of stroke survivors are substantial and follow up support and care is limited.

Some of the common issues include:

- Carers take on a caring role without knowing what to expect
- At discharge from hospital:
  - 50% of carers requiring carer training do not receive it
  - 49% of carers do not have their needs assessed
  - 47% of stroke survivors are not provided with a discharge plan and
  - 57% do not receive patient education.<sup>17</sup>
- The burden of caring impacts emotionally with two thirds of carers admitting to having felt depressed since taking a caring role, and over 50% expressing ongoing feelings of depression.<sup>18</sup>

In summary, in the case of the majority of stroke survivors and carers, there is a need for early assessment and assessment at different time points in order that they can access support services that will enable them to live independently in the community and thus delay the need for aged care services.

**The NSF recommends that:**

- **in the process of implementation consideration be given to how assessment described in this report interacts with other assessment processes such as the one being undertaken by StrokeConnect.**
- **the baseline assessment undertaken at the Gateway should routinely screen for carer depression and anxiety and respond with referral to appropriate forms or support including counseling services and peer support programs.**

**The NSF would welcome the opportunity to be part of the implementation taskforce to assist in addressing these issues and to provide stroke specific expertise.**

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<sup>16</sup> National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne

<sup>17</sup> National Stroke Foundation. *National Stroke Audit Acute Services Clinical Audit report 2009*. 2009 Melbourne Australia

<sup>18</sup> National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne.



## 2. Recommendation 8.2

The Inquiry's draft report acknowledges the need to better link community based non-aged care funded services, aged care services and health. It makes reference to the need for a seamless system linking discharge planning and community response to individual need. With 50% stroke survivors being discharged without a discharge plan, this seemingly simple change will require significant attention and leadership.<sup>19</sup>

There are new developments in the health sector, for example Medicare Locals, which have the potential to enhance this outcome if the planning and delivery are linked to the new Gateway.

The building block approach acknowledges the need for improved access to rehabilitation. NHMRC endorsed clinical guidelines recommend that stroke survivors should have access to:

- ongoing rehabilitation to set new goals and improve task-oriented activity if there is residual impairment.<sup>20, 21</sup>

The NSF is aware that stroke survivors and their carers find accessing these services in the community and residential care very difficult. They are costly, difficult to access and in the case of residential care, often not provided at all.

Access to rehabilitation services should include both restorative rehabilitation and maintenance rehabilitation.

The report, while acknowledging the need for improvement in this area, does not indicate how access to these services will be improved.

### **The NSF recommends:**

- **A framework be developed which clearly articulates how all agencies will work together to achieve the stated desired outcome**
- **increased rehabilitation provision be accompanied by simple and clear processes for accessing these services and be provided with sufficient additional funds to ensure increased and sustainable delivery.**

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<sup>19</sup> National Stroke Foundation, *Walk in our shoes*. 2008, NSF: Melbourne

<sup>20</sup> *Therapy-based rehabilitation services for stroke patients at home*. Cochrane Database Syst Rev, 2003(1): p. CD002925.

<sup>21</sup> Legg, L., et al., *Occupational therapy for patients with problems in personal activities of daily living after stroke: systematic review of randomised trials*. Bmj, 2007. **335**(7626): p. 922.



### 3. Recommendation 8.4

The NSF welcomes the report's reference to the need for programs that promote wellness, social inclusion and engagement.

NHMRC endorsed Clinical Guidelines for Stroke Management (2010)<sup>22</sup> make a series of recommendations about services that should be provided to stroke survivors and carers before leaving hospital, and in the community, for ongoing recovery and independence and optimal quality of life. Many of these services straddle the health and community sectors and a large number are not receiving aged care funding. The relevant NHMRC recommendations include:

- Stroke survivors should be encouraged to participate in community exercise programs<sup>23</sup>, and be made aware of self management programs<sup>24, 25</sup>, peer support and targeted occupational therapy programs to increase participation in leisure activities<sup>26</sup>;
- tailored information and support should be provided to survivors and carers during all stages of the recovery process; and
- access to counselling<sup>27</sup>, leisure programs<sup>28</sup> and self management programs<sup>29</sup> have been shown to be effective in reducing depression amongst stroke survivors.

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<sup>22</sup> National Stroke Foundation, *Clinical guidelines for stroke management*. 2010, NSF: Melbourne.

<sup>23</sup> Langhammer, B., B. Lindmark, and J.K. Stanghelle, *Stroke patients and long-term training: is it worthwhile? A randomized comparison of two different training strategies after rehabilitation*. Clin Rehabil, 2007. **21**(6): p. 495-510

<sup>24</sup> Kendall, E., et al., *Recovery following stroke: the role of self-management education*. Soc Sci Med, 2007. **64**(3): p. 735-46.

<sup>25</sup> Lorig, K.R., et al., *Chronic disease self-management program: 2-year health status and health care utilization outcomes*. Med Care, 2001. **39**(11): p. 1217-23.

<sup>26</sup> Walker, M.F., et al., *Individual patient data meta-analysis of randomized controlled trials of community occupational therapy for stroke patients*. Stroke, 2004. **35**(9): p. 2226-32.

<sup>27</sup> Hackett, M.L., et al., *Frequency of depression after stroke: a systematic review of observational studies*. Stroke, 2005. **36**(6): p. 1330-40.

<sup>28</sup> Desrosiers, J., et al., *Effect of a home leisure education program after stroke: a randomized controlled trial*. Arch Phys Med Rehabil, 2007. **88**(9): p. 1095-100.

<sup>29</sup> Warsi, A., et al., *Self-management education programs in chronic disease: a systematic review and methodological critique of the literature*. Arch Intern Med, 2004. **164**(15): p. 1641-9.





**The NSF seeks to be a member of the implementation taskforce in order to:**

- **contribute evidence to demonstrate the effectiveness of community based programs in stroke recovery and**
- **contribute stroke expertise during the development of referral pathways.**

## **Conclusion**

The National Stroke Foundation supports structural reform of the aged care system to assist older people to remain independent and make decisions about the direction of their lives for as long as possible. We support the establishment of a simpler, single gateway into aged care and have raised implementation questions throughout our submission as to how the gateway would be set-up and operate.

Finally, in order to ensure coordinated delivery of the recommendations outlined in this draft report the NSF would suggest recommendations be supported by the addition of:

- The assignment of lead agencies or governmental coordination mechanisms to achieve policy goals;
- An evaluation strategy.

We look forward to working collaboratively to ensure the needs of stroke survivors and carers are responded to in the implementation of this important and innovative new initiative.