

# National Stroke Foundation



**stroke**foundation

## **Submission to the Senate Community Affairs Legislative Committee inquiry into the Living Longer Living Better Aged Care Bills**

### **Key Contact Person:**

Name: Rebecca Smith  
Position: Director Advocacy

## **Introduction**

### **About the National Stroke Foundation**

The National Stroke Foundation (NSF) is a not-for-profit organisation that works with stroke survivors, carers, health professionals, governments, and the public to specifically minimise the impact of stroke, a disease which will affect one in six people worldwide in their lifetime and which affects one Australian every ten minutes.

In delivering programs and services the NSF operates across the full spectrum of preventative health, acute care and sub acute patient support.

### **The Living Longer Living Better Reform Package (LLLB)**

The NSF welcomes the opportunity to provide a submission to the Senate Community Affairs Legislative Committee inquiry into the Living Longer Living Better Aged Care Bills:

- Aged Care (Living Longer Living Better) Bill 2013
- Australian Aged Care Quality Agency Bill 2013
- Australian Aged Care Quality Agency (Transitional Provisions) Bill 2012
- Aged Care (Bond Security\_ Amendment Bill 2013
- Aged Care (Bond Security) Levy Amendment Bill 2013

We note that many aspects of the reforms proposed as part of the LLLB package are being developed in partnership with the sector (largely through NACA and other key stakeholders including National Seniors Australia, the AMA, HACC providers and local government) and implemented administratively in delegated instruments. Our submission touches on some elements of the package which fall into this category that are of importance to stroke survivors. These include:

- the Aged Care Gateway design and implementation; and
- special needs and the definition of the *Specified Care and Services Schedule* which will define the package of care provided to all residents.

In addition, we would also like to take the opportunity to highlight the importance of careful planning of the interface between the aged care reforms and the services provided under the system and those provided under DisabilityCare Australia.

### **Impact of Stroke**

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>.

Currently, an estimated 420,000 people are living after stroke in Australia and this is projected to rise to over 700,000 by 2032<sup>2</sup>. 69% of stroke survivors are aged over 65 and the prevalence of stroke generally increases with age.

- 25% of stroke survivors are aged 65 – 74 years
- 28% are aged 75 – 84 years and
- 16% are aged 85 years and over<sup>3</sup>.

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.

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>.

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
- 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>8</sup>

Stroke is a devastating event which often leaves survivors with significant physical, psychological or cognitive impairments. There are 50,000 strokes in Australia each year and 420,000 people living in the community who have suffered a stroke. Two thirds of survivors sustained a disability that impeded their ability to carry out activities of daily living unassisted. They and their carers require significant support in the community many years after the acute event.

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

<sup>2</sup> Deloitte Access Economics - *The economic impact of stroke in Australia* 2013

<sup>3</sup> Deloitte Access Economics - *The economic impact of stroke in Australia* 2013

<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, *Stroke Support Strategy*. 2008 NSF: Melbourne.

These services will include those provided under the aged care system, but also include those provided by community organisations such as lifestyle programs, support programs and private providers of rehabilitation and allied health services. Recovery from stroke takes place over many many years, far beyond the few months of care provided by the tertiary health sector.

Some of the effects of stroke less recognised by the community include:

- Communication difficulties – difficulty with language, such as talking, understanding what people are saying, reading, writing or a combination of these. This is also called aphasia or dysphasia.
- Slurring words – difficulty with talking, called dysarthria.
- Cognitive difficulties unrelated to dementia – for example, poor attention, difficulty remembering things, planning or organising or solving everyday problems.
- Behaviour and personality – difficulty with ‘insight’ or acknowledging that they have difficulties because of the stroke. Poor safety and judgement may lead to behavior being ‘impulsive’ or ‘inappropriate’ to a particular situation. Some people experience personality changes after a stroke. Some laugh or cry uncontrollably even though they don’t feel happy or sad.

It is critical that the system outlined in the LLLB reforms is accessible to stroke survivors and that it caters for their needs.

The NSF recommends that stroke survivors are recognised as a special needs group under the Aged Care Act to ensure that their needs, including non-dementia related cognitive difficulties are adequately met through the reforms. In addition an appropriate supplement should be considered to ensure specialist services, support and aids are available for the significant and growing stroke survivor community in Australia.

## **The Gateway**

The NSF is disappointed that the government didn’t adopt the Productivity Commission’s recommendation of a gateway with a physical presence and regional outlets. The lack of a physical presence provides specific issues for stroke survivors needing to access the system.

The specific challenge in providing information to stroke survivors is that, unlike the general aged population, health literacy is impacted in many ways 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>9</sup> Tailoring information services to accommodate these deficits will be a critical aspect in ensuring the Gateway is successful and is not a barrier for access.

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

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<sup>9</sup> Berens A, Rose T and Howe T, *The Australian Aphasia Guide 2008*.

- Design and content responding to low literacy level and the cognitively impaired.<sup>10</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 refer this large group to wellness and community engagement as well as intervention and service provision.

### **LLLB Reforms & DisabilityCare Australia Interface**

The dual reform processes underway across the aged care and disability systems are vitally important to the stroke community given stroke is a disease which largely affects the elderly and also a disease of significant disability burden.

We have been very encouraged by the commitment of the government to both reform agendas and the recognition that the two pieces of significant reform need to co-evolve to ensure integrated systems are established across the two sectors. These systems need to reflect the changing needs of older Australians and the needs of those particularly under 70 who may be more oriented towards the work force and therefore aligned to the assessment and services of DisabilityCare Australia than aged care.

Services under both systems should be available to consumers based on individual need and not on age or the sector that they are managed under. We strongly support this principle as stroke impact can vary widely. For many stroke survivors the aged care system, as it is currently structured, does not provide the services and support required for re-ablement, whether it is a return to work or a return to something resembling a stroke survivor's previous lifestyle.

The National Stroke Foundation recognises the need for a defined point at which people must transition through DisabilityCare Australia into aged care, though we believe this transition should not result in a reduction in availability of services.

In some instances people over 65 will benefit most from services that are provided by the disability sector. Whilst access to services for these people might be funded by aged care, the systems should be flexible enough to enable individuals to select the services most appropriate to their need. This would mean that funds available through aged care and DisabilityCare Australia would need to be similar for similar levels of need and if services are not available through aged care, those over 65 should be able to source them from outside the sector.

It is critical that the LLLB reforms meet the needs of older Australians with disability and that transition to the aged care sector does not result in unmet need for those with disability.

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<sup>10</sup> National Stroke Foundation, Internal report, 2011