



**Towards a National Carer Strategy:
A discussion paper from the Australian Government**

Comments from:
Brain Injury Australia

and its member organisations

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With significant input from BrainLink Services Ltd

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National Carer Strategy

Brain Injury Australia and its member organisations welcome the opportunity to comment on the Discussion Paper, and congratulate the Australian Government on taking this initiative.

We acknowledge the Government's formal recognition of the vital role played by carers, and the importance of a National Carer Strategy to follow from the Carer Recognition Bill 2010.

We trust that these steps will contribute to tangible benefits for carers in the form of support, respite, and improved health and wellbeing for carers.

In our comments below, we have focused on the specific issues that face carers of people with an acquired brain injury (ABI), to ensure the Government is aware of these issues when finalising the Strategy, and to highlight the importance of the unique and individual nature of each carer's life. We recommend that the Government ensure that there is a flexible approach to the implementation of the Strategy, recognising the diverse needs of different carers.

This is not intended to be an exhaustive response to the draft Strategy, and we trust there will be opportunity to comment on the relevant policy and programs that will be formulated in the future in relation to the Strategy.

About Brain Injury Australia (BIA)

Brain Injury Australia is the national peak ABI advocacy organisation representing, through its State and Territory member organisations and network relationships, the needs of people with an ABI, their families and carers.

Brain Injury Australia advocates for Australian Government program allocations and policies that reflect the needs of people with an ABI and their families, and provides input into policy, legislation and program development through contact with Australian Government ministers, parliamentary representatives, Australian Government departments and agencies, and national disability organisations.

About ABI

Acquired brain injury refers to the multiple disabilities arising from any damage to the brain that occurs after birth. Common causes of ABI include stroke, infection, alcohol or other drug abuse, and degenerative neurological disease. Traumatic brain injury (TBI – see above) is an ABI caused by a traumatic event, from an external force to the brain such as a motor vehicle accident, a fall or a blow to the head.

The Australian Institute of Health and Welfare Health Bulletin No. 55 in 2007 states that around 1 in 45 Australians have an ABI that resulted in some degree of disability, and about 20,000 children under 15 yrs have an ABI.¹

The consequences of an ABI can be profound, complex and multiple. The physical problems commonly reported by people with an ABI include:

- Physical Changes:
 - In body movements, there can be reduced coordination or weakness.
 - Some paralysis
 - Balance problems and dizziness
 - Epilepsy and seizures

¹ Australian Institute of Health and Welfare. 2007. Disability in Australia: acquired brain injury. Bulletin no. 55, Cat no AUS 96. Canberra: AIHW

- Fatigue and headaches
- Sensitivity to light and/ noise

- Cognitive Changes
 - Shortened attention span
 - Easily confused and overwhelmed (eg having problems keeping up with a conversation)
 - loss of memories
 - forgetting things – word-finding difficulties
 - problems in learning new things
 - Having problems planning and getting organised
 - Rigid thinking patterns

- Sensory Changes
 - Changes in smell or taste, speech, hearing, and/or sight.

- Behaviour and Personality Changes
 - Changes include: more impulsive, impatient, problems with anger management, inability to control emotions, apathy or low motivation

- Social Changes
 - Social networks and relationships change. Old relationships may be lost. Establishing new ones can be difficult

- Emotional Changes
 - Loss of self-esteem
 - Sadness and grief
 - Depression and/or anxiety
 - Irritability and “short fuse”

A complex disability

People with ABI tend to have more complex needs than people with other forms of disability. They are more likely to need help with cognitive and emotional tasks (eg. attention, concentration, cognition and understanding, planning and organisation)

There is a high rate of co-morbidity with mental illness and/or other physical disabilities. For example, of people aged under 65 with an ABI:

- 80% had another physical disability (eg. neurological conditions, cardiovascular and respiratory conditions, physical disability)
- 40% had psychiatric disability,
- 39% had a sensory/speech disability, and
- 29% had an intellectual disability.

The areas with which people with ABI most commonly require assistance relate to cognitive and emotional tasks. Over 30% (> 100,000 people) of people with ABI aged under 65 years reported needing help in this area.²

² Australian Institute of Health and Welfare. **2007**. Disability in Australia: acquired brain injury. Bulletin no. 55, Cat no AUS 96. Canberra: AIHW

This means that the expected role of a person's carer/s may comprise support with the full range of physical functions, as well as continuous assistance with a broad number of emotional and cognitive functions.

Added to this, the most difficult part of the role reported by many carers is living with challenging behaviours. One study found that three quarters of relatives of a person with an ABI said the person's personality changes were the most difficult things they had to deal with³

Many people with an ABI lose friends and family who just can't cope with the changes. They then find it difficult to make new friends, and may spiral into greater and greater social isolation.

How many people are affected by ABI?

The AIHW estimates there are, estimated that there were 338,700 Australians (1.9% of the total Australian population) who had a disability related to ABI. Of these, 160,200 were severely or profoundly affected by ABI and needed daily support.⁴

The AIHW's acquired brain injury prevalence figures are:

- 113,300 NSW residents (1.8% of the NSW population)
- 72,700 Victorian residents (1.9% of the Victorian population),
- 74,300 QLD residents (2.6% of the QLD population),
- 29,200 WA residents (2% of the WA population),
- 33,600 SA residents (2.2% of the SA population),
- 7,800 Tasmanian residents (1.8% of the Tasmanian population),
- 4,700 ACT residents (2.3% of the ACT population),
- 3,100 NT residents (3.6% of the NT population).

Carers and ABI

While people in caring roles across Australia share common experiences and concerns, we believe the National Carer Strategy must also acknowledge that there are specific experiences and concerns that affect carers of individuals with specific disabilities. Experience shows us that community awareness of ABI significantly lags behind that of other disabilities.

The impact on carers of a person's social isolation

People with ABI and their families and friends consistently report that the lack of community awareness (by government, service providers, community organisations, employers, and the broader community) is the single greatest obstacle to social participation. The cognitive and behavioural challenges that many people with an ABI experience exclude them from social participation precisely because those challenges are not understood as being a function of their disability.

A recent study looking at the impact on carers and family members of caring for a person with an ABI concluded that "the distress experienced by relatives was not due to the direct impact of the neurobehavioral impairments, but the effect of these impairments was mediated by the degree of community participation achieved by the person with TBI."⁵ In other words, where the person with ABI is unable to participate in the community, there is significant impact on relative and carer distress. This point is particularly pertinent when, as noted previously, we remember that people with an ABI commonly experience significant barriers to community participation.

³ Scory et al, cited in Living with Brain Injury- A guide for families Senelick & Dougherty 2000.

⁴ Australian Institute of Health and Welfare. 2007. Disability in Australia: acquired brain injury. Bulletin no. 55, Cat no AUS 96. Canberra: AIHW

⁵ Winstanley, J; Simpson, G; Tate, R; Myles, B (2006) Early Indicators and Contributors to Psychological Distress in Relatives During Rehabilitation Following Severe Traumatic Brain Injury: Findings From the Brain Injury Outcomes Study; J. Head Trauma Rehab: 21(6)

Lack of understanding of ABI and the carer role

Broad social lack of understanding of the impact of the carer role is exacerbated by lack of understanding of ABI.

In the case of any acquired disability such as ABI, carers and families undergo a process of adapting to changes, and many carers report this is often not well understood by people working in the service system or government departments. All carers will have 'good days' and 'bad days'. The coping styles, internal family dynamics, and other factors contributing to a carer's capacity for resilience will all have a bearing on a carer's sense of how well they are supported, and how well they will cope on any given day. There may be family conflict as a result of the increased stressors, fears and anxieties, and sense of uncertainty about the future.

Dramatic life changes

The impact on a person's life when thrust into the role of carer cannot be under-estimated. Along with the emotional impact of the acquired disability / chronic illness, families will commonly experience the following profound changes and impacts on lifestyle:

- practical lifestyle stressors: finances, housing (sometimes including moving/relocation), separation, travel, medical interventions;
- grief and loss;
- social isolation and not feeling understood;
- lack of privacy, with care providers, attendant care, etc accessing the home;
- loss of employment, incorporating social roles and financial stability;
- role, relationship and responsibility changes;
- Information overload, trying to make sense of the injury and hospital system; and
- The carer's own needs being put on hold or not addressed.

Significant and long term need for care and support

The effects of an ABI on an individual can be significant and life-changing, resulting in a need for **care across their lifetime** (sometimes continuous, and sometimes episodic). Moreover, ABI is very often a "prime of life" disability, often occurring just as the person is entering adult life and everything that means/ entails – embarking on further study, employment, leaving home.

Several outcomes studies⁶⁷ demonstrate that as many as 90% of people with a moderate to severe ABI return to the care of their family, and in a state of high dependence that extends over the course of their life time. Also, Australia is facing a 'perfect [demographic] storm': the combined effect of increased life expectancy and enhanced survivability from injury, due to improvements in acute care.

Broader issues facing carers

Carers of people with an ABI also report experiencing the same issues cited by carers of people with a diverse range of disability and / or chronic illness, including the following:

⁷ For example: Tate, Ponsford

- Financial concerns: Many carers cannot commit to permanent or full time work, relying on government benefits or personal assets to meet the costs of living and caring. BrainLink reports that more and more carers are cashing in their superannuation to meet these costs.
- Respite: getting a break is crucial for enabling carers to look after their own health and wellbeing and/or to remain in employment. The system needs to be flexible enough to be useful for carers. The dominant model is still ‘a couple of weeks in residential care’, but while this suits some people, it doesn’t suit everyone. More flexible respite, including appropriate in-home respite, is required.
- Peer Support: Carers report that often the best support comes from other carers. They need more opportunity to share their caring experiences and learn from each other. Again, this has to be available in a flexible manner, as many carers of people with an ABI have unpredictable lives, and express frustration when having to fit into a structured program.

A peer mentoring program run by the Brain Injury Association of NSW commonly hears from its participants statements expressing relief that somebody out there understands what they’re going through. One participant said: *“My mentoring partnership is a great blessing to me. We have quite parallel lives in many ways and a great understanding of our difficulties. Some weeks the wheels fall off regarding our phone calls but neither of us are phased by this and email when we can to share whatever crisis has taken us out of communication”.*

- The additional barriers and problems faced by people in rural, remote, and other under-served areas: Each of the issues highlighted in this document are exacerbated in areas where there is simply no access to support.
- Carers and families are a resource for care providers and policy makers, and need to be treated as such, rather than excluded from decision-making processes.
- Support for carers is needed even when the person with a disability resides in residential care: It is a myth that caring ceases once an individual enters residential care. A caring work/effort continues both in a physical and emotional sense, not to mention the impacts from years of caring in the home such as injuries/trauma (physical/mental from caring). There may still be significant responsibilities visiting and still taking the individual to regular health check appointments, shopping and purchasing their medications etc... Regardless of whether someone is no longer in the family home extra caring costs – e.g. equipment, medication still continue.
- Carers report that Government staff (most notably Centrelink) need to better understand the carer’s role, and display more respect for carers. Carers report a lack of understanding of carer issues, lack of respect/dignity (e.g. – questioning why a carer has not been actively job seeking), and often a lack of clear and accurate information, and poor communication systems/structures overall.

Recommended wording change

Brain Injury Australia and its member organisations recommend an addition to the Aim of the Strategy which would capture the active involvement of carers in planning and implementing the “policy, programs, and services”. The following suggested wording is one option

“Policy, programs and services for carers are [**developed in partnership with carers and are**] coordinated, responsive and targeted at all stages of caring”

Final comments

Brain Injury Australia and its member organisations commend the development of the National Carer Strategy as an important recognition of the work of Australia’s growing ‘care force’. It needs involvement and voice from all involved. In particular, it is essential that carers are directly involved in planning and implementing policy and programs under the Strategy.

Clearly the draft National Carer Strategy is a high level strategic document, and we would not expect too much detail about interventions. However, whilst the goals are positive statements, they must be much more than symbolic words, and at the heart of their foundation must be measurable outcomes that really make a difference to a carer's life.

Many carers experience the role a rewarding one, but just need **better support** to do the best they can while also maintaining their own health and wellbeing. This Strategy is an opportunity to genuinely support carers in their role, and while the goals and directions articulate this well, the challenge will lie in bringing the Strategy to life.

The language that captures **flexibility** of approach, now used extensively in disability policy, including 'person-centred' and 'individualised', should also be applied in the context of carers. Every carer's situation is different, and solutions will not be found in blanket approaches.

The strategy must have a robust and flexible approach to carer support that recognises the complex range of factors that impact on each carer's health and wellbeing.

Information, support, education, and training must all include the **specific resources** required by the carer relating to the disability or chronic illness in question. In the case of ABI, carers need specific, useful, and practical information about ABI and its impacts to support them in understanding and optimising their caring role.

Finally, the impact of a person's disability or chronic illness on carers is in part a result of an inadequate **service system**. Carers fear loss of service, find the system confusing hard to navigate, remain unaware of what is available or possible, don't understand the divisions between different government programs and responsibilities, and don't know their entitlements or how to access them. Importantly, many carers do not have the energy or the time to find out. We applaud the Federal and many States' Government's efforts to reform the aged care and disability sectors, and trust that the National Carer Strategy will dovetail into the National Disability Strategy and other relevant strategies wherever possible.

Critical to the Strategy is that it is not viewed in isolation. It must directly address the causes of systemic discrimination and commit to specific actions and targets. The National Carer Strategy should align and consider in its development the National Disability Strategy, national health and hospitals reform, the Productivity Commission's inquiry into "disability care and support", and other key strategies and initiatives.

Coupled with this, the social welfare system has a history of difficulty and inflexibility; that it, in fact, often disadvantages families and individuals who might choose to work. For the strategy to make a real difference to the lives of people and families it must encompass all factors affecting the carer and the rights of people living with disability to be included and participate equally in all aspects of the community.

The strategy should contain clear actions and expected outcomes for carers in all major areas of public life (work, leisure, transport, housing, built environment, civic participation, education, etc), measured against the principles within the United Nations Convention on the Rights of Persons with Disability.