



**Submission to the
Federal Parliamentary Inquiry
Into Better Support For Carers**

Make Caring Count!

July 2008

EXECUTIVE SUMMARY

BrainLink believe that the inquiry into better support for carers represents an important step forward for carers and we are pleased the government sees the importance of being informed by calling for a major consultation exercise with carers and carer agencies and groups across the country.

Whilst there are many supports that make a difference to carers' lives, we see this as the beginning of a process of improvement.

This submission highlights significant difficulties faced by individuals and families who care for someone with an **acquired brain injury or neurological condition**; and details a rapid rise in **male carers** who find the caring role challenging to the extreme.

Most importantly, it outlines the words from carers about issues and solutions brought to light in a number of recent BrainLink consultations; this is their opportunity to voice their concerns. They do want to be heard but it is simply not possible for all of them to take time out from their important caring roles to submit their words in writing. In this BrainLink has been entrusted.

All carers are individuals with their own needs, caring for people with a huge range of requirements and abilities in what can be very complex and emotionally charged relationships. There is not one solution fits all - carers deserve real choice based on their individual circumstances.

BrainLink want to ensure that the contribution of carers is fully recognised and that the work and support they provide is what makes a difference to the lives of the vulnerable members of the community who want 'ordinary', independent lives too.

With an ageing population the growing need of care is a serious challenge, therefore informal care should be embraced and seen as vital. Policies must acknowledge the importance of this provision of care to the healthcare system and the reality that it saves them, and not just in monetary terms. Investment in carers and their active contribution to society as a whole benefits our economy and Australia's long term future as a socially responsible society.

Carers have a right:

- to be respected as an expert '**care force**' and have total access to all resources to support them in their caring work;
- to live a life of their own alongside their caring role;
- to be supported so they are not forced into financial hardship due to their caring role;
- to be supported to ensure their mental and physical well-being and health and to maintain their dignity; and
- to be supported in and into work if they choose.

BRAINLINK SERVICES - Who we are?

BrainLink Services Limited is a Victorian ABI (Acquired Brain Injury) charitable organisation providing:

- education/support services,
- respite,
- specialised case management and
- significant carer/family support to the community.

Those who access us are drawn from the National ABI definition:

Acquired Brain Injury..... 'injury to the brain which results in deterioration of cognitive, physical, emotional or independent functions. It can occur as a result of trauma, hypoxia, infection, substance abuse, degenerative neurological disease or stroke. These impairments to cognitive abilities, sensory or physical functional can be either temporary or permanent and cause partial or total disability or psychosocial maladjustment.'

The priority, whilst not exclusive, is carers of someone with an ABI who is **non-compensable**.

BrainLink acts as a first point of contact for people with an ABI, their families, carers, service providers and the general community in relation to ABI issues. Where a person is seeking support, BrainLink provides a range of information and referral options. In the last 12 months **1376** individuals have sought information requests, and of that number around 800 were family members and carers.

Unique services that help families navigate the service system have been created as well as respite breaks of a type that carers might choose and want to take part in, if they weren't in difficult situations.

This year alone **717** individuals have been provided respite and education/training sessions, significant considering we are a very small organisation consisting of a team of five.

THE HIGH IMPACT OF ABI ON CARERS

The effects of an ABI on an individual can be significant and life changing, resulting in a need for **LIFETIME CARE**. In a population that is living longer this can be a very **LONG TIME**.

An individual can suffer from a range of physical and psychosocial impairments presenting as multiple, complex and severe disabilities. Carers, who are usually family members, in most instances take responsibility for the bulk amount of care. In many cases, caring is 24/7 and involves assisting with everyday activities including eating, bathing, toileting and dressing.

Difficult cognitive changes in the person they care for are the most stressful. Changes to a person's behaviour are very common after ABI and range from subtle changes such as talking too much, to markedly altered behaviour, such as physical aggression.

Challenging behaviour after ABI is particularly distressing for carers, family members and friends and is usually the result of a complex combination of factors that relate to an individual's brain injury, their environment and personal factors. Sometimes those closest to a person with an ABI bear the brunt of their anger and frustration.

How an individual reacts to life after brain injury will often depend on their personality, resilience and coping skills. Some personality traits may become more prominent and some will have a complete change from their previous personality.

The grief and loss for the 'original person' on the carer is enormous.

'Rosie is completely reliant on Jack, since her stroke 11 years ago. These days a holiday, or time alone for just a few hours or to have a normal conversation with other people, is a luxury. She is not the same person she was before the stroke. Her personality has changed - she forgets who he is sometimes! Lately he finds himself at breaking point'.

Coupled with physical problems, emotional control and memory problems the person with an ABI may have:

- **Impulse control** - they may say and do inappropriate things without thinking;
- **Initiation** - a lack of 'get up and go', difficulty generating ideas, making plans and following through may occur; and
- **Lack of insight** - the person may deny having any significant problem or acknowledge some problems, but have reduced awareness of their impact on others, their daily life and future plans.

Carers dealing with these issues on a daily basis pay a huge price if they too are not supported, and they experience depression and anxiety due to such unrecognised grief & loss. The biggest problem is the loss of friends and outside interests, often as a result of the significant changes in the person they care for, thus leading to social isolation for the carer.

'At age 7, Bill fell from his bunk bed, sustaining a permanent acquired brain injury, and resulting in a lifetime of care by his mother. Although now a grown adult, Bill needs constant supervision as he has an innocent child's mind, many deficits, and often displays inappropriate behaviour towards strangers. Twenty years on, Jean has faced divorce, shock, daily stress, estrangement from her other children, and social isolation as she is afraid to take him out, but she remains her son's full time carer'.



MALE CARERS

BrainLink has seen a considerable increase in male carers with more than 200 in the last 12 months accessing respite and education services provided by our organisation.

Whilst this increase in accessing services is positive, it is important to note and accept the major difference in men and women and their approach to caring.

Simply, the expectations placed upon women and their own expectations of themselves are quite different from men.

Caring and learning to care about others, first happens in a family context. Dominant societal views and actions of appropriate gender roles in a family are still reinforced in many ways.

Generally, community accepts that families are the traditional focus of caring and women are seen as the 'natural, nurturing' carers.

Men do not care less but women's situations are strongly influenced by their socialisation, their economic situation and their own skills and experience.

However men in a caring role are doing it tough and experiencing high levels of distress and depression without strong support networks that carers need to survive.

It's never ending - physically, financially, emotionally and daily; and male carers don't often cope as female carers do. Many have given up work which was the bulk of their life's activity to care for a spouse or child, and it is life changing for them. They don't naturally have a support network as meaningful as women do.

'Rosie is completely reliant on Jack and can never be left alone. He took early retirement to care for her and learned to do everything, including the most intimate of tasks while trying to keep Rosie's dignity. He has used his super to modify the house and they exist on a pension and carer payments.'

CULTURAL AND LINGUISTIC DIVERSITY

Although carers are a heterogeneous group with widely differing circumstances and influences, there are common concerns that cross family and cultural differences.

Carers contribute immensely to the community but often pay a huge price if they are not themselves supported. The biggest issue is the loss of friends and outside interests leading to social isolation.

As mentioned previously, men seem to be more isolated than women carers. This is true too of CALD communities who share bigger issues on top of those already stated. Often these are ageing individuals in caring roles; who are stereotyped by their place of origin; who have feelings of displacement; or are discriminated against and excluded; combined with strong beliefs of privacy and the need to keep problems facing them within their own family circle. All this makes the caring role and increased challenges insurmountable.



FEEDBACK FROM CARER CONSULTATION

1. Financial concern is the major issue facing carers. The rising cost of living is putting severe pressure on a carer's ability to provide adequate support for their family members and in many cases putting themselves and the care force at risk by foregoing their needs in favour of the care recipient.
2. Carers believe that getting a break is crucial for enabling them to look after their own health and well being and to remain in employment. Carers told us they don't get enough breaks, and the provision for breaks is sometimes not good quality, making them feel 'second class' and thus reluctant to use them.
A better respite care system – more flexibility – the dominant model is still 'a couple of weeks in residential care' – while this suits some people it doesn't suit everyone. Often residential respite is disruptive for client and carer, and frequent failures to adequately meet client's needs. More flexible respite – eg a few hours here and there, weekends, especially for in-home respite rather than residential care.
3. **Peer Support** was the biggest request with demand for lots more. Carers were unanimous, agreeing that often the best support came from each other. They needed more opportunity to come together to share their caring experiences and learn from each other. Having said this it was vital that in doing this the person they cared for was adequately supported by other supports whilst they attended. Many times such service was difficult to access without jumping through major hoops and even then the level of trust in leaving their family member was limited.
4. No carer services/support/funding after care recipient has gone into Residential Care – the myth that caring ceases once an individual enters residential care must be dispelled. 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).
No time to work full time if 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 – eg equipment, medication still continue.
5. A very consistent complaint that **Centrelink is problematic** – give the impression of a very negative attitude towards caring. A lack of understanding of carer issues, lack of respect/dignity (eg – what have you been doing with yourself? Why haven't you been working etc), and often a lack of clear and accurate information, and poor communication systems/structures overall.
6. More and more carers in particular males are cashing in superannuation to survive in the caring role. Loss of Super – people cash in superannuation to meet costs of caring, equipment etc.
7. The **Service System** for people with disabilities, chronic illness, and frail aged is ineffective, fragmented, problematic in many ways, which in turn makes the role of carer more difficult. People fear loss of service, hard to navigate, not sure what is available/possible, conflicting information, divisions between HACC and Disability and Aged Care, etc. Lack of clarity regarding 'entitlements', eligibility, multiple 'buckets of

money'. For instance, multiple agencies involved with one individual, multiple funding streams, so complex that most professionals can't figure it out, never mind the general public who need assistance. If you are caring 24/7, exhausted and emotionally struggling, what hope have you got!!!!

8. Exclusion from optimal care and support on the basis of how an injury or disability occurred. Many carers are shouldering the load because individuals were not '**lucky enough**' to be injured in a traffic accident or at work and are not compensated! Therefore we have a system that discriminates by cause of disability/injury.

RECOMMENDATIONS

On behalf of carers BrainLink recommends that:

- flexibility be key in the way direct payments can be received and used, giving families more choice about the care they receive over an entire **lifetime**;
- Recognition of the real costs of caring;
- there is provision of clear, consistent information about carer entitlements for the long term;
- flexible respite be expanded;
- a 'Care Cover' be developed for those in the care force injured/impacted in the caring role;
- a carer super scheme be considered;
- carers have access to a grievance hotline, a single central consistent agency that is flexible/adaptable to individual situations;
- Governments investigate a move to an entitlement/voucher system, based on assessment and funds available over an entire **lifetime**, based on needs of client/carer - with capacity to change over time as disability and carer situation change;
- a national no-fault compensation system for catastrophic injury/disability be in place;
- better training and customer service focus be raised in the frontline system;
- culturally sensitive and appropriate services are ensured.
- incentives be considered to assist carers who are employed.

CONCLUSION

It is vital that governments, agencies and service providers understand and acknowledge the very real emotional life-changing situations that carers face, like grief and loss and relationship problems.

These are not easily fixed and are time and support intensive.

Therefore, systems and processes that provide practical assistance such as financial, accommodation, health, information, education, and time-out resources need to be effective and easily accessed and understood by carers and families.

If they are, then carers will have time to deal with the difficult, less quickly resolved emotional issues.

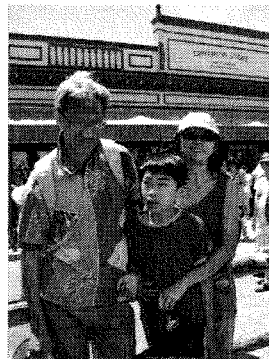
Economically, carers provide a service that is immensely valuable and at a fraction of the cost if the health & hospital system were to provide it. Carers are essential and a valuable 'care force' that work long hard and relentless hours, and need to be recognised financially and socially like any workforce.

The government must acknowledge that carers are facing a huge crisis. They must realise that Gloria, who a few years ago would have taken her mum home to care for her after her stroke, can't because she now works part time to supplement her husband's salary so they can keep up with the rising cost of living.

And Shirley, who against her wishes, places her young daughter in an inappropriate aged care facility, so she can work full time and meet mortgage repayments and other expenses.

And Joe, who cares for his wife 24/7 – she provides his only form of socialisation with limited conversation. This is now his life.

It is complex, it is serious, and it is difficult and not easy to fix, and BrainLink acknowledge that much has been done to date but please, **'Make Caring Count'!**



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