



Support needs of carers

One of the issues with a brain injury is its incredible complexity which affects each individual differently. This causes significant problems when trying to predict prognosis, recovery outcome, and establishing the injured individual's needs during the recovery process.

In this article

- Common issues faced by carers
- Common needs of carers

The care needs of people affected by a brain injury often fall informally onto their parents, spouse or siblings. In Australia, 97% of people under 65 years with a brain injury live in households, whereas only 3% live in cared accommodation.

Research by Pakenham et al. (2005) found these caregivers reported caring an average of 114 hours per week, and that half earn under \$20,000 per annum. The sudden and abrupt nature of brain injury places huge demands on family members, and comes at a personal cost to the primary carer.

Common issues faced by carers

The psychological and physical impact Caring for their loved one with severe disabilities is often a huge psychological burden. Many carers can experience depression, distress, frustration, anxiety, social isolation, family strain, sleep deprivation, burn out and adrenal fatigue. Carers can also feel a tremendous sense of loss - the loss of a partner or child as well as the loss of their own identity.

One of the major challenges is the sudden and abrupt nature of the injury, allowing no time for emotional, psychological or financial preparation. Uncertainty and the lack of direction for their loved one's present and future circumstances is a source of significant stress.

Social isolation

A common issue faced by carers is the feeling of isolation that can occur after brain injury. Friends and family often drop away when they don't understand the impact of a brain injury, and distance themselves to avoid embarrassment or being offended. Emotional and behavioural changes can occur after a brain injury which often lead to social situations which are strained and/or embarrassing for the carers.

Carers often need to constantly adapt to new situations due to the unpredictable nature of the effects of a brain injury. Friends and family seem to struggle the most with the changes.

Change in roles

Another issue that carers face is the changing of the roles within their family. The lack of employment opportunities for people with disabilities, costs involved with caring, lack of time, and the everyday costs of running a household places a significant financial strain on themselves and their families.

Getting to know the new person

The behavioural disturbances that can result after a brain injury have a tremendous affect on day-to-day life for carers. These can include emotional and personality changes, violent outbursts, substance abuse and inappropriate sexual behaviour. These changes place significant pressure on relationships within the family.

Lack of services & support

A major issue is the frequent lack of appropriate services and support available for carers and their family member when they return back to work, study and/or the wider community. A common issue for carers is the lack of knowledge of where, who and what they need to be looking for in terms of support.



Common Needs of Carers

Depending on the loved one's injury severity, your needs will vary. A severe brain injury means the family is likely to be concerned with the following issues:

- Medical care
- Respite access
- Assistance with incontinence
- Equipment access
- Education
- Social support
- In home support
- Counselling support
- Future planning.

Suggested solutions

Maintain your identity

Emphasise the importance of keeping your own identity throughout the caring role. Make a conscious effort of taking control of your situation - don't let your circumstances control you.

Taking time just for yourself

Find ways that can help you cope through stressful periods. Taking time out just for yourself is incredibly important to maintain your quality of life. This could include things like exercise, using social media and taking a hot bath. The point is to stop, breath and focus on you. You need to make sure you are looking after yourself in order to care for your loved one.

Find the positive aspects

Although the stresses and demands of the caring role have a negative impact, there are still many positive aspects. Realising that you are helping to make someone else's life better can lead to closer relationships within the family - this is a common positive experience for carers. The role can generate new appreciation of life, providing valuable life lessons that can lead to rewarding experiences.

Know where to find support

Knowing where to look for support can be incredibly daunting and frustrating. Depending on your area of location, services and support will vary and it is often up to the carer to go out and source these services for themselves.

Start by:

- Searching for your local disability services in the area
- Searching for local respite agencies
- Contact a counsellor
- Join online forums to connect and share experiences
- Contact the Brain Injury Association in your State.