Impact of Brain Injury on Families and Carers

Caring for a person with a disability is one of the most difficult challenges that can confront a family especially for those providing direct care.

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The caring role
Carers often feel that their life is not their own. Some feel that due to the demands of the caring role they have very little time alone to pursue their own interests and social life. Carers often have to do everything on their own where before the injury, they may have relied upon their loved one’s support for everyday pressures. Following the injury the workload increases while at the same time there is reduced support to help the carer cope.

While there are many types of brain injury the difficulties faced by carers remain the same. They may have difficulties accessing therapy for intensive rehabilitation for their loved one. Over time carers often become their own advocates and even act as case managers to ensure that their loved one receives the much needed care.

Personality & behavioural changes
Families may be confronted with many personality and behaviour changes in the individual impacted by brain injury, including:

- egocentric behaviour
- poor social skills
- challenging behaviours
- emotional outbursts
- an apparent lack of gratitude
- depression and/or anxiety
- impulsivity and financial irresponsibility
- alcohol and drug abuse
- poor frustration and stress tolerance

When self-awareness has been affected, this places further stress on family as the family member disagrees that they are acting inappropriately and responds angrily to feedback.

Lack of understanding outside the family
People who are somewhat distanced from the person with the injury often have little understanding of what they are going through. The person with the injury may be able to act ‘normally’ for short periods in front of visitors or publicly, so that many won’t believe the difficult home situation as described by the family. Rather than offer support, friends or members of the extended family may make judgements about how a person cares for their relative.

Common reactions for carers
All carers respond to the demands of caring for their loved one in their own way. Common reactions are feeling overwhelmed, confused and shocked. There are no right or wrong feelings. These feelings are a natural and normal reaction to caring.

Guilt can be a common feeling. Carers may feel responsible for the brain injury occurring, not wanting to be a carer, losing their temper or being embarrassed by the person being cared for. Carers may particularly feel guilty about taking a break from caring or placing the person in residential care.

Anger can arise when someone is the sole carer or others in the family don’t do their fair share. They may become frustrated when faced with regular challenging behaviours, angry outbursts, self-centredness or many of the other issues that can arise after a traumatic brain injury.
Resentment can arise from lack of support when friends don’t make contact anymore, support services don’t provide enough help and the focus always is on the person with a traumatic brain injury or other type of brain disorder.

Fear and anxiety about the future are common. How much with the injured family member recover? What will happen if the family can’t cope? Legal issues such as a compensation claim can be very stressful.

Grief is experienced by many families. Personality changes often result in feeling they have lost their loved one but being unable to say ‘goodbye’. Caring duties can be so overwhelming that there is also the loss of one’s former lifestyle when life starts to revolve purely around the person with the brain injury.

Stress may bring physical symptoms such as headaches, difficulty sleeping, fatigue, anxiety and frequent illness. Carers may also find themselves feeling out of touch with reality, forgetful, not looking after themselves, crying easily and not eating properly.

Look after yourself
Carers need to maintain their health and wellbeing to provide the best frame of mind to care for another individual. Read more about respite and self-care for carers and family members.

References and Further Information
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