Impact of brain injury on caregivers and family

The diverse effects of a brain injury create multiple impacts on relationships and families

Caregivers often feel that their life that is not their own, or as one caregiver states: “not having a life”. 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. Caregivers often have to do everything around the house. Prior to the injury they may have relied upon their loved one’s support for everyday pressures such as housework and managing finances. Following the injury the workload increases while at the same time there is reduced support to help the caregiver cope.

Caregivers may have difficulties accessing therapy for intensive rehabilitation. Over time, caregivers often become their own advocates and even act as case managers to ensure that their loved one receives the much needed care.

PERSONALITY AND BEHAVIORAL CHANGES

Families may be confronted with childlike behavior, self-centeredness, tactlessness, reduced emotional sensitivity and lack of gratitude. The survivor may show marked changes in their social skills and self-care. Impaired control may be displayed in a number of ways including impulsivity, verbal and physical aggression, increased/decreased libido, financial irresponsibility, alcohol and drug abuse, poor frustration and stress tolerance, impatience, restlessness, and a lack of mental flexibility with the need for a highly structured and routine environment. Common emotional difficulties, such as depression and anxiety may lead to challenging behaviors such as withdrawal and avoidance. Increased dependency, which may be related to emotional problems, may also lead to increasing demands for attention from caregivers.

When self-awareness has been affected, this places further stress on family as the loved one may refuse to believe they are acting inappropriately and respond angrily to feedback.

LACK OF UNDERSTANDING

People who are somewhat distanced from the person with the injury often have little understanding of what they are going through. The brain injury survivor 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 judgments about how a person cares for their relative.

EMOTIONS

All caregivers respond to the demands of caring for their loved one in their own way. Feelings are always individual and everyone will react differently. Feelings act as signposts, showing when things are not going well and need attention. Some of the feelings that caregivers often say that they experience are feeling overwhelmed, confused and shocked by the diagnosis of brain injury, or realizing the changes that caring will bring into their lives.

Given the many ways a brain injury can impact on a family, it is not surprising that caregivers will encounter a wide range of emotions. There are no right or wrong feelings. These feeling are a natural and normal reaction to caring.

Guilt can be a common feeling. Caregivers may feel responsible for the brain injury occurring, not wanting to be a caregiver, losing their temper or being embarrassed by the person being cared for. Caregivers 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 caregiver or others in the family don't do their fair share. They may become frustrated with the person they are caring for if they regularly face challenging behaviors, angry outbursts, self-centeredness or many of the other issues that can arise after a 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 the brain injury.

Concerns about the future can result in **fear**, wondering how well the loved one will recover, what will happen if you don't cope or who will take up the caring role if you can no longer do so. There is frequently stress associated with the litigation process and the uncertain outcome in court.

Caring can mean being cut off from others and facing high **stress** over a very long period of time. Caregivers are very vulnerable to stress because of the demands of caring. Stress may bring physical symptoms such as headaches, or difficulty sleeping. Some people become very emotional or anxious. Others report feeling persistently tired and chronically unwell.

Sometimes being a caregiver can feel like an endless grind. Over time, you can stop feeling angry or sad about your situation and become **depressed**. Even happy times don't seem to lift you, and the simplest tasks seem to take too much energy. You may find you are sleeping too much, or waking early or during the night. You might feel worthless or agitated most of the time, and have difficulty making decisions.

Family members also experience **grief**, often feeling they have lost their loved one but being unable to say *Goodbye.* For some, the caring duties have overwhelmed their life to the point they feel they have also lost their former lifestyle, and now all they do revolves purely around the survivor.

STRESS

Stress itself is not a negative phenomenon. In fact, we need some stress in our lives to feel motivated, a sense of achievement and stimulation. It is typically the day-to-day stresses which take a greater toll on a person's physical and mental health because people are less aware of the cumulative effects. When people experience a major life change, people are more likely to recognize the need for support and use various coping strategies.

Caregivers may initially seek support after the brain injury has occurred, but often they don't seek help years down the track as the day-to-day stress of caring gradually wears them down.

Physical signs of stress may include a lowered immune system, breathing difficulties, fatigue, sleep disturbance and muscular tension. Caregivers may also find themselves feeling out of touch reality, forgetful, not looking after themselves, crying easily and not eating properly.

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