

Understanding Family Issues after Acquired Brain Injury - Tips for Working with Families

Acquired brain injury (ABI) can have a significant impact on an individual, but it can also result in changes for all members of a person's family and community. For family members in a close relationship with the person with ABI, there can be a range of changes in roles and responsibilities, and involvement in a person's life. We need to understand to work effectively with families and carers as well as the person with ABI.



Understand Each Family

- It is important to have a good understanding and knowledge of each client with ABI and their family, friends and community networks.

Respect Knowledge and Skills

- Recognize and respect the knowledge, ability, resources, needs, skills and coping ability of each family member and their relationship with the individual with ABI.
- A family member or carer for a person with an ABI may have a good appreciation of the person's strengths, abilities, and also their impairments or limitations. Close proximity and regular contact allows them to gain an accurate understanding of the problems that a person with ABI may have. Sometimes, other family members, friends, community members, and even health professionals may not have this information and may not understand the daily reality and burden of care for them. Others may also see the person for only short periods, at their best, or on their best behaviour, so they may not appreciate the burden of caring for someone with severe cognitive, behavioural and emotional changes.

Ask for Information

- Ask for information, for feedback and for family input. Make sure you ask about what has been tried before, how long it was tried, who was involved and whether or not it worked, and why.

Work Collaboratively with Family

- Think of the family as part of a team or partnership. When the person with ABI is

comfortable involve family in discussions, planning, and goal setting.

- Ask family members about the level of involvement or participation that they may want or need to have in planning support arrangements or activities.
- Involvement may change over time, so you may need to be flexible in your expectations.

Involve Family

- If the person with ABI has capacity to make their own decisions (about personal matters, accommodation, finance, health etc), and does not want you to involve family, or to provide information to family, you must respect their confidentiality and privacy. You may need to ask the person for permission to give information or feedback to family members. Be sensitive in how you discuss this with the person with ABI and their family.

Have clear guidelines

- Establish clear guidelines with the person with ABI and their family about your working role as early as possible. This helps prevent unrealistic expectations of what you can achieve.
- It is essential to have firm, clearly communicated boundaries regarding what you can and cannot do.

Be consistent

- Be consistent in the way you communicate with family and in meeting their expectations.
- If you say you will do something, do it.
- If there is more than one person providing support or care, you need to discuss and agree on what each person will do.

Work at the Family's Pace

- Introduce new ideas or changes slowly. It is important to judge how quickly both the client and their family can cope with change and how much effort and energy will be required to make that change. Try to discuss concerns or worries that the family may have when you are introducing new activities or ideas.
- Try to put into place strategies, solutions or activities that you know are sustainable and practical for the person with ABI and their family. It will be disappointing and discouraging if you set up activities that cannot be sustained by the person with ABI without a lot of support or energy or involvement from family members. Remember also that families are generally there for the long-term. Workers and services may come and go.

Offer Support and Counseling

- Be aware that family members may also be dealing with emotional reactions and issues, including grief, sadness, anger, frustration, anxiety, or depression. This

may be the case even many years after an injury has occurred.

- Make sure that family members are aware of support that they can receive (information, counselling, and respite) to help them to cope better.

Don't take family issues personally

- Try not to take it personally if family members are frustrated, angry, or critical or communication is difficult.
- Try to keep things in perspective, and think about what you can change, and what you cannot.
- It is important to be aware of your own stress in working with individuals with ABI and their families. Working closely with people in their own homes demands good communication, relationship, negotiation, goal-setting and conflict management skills. You need to establish strategies to talk about these issues and your support and skill development needs. You could do this with a supervisor, other workers, or with a counselor.



Resources for Working with Families

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- Florian, V., & Katz, S., (1991). The Other Victims of Traumatic Brain Injury: Consequences for Family Members. *Neuropsychology*, 5 (4), 267-279.
- Lash, M. (1993). ***When a parent has a brain injury: Sons and daughters speak out***. Massachusetts Head Injury Association. Worcester, MA.
- Lezak, M. (1988). Brain Damage is a Family Affair. *Journal of Clinical and Experimental Neuropsychology*, 10, 111-123.
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- Tunstall, J. (2001). ***My Mum had a Stroke***. Neuropsychology Unit. Griffith University.
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