

# FACT SHEET:

**Category:**  
Support for families

**Audience:**  
Support Workers  
and Professionals

For more information  
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ABIOS Social Worker



# ABIOS

Acquired Brain Injury Outreach Service

## Understanding Family Issues after an ABI

### Introduction

Acquired brain injury (ABI) can have a significant impact on an individual and members of their family and community. For family members in a close relationship with the person with ABI there can be changes in roles, responsibilities and the form of the relationship.

### Impact of Brain Injury on the Family

Families have little or no opportunity to prepare for a brain injury.

Initially they are called on to rapidly cope with a major trauma, hospitalisation, treatment and rehabilitation. Then they need to cope with the ongoing impacts of the injury and the uncertainty this brings for the future - for both them and their family member.

The speed and success with which families adapt and cope varies greatly, and the process is never easy.

Families may need information, education, support and counselling to assist them in adapting, coping and planning for the challenges an ABI brings.

### Changes in Roles

One main impact for families is that roles change because a person with an ABI is unable to continue to do things that they had done before.

This can mean that other family members have to take on new or additional responsibility for work, transport, managing finances, family decision-making, emotional support, basic personal care and assistance with daily living.

Family systems struggle to find a new equilibrium and often outside support is needed for equilibrium to be rediscovered.

### Burden of Care

These additional roles and responsibilities add to what is known as the "burden of care". Managing the burden of care is challenging and can depend on the supports available to a family. Family can often have many "informal" supports immediately post injury but this can fade over time and other options, including "formal" supports may be required.



## Competing Demands

The care that is provided to a person with an ABI is complicated by the range of other demands and needs that family members have competing for their time and energy.

Managing competing personal demands can result in a range of issues.

### Families and friends

Providing care may result in less involvement with other family members or friends.

- Partners, spouses, children and friends may feel left out, neglected or excluded.
- Relationships with family and friend may be damaged or lost.
- Carers may become increasingly isolated as relationships diminish or are lost.
- Carers themselves may receive less emotional or practical support over time.

### Self

Carers may find that their own needs become less important or neglected in the urgency or demands of providing care and support.

- They may not get time for their own interests, recreation or relationships.
- They may not pay enough attention to their own psychological or physical health.
- They may not take time out to have rest and relax and to renew their energy.

## Carer Fatigue

A person with an ABI may lose their ability to be functional independent and/or they may experience changes in their personality and behaviour. Family can be called upon to step into a role of carer and/or supervisor.

Family members can be overwhelmed and exhausted by the emotional and physical demands of providing this care.

## Working with families

Working with families of a person with an ABI requires awareness of family dynamics, roles and responsibilities, burden of care and carer fatigue.

Taking time to check the care families are providing, who is providing it, what informal and formal supports are in place, and how the family is coping (both as individuals and as a unit) is an important step in working with them.

### Some points to consider are:

- Carer fatigue can mean family can seem to be difficult, critical, uncooperative or unsupportive when dealing with their family member with an ABI or support services.
- Be sensitive to family structures and relationships - work with the whole family.
- Individuals with ABI and their family may feel that they have lost some of their sense of independence, autonomy and personal privacy, as they become involved with health and support systems.
- Communicating and negotiating with professionals in services is a new thing, and may be something families are not prepared for.
- Families may be wary or reluctant to disclose information, to be involved, or to commit their energy and time to people making demands or providing community based services.
- Families may have had a range of experiences (negative and positive) with medical, health or community services that present barriers to new work.
- Family members can sometimes be more protective of the person with ABI following a severe injury. Particularly in cases of a sudden injury, such as a traumatic brain injury or a stroke, where a person was severely injured, or close to death, they may be reluctant to risk further injury or have harm come to their family member.
- Families can sometimes be cautious, wary of new ideas, and worried regarding the consequences of small changes and what might happen in the future.



### Grief and Loss

It should also be remembered that families may have ongoing issues with grief, loss and adjustment to changes associated with an ABI.

Families experience the losses for the person with the ABI (loss of hopes, dreams, ambitions, and ability to be independent) but also their own losses (loss of independence, loss of intimacy, loss of friendship, loss of sexual relationships, loss of financial security, loss of family, loss of time alone).

The grief can also restart several times when families are reminded of what has been lost. Their family member is still with them and although they are learning to relate to them as a different person they periodically remember important facets of them that have been lost.

#### Further information

The Synapse website <http://synapse.org.au/> contains further information on supporting and caring for someone after an ABI

<https://synapse.org.au/understanding-brain-injury/family-and-carers/>



### Resources

See other Acquired Brain Injury Outreach Service (ABIOS) Information sheets at <http://www.health.qld.gov.au/abios/>

### Notes:

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