

# Working with families and carers after brain injury

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Coping with the impact of brain damage is one of the most difficult tasks which confronts a family

□ *Florian et al. 1989; Brain Injury 3 219-233*

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Working with families is one of the most difficult tasks that confronts staff in brain injury rehabilitation

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# Why?

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- ❑ The sudden onset (compared to progressive conditions)
  - ❑ The lack of warning (compared to psychiatric conditions)
  - ❑ The nature of the deficits: the perception of personality change; the particular constellation of behavioural, emotional and cognitive sequelae
  - ❑ The complexity
  - ❑ The permanence
  - ❑ Practical changes including reduced participation
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# Aims of intervention

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- To alleviate stress in family
  - To change family functioning
  - To promote the individual's functioning
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# Role of the family in rehabilitation

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- ❑ Informants:
  - ❑ Family knows the person best, can give information regarding pre-morbid personality, interests, history etc. They are the experts as far as their relative is concerned
  - ❑ In the acute phase they often observe the patient more closely than anyone else
  - ❑ After discharge they are the main observers of the person's strengths and weaknesses
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# Role of the family in rehabilitation

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- ❑ Relationship to client:
  - ❑ They have an ongoing, established relationship with the client. They are able to persuade the client to collaborate with rehabilitation. If you do not have the family on your side rehab will fail. They can motivate and reassure the client.
  - ❑ They are often the main providers of long-term support.
  - ❑ Their role is to advocate on behalf of the client.
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# A working partnership

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- ❑ Family has in-depth knowledge of one individual
  - ❑ Professional has broader based knowledge but not such deep knowledge
  - ❑ Family has first hand, emotionally-involved, experiential knowledge
  - ❑ Professional has theoretical understanding, technical knowledge and observational experience of wide range on individuals
  - ❑ Complementary experience
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# Families v. professionals knowledge of brain injury

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The family

The professional

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# Role of the family in rehabilitation

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## □ **For good:**

- Family who continued and extended ideas used at rehab centre for memory strategies
- Families who fight for good service for their family member often prove positive assets in long run

## **For ill:**

Father who exhorted his son to try harder to overcome his ataxia

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Need to know what it is the family is coping with.

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- ❑ 1. Family will feel supported and understood.
  - ❑ 2. To prevent members of family blaming themselves or the person with a head injury rather than the injury itself.
  - ❑ 3. A 'full' understanding of the problems the family are facing enables you to help alleviate specific problems.
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Carers work is hidden,  
unappreciated (Knight et al.  
1998)

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Caregivers feel alienated,  
overwhelmed, mentally  
preoccupied (Gervasio and  
Kreutzer 1997)

# Correlates of distress in families

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- ❑ Distress more closely related to cognitive and personality changes than to other consequences (physical, ADL etc)
  - ❑ High levels of stress continue long after injury
  - ❑ Social isolation, reciprocal relationships, wider family support
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# Douglas and Spellacy (1996)

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- 58% of variance in family functioning (communication and conflict) explained by:
  - Severity of injury (PTA)  
Residual neurobehavioural function  
Adequacy of social support
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## Wives of head injured soldiers when compared to wives of paraplegics:

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- ❑ 1. experienced greater role changes in their marital relationships;
- ❑ 2. disliked physical contact with their husbands more;
- ❑ 3. found husband's disability more of a social handicap, leading to a greater loss of contact with friends
- ❑ 4. had significantly more symptoms of low mood

Rosenbaum & Najenson (1976)

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Winstanley, J., Simpson, G., Tate, R.  
and Myles, B. (2006). Journal of Head Trauma  
Rehabilitation **21**(6): 453-466.

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- Distress experienced by relatives was not due to the direct impact of the neurobehavioural impairments, but was mediated by the degree of community participation achieved by the person with TBI.
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Testa, J. A., Malec, J. F., Moessner, A. M. and Browt, A. W. (2006). Journal of Head Trauma Rehabilitation **21**(3): 236-247.

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- TBI, patients at the greatest risk for distress at follow-up were those with family dysfunction at discharge and continued neurobehavioral problems.
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Weddell, R. A. and Leggett, J. A. (2006).  
Brain Injury **20**(12): 1221-1234.

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- Relatives' (and patients') emotional reactions were the best predictors of relatives' judgements about personality changes in the patient
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# Continuity and discontinuity

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- Families may focus on the continuities or the discontinuities in the personality of the person with the brain injury – those who concentrate on the continuities tend to cope better?
    - Oddy 1996
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Hanks, R. A., Rapport, L. J. and Vangel, S. (2007). Neurorehabilitation **22**(1): 43-52.

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- ❑ Majority of caregivers in those with moderate to severe brain injuries experienced dissatisfaction with many aspects of care-giving, especially with respect to feelings of burden and mastery.
  - ❑ Emotionally-focused coping, behavioural control issues with respect to family functioning, and perceived social support appear to be most highly related to perceptions of burden,
  - ❑ Perceived social support alone was the strongest factor in one's perception of care-giving mastery and satisfaction with the care-giving relationship.
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# Successful coping

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- ❑ Emotional resilience and a positive coping style
  - ❑ Redefinition or re-interpretation of stressful events to make them more meaningful
  - ❑ (eg family that views a brain injury as a manageable family challenge rather than as a catastrophe will adapt successfully)
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Happiness is a state of  
ignorance of how bad things  
really are.

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Boschen, K., Gargaro, J., Gan, C., Gerber, G. and Brandys, C. (2007). Neurorehabilitation **22**(1): 19-41.

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- 'At present there is no strong research evidence supporting any specific intervention method for family caregivers of individuals with ABI or any of the other chronic condition groups surveyed, although an abundance of anecdotal, descriptive, and quasi-experimental support exists in the rehabilitation literature.'
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# Family interventions

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- ❑ Often not formal family therapy/ couple therapy – though may be
  - ❑ Supporting family in a very difficult situation
  - ❑ Practical advice, strategies
  - ❑ Working with family to achieve shared goals
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# Holistic approach to families

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- ❑ Involve families in the pre-admission process. Obtain information from them (pre-morbid personality/interests), explain service, start setting goals. Ask family to fill in forms giving information about the client
  - ❑ Consider process of welcoming client and their family on entry to the service. Give high priority to a member of staff meeting and greeting, explaining, listening to concerns.
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## Holistic approach to families 2

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- Allocate member of staff to make regular calls to family.
  - Family given name of key worker to call with their concerns or questions
  - Key family members identified in consultation with client and family - these key individuals invited to reviews
  - Feedback forms sent to family
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# Holistic approach to families 3

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- ❑ Where possible help family cope with their distress – at least refer to services who can
  - ❑ Feedback forms sent to family
  - ❑ Thoroughly and objectively investigate any complaints made by family and provide a written response
  - ❑ 'Families will at all times and by all members of staff be treated with courtesy and respect'
  - ❑ 'All staff will be sensitive to the needs of families'
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# Holistic approach to families:

## Additional good practices

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- ❑ Relatives groups – occasional, regular or an occasional series of meetings
  - ❑ Relatives offered individual support sessions
  - ❑ Provide written information to families about the rehabilitation process and relevant aspects of brain injury
  - ❑ Training for all staff on working with families
  - ❑ Annual social event to which current and ex-clients are invited
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# Well functioning families v dysfunctional families

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- Families can be dysfunctional in different ways
  - Anxious, depressed
  - Chaotic, disorganised
  - Lack warmth
  - Distant, separate
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# Needs of functional families

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- Information
  - Knowledge
  - Advice
  - Support
  - Convinced that the best is being done for their relative
  - Need to work with family in a collaborative fashion
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## Rocchio C. (1999)

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- ❑ No family readily understands how brain injury affects cognition, creating changes in functional capabilities
  - ❑ Family members need to 'witness it first hand in a setting with trained personnel demonstrating strategies for reducing the impairment'
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# Oddy and Herbert (2008)

In Oddy and Worthington Rehabilitation of Executive Disorders OUP

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- ❑ By their very nature, executive disorders are difficult to describe and hard to understand.
  - ❑ Yet they can make a huge difference to the way an individual behaves and their ability to function in all aspects of life.
  - ❑ These changes are clear to those closest to the individual concerned and often perceived as changes in the very essence of the individual but are often not apparent to others with less close contact.
  - ❑ This places family members and close others in a lonely position as they frequently have a sense of loss and often find living with these changes extremely difficult yet others are oblivious to their predicament.
  - ❑ Although they recognise them they may have no way of understanding them
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# Rocchio C. (1999)

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- During the rehabilitation process issues are almost never discussed with the family include:
- Inappropriate behaviour
- Sexuality
- Use of alcohol and other substances
- Importance of structured environments
- Consistency of family members in reinforcing strategies
- Planning for a stimulating and productive lifestyle

# Family A

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- ❑ Julia – excellent use of memory aids and strategies
  - ❑ Family have worked closely with Julia and professionals
  - ❑ Helping tailor ideas gleaned from rehab staff to her particular needs
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# Achievements

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- ❑ Travels distances of 300 miles, journeys with a number of components
  - ❑ Has acquired new skills – touch typing, computer skills (databases/spreadsheets)
  - ❑ Computer Literacy and IT Stages I and II
  - ❑ Diploma in Information Technology
  - ❑ Integrated Business Technology Stage II
  - ❑ Voluntary work
  - ❑ Lives independently
  - ❑ Keeps contact with friends by e-mail
  - ❑ Maintained pre-morbid fluency in French
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# Supportive families

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- ❑ Not only emotionally supportive but also:
- ❑ Prepared to be actively involved
- ❑ Understand this involvement needs to continue
- ❑ Have relationship to person which allows both to work together amicably/constructively
- ❑ Understand or have imagination to develop successful strategies that allow desirable goals to be achieved
- ❑ Able to give the right combination of support, encouragement and freedom

# Families with difficulties

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- ❑ Brain injury may have provided an opportunity to obtain help
  - ❑ Need to identify the nature of their difficulties
  - ❑ Need to provide help/refer to address their particular difficulties
  - ❑ eg anxiety, depression, organisation
  - ❑ In many cases the existing difficulties and those relating to the brain injury interact
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# Long term needs of families

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- Brain injury is for ever
  - Some families need continuing intermittent intervention
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# Family B

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- HI in 1988
  - Relatively mild, has been able to carry on at work ever since
  - Direct advice and support to client
  - Husband at family group
  - Couple counselling
  - Support of daughters
  - Mother and daughter counselling +15 years
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# Conclusions

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- ❑ Family plays a vital role in rehabilitation which we neglect at our peril.
  - ❑ It is easy to neglect the family's part.
  - ❑ We need to engage with the family in the rehabilitation process.
  - ❑ Addressing the distress of family members and the rehabilitation of the client amounts to the same thing – the wellbeing of all.
  - ❑ We can work productively with some families, with others this is more challenging.
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