# Psychological effects of brain injury

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the brain injury association

Headway



This booklet has been written for the families and carers of people who have had a brain injury. It outlines the possible psychological effects of brain injury and describes some of the services that are available to help. This e-booklet is an adaptation, created in May 2016, of the Headway print booklet *Psychological effects of brain injury* and may contain minor updates to the original version.

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# Introduction

n this booklet, the term psychological effects is used to refer to the cognitive, behavioural, emotional, occupational and social impact of brain injury. Each of these issues is discussed in turn.

Psychologists are the professionals best equipped to assess and treat the problems. However, there are a range of other professionals also involved in the psychological rehabilitation of brain injury. The booklet therefore concludes with a summary of 'Who's who in treatment and rehabilitation'.

A brain injury can result in a confusing array of psychological changes. These range from subtle and temporary lapses in ability and behaviour, to a profound and permanent reduction in basic skills and loss of control of emotion and behaviour.

Severe brain injury can be a devastating experience for both the individual concerned and their family and friends. The impact is all the more confusing due to the lack of public awareness of the nature and effects of brain injury. To learn that a loved one, whose life may be in danger, has sustained a brain injury is intensely distressing for the family. When the person has recovered sufficiently to appreciate that he or she has sustained a brain injury, this can be both disturbing and threatening to them. Having weathered the immediate crisis following the brain injury, there may follow a long struggle to regain physical, cognitive and social skills. The process of recovery may continue for many years, often with a remarkable degree of improvement. Specialist neurological rehabilitation facilities may be required for those with more severe injuries, but for many, even prolonged periods of intensive treatment will not ensure a restoration of previous skills and lifestyle.

#### Headway information and support

It would be very useful at any stage to contact Headway's freephone helpline on **0808 800 2244**, where our trained staff can talk through the situation, send out free copies of publications and provide details of our groups and branches throughout the UK.

The groups and branches provide a wide range of support services for brain injury survivors and carers, including rehabilitation, carer support, social re-integration, community outreach and respite care.

For further information visit our website.

# **Cognitive impairment**

All those with a moderate to severe brain injury are likely to have some difficulties with their cognitive skills, at least in the early stages of recovery, as will some people with minor injuries. The most common cognitive problems after brain injury involve concentration, memory and general speed of thought. However, a broad spectrum of cognitive skills may be affected, including perception, language and the awareness of self and others. A set of skills known as 'executive functions', including planning, organisation, multi-tasking and flexible thinking, is also commonly affected and this can be particularly debilitating.

Soon after injury, whether in the hospital or home environment, the demands on the person with a brain injury can be relatively limited, and so the presence of subtle cognitive changes may not be readily apparent. Their memory of the distant past and their established prior knowledge (e.g. educational skills) may appear to be relatively unaffected. The person may therefore seem to have no obvious problems when holding general conversations about familiar topics. However, problems may later become apparent during formal neuropsychological assessment, during active rehabilitation or on returning to work.

While cognitive difficulties generally show marked improvement during the course of recovery, some degree of permanent impairment is common amongst those with a more severe injury. This can often prevent or hamper a person in returning to their previous employment, studies or lifestyle.

#### **Memory function**

Memory problems take many forms and are the major area of difficulty after brain injury for many people. Memory problems usually include a period of amnesia surrounding events that took place before and after the injury, and difficulty in remembering new information.

#### **Retrograde amnesia**

The loss of memory for events leading up to the injury is known as retrograde amnesia. People with a brain injury rarely recall the circumstances of their injuries. Retrograde amnesia may extend from just a few seconds to minutes, hours, days, weeks, or even longer. In addition to the period of total amnesia, people frequently complain of incomplete or vague recall spanning days, weeks, or months before their injury. However, they may be able to recall some of this information when prompted by family or friends. In extreme cases, when the period of retrograde amnesia extends to a period of years, this is very disturbing for the person and distressing for their relatives.

#### Post-traumatic amnesia

The period of confusion and memory loss that follows the injury is known as post-traumatic amnesia (PTA). This covers the period of time from the injury until the person starts to regain some continuity in their memory function and retain some information. This may range from a few minutes (after a mild injury), to a period of weeks, months or years (after a very severe injury). In post-traumatic amnesia, people may be able to hold a sensible conversation about familiar subjects, such as the weather or something that has just happened, but then remember nothing afterwards.

#### Anterograde amnesia

The inability to remember new information after the injury is known as anterograde amnesia. People with brain injury commonly experience different degrees of this problem. This ranges from occasional forgetfulness to an inability to recall basic information, such as personal and family details, current circumstances, and daily routines. Many people with a severe injury report problems in learning and remembering names, messages, appointments, routes, and plots of books or television programmes, etc. People with more severe memory difficulties may forget where they are going or what they are doing, and may be dependent on family members to remind them of daily activities. In contrast, memory for the long-term past (such as school, work and family history) may be well retained.

 For further information on memory function, see the Headway booklet *Memory problems after brain injury*.

#### Attention and concentration

Another common complaint is that of difficulty in attending to or maintaining concentration or interest in activities. While some people with brain injury struggle specifically with tasks requiring divided attention or multi-tasking, many others find that their concentration and train of thought is easily disrupted, for example by noise or interruptions. They may have to start an activity over again, or ask for information to be repeated. Difficulties with attention and concentration can have far-reaching effects on work, leisure, and social activities. Such problems may be worsened when the person is tired or uninterested in the subject matter.

#### **Speed of information processing**

People also commonly experience a reduction in their speed of thought and their responses, even after a relatively minor brain injury. They may find, for example, that they are unable to take in new information as quickly as they used to. They may often find themselves left behind by conversations or television programmes, slow to read newspapers or books, sluggish in their reactions, or generally slow at work or in their leisure activities.

#### Language skills

While severe loss of language skills is relatively uncommon after generalised brain injury, people may have word-finding difficulties and may experience a reduction in their vocabulary. People may also experience difficulties in organising their communication and expressing themselves, especially when conveying complex ideas. More marked difficulties in understanding and expressing language are common after more localised damage to language-sensitive parts of the brain, for example after a cerebro-vascular accident (stroke) or a bleed following traumatic brain injury. People may have difficulty recognising speech sounds, identifying individual words, or breaking down the structure of sentences to extract the meaning. People may also have difficulty in selecting and expressing words or in constructing sentences. Specific difficulties with reading, writing or spelling may also occur.

 For further information on language skills, see the Headway booklet Coping with communication problems after brain injury.

#### **Perceptual skills**

People with severe brain injury may have problems with one or more of their senses, and/or difficulties with their perceptual skills (i.e. their ability to interpret the information they receive from their senses). The most commonly reported perceptual problems are visual – involving the ability to recognise and identify objects, faces, and other visual material. These problems may be complicated by double vision, loss of co-ordination of the muscles controlling eye movements, or a reduction in the person's field of vision. Perceptual problems are not, however, confined to vision. Parallel problems in auditory (hearing) or tactile (touch) perception may occur, whereby the person has difficulty identifying and recognising sounds or sensations.

#### **Spatial and constructional skills**

People with brain injury may perceive objects accurately, but have difficulty with their spatial skills - i.e. in judging spatial relationships between two or more objects, or between themselves and objects in their environment. This may lead to them misjudging distances (e.g. reaching out to pick something up and missing), perceiving things the wrong way around (e.g. trying to read a newspaper upside down), confusing left and right, or having difficulty in locating objects or following even familiar routes. Occasionally people may fail to respond to stimuli coming from their left or right or may ignore a particular side of their body, for example when shaving or dressing. This is known as visual neglect. There may also be problems with constructional skills (e.g. in copying or drawing, completing puzzles/jigsaws/models, or in household tasks such as DIY). Others may retain spatial and constructional skills but have difficulty in completing complex activities, e.g. dressing or cooking, in the right order.

#### **Executive function**

People with a brain injury often experience difficulties with executive skills – that is, in planning, problem solving, reasoning, decision making, and self-monitoring. In general conversation they may lose their train of thought and go off at a tangent. Others may be inflexible in their thinking, repeating one rigid opinion and failing to appreciate other people's points of view. This means that conversations can be frustrating and unrewarding for others, particularly when the same conversation is repeated several times. It may be hard for a person with brain injury to identify and analyse problems, think of possible solutions, make decisions, and implement coping strategies. They may also be poor at planning, monitoring and evaluating their performance, and organising their lives effectively.

 For further information see the Headway factsheet Executive dysfunction after brain injury.

#### Awareness and insight

The awareness of oneself and of others can be profoundly affected by brain injury. People with brain injury may be unaware of how they are presenting themselves and can lack insight into their difficulties. This is particularly common in the early stages of recovery. As people recover, they may gradually regain their self-awareness and insight into their more obvious problems (such as mobility, speech or memory), but may never achieve insight into more subtle changes in their skills or behaviour. They may, as a result, fail to pick up on hints or social cues and may therefore misjudge social situations, appearing clumsy in their social skills and inappropriate in their behaviour.

# Behavioural and emotional changes

Brain injury can result in a wide range of emotional and behavioural changes. These reflect a combination of organic damage and psychological reactions to the injury and its consequences. Primary changes due to damage to the brain (such as irritability and impulsivity) interact with secondary reactions to these (such as frustration, loss of confidence and depression). Such reactions are similar to those experienced by other injured or stressed people, but are influenced by the cognitive, behavioural and emotional changes that arise directly from the brain injury.

While behavioural and emotional changes are very common after severe brain injury, some people with a more minor injury suffer post-concussion syndrome, which comprises a constellation of symptoms including dizziness, headache, fatigue, irritability, and poor memory and concentration. This is usually short-lived, but may persist with subtle changes in cognition, behaviour or emotion, of which only the person or their close family may be aware. Where such changes are not acknowledged or appropriately managed, this can add to the anxiety of the person and their family and can lead to longterm emotional difficulties. People may appear to have recovered well after a brain injury, and yet be left with the disconcerting feeling that they are not quite the person they once were.

#### **Behavioural changes**

Behavioural changes after brain injury are many and varied. Some appear to be an exaggeration of previous personality



characteristics, while others may seem completely out of character for that person.

#### Disinhibition

A common change early in recovery is disinhibition, that is, loss of control over behaviour, resulting in socially inappropriate behaviour. This ranges from a tendency to divulge personal information too freely, to disturbing and unpredictable outbursts of uncontrolled rage. Common complaints include a tendency to make tactless remarks, to laugh inappropriately, and to be over-familiar towards others. A major area of difficulty, especially early in recovery, is that of sexual behaviour - making inappropriate sexual advances or remarks. Abusive or crude language may cause offence and be acutely embarrassing for relatives or in social situations. Most people gradually regain control over their behaviour, but those with a severe injury may remain impulsive and/or inappropriate in their actions. A few people never regain adequate control over their behaviour, remaining unpredictable, aggressive, and reliant on others to exercise a degree of control over their behaviour.

#### Irritability and aggression

Perhaps the most common behavioural change after brain injury is that of increased irritability. People with a brain injury are often impatient, intolerant of others' mistakes, and easily irritated by interruptions, such as noise from children or machinery, which disrupt their concentration. They are frequently reported to be short tempered, for example when things do not work out as expected or where there are differences of opinion with family or work colleagues. Where this is associated with poor behavioural control, it may result in outbursts of verbal or physical aggression. For further information see Headway factsheet Managing Anger.

#### Apathy and loss of initiative

In contrast with those who exhibit poor control over their behaviour or increased irritability, some people with a brain injury may become passive, unresponsive and lacking in initiative. Some people may appear unconcerned and even unaware of their difficulties, especially in the early stages of recovery. Others may appear interested and have good intentions to carry out activities, but are unable to organise themselves and initiate action. This may happen to any of us when feeling depressed, but for the person with a brain injury, this can result directly from the injury itself rather than solely as a result of depression.

#### Egocentricity

People may also become egocentric after brain injury, tending to be self-centred and appearing not to consider the feelings or needs of their family and friends. In adversity, it is common for anyone to tend to focus on their own needs, but this can be greatly exaggerated for a person with a brain injury. Cognitive impairments can mean that they are oblivious to, or unable to appreciate, others' points of view, and they may be unaware of the needs of others.

#### **Emotional changes**

The emotional impact of brain injury depends upon the individual's previous personality and coping skills, their appreciation of their own difficulties, and the family and professional support that is available to them.

#### Lability

In parallel with their loss of behavioural control, many people with a brain injury experience loss of emotional control. They may react strongly and unpredictably to events which would not previously have troubled them, and may also be subject to rapid and marked swings in mood - for example, being happy and joking one minute and tearful the next.

#### Depression

For some this may be an early reaction to the trauma of the injury and subsequent disability, whereas for others it may develop as they struggle painfully and seemingly helplessly to regain their lost skills. Commonly, depression presents itself when active treatment is complete and the person returns home, only to be confronted by the realisation that life will probably never be as it was before. The loss of former physical, cognitive, and social skills, the impact on personal relationships, and the fact that they are unable to return to their previous leisure and social activities or fulfil their former work aspirations, can be extremely hard to accept, and can understandably lead to depression.

#### Anxiety

Many people suffer from anxiety after brain injury, which impacts upon their daily lives and may obstruct their rehabilitation. Those with a less severe injury may be anxious early in recovery, feeling disturbed by the changes to their cognitive skills and personality. People with a more severe injury may become anxious later on, when they come to appreciate the extent of their long-term disability and feel anxious about the future. A few who suffer anxiety may become obsessional in their thoughts and actions.



#### Post-traumatic stress disorder

Some people may experience post-traumatic stress disorder (PTSD). This is a severe psychological reaction to a traumatic event. It involves the persistent re-experiencing of the trauma, avoidance of stimuli which remind the person of the event, increased arousal, and a numbing of emotional responses. Loss of memory for the circumstances of the injury means that most people with severe brain injuries are not troubled by disturbing memories of the event. As such, PTSD is most commonly experienced after mild brain injuries when memories of the circumstances surrounding the injury are retained. However, some others develop a fear of circumstances similar to that of their injury (e.g. being assaulted), and a small number of people have disturbing memories of the early stages of their recovery.

#### Frustration and anger

Many people become frustrated by their failings and their slow rate of recovery from brain injury. Some are bitter about their accident, and some feel intensely angry, either at themselves for not progressing as they think they should, or at others whom they hold responsible for their injuries. Impaired impulse control can also reduce control of anger, irritability and aggression.

#### Changes in self-concept

After brain injury, people may experience marked changes in their view of themselves, that is, in their self-concept. Those with a minor injury may have the nagging doubt that they are not quite the person they were beforehand, while those with a more severe injury are confronted by complex and confusing neurological disability, totally outside the realm of normal experience. Those with marked physical disability may struggle to perform basic personal and domestic activities, while those with severe communication problems may experience immense frustration and a distressing sense of isolation. Severe perceptual or spatial disorders present a confusing and bewildering world within which it is difficult to play one's full part. For those with reasoning difficulties, life may appear at times an insoluble puzzle. Severe memory problems may result in a disturbing lack of continuity and order to one's life, particularly for those experiencing a long period of amnesia for events before, as well as after, their injury. Changes in behaviour and emotion, especially those involving loss of control over emotions, thoughts or actions, can be profoundly disturbing.

While frustrated by their current failings, people with brain injury tend initially to view such changes as temporary, being confident of a good, if not full, recovery. Often, it is only on completing treatment and returning home to familiar surroundings that they are confronted by their limitations. There may follow a gradual and painful process of realisation of their disabilities, and an appreciation that they may not, after all, recover their former skills and lifestyle. This can result in a period of depression characterised by confusion and uncertainty.

Such reactions are delayed for some people, who understandably find it hard to accept their limitations and respond with determination to make a full recovery. They may set themselves unrealistic targets, which may lead to repeated disappointment and despair.

The limited opportunities in our society for people with brain injury can create a sense of helplessness and futility, until survivors can find a new direction and meaning to their lives.

# Work, social and family changes

Many people with brain injuries face major changes in their work, leisure and social activities, and in their family relationships.

#### **Occupational changes**

The combined effects of physical, sensory, cognitive, behavioural, and emotional changes mean that many people with severe brain injury will be unable to return to previous work, except perhaps in a reduced capacity. For some there will be the opportunity to re-train for alternative work or to work in a supported capacity. Others may undertake voluntary work, or attend a sheltered workshop or day centre.

For those who may be able to return to work following a brain injury, it is important not to rush back too soon, underestimating the effects of fatigue and subtle cognitive changes. It is often possible to organise a phased return with reduced responsibilities to avoid getting overloaded too early.

For detailed information on this subject, see the factsheets entitled *Returning to work after brain injury* and *Returning to education after brain injury*.

#### Leisure and social activities

Many people with brain injuries do resume their former leisure and social activities, although they may find that they have lost the edge in their performance in sports, or that they no longer quite fit in with their friends as they did before.

Those with severe injuries may find that former hobbies and sporting activities are ruled out because of physical disability, slowed reactions, or reduced concentration. Some people who have marked cognitive impairment may lack the interest and initiative to pursue former activities.

Often friendships gradually fade away following severe brain injury, although the friends who remain can provide vital support. The person with a brain injury may find that they struggle to participate as before, and their friends may feel embarrassed by the person's disability or lack of social skills.

For some, making new friends and forming intimate relationships can pose real problems. This can often lead to emotional and sexual frustration.

People may find themselves socially isolated and dependent upon their family until they are able to rebuild their social lives. Families are often very resourceful in organising leisure and social activities, but this can put an extra strain on family members until the person starts to make new friends.

#### **Family relationships**

Brain injury can be a major source of stress for close family members. The shock of the initial injury, and the anxious wait for signs of recovery in the early stages, are acutely stressful. The family then share in the long and often painful struggle to regain lost skills. Throughout, the family is a vital source of comfort, reassurance and support. Family members may also have to assume the role of carer for the dependent person and, later, perhaps take on the role of therapist in retraining lost skills. This can be a source of friction for the injured person and their relatives. Families may also experience a similar sense of social isolation to the person with the injury.

Ultimately, the family is faced with the difficult task of adjusting to the many physical and psychological changes in the person with a brain injury, particularly the changes in personality. It is these latter effects which tend to place the greatest strain on family members.

Parents may naturally resume the role of carer, but find it hard to allow the person more independence as recovery takes place. Brothers and sisters may find that their injured sibling now looks to them for leisure and social activities. Spouses may find the role of carer or therapist irreconcilable with that of sexual partner. They may feel that the altered personality and behaviour of the injured person is no longer attractive or compatible with their own.



Those with children may find themselves torn between the needs of their children and those of their partner. The children themselves are likely to be confused and distressed by any strange or unpredictable behaviour on the part of the parent with a brain injury. Parents may therefore have the additional task of protecting children from the effects of the injury and helping them to understand and adapt to the changes in their injured parent.

 For further information see the Headway booklet Parenting after brain injury.

Readjustment after brain injury is perhaps most difficult for partner relationships, particularly where there are marked changes in the personality of the injured partner. All carers, whatever their relationship to the person with brain injury, may feel isolated and trapped, but a spouse may feel in a 'social limbo', still living with a partner, but one with whom they no longer enjoy their previous leisure, social, and sexual lives.

Many families therefore encounter marked changes following brain injury. However, that is not to suggest that all families will experience significant problems. Many show great resilience in adapting to such changes, often with little or no support. Some make the required adjustments quite naturally and may feel closer as a result, while others may struggle and need help in finding a positive way forward.

# **Psychological services**

Psychological services can help people with brain injuries and their families throughout the course of recovery, from acute care and rehabilitation to resettlement and long-term support.

The types of psychological needs outlined in this booklet are generally dealt with by clinical psychologists, but are also appropriate to other professional groups, such as nurses, occupational therapists, psychiatrists, social workers, speech therapists, and teachers. Unfortunately, clinical psychology is a small profession within the NHS and only a small number of specialists (known as clinical neuropsychologists) work with people who have a neurological illness or injury. While most regional neurosurgical centres and neuro-rehabilitation services have access to specialist neuro-psychological services, some areas have to rely on general clinical psychology services.

Expert psychological advice may not therefore be readily available in the acute hospital, but most areas should be in a position to provide at least some of the psychological services outlined below.

#### **Cognitive assessment**

As people with brain injury regain consciousness, they generally experience a period of disorientation and confusion. Nursing staff on the ward may request help from a clinical psychologist in managing this confusion and in promoting the early recovery of cognitive skills, through a structured programme of graded orientation exercises.



As the person improves, a formal neuropsychological assessment of cognitive skills is often required. Such an assessment is likely to include tests of general intellectual abilities, memory and learning skills, and may also include tests of attention, speed of information processing, and executive skills.

The assessment of intellectual ability may include basic education tests (such as general knowledge, arithmetic, vocabulary, word reading) and various reasoning tasks to assess the ability to apply this knowledge to new problems.

Assessment of memory function is likely to include recall, learning and retention of both verbal material (such as stories and lists of words) and visual material (such as geometric shapes, faces or objects).

More specialised tests of other areas of cognitive function, such as perception and language, might be included depending upon individual need.

#### **Cognitive rehabilitation**

A formal cognitive assessment should identify the extent of any impairment, as well as areas of strength on which to draw in rehabilitation. A range of treatment strategies may then be adopted, depending on the specific nature of problems and the stage of recovery. This may start with orientation exercises and education, and progress to the development of strategies to manage difficulties with cognitive skills (such as attention, memory, or perception), or to compensate for lost skills through the use of external aids. As the likely extent of long-term problems becomes more apparent, the focus is likely to shift to alternative ways of organising and approaching tasks in order to cope with the difficulties that remain.

Re-assessment is important both in monitoring progress, reviewing treatment strategies and goals in the light of improvement and, later, in guiding resettlement plans.

#### **Behavioural management**

Early on in their recovery, people with brain injury often become restless and agitated, or exhibit disinhibited or aggressive behaviour. Ward staff may seek psychological advice about the management of such behaviour. In some cases a psychiatric opinion and medication may be required to contain agitated, disruptive, or aggressive behaviour.

Where such problems persist, a specific behaviour modification programme may be required. This involves staff and relatives working together to systematically discourage disruptive behaviour and actively encourage positive behaviour. In extreme cases, there are a few units that specialise in the management of very severe behavioural problems.

#### Social skills training

While severe behavioural problems affect a small proportion of people with brain injury, many more experience difficulties with their social skills and relationships due to a combination of cognitive, behavioural and emotional changes.



Social skills training may be of value in raising self-awareness and social awareness, as well as providing a forum for peer support. It can also help people to appreciate the inappropriateness of some of their conversation and behaviour, and the need to be more controlled and positive in their social activities. This can help people to rebuild their confidence, both in maintaining their established relationships and in making new friendships.

#### **Psychological counselling**

People with brain injuries benefit from being given feedback and advice about the nature of their psychological difficulties. This is especially important where there is a tendency for the person to underestimate the extent of their difficulties, and to overestimate future recovery. In the early stages of recovery, this belief may protect people from becoming depressed and serve as a powerful motivating function. However, continued reliance on unrealistic expectations of recovery may impede both progress in rehabilitation and adjustment to long-term disability.

A detailed explanation of the nature of the person's difficulties, and guidance about the likely extent of recovery, can help them gain a more realistic outlook, and so help them make appropriate plans for the future. This is not to suggest that people should give up hope of further recovery, but rather that they cannot afford to wait for full recovery to happen, and that they need to get on and make plans on the basis of their current capabilities. Psychological counselling may also help in evaluating re-employment options and getting back into social and leisure activities. The family should be included as fully as possible in such counselling. Relatives usually benefit from detailed feedback about the results of formal assessments, the nature and implications of acquired disability, and some explanation of the rationale and goals of treatment. They often seek advice about the management of cognitive and/or behavioural problems, and may assume the role of co-therapist in reinforcing treatment strategies at home. They too may benefit from guidance about what to expect in terms of further recovery, and from help in making appropriate plans for the future.

#### Individual psychotherapy

Some people, understandably, feel devastated by the effects of their brain injury. Where people do suffer marked depression or anxiety, psychological therapy or psychiatric treatment may help them through a difficult phase. However, it is not only people who are acutely distressed who benefit from psychotherapy. Unsurprisingly, in the confusion of the present and the uncertainty about the future, people often cling to the past following their brain injury. Some people attempt to carry on as before, unable to accept the changes that have occurred, and may continue to judge themselves by the pre-injury standards that they can no longer meet. For others, the preoccupation with what they have lost may cloud their appreciation of the positive attributes and potential that remain. Psychotherapy can help people to re-appraise their new situation. With support and guidance, they can often be helped to move forward to explore their new selves, and search for a new direction and purpose to their lives.

#### Family therapy

Family members face a similar process of adjustment following brain injury. As the person improves, regains their independence and resumes former roles, family relationships can naturally revert to their previous pattern. However, for those with permanent disability, some changes in family roles and relationships may be inevitable.

Many families adjust well to such changes, and some report feeling closer as a result. Where changes do cause problems, family therapy can help with resolving the conflicts that have arisen. Children may also benefit from help in understanding and coping with the changes in their parent.

Where families find the changes too great to cope with, therapy can help them move forward with the minimum of recrimination and guilt.

# Conclusion

The psychological effects of brain injury outlined in this booklet are many and varied, and often appear daunting. However, people can, and do, show marked improvement during the course of their recovery, and individuals, couples and families often make very successful adjustments to the disabilities that remain.

The psychological services described here can be of assistance. While local services are not always well developed in many areas, people with a brain injury, along with their families and carers, are encouraged to seek out the psychological advice and support that is available. This applies both during active rehabilitation and also in response to any difficulties that emerge later in recovery.

If you feel that such services might help, it is advisable to discuss this with your consultant, general practitioner, social worker or current therapist. You can also find rehabilitation services through the useful organisations at the back of this booklet.

#### Headway approved care providers

Headway has developed the Approved Provider scheme, an accreditation scheme appropriate for NHS and independent care settings, including hospitals and neuro-rehabilitation units, residential and nursing homes and respite facilities, specialising in acquired brain injury (ABI).

# **Further reading**

he following books are available from Headway and provide a good introduction to brain injury and its effects:

- Clare, L. & Wilson, B.A. (1997) Coping with Memory Problems: A practical guide for people with memory impairments, relatives, friends and carers. London: Pearson Assessment.
- Daisley, A., Tams, R. and Kischka, U. (2008) Head Injury: The Facts. Oxford: Oxford University Press.
- Hedley, N (2011) Living with an Acquired Brain Injury: The Practical Life Skills Workbook. Milton Keynes: Speechmark Publishing Ltd.
- Johnson, J. (2011) My Parent has a Brain Injury...' A Guide for Young People. Self-published.
- Powell, T. (2004) Head Injury: A Practical Guide. Milton Keynes: Speechmark Publishing Ltd.
- Powell, T & Malia. K. (2003) The Brain Injury Workbook. Milton Keynes: Speechmark Publishing Ltd.

Headway also produces an extensive range of printed booklets and factsheets covering the problems that brain injury can cause. Titles of particular relevance to the information in this booklet are:

- Coping with communication problems after brain injury
- Difficulties with decision making after brain injury
- The effects of brain injury and how to help
- Executive dysfunction after brain injury
- Memory problems after brain injury
- Minor head injury
- Parenting after brain injury
- Rehabilitation after brain injury

# **Useful organisations**

## Rehabilitation and counselling services

The following organisations provide information on rehabilitation or counselling services in the UK. Some have online directories of professionals in NHS or private practice. Headway does not recommend any specific services and it is suggested that you contact more than one before making a decision.

#### **ASSIST Trauma Care**

Employ experienced therapists trained to work with PTSD. Helpline: 01788 560 800 Web: www.assisttraumacare.org.uk

#### Association for Rehabilitation of Communication and Oral Skills (ARCOS)

Helpline: 01684 576 795 Web: www.arcos.org.uk

#### Association of Speech and Language Therapists in Independent Practice Tel: 01494 488 306 Web: www.helpwithtalking.com

British Association for Behavioural and Cognitive Psychotherapies (BABCP) Tel: 0161 705 4304 Email: babcp@babcp.com Web: www.babcp.com

British Association for Counselling and Psychotherapy Tel: 01455 883 300 Email: bacp@bacp.co.uk Web: www.bacp.co.uk

#### British Association of Brain Injury Case Managers (BABICM) Tel: 0161 764 0602 Email: secretary@babicm.org Web: www.babicm.org

British Association of Occupational Therapists and College of Occupational Therapists Tel: 020 7357 6480 Email: reception@cot.co.uk Web: www.cot.co.uk

# British Psychological Society (BPS)

Tel: 0116 254 9568 Email: enquiries@bps.org.uk Web: www.bps.org.uk

#### Headway - the brain injury association

#### Chartered Society of Physiotherapy

Tel: 020 7306 6666 Web: www.csp.org.uk

#### College of Sexual and Relationship Therapists

Tel: 020 8543 2707 Email: info@cosrt.org.uk Web: www.cosrt.org.uk

#### Counselling Directory

Tel: 0844 8030 240 Web: www.counsellingdirectory.org.uk

#### Find a Therapist – UK & Ireland Directory of Counselling and Psychotherapy Web: www.cpdirectory.com

Physio First Tel: 01604 684 960 Email: minerva@physiofirst.org.uk Web: www.physiofirst.org.uk

#### Relate – the relationship people Tel: 0300 100 1234 Email: enquiries@relate.org.uk

Web: www.relate.org.uk

#### Royal College of Speech and Language Therapists (RCSLT)

Tel: 020 7378 1200 Email: info@rcslt.org Web: www.rcslt.org UK Council for Psychotherapy Tel: 020 7014 9955 Email: info@ukcp.org.uk Web: www.psychotherapy.org.uk

#### United Kingdom Acquired Brain Injury Forum (UKABIF)

Tel: 0845 608 0788 Email: info@ukabif.org.uk Web: www.ukabif.org.uk

#### Carer's organisations

#### **Carers Federation**

Tel: 0115 9629 310 Email: info@carersfederation.co.uk Web: www.carersfederation.co.uk

#### **Carers Trust**

Tel: 0844 800 4361 Email: info@carers.org Web: www.carers.org

#### Carers UK Tel: 020 7378 4999

CarersLine: 0808 808 7777 E-mail: adviceline@carersuk.org Web: www.carersuk.org

#### **NHS Carers Direct**

Helpline: 0300 123 1053 Web: www.nhs.uk/carersdirect

# Who's who in treatment and rehabilitation

The following professions are commonly involved in the assessment, diagnosis, treatment or rehabilitation of the psychological effects of brain injury.

Case manager: responsible for overseeing and managing the overall care of people with a brain injury. They prepare an individually-tailored care plan or treatment programme for each client, which is designed to meet the person's specific health, social and emotional needs. Case managers can come from a variety of professional backgrounds, such as social work, occupational therapy, or nursing. They are not funded by the NHS or social services, so are often only available through compensation claims or self-funding.

Clinical psychologist: aims to reduce psychological distress and enhance and promote psychological wellbeing. Many work as part of multi-disciplinary rehabilitation teams under specialist clinical neuropsychologists and often have particular skills in different forms of counselling. Unlike psychotherapists, psychologists use psychometric tests, interviews and other methods to assess and treat patients.

Clinical neuropsychologist: specialises in the assessment and treatment of behavioural, emotional and cognitive (thinking) problems following brain injury. A neuropsychologist can advise on how to build upon the person's existing skills and abilities, and how to reduce some of their difficulties.

Cognitive behavioural therapist: a type of counsellor who uses cognitive behavioural therapy (CBT) to help people to overcome emotional difficulties. CBT works by helping people to change the way they think about themselves and the world and to alter problem behaviours. This is a particularly popular approach for people with brain injuries as it focuses on the here-and-now rather than the past.



- Doctor: many different kinds of doctors are involved in the care of people with brain injury. A consultant will co-ordinate the day-to-day medical care, carrying out examinations and prescribing medication while the patient is in hospital. General practitioners (GPs) are also important for people after brain injury as they are the first point of contact for most problems and can use their knowledge of a patient's medical history and other factors to assess, treat or refer to specialists.
- Neurologist: a medical specialist trained in the assessment, diagnosis and treatment of disorders of the brain and central nervous system.
- Neuropsychiatrist: a medical specialist who assesses and treats psychiatric disorders caused by acquired brain injury and diseases of the nervous system. Neuropsychiatrists often have experience in many aspects of the assessment and rehabilitation of brain injury and some run rehabilitation services. Sadly, there are a limited number of specialists in this field practising in the UK.
- Nurse: plays a vital role in acute treatment, rehabilitation and residential care after brain injury. Nurses provide day-to-day care and help therapists to implement rehabilitation strategies. In many in-patient rehabilitation units the care provided by the nursing team is the foundation for the rehabilitation programme provided by the multi-disciplinary team. On in-patient units and in the community there may be specialist nurses who take on specific roles, such as management of epilepsy or behavioural programmes.
- Occupational therapist (OT): helps people to develop independence in carrying out daily tasks such as dressing, washing, cooking and leisure activities. An OT will also help the person to develop the skills that underlie these activities, such as budgeting and planning, and help to find ways to compensate for any remaining problems. They help and advise on difficulties that may be encountered in the home environment, advise on any home adaptations that may be needed and are also involved in helping people to return to employment.
- Psychotherapist: a UK Council for Psychotherapy member psychotherapist undergoes extensive training in working with a wide range of emotional distress and mental health issues. Psychotherapists are trained in more than one form of talking therapy and are different from counsellors in that counsellors can practice after relatively short training and tend to provide shorter term therapy.



- Social worker: provides practical advice and support on issues such as benefits, housing, transport and assistance at home. They are able to assess the support needs of brain injury survivors and their carers and help to access appropriate services. They are also trained to offer emotional support to individuals and their families.
- Speech and language therapist (SLT): helps people to improve their communication skills. This may include understanding and expressing both written and spoken language, and improving speech clarity. The speech and language therapist will work with family members to help the person to communicate as best they can in their daily life, and will identify any communication aids that may be helpful. They may also be required to assess swallowing difficulties and provide guidance on how this should be managed safely.

### How to donate

eadway – the brain injury association is a registered charity (1025852) and relies upon voluntary support to fund its work.

If you would like to help Headway by making a donation you can do so by donating online, contacting the Fundraising Team on **0115 924 0800** or sending a cheque to:

Headway - the brain injury association Bradbury House 190 Bagnall Road Old Basford Nottingham NG6 8SF

# **About Headway**

eadway – the brain injury association is a charity set up to give help and support to people affected by brain injury.

A network of local Headway groups and branches throughout the UK offers a wide range of services including rehabilitation programmes, carer support, social re-integration, community outreach and respite care. The Headway helpline provides information, signposts to sources of support and rehabilitation services, and offers a listening ear to those experiencing problems. Other services provided by Headway include:

- Supporting and developing local groups and branches
- Promoting understanding of brain injury and its effects
- An award-winning range of publications on aspects of brain injury
- Accreditation of UK care providers through the Approved Provider scheme
- A comprehensive, newly launched website
- Campaigning for measures that will reduce the incidence of brain injury
- Providing grants from our Emergency Fund for families coping with financial difficulties
- Headway Acute Trauma Support (HATS) nurses to support families with loved ones in hospital
- Freephone helpline: 0808 800 2244 (Monday–Friday, 9am–5pm)
- Telephone: 0115 924 0800
- Website: www.headway.org.uk
- Fax: 0115 958 4446
- Email: helpline@headway.org.uk

# **Psychological effects** of brain injury

#### **Dr Andy Tyerman**

This booklet has been written for the families and carers of people who have had a brain injury. It outlines the possible psychological effects of brain injury and describes some of the services that are available to help.



the brain injury association

Website: www.headway.org.uk Helpline: 0808 800 2244