Providing effective support following brain injury

About this report

This report is produced by Brake, the road safety charity, and aims to spread awareness and understanding of the devastation caused by brain injury, including brain injuries caused by road crashes. Brake thanks Hyphen Law, a specialist Deputyship services and Personal Injury Trusts firm and Novum Law, a national firm specialising in brain injury and serious injury, for sponsoring this report.
Introduction

Brain injury is a major public health challenge; of all types of injury, those to the brain are the most likely to cause death, long-term damage or disability. Effects of a brain injury can vary from mild concussion, to long term disabilities and challenges, short and long term memory loss, cognitive difficulties and speech and language challenges which can have devastating consequences for an individual and their family.

In the UK, around one million people are currently living with long term effects of a brain injury. The most common cause of brain injury are road crashes; in the UK these are responsible for up to 50% of all brain injuries. In the UK, men are 1.6 times more likely to receive a brain injury than women, although female admissions for brain injuries have risen in recent years.

An acquired brain injury (ABI), refers to brain damage that occurs after birth. In 2013/14, 348,934 people were admitted to a UK hospital with an acquired brain injury. Injuries fall under two categories; traumatic brain injuries (TBI) that are caused by trauma to the head, and acquired brain injury, which can be caused by a stroke, tumour, brain haemorrhage and many other non-traumatic causes.

Common causes for a TBI include road crashes, sporting injuries, workplace accidents, falls and domestic violence. 500,000 people in the UK have been reported to suffer long term disabilities as a result of a traumatic brain injury, and it is believed that many more cases are unreported. Although the effects of traumatic and acquired brain injuries can be similar, there are key differences in methods used for treatment and support.

This Brake guidance will focus on symptoms, effects and best practice advice for supporting people with a traumatic brain injury. Symptoms and treatment relating to other forms of acquired brain injury will not be covered in this report.
Classification of Traumatic Brain Injury (TBI):

There are a variety of methods that can be used to classify a traumatic brain injury. TBI can be categorised as open and closed, and ranked either as mild, moderate or severe, with the Glasgow Coma Scale (GCS)

Assessment of Post-Traumatic Amnesia (PTA) and loss of consciousness (LOC) are also reliable indicators for injury severity that are used by clinicians.

The Mayo System, which uses multiple criteria rather than the single indicator method used by the GCS, PTA and LOC, has also been found to accurately classify TBI severity.

A closed TBI refers to any trauma to the head that does not fracture or breach the skull, or is acquired from a sudden violent motion that causes the brain to knock against the skull. Injuries can be diffuse, affecting cells and tissues located throughout the brain, or focal, with damage occurring in one area. In contrast to a closed head injury, an open TBI involves direct penetration of the skull or brain.

Secondary injury:

A secondary injury can also occur after the primary injury, further intensifying the severity of trauma. It can take only the briefest, or slightest impact, to cause devastating consequences. This secondary injury can occur hours or days after the initial trauma, meaning that early intervention is essential. The most common causes are issues relating to oxygen or blood flow to the brain. Complications from the primary injury may also lead to swelling of the brain, which can be fatal.

Models and scales used for classification:

Glasgow Coma Scale:

The Glasgow Coma Scale is often used to evaluate injury severity during the acute stage. This neurological scale uses Eye Response, Verbal Response and Motor Response as criteria to assess patients. Scores are ranked between 3 and 15, and decrease with severity. A Glasgow Coma Scale score of 13-15 is defined as mild, 9-12 as moderate and 3-8 as severe. Approximately 85% of traumatic brain injuries are classified as mild, with 10% categorised as moderate and 5% as severe.

Post-Traumatic Amnesia:

Post-Traumatic Amnesia refers to a state of confusion, disorientation and memory difficulty that may immediately follow a TBI. The length of this period can be used to categorise severity of the injury, although patients may experience long term post-traumatic amnesia without other symptoms of moderate or severe TBI.

Loss of Consciousness:

Loss of Consciousness is another indicator that clinicians may use to categorise injury severity. Similar to post-traumatic amnesia, the severity of the injury is classified through the duration of unconsciousness that a patient experiences following a TBI, with longer periods associated with more severe injuries.

Whilst these scales and models can be useful in classifying and categorising injury severity, accuracy is not guaranteed, particularly in patients with milder TBI, which can be more difficult to detect and sometimes missed.

Symptoms of TBI

Symptoms can vary widely in relation to injury severity. A mild TBI, which could occur as a result of an individual slipping and banging their head, may only cause a brief period of unconsciousness, or even just dizziness.

Whilst there are symptoms that are typical of brain injury, the nature, extent and impact of these will differ in each individual patient. Although injuries received may result in an almost complete recovery in some cases, they could equally result in permanent, life changing symptoms in others.

Injury severity classification, and commonly experienced symptoms:

The sections below detail the most commonly associated symptoms of mild, moderate and severe traumatic brain injury. However, it is important to note that injuries that are categorised as ‘mild’ or ‘moderate’ can still be devastating to an individual.

Mild TBI

The most commonly associated symptoms of mild TBI are concussion and nausea. Some sensory issues, such as sensitivity to light and sound and difficulties with smell and taste, may also arise. Post-traumatic amnesia can last for up to 60 minutes following the injury, and mild TBI is also associated with a loss of consciousness of up to 30 minutes, whilst symptoms may not be as debilitating as those in a severe TBI, many patients will still benefit from professional assistance.

Moderate TBI

Post-traumatic amnesia can be expected to occur for up to 24 hours in TBI defined as moderate. Patients may also experience a loss of consciousness for between 15 minutes and six hours.

Other symptoms include tiredness, dizziness and headaches, cognitive difficulties including problems with memory, and concentration and behavioural problems such as irritability. Symptoms often last for between six and nine months, but in some cases can be longer and may result in permanent difficulties.
Defining TBI as mild or moderate does not mean that an individual will not experience more subtle residual effects, and symptoms are sometimes not immediately clear to a patient or their family. Often, it is not until an individual attempts to return to life before the injury, such as resuming employment, that symptoms or difficulties become evident. The effects of brain injury may become more apparent when returning to normal day to day activities, and common challenges can include cognitive difficulties relating to decision making, planning and organising.

**Severe TBI**

Severe TBI is diagnosed after a patient has been unconscious for more than six hours, or has experienced post-traumatic amnesia for over 24 hours. Due to this extended period of unconsciousness, patients are more likely to experience more serious physical, behavioural and cognitive effects than those associated with a mild or moderate TBI.

Initial physical symptoms can include fluids or blood draining from the ears and nose. Seizures and fits are also associated with severe TBI, and can lead to long term post-traumatic epilepsy. In the most extreme cases, patients may remain in a coma, failing to respond normally to painful stimuli, light or sound, for an extended period. Furthermore, the severe nature of the injury can also have an impact upon an individual’s life expectancy, particularly if they suffer with epilepsy as a result of their injury.

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**Case study:**

**Dr Steven Allder, Re:Cognition Health.**

**The role of the Neurologist in the management of patients with Traumatic Brain Injury:**

In truth, in the UK the role is much more limited than is ideal. In other systems, Neurologists are involved in research and designing services. They also work in partnership with emergency providers to ensure patients with possible traumatic brain injury (TBI) are noticed, comprehensively assessed and advised about the ongoing management of symptoms. Neurologists also work in outpatient and inpatient teams to contribute to the ongoing management of patients with TBI. They particularly help with diagnosis, prognosis and management of neurological symptoms, such as headache and seizure.

Of all the potential contributions that Neurologists can make, I have found that providing an accurate diagnosis and prognosis remains a critical area. Most patients with TBI do not have obvious damage on their brain scans, so determining the cause of ongoing symptoms requires a skilled and experienced clinical assessment. Even in patients with scans that demonstrate abnormality, it is important to unpick co-existing psychological injury, as this can effect up to 50% of patients with TBI.

I find the assessment of patients with TBI challenging, stimulating and hugely rewarding. For the majority of the patients I see, the TBI has a profound impact on their lives. However, the symptoms -such as fatigue, difficulties with memory and emotional control – are invisible to others. Championing and developing better services for patients with TBI is the focus of the next phase of my clinical work.

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**Commonly experienced injuries:**

Injuries that are often experienced as a result of a TBI include:

- **Traumatic subarachnoid haemorrhage.**
  This condition can be caused by other injuries, but is most commonly associated with TBI. It involves bleeding between the brain surface and the 'arachnoid', one of the tissues covering the brain. Symptoms include severe headaches, vomiting and blurred or double vision. It occurs in up to 40% of moderate and severe TBI patients, and around 5% of minor TBIs.

- **Haematomas.**
  Trauma can also cause haematomas on the brain, although these are far less common in patients who have suffered a minor TBI. The most common type is
**subdural haematoma**, which occurs in 20% of moderate and severe TBIs, and 30% of fatal TBIs. This condition occurs when blood vessels in the ‘subdural’ space between the brain and the skull are damaged, leading to blood clots forming on the brain. As blood clots can place severe pressure on the brain, this condition is very serious, particularly in older people. Symptoms can include headaches, personality changes and confusion. Immediate treatment is normally required and may involve surgical intervention.

Around 10% of patients with moderate to severe TBI experience **epidural haematomas**, a potential fatal condition which is caused when blood accumulates between the outer layer of the ‘dura mater’ and the skull. Confusion, dizziness and even loss of consciousness are all symptoms, ensuring that immediate medical attention may be required.

**Intracerebral haematomas** occur when a blood vessel within the skull is ruptured, and affect between 10 and 30% of moderate to severe TBI patients. Both **intracerebral and epidural haematomas** affect around 1% of individuals with a TBI.

- **Contusions**
  Cerebral contusion is bruising on the brain caused by trauma. Severity of symptoms vary, but include confusion, headaches and difficulty with coordination, and occur in between 20 and 30% of patients with moderate to severe TBI. Prevalence is also far lower in mild TBI patients, with around 6% affected.

- **Diffuse axonal injury**
  Diffuse axonal injury (DAI) is a major cause of neurocognitive defects experienced after a TBI. It is instigated by trauma that causes severe acceleration and deceleration of the brain against the skull. This movement damages axons, which form part of nerve cells and are used to transmit impulses between neurons. A shearing injury is also caused as tissue slides over tissue, and damage is caused in the form of lesions in white matter tracts. DAI can be diagnosed through CT, Electroencephalogram (EEG) and MRI scans, and often leads to patients suffering a comatose state. DAI is common among all TBI patients, but symptoms are far more debilitating, and potentially fatal, for individuals with a severe TBI.

**Immediate treatment**

**Mild TBI**
In a mild TBI, it may not be necessary for any further treatment aside from the use of over the counter painkillers and continued monitoring of the injury. However, it is advisable for the patient to continue to have regular medical check-ups, to ensure that they are not experiencing any more severe effects of the injury. It is important to be aware that mild TBI can still result in permanent fatigue, memory issues and difficulty with concentration.

**Moderate and severe TBI**
For a moderate to severe brain injury, emergency medical attention and surgery may be required. This is particularly crucial if there is a bleed in the brain or building pressure that needs to be relieved, although in some cases it may be possible to treat the injury conservatively through monitoring. Early intervention is essential in preventing the occurrence and limiting the severity of a ‘second injury’.

Immediate emergency care will aim to prevent any further injury to the head, and ensure that blood and oxygen levels are maintained. In an ‘open’ TBI, attention may be required to prevent the risk of infection, and extensive surgery can be necessary to prevent skin necrosis and to evacuate haematomas. In some cases, this may even be required in mild traumatic brain injuries.

To limit the potential for a ‘secondary injury’ to occur, medical staff may decide to use diuretics, which reduce the amount of fluid in tissues and pressure on the skull. Coma-inducing drugs can also be used, as the comatose brain requires less oxygen. Surgery may also be necessary, to remove any clotted blood or prevent further damage to brain tissue. Considering the risk of post-traumatic epilepsy, the use of anti-seizure drugs is sometimes suggested.

**In-patient rehabilitation**
In cases where the TBI is severe, inpatient rehabilitation may be required. Treatment will be led by experienced health care professionals, who will work alongside the patient with the aim of restoring their abilities to conduct as many day-to-day activities as possible. This stage of rehabilitation will depend on the severity of the damage, but generally covers regaining skills such as walking, speaking and eating and personal hygiene, alongside other activities required for independent living.

A structured course of rehabilitation will be tailored for the patient’s needs, although intensity can vary from provider to provider. The team responsible for this initial acute rehabilitation could include:

- Speech and language therapists
- Neuropsychologists
- Occupational therapists
- Physiotherapists
- Rehabilitation physicians, amongst other professionals.
Post-acute rehabilitation
Following the initial, inpatient rehabilitation, an individual with TBI may be judged to have responded sufficiently well to treatment to be allowed to return home. Treatment will then continue at either a local hospital or rehabilitation centre, and can include training to regain confidence in conducting day-to-day tasks. It is also possible, in some cases, for post-acute rehabilitation to take place in the community, although this may be limited due to funding.

Adaptations to the family home may be required before an individual is able to return. Installing aids to assist usage of stairs and bathrooms and doorway widening can be helpful, and if a TBI patient is reliant on a wheelchair it may be necessary to build a ramp for access to the home and garden. Paid support workers might also be required to help assist the family, and a case manager could be considered to assist in sourcing necessary therapists and implementing and maintaining the care regime and rehabilitation required. A case manager will also be able to help recommend and implement any aids and equipment that may be required.

Community rehabilitation
Patients who have completed their inpatient rehabilitation, but have not been judged to have sufficiently recovered to immediately return to full outpatient status, may be transferred to a community-based setting in a residential unit. Patients will then be encouraged to develop independent living skills, to allow them to achieve out-patient status.

Community rehabilitation may also be offered to individuals who return to their home, but still require therapists and support workers. An outpatient programme will be developed in liaison with the affected individual. When selecting a community rehabilitation provider, it is very important to consider the specialist needs of the TBI patient.

Case study:
Anita Pascoe, Westcountry Case Management.
How does Case Management work?
Zak’s story.
In Case Management, there is no ‘typical’ client. Every person we work with has individual needs and circumstances. Zak’s story is an example of how case management might work for a person with complex needs following an injury.

Zak was in his twenties when he was hit by a van and sustained a severe brain injury. He was referred to Westcountry Case Management for an initial assessment while still on an acute ward in the south west of England.

An assessment was undertaken with Zak, his family and clinical staff, and Zak’s needs over the next 6 months were identified by the case manager. Once case management commenced, Zak’s case manager monitored his progress in NHS rehab, provided information and support for his family, and worked collaboratively to plan for his move to a facility more local to his home.

A process of monitoring and planning for his eventual move to the community was implemented, which included identifying needs, recruiting a support team and selecting a suitable property. Support plans were written, risk assessments completed, and a support team trained, ensuring Care Quality Commission and employment requirements were met. Equipment and furniture were purchased and a vehicle sourced through Motability. Utilities were set up and practical plans for a move were made with the team.

Once Zak moved into the community and was discharged from the NHS provision, he continued to access physiotherapy on a private basis, and a neuropsychologist was involved in working with his support team and in setting rehab goals with Zak and his case manager. These included establishing structure to Zak’s days and weeks, identifying activities which gave him a sense of purpose, owning a pet and enabling him to make choices in his life as far as he was able to. He also wanted to go on a holiday, which he did with some of his support team.

Several years on, Zak continues to live in his own home, with a team of support workers and his own vehicle. He engages in activities he enjoys, holidays abroad and has been supported to take risks, meet people and try new things. His case manager continues to lead the team, holding regular team meetings, organising training and recruiting when needed.
Alongside his rehabilitation, Zak went through a litigation claim. The case manager’s role in this was to provide 6 monthly update reports, detailing Zak’s progress and identifying needs and costs for next 6 months, attending some of his litigation appointments to inform the experts, and preparing witness statements with a view to giving evidence as a Witness of Fact if necessary. Once the litigation was over, the case manager worked closely with the Court appointed Deputy to ensure Zak’s needs were being met within the budget available to him.

Throughout this progression, which took place over several years and is still ongoing, the case manager worked through a process which will be the same for each client, although their needs will all be different:

- Assessment
- Identifying needs
- Setting out in a report, recommendations and a case management plan to meet those needs
- Implementing the case management plan
- Monitoring progress, reviewing needs and making changes as required
- Formally reviewing progress every 6-12 months
- Re-assessing and working through the process again over the next stage of progression

Case study:
Kim Chamberlain, Novum Law.
Transition to Independent living following a Traumatic Brain Injury:

At the age of 13, ‘B’ was struck in the head by a powerboat whilst taking part in an Offshore National Championship race. As a result of the impact, ‘B’ sustained a severe traumatic brain injury, despite wearing a helmet at the time. He was airlifted to hospital and was ventilated and intubated, due to the subarachnoid haemorrhage and significant bleeding in other areas of the brain. His family were warned to expect the worst. Fortunately, he survived the night.

When he initially awoke from his coma he was in a locked in state. Even once he had started to improve, he was unable to communicate and needed support to undertake even the most basic of tasks, such as swallowing, toileting and hygiene. The catastrophic nature of the brain injury sustained meant that ‘B’ was presented with a host of cognitive, behavioural and executive difficulties which included limited attention and concentration, poor memory, and reduced information processing. He suffered from excessive fatigue and insight into his limitations was impaired. He was also often disinhibited in his behaviour.

Such difficulties have continued to date and are permanent.

‘B’ was also left with significant left limb weakness impacting upon his mobility. The limited movement on the left hand side of his body impacted upon day to day living, including climbing the stairs, and ‘B’ was unable to carry anything other than the lightest item hooked onto his left hand. He was wheelchair dependent for a number of years and wholly reliant on others to mobilise. He also suffered from bladder urgency, and also initially daytime incontinence. In essence, every aspect of ‘B’s’ life was affected by the injury sustained. ‘B’ remained an inpatient at hospital for four months after the accident. He was then discharged home to the full time care of his mother, who had to take 18 months off work in order to care for her son, who required assistance and support with almost all aspects of daily life.

Once he was discharged from hospital he continued to receive some rehabilitative support on an outpatient basis, via the NHS. However, after ‘B’ turned 18, he was only able to access adult services, making it far harder to obtain the rehabilitation he so greatly required. ‘B’ remains reliant upon walking aids and a mobility scooter.
‘B’ pursued a personal injury claim against the organisers of the Offshore Championship race and the overarching regulators of the club. He instructed Novum Law in this respect and they were able to obtain an interim payment on his behalf. Until then, he had no alternative but to continue relying on care from his mother at the family home, a situation greatly removed from what he and his parents had hoped for him in the future. The payment obtained enabled ‘B’ to access expert private rehabilitation, with a view to him being able to live as independently as possible, and to allow his family to step back from the carer roles they had been required to adopt for so many years.

Appropriate one storey accommodation was sourced for him by a dedicated brain injury case manager, and a support regime was put in place. In order to assist with the transition to independent living, the move to his own property had to be gradual and well supported. A team of dedicated ‘live-in’ support workers were recruited and ‘B’ had support for 24 hours a day. He also had access to Occupational Therapy, Physiotherapy, Psychology and Vocational Rehabilitation.

Whilst the life changing impact of the brain injury is ongoing, and the cognitive and behavioural changes caused by the accident are regarded as permanent, over time ‘B’ has become more confident living independently from his family. He has relished the opportunity to have his own home, as he would have expected but for his injury. Having intensive rehabilitative support allowed ‘B’ to successfully make the transition from living with his mother, to living in his own home with support. Such support gave him a sense of independence, identity and self-worth that can so often be lacking for those who suffer such life changing injuries.

Case study:
Christine Bunting, Hyphen Law.
Capacity, Deputyship and the role of the Court of Protection:

It is important not to presume that patients who have suffered a traumatic brain injury will lose the ability to make decisions for themselves. Unless there is medical evidence to the contrary, capacity will always be presumed in the first instance. Alongside being legally incorrect, it can be very upsetting and disempowering if decisions are made on behalf of an individual who is able to make these choices for themselves.

However, in cases where the brain injury has impaired an individual’s decision making capabilities, some thought must be given as to how their personal, health and financial affairs will be managed in the future. If concerns arise around a person’s capacity after a TBI, best practice guidance recommends that this should be assessed by a qualified professional. This will usually be a doctor.

If this assessment finds that an individual is lacking the necessary capacity required to make a decision, they will be protected under the Mental Capacity Act 2005, which exists to empower people where possible. It is important to remember that capacity is time and decision specific, and that it will need to be assessed at various times, and for various reasons. Individuals may have the capacity to make one decision, but not to take others. For example, a person with TBI may have the capacity to consent to a blood test, but not to make a decision regarding a major operation. Individuals may be able to control a small weekly budget, but would struggle to manage their finances overall.

In order for someone to have capacity they must be able to:

- Understand information about the decision to be made;
- Retain that information in their mind;
- Use or weigh up the information as part of the decision process; and
- Communicate their decision.

Where a person lacks the capacity to make decisions, this can present complications for both the individual and their family. It may result in bank accounts being frozen, household bills going unpaid and it can delay crucial decisions about care and treatment. Family members can feel excluded from the decision making process and feel a loss of control.
The role of the Court of Protection

If the incapacitated person does not already have an Enduring or Lasting Power Attorney, the Mental Capacity Act 2005 provides the legal framework for someone to be appointed to act on their behalf and to make the decisions which they are unable to make. This person is known as a Deputy, and are appointed by the Court of Protection and supervised by the Public Guardian.

Decisions that we have to make in our everyday lives fall into two categories in the Court of Protection.

1. Decisions about our Property and financial affairs; and

Applications can be made to the Court of Protection for the appointment of a deputy under one or both of the categories above. It is crucial that careful consideration is given to ensure an appropriate person is assigned; acting as a deputy can bring with it a lot of responsibility, and the role can take up a lot of time. Sometimes it can be better to appoint a professional, rather than a family member, as Deputy, as the role may involve extensive financial responsibilities, and can include very difficult decisions that can be challenging within the family.

The appointment of a Property and Financial Affairs Deputy is more common and straightforward than the appointment of a Health and Welfare Deputy. This is because the appointment of a Health and Welfare deputy provides the proposed deputy with a considerable amount of authority over an individual’s life. This is in contrast to one of the underlying principles of the Mental Capacity Act, which holds that any acts done, or decisions made, on behalf of someone else should be those which are the least restrictive of the individual's basic rights and freedoms, while still providing the treatment and care that they need. The Court of Protection will become involved if this is necessary, but should be viewed as a last resort in relation to Health and Welfare decisions.

Applications to the Court of Protection take time. On average, a property and financial affairs application takes around 4 to 6 months from the date that the application is submitted to the date the order is made. Applications that are contested will take longer, as will health and welfare applications.

Wills for people who lack capacity

In October 2014 The Law Society (the representative body for solicitors) published the outcome of its research into Will making, which revealed that the majority of Britons have not made a Will. The research revealed that whilst 64% of those aged over 55 have a will, 73% of 16-54 year olds do not. The report also found that £8 million went to the state in 2013 as a result of people dying intestate (without a Will).

If someone with a TBI doesn’t have a Will, or their Will is no longer appropriate and they no longer have capacity to make one, it is possible to apply to the Court of Protection for a Will to be made on their behalf. This is known as a Statutory Will. The Court will authorise a Will in terms which it believes to be appropriate for the individual circumstances and the Will they would make if capable of doing so.

It is important to note that if a person dies without a Will, their estate will be distributed in accordance with the intestacy rules which are laid down in an Act of Parliament. In some circumstances the provisions contained within the act are sufficient but in other cases they could result in considerable hardship.

Effects

Effects of a TBI can be physical, cognitive, emotional and behavioural. The nature of the injury can depend on which part of the brain is damaged; injury to the cerebellum may result in very different symptoms to damage impacting the frontal lobe.

Physical and cognitive effects

Mobility impairments:
A common effect of TBI is mobility impairment. The severity of impairment can range from balance issues to requiring a wheelchair for movement.

Balance issues:
Balance issues following a traumatic brain injury are very common; between 30 and 65% of TBI patients state that they experience problems such as dizziness or disequilibrium during their rehabilitation. Challenges relating to balance can arise both as a direct result of the injury and subsequent side effects that impact the ear, but also as a reaction to medications used to reduce blood pressure, alleviate seizures and prevent infections which may cause light-headedness and dizziness.

Whilst more inhibiting mobility impairment is generally only seen as a result of severe traumatic brain injury, issues relating to balance can follow damage of any severity, although periods of disequilibrium would be expected to last for shorter periods in mild traumatic brain injury patients.

Benign Paroxysmal Positional Vertigo:
Benign Paroxysmal Positional Vertigo (BPPV) is a condition often caused by mild to severe head trauma, and is the most common vestibular condition in people with a TBI. The pathological condition occurs in around 28% of head injury patients, but is also prevalent in older people who have not experienced a brain injury.
The condition is caused by damage to the ear that results in vertigo. Head trauma can impact the Otolith organs, a structure in the inner ear. Otolith organs contain crystals, which are used to sense gravity, movement and balance. If these crystals become dislodged, as can happen following a brain injury, they can move into the vestibular labyrinth, causing dizziness. This small organ is also located in the ear, and consists of three semi-circular canals.

Other conditions affecting balance that are associated with head trauma include labyrinthine concussion, which is often associated with mild TBI, and more rarely, Post-Traumatic Meniere’s Disease, where symptoms include a combination of vertigo, tinnitus and hearing loss.

Cerebellum damage:
Alongside mobility problems relating to balance issues, damage to the cerebellum can also cause psychological impairment. Trauma to the cerebellum can cause acquired ataxia, a condition for which initial symptoms include difficulties with limb coordination, and later challenges such as numbness and shaking.

Other disorders that direct trauma to the cerebellum can cause include Dysmetria, a condition that can cause difficulty in distance perception, and Asynergia, a loss of motor movement coordination.

Spasticity and impaired mobility:
In addition to experiencing mobility impairment through dizziness, TBI patients may also suffer muscle spasticity. Spasticity can occur as early as within one week of the initial injury, and may severely limit movement. The extent of the severity of muscle spasms varies, but patients may find that one side of the body is particularly affected. Symptoms of spasticity include involuntary muscle tightening, hyperactive reflexes and difficulty in stretching that can make movement control challenging.

Sensory impairment:
Trauma can also cause TBI patients severe sensory issues, particularly relating to vision and touch. Post-traumatic anosmia, which reduces smell and taste, effects up to 30% of TBI patients.

Vision impairment:
Due to the potential for head trauma to damage the nervous system, there is a high chance of a TBI causing visual dysfunction. Indeed, it is believed that between 20 and 40% of TBI patients have experienced visual impairment, which can have a severe effect on an individual’s rehabilitation and recovery, and can impact on other symptoms. Eyesight challenges may be more prevalent in patients whose TBI was acquired in combat, where the potential for direct blunt trauma to the eye is higher.

Common difficulties include blurred and double vision and decreased peripheral vision, and can affect either one or both eyes. Patients may also experience difficulty in reading and concentrating, and find bright colours and background patterns irritable. Issues relating to vision may not be initially identified in a severe TBI, where the immediate medical concern will focus on stabilizing the patient and assessment of vital functions and physical injuries. Furthermore, it is possible that evidence of ocular damage is not initially obvious and that the injury is concealed.

Blurred vision:
Changes to refractive error and the eyes structural component, cortical deviations and anomalies on the oculomotor and primary visual pathway are all common causes of blurred vision among individuals who have experienced a TBI. Blurred vision can occur in both mild and severe TBI, and exacerbate issues with walking and balance, causing difficulty and frustration with the process of rehabilitation. Challenges relating to vision may also intensify and aggravate other symptoms relating from the head trauma, particularly headaches and issues relating to concentration.

Speech and language:
There are two main causes for speech and language problems among TBI patients: direct injury to the brain that impacts the nervous system and muscles required for speech (dysarthria and dyspraxia), and also injury that impacts areas of the cortex responsible for language and vocabulary, known as speech aphasia. Whilst these causes can occur independently, patients will generally experience symptoms of both, intensifying the challenge of restoring speech and language faculties and capability. Neurological speech disorders have been found to be particularly prevalent among closed head injury patients.

Dysarthria:
Acquired dysarthria occurs as a result of damage caused through a TBI that impacts areas of the nervous system responsible for controlling muscles required for speech. Dysarthria can also cause impairment through direct damage to these muscles after trauma. Whilst dysarthria alone does not cause language or comprehension difficulty, TBI patients will often experience symptoms of both acquired dysarthria and aphasia.

Dysarthria has a major impact on speech clarity, and often results in slurring and issues with articulation. Symptoms also include difficulty in adjusting speech volume and tone, and are generally caused by
weaknesses in muscles that control the mouth, lips and tongue. Respiratory impairment may also cause speech impediment.

Dyspraxia:
Acquired dyspraxia is caused by trauma to the frontal lobe. The condition can cause difficulty with non-spontaneous speech, and symptoms also include challenges with comprehending complex language.

Aphasia:
Aphasia occurs when damage occurs to areas of the brain responsible for language understanding. Injury can impact two parts of the cortex, Wernicke’s area and Broca’s area, which are generally located in the left cerebral hemisphere, the area with dominance for language function in most right-handed people.

Damage caused and symptoms experienced in aphasia vary for which area of the brain has been injured.

Wernicke’s aphasia:
Wernicke’s aphasia (also known as fluent or receptive aphasia), is most commonly caused by injury to the left posterior temporoparietal cortex. Patients with Wernicke’s aphasia generally retain the ability to speak fluently and with correct grammar, but struggle to comprehend word meaning, and may be prone to repetition.

Whilst individuals with mild receptive aphasia will be able to recognise most words, complicated language can be challenging, and patients may rely on simple, single-word comprehension. In severe cases, individuals may be unable to follow conversations or comprehend written language. This can present severe challenges with reading, particularly if combined with symptoms of visual impairment.

Broca’s aphasia:
Whereas impairment in Wernicke’s impairment relates to a failure to understand words and vocabulary, Broca’s (or expressive) aphasia causes difficulty with articulating language.

Fluency can be severely constrained, with vocabulary constricted and delivered stutteringly, and grammar is often limited. Despite extreme challenges in expressing language, patients often maintain developed understandings of vocabulary, causing extreme frustration. Expressive aphasia can also cause difficulty in remembering names and other nouns.

Issues with speech can also be reflected in written language. Individuals may fail to recognise letter order for correct spelling, be unable to write specific letters, or in extreme cases, struggle to produce simple written sentences.

Other conditions and disorders:

Post-traumatic epilepsy:
Post-traumatic epilepsy is believed to represent around 5% of all epilepsy cases, and 20% of symptomatic epilepsy (epilepsy that is a symptom of an underlying condition). For people aged 15 to 24 years, TBI has been found to be the most significant and frequent cause of symptomatic epilepsy. Other long term symptoms may include persistent headaches that may continue long after the injury is acquired and weakness or numbness.

TBI and early onset dementia:
TBI has also been linked to a range of neurological disorders, including dementia. Academics have discovered that the risk of dementia is 50% higher in severe traumatic brain injury patients who suffered loss of consciousness than control patients. Research has also found that damage to axons in the brain can continue for an extended period after the initial trauma, with this prolonged axonal degeneration linked as a cause of the development of Alzheimer’s. Although the risk of Alzheimer’s is higher in individuals with a moderate to severe TBI, even mild TBI has been found to be a significant risk factor for dementia.

Other cognitive difficulties:
Further cognitive effects can include memory loss, difficulty concentrating and issues with planning and day to day tasks. Problems of this kind can continue for an extended period and may never completely recede. This can make it challenging to participate in conversations, and have a negative impact upon an individual’s ability to socially engage. This is sometimes referred to as post-concussion syndrome.

Emotional and behavioural challenges
Emotional and behavioural challenges vary from social anxiety to more extreme issues such as violence, aggression and irritability. Those with a TBI may find themselves to be more easily tired, or short-tempered.

Injury to the frontal lobe may cause executive dysfunction, a term that covers impairment of normal emotional, behavioural and cognitive function. Assessment for the impact of a TBI on executive function is normally undertaken by a clinical neuropsychologist. Some common effects of executive dysfunction include:

- Mood swings, increased irritability and aggression
- Relationship problems
- Reduced capability of memory, concentration and attention
- Difficulty in socialising
- Depression and motivation issues
- Anger, irritability and aggressive behaviour
• Anxiety
• Planning, organising and flexible thinking
• Decision making
• Multi-tasking
• Taking on new information

Improvements in coping with these day-to-day difficulties can be helped by friends and family encouraging independence and autonomy, alongside more specialised support as listed below. Traumatic brain injury can result in life changing consequences that are often permanent and therefore coping strategies, therapies and care and case management, when required, are essential to maximise independence, day to day to function and quality of life.

**Emotional lability:**
Emotional lability, otherwise known as the pseudobulbar affect, a term that covers uncontrollable episodes of crying, laughter or other emotions, is a common effect of TBI. Although emotional balance often returns after the first few months of the injury, emotional issues can be challenging for both the TBI patient and those providing support to an individual. For extended cases of emotional lability, it is recommended that those with a TBI seek therapy from medical professionals, who may offer psychotherapeutic or other forms of treatment.

Options for treatment may include either separate or combined uses of pharmacological, cognitive and education based therapy. Studies have found that through highlighting the condition’s involuntary nature, TBI patients and their families may experience a more positive response to symptoms and expand understanding of emotional issues. Cognitive behavioural therapy may also have a positive impact and emotional distress may also be reduced with a programme of metacognitive and Direct Attention training.

Direct Attention training seeks to improve memory and cognitive function through repetitive, neural stimulus. Meta-cognitive training helps to raise awareness in an individual of the impairment that a traumatic brain injury is having, and seeks to allow positive development through the identification of mistakes and subsequent improvement. This technique is particularly helpful in allowing patients to understand limitations the injury may be causing, in a positive and open context.

**Irritability and aggression:**
Studies have found that up to 71% of people who have survived a TBI frequently experience irritability. This can be exacerbated by discontent and frustration with other effects of the injury, for example memory problems, tiring easily and severe headaches. Violent outburst and aggression in a TBI patient may be unpredictable, and lack clear evidence of provocation or triggers. Research has also found that up to 70% of TBI patients may show characteristics of aggressive behaviour. It is believed that damage caused to the orbitofrontal and ventromedial prefrontal structures - areas located in the prefrontal cortex, which sits at the front of the frontal lobe - is responsible for aggressive behaviour expressed by individuals with TBI.

Relaxation and breathing techniques, activities such as running, swimming and gardening and keeping a diary to monitor anger and reaction and review feelings in a calmer setting can all help with anger and irritability issues. It may be advisable to seek the support of a case manager, who will be able to identify and advise patients and their families about further methods of support. For pharmacological treatment, a strategy of ‘start low, go slow’ is often recommended, and a GP’s advice or other medical advice should be sought.

**Socialising and relationships:**
Even individuals who make good recoveries may experience significant personality changes. Executive dysfunction can reduce inhibitions, and TBI patients may initiate inappropriate behaviour, or be unsure of how to respond in difficult social situations. Speech and language issues, such as difficulty with finding words, slurred speech, speaking too loudly or quietly, too quickly or too slowly will impact on self-confidence in social situations.

**Depression and psychological disorders:**
Depression can also occur after a TBI both as a response to the physical and emotional changes the injury can cause, and also if there is damage to the frontal lobe. Research suggests that around half of traumatic brain injury patients experience depression in the year after the injury, regardless of the severity of the injury.

Research has found that psychiatric disorders that arise after a TBI can continue for over five years post-injury. Due to the nature in which a TBI is acquired, there is a chance of Post-Traumatic Stress Disorder (PTSD) developing, even in cases of a mild injury. Obsessive Compulsive Disorder (OCD) has also been linked to TBI, with damage to cerebral tissue suggested as a cause of the condition.

**Treatments and care recommendations**

**Treatment and care for physical symptoms:**
Due to the severe physical impact that a traumatic brain injury can have, patients may require extensive lifestyle changes and therapy. People who have suffered a TBI and who have physical symptoms may need to adapt their home environment to be more accessible, or require long periods of physical rehabilitation. As many symptoms may be interrelated, encompassing support is vital.
Treatment and rehabilitation for balance issues and dizziness:
Balance issues are one of the most frequently experienced symptoms of traumatic brain injury, ensuring that rehabilitation is essential. The length and extent of balance problems varies depending on injury severity. Brain injury charity Headway recommend that TBI patients keep a ‘balance diary’, which allows individuals to recognise potential triggers, and to help monitor progress of dizziness. Therapy such as CBT may be beneficial in overcoming anxiety that exacerbates balance problems.

Remaining active is essential to overcoming balance issues, and boosting confidence and self-esteem. Inactivity can have a negative impact on recovery, and may prevent the body’s ability to naturally repair damage to the vestibular organs through the vestibular compensation process.

Exercises that boost core strength and flexibility can be very helpful. Yoga, Pilates and Tai-Chi are all recommended for developing flexibility, and are also able to build abdominal strength. With any exercise, it is important to ensure progress is steady, and TBI patients may benefit from simple tasks such as walking in straight lines to restore confidence in stability, and using balance boards.

Compensatory strategies may also be sought to compliment the process of rehabilitation. Using a walking stick, making home adjustments and wearing protective head gear can help reduce the more extreme impacts of dizziness.

Vestibular rehabilitation:
Vestibular rehabilitation is a series of head, eye and neck movements, specifically developed to reduce dizziness and imbalance. The approach identifies specific causes of vertigo in individuals, and works to address these and aims to facilitate compensation in the vestibular process. The rehabilitation is normally led by a qualified physiotherapist and can be very effective in restoring balance.

Spasticity and muscular weakness:
In severe cases of TBI, in-patient rehabilitation may be sought to treat physical impairment. However, for TBI patients who have not received severe injuries, a variety of treatments are available to limit the impacts of spasticity. Due to the nature in which the trauma is acquired, patients may need rehabilitation for bone fractures and breaks before rehabilitation for spasticity commences.

Options for rehabilitation include:
- Regular stretching, which can reduce the impact of muscle stiffness and improve flexibility. Early intervention is important – late rehabilitation will be more challenging, and may take far longer to address issues relating to muscle strength and gait.
- Using splints and braces can also be effective in stretching muscles.
- Medication may be helpful to reduce muscular pain – however, it is very important for TBI patients to be aware of potential side effects, particularly if they are suffering from other symptoms.
- Keeping regular hygiene routines are very important to avoid broken and damaged skin.

Treatment options for visual impairment:
For extreme cases of vision impairment, surgical solutions may be sought, following examination by a neuro-ophthalmologist. In less severe cases, a process of visual rehabilitation may be sought to recover vision. A period of optometric visual therapy can be useful, and may be able to restore a patient’s vision to allow them to read printed text. Exercises included in rehabilitation may include looking at targets that vary in distance to improve vision clarity, using concave and complex lenses and coloured tints, depending on the specificity of the damage to the eye.

A range of compensatory strategies can also assist TBI patients with visual challenges. Using extra light whilst reading and writing tasks can be effective, as can maximising contrast between objects, which may help compensate for some visual problems. Professionals may recommend using corrected or specialised glasses and lenses, or suggest that an individual ‘patches’ an eye to reduce the impact of double vision. Using larger and clearer font, and yellow paper, can also help with issues relating to reading.

Support for speech and language problems:
For patients who are struggling with conditions such as receptive aphasia, which limit an individual’s perception of spoken language, non-verbal communication is sometimes able to offer a way of increasing understanding. Pictures, gestures and written language can all be helpful for TBI patients who are struggling with communication and do not have visual impairment.
Non-verbal communication also provides a method for expression for TBI patients with speech problems.

Following immediate treatment, a speech and language therapist may also be required to assess individuals and plan rehabilitation strategies. An initial assessment will be undertaken to gauge the extent to which support is
required. This could include tests to consider an individual’s swallowing and tongue muscular capability, assess language and concentration skills and examine current memory capacity. Activities and skills that rehabilitation could focus on include strategies to include tongue muscle strength, speech drills that improve intonation and plans that help develop memory and vocabulary.

Coping strategies such as slowing the rate of speech can also help to overcome impediments. Technology may be used to help with speech problems, and in cases where issues are more challenging, the use of electronic speech generating devices and other forms of augmented and alternative communication use can be very beneficial.

**Treatment and care for memory and organisational challenges**

While strategies such as memory games and exercises will not harm memory, research indicates that these are not effective methods of improving memory. Instead, people with TBI may find that developing strategies, structure and forward planning are the most effective way of tackling memory issues. Alongside the assistance of friends and family, support workers, cases managers and therapists can help introduce and maintain these strategies, and a multi-disciplinary approach may help optimise potential improvements.

Brain injury charity Headway recommends dividing large amounts of information or complex activities into smaller, manageable ‘chunks’. Using alarms, reminders and prompts can also be helpful. People with TBI may also find it beneficial to keep a notebook, journal or ‘cheat sheet’ with important information included in their bag or wallet.

The charity also recommends developing back up plans in advance, using step by step checklists and rehearsing plans. Preparing a weekly routine or discussing plans can also assist people with TBI to manage organisational challenges. Strategies such as mentally preparing for difficult situations and considering likely outcomes, can help.

**Treatment and care for depression and anxiety:**

Treating depression in TBI patients is important, particularly as research has found that depressed TBI patients are more likely to report severe post-concussive symptoms, such as memory impairment and headaches, than non-depressed TBI patients.

Treatment for depression in TBI patients normally falls under two categories; psychotherapy and counselling, and use of medicines such as anti-depressants. Strategies often will include a combination of both.

Psychotherapeutic methods such as Cognitive Behavioural Therapy (CBT) have been found to be helpful in support those experiencing depression following a TBI. Cognitive behavioural therapy encourages patients to talk through and break down overwhelming problems, to ensure that they are more manageable and to prevent negative patterns developing. CBT can also be essential in helping to provide an individual with coping strategies that will help them adapt to changes they may experience as a result of the TBI.

Academics recommend a considered approach to psychotropic drug treatment, as TBI patients may be more susceptible to the side effects of psychotropic drugs. Several studies recommend using ‘selective serotonin reuptake inhibitors’ (SSRIs) for initial treatment, due to the low levels of side effects associated with these drugs. However, psychologists’ opinions on drug treatment may vary, and the advice provided will differ from case to case. Practitioners and carers can limit the effects of anxiety on a TBI patient. Reducing unnecessary stresses and providing reassurance are helpful, as are providing a structured routine for the TBI patient. Medication and counselling may also be effective.

**Treatment and care for anger, aggressiveness and irritability:**

There are three key methods that are recommended for treating anger and aggressiveness in TBI patients. Best practice guidance indicates that pharmaceutical intervention can play an important role, although it is important for medical professionals to ensure treatment is as a direct response to TBI and to ensure that misdiagnosis of symptoms as evidence of mental illness is avoided. Both cognitive and behaviour therapy have been found to be helpful. Behavioural problems in TBI patients may continue after treatment, and it is advised that treatment should seek to modify rather than completely overturn issues. Carers and support workers seeking to implement a behaviour plan should ensure that the TBI patient is involved.
Best practice guidance

Case study:
Dr James Tonks, Haven Psychology and University of Exeter.

The role of a Clinical Psychologist supporting people after a brain injury.

There are sometimes moments in a person’s life that will change their course from that point. An event which causes brain injury can be one such moment. There can be significant changes for the individual, but there are also changes for families and friends. As a researcher and a clinical psychologist specialising in working with brain injury, I have come to know that according to the World Health Organisation, brain injury is the biggest cause of death and disability. Before my training I actually thought it was just my family that had been affected by such events. I suspect many families and individuals feel this way. My gran died from her brain injuries in the 1960s after being hit by a drunk driver when she was using a zebra crossing. It was an event that caused aftershocks for generations.

Freud, who is not a psychologist I particularly align with, would probably say that we all choose our jobs for a reason, and that I have chosen my occupation in an unconscious attempt to repair an unwanted part of my past. It is certainly the case that I didn’t consciously plan to become a psychologist as a child (I think I fancied being an astronaut), but now that I am in this position I am firmly of the view that working with anyone after a brain injury is an incredible and privileged position to be in. I don’t share Freud’s pessimism, or his view that our past can determine what we become. This is especially after a brain injury.

Understanding a person after brain injury is rather like solving a complex puzzle. Psychologists first have to understand what happened. What was the nature of the incident and what happened in the minutes and hours after the injury? How severe was the event and what can I expect? The problem here is there are always exceptions. One person I see insisted that they wanted to return to university just one year after being in a deep coma (Glasgow Coma Scale 3). They have just passed the first year with outstanding success.

Even if I accept that the physical brain injury is an intrinsic feature that is unchangeable, and cannot be improved in a small way with psychology (and I don’t for a second think that I should), there are then the extrinsic factors. Did you know that the most reliable predictors of outcome after brain injury have nothing to do with the physical brain injury? They are things like social economic status and family functioning. In other words, if there are limited funds and resources available to deliver rehabilitation, or if the family is not functioning well, this will have a negative effect on outcome.

Delivering the best rehabilitation possible and supporting families is something that is completely extrinsic to brain injury, it is a very changeable part of the puzzle and it is a very reliable way to improve outcome.

What is rehabilitation and what does it involve? In its simplest form it involves people who are affected by brain injury working together with professional staff like myself, relatives and the wider community to achieve their optimum physical, psychological, social and vocational well-being (McClellan, 1991). Sometimes I work with the person to help them regain lost functioning. If I cannot do this, then we can look at compensation strategies. This used to involve a basic pager to prompt someone. From here, it progressed with advances in assistive technology, into mobile phone text alerts generated from an electronic calendar, and now I can put a sticker on your washing machine, and when you touch your tablet computer upon it, a video of you reminding you how to use a washing machine will open on the screen. Some young adolescents I work with will be finding their way around secondary schools this autumn by staring only at their phone (just like the other children) as it directs them independently around their new large comprehensive school. The same phone will remind them of what to pack in their bag and even has pre-recorded self-calming messages from our cognitive behaviour therapy sessions if they begin to feel anxious.

There is often trauma involved after brain injury. Some of my work is about therapy for trauma, or it can be about helping the individual and others to adjust. Psychological therapy with anyone who is not affected by brain injury, for example in the context of ‘ordinary mental health’ is quite different. Paradoxically, outside the context of brain injury, difficulties often stem from frustration and failure in the pursuit of things that the person believes will actually make them happy [we work with beliefs not truths]. Mental health difficulties in the context of brain injury grow from more complex factors, but beliefs and truths are intimately involved. We can superficially simplify the various difficulties that clients I see have and say that all of us [whether we have brain injury or not] need someone to love, somewhere to live and something to do. These are the common goals that people come up with after brain injury and part of my role is to help the individual problem-solve in either obtaining, or maintaining these.

Continued→
Help from friends and family

Friends and family can assist TBI sufferers enormously. Remaining calm and making allowances for changes in personality are vital. Experts advise that helping a person suffering emotional lability through techniques such as taking them to a quiet place, acknowledging their feelings, and allowing the individual to express their feelings, can be beneficial. It may also be necessary to support TBI sufferers during social interaction. It may be helpful to remind individuals who are struggling or overwhelmed by social situations of appropriate responses.

For extended cases of emotional lability, it is recommended to seek therapy from medical professionals, who may offer psychotherapeutic treatment.

Recommendations

- Regular monitoring of an injury is vital, even if it does not initially seem severe. Early intervention and seeking rehabilitation quickly can be essential. Observation is also important if the patient shows symptoms of post-traumatic epilepsy.

- Gaining the correct level of support following the initial rehabilitation and medical care is vital. If a care plan is developed, the patient should be involved in this process.

- Medication can be helpful; however, it is important that an accurate diagnosis is made and treatment is correctly directed. Practitioners and medical staff should take care to ensure that symptoms and effects of a TBI are not confused with mental illness.

- For issues relating to aggression and depression, CBT and other psychotherapeutic methods can be very useful for traumatic brain injury patients.

- Patients should be helped to recognise that their symptoms may continue, despite rehabilitation and care, and be given advice on coping mechanisms. Help from family and friends should be sought.
Best practice guidance


34 Interested in attending one of our upcoming events on support following serious injury? Please scan the QR code, or visit http://www.brake.org.uk/victim-support/support-professionals-events-resources-and-training to view our calendar of professional development seminars and conferences.

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