The ‘hidden disability’: undiagnosed brain injury

There are estimated to be at least two million people in the UK living with the effects of acquired brain injury (ABI). There are many causes of ABI, including:

- Traumatic brain injury, such as from road traffic collisions, falls and assaults
- Stroke and other vascular disorders
- Brain tumour
- Meningitis
- Encephalitis
- Hydrocephalus
- Hypoxia/anoxia, such as from heart attacks, carbon monoxide poisoning, secondary complications of traumatic brain injury or complications during surgery (such as respiratory depression or embolism)
- Brain abscess
- Metabolic disorders (e.g. liver and kidney diseases and diabetic coma)
- Other forms of poisoning and infectious disease
- Electrolyte imbalances

Many of these people receive little or no provision of rehabilitation or other support services after discharge from hospital. Sometimes this is because a possible brain injury is not given sufficient consideration due to other reasons for admission. Ward nurses can help to prevent this by being aware of possible indicators of brain injury and by providing patients with the right information on discharge. This factsheet is designed to help nurses to do this effectively.

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It can be all too easy to miss an ABI if a patient has other primary injuries or illnesses. For example, if you are treating someone on a cardiac ward it is important to consider the possibility that they may have a hypoxic brain injury. If they are on an orthopaedic ward and have had other injuries treated, the possibility of a relatively minor head injury may be overlooked. In many cases, people with ABI show no external signs of injury, so there are no visual clues to the condition. For this reason the condition is often referred to as the ‘hidden disability’.

Symptoms can overlap with other conditions, such as depression, post-traumatic stress disorder (PTSD) and other mental health problems, and if someone has a complex medical condition or multiple injuries it can be easy to focus on the wrong thing. The patient may also lack insight and awareness of their own problems and fail to report relevant information, therefore complicating matters further.

Even if a CT or MRI scan has been performed and shown no injury, there may still be problems. CT and MRI scans do not show damage at a microscopic, cellular level, and widespread disturbance of neurons can occur without being visible. White matter abnormalities are associated with post-concussion symptoms after minor brain injuries. Such deficits are only apparent on diffusion tensor MRI scans and these are not commonly performed.

Also, problems may only become apparent when a patient is discharged and returns to everyday life. For all these reasons, it is important to remember that if ABI is involved a seemingly simple discharge could in fact be a complex one.

**Signs and symptoms**

It is important to know the signs and symptoms which may alert you to a previously undiagnosed brain injury. The effects can be subtle and easy to mistake for aspects of normal behaviour in the unusual environment of a hospital. It may be necessary to consider brain injury as a reason for the following behaviours:

- Inappropriate disinhibition or aggressiveness towards staff
- Extreme fatigue - this may be put down to illness, medication or normal recovery
- Lack of emotional engagement with family and friends
- Making irrational decisions, such as trying to discharge themselves
- Failure to retain information in order to consent to medical procedures
- Lack of engagement and compliance with treatment
- Personality changes
- Extreme mood swings
- Lack of self-awareness or understanding of the current situation
Discussing the situation with a patient’s family members and friends who know them well can help you understand whether their behaviour is particularly unusual for them. It would also be advisable to consider the symptoms of brain injury listed on the following page. Any combination of these could be an indication of brain injury:

**Physical symptoms:**
- Continence problems
- Epileptic seizures or absences
- Headaches, often severe and persistent
- Loss of taste and smell
- Nausea/vomiting
- Sensitivity to noise
- Sleep disturbance
- Tinnitus
- Visual disturbances
- Dizziness and balance problems
- Fatigue, often severe
- Hormonal imbalances
- Movement and co-ordination problems
- Neuropathic pain
- Sexual dysfunction
- Speech difficulties
- Weakness or paralysis

**Cognitive symptoms:**
- Attention and concentration problems
- Decision-making problems
- Language and communication problems
- Object recognition problems (agnosia)
- Face recognition problems, even family and friends (prosopagnosia)
- Perception problems (e.g. inability to perceive particular colours, sounds, shapes, movement, etc)
- Acquired dyslexia
- Information processing difficulties
- Memory problems
- Problem-solving difficulties
- Planning and organisation difficulties

**Emotional and behavioural symptoms:**
- Anger
- Apathy and loss of motivation
- Disinhibition
- Anxiety
- Depression
- Egocentricity
Referral guide

If you suspect a patient has an undiagnosed brain injury, a referral should be made as early as possible to one of the following specialists:

- **Neurologists and neurosurgeons:**
  For any neurological deficits, whether physical, cognitive, emotional or behavioural. Often the best first option for assessment and further referral to other professionals or for brain scans

- **Neurophysiologists:**
  For assessment and diagnosis of epilepsy and other disorders of nerve function

- **Neuropsychologists and neuropsychiatrists:**
  For cognitive, emotional and behavioural problems and their impact on the patient and their family

- **Rehabilitation medicine consultants:**
  For any rehabilitation input and advice

When a patient is to be discharged, other rehabilitation professionals can help them to overcome their everyday problems. Again, it is important to access these services as soon as possible. Consider asking the consultant to write to the patient’s GP recommending referral to the following services:

- Community brain injury services
- Neuropsychologists
- Neuropsychiatrists
- Counsellors and cognitive behavioural therapists
- Physiotherapists (particularly neurophysiotherapists)
- Occupational therapists
- Social workers
- Speech and language therapists

If the above services are not available on the NHS then chartered professionals in private
practice may be available. Addresses of online directories are provided at the end of this factsheet.

For patients with epilepsy the following professionals specialise in diagnosis, treatment and management:

- Epilepsy nurse specialists
- Epileptologists
- Neurologists
- Neurophysiologists

On some other occasions it may be necessary to refer to the following specialists:

- **Continence advisors:**
  For any continence issues

- **Endocrinologists or neuroendocrinologists:**
  For hormonal imbalances related to the endocrine system, for example, hypopituitarism caused by damage to the pituitary gland (there is a large body of evidence that hormonal dysfunction is underdiagnosed after traumatic brain injury and can also occur due to tumours, strokes and other conditions affecting the pituitary gland and hypothalamus)

- **Ophthalmologists or neuro-opthalmologists:**
  For eye conditions caused by injury to the brain and central nervous system

Dizziness and balance problems are common and are often related to the vestibular system. If you suspect this is the case then you could ask about referral to a local balance clinic if available. Other referral options include:

- Audiologists
- Audiovestibular specialists
- Ear, nose and throat surgeons
- Neurophysiotherapists
- Otologists and neuro-otologists
- Physiotherapists

**Family support**

Families of people with a brain injury may also need advice and support. The brain injury impacts greatly upon the lives of family members, and it is easy for their own needs and
difficulties to be overlooked. Try to discuss the situation with the family and provide them with as much information as possible, while also referring them to the Headway helpline and local support group (see next page).

**Driving after brain injury**

All drivers are required by law to report any condition that may affect their ability to drive to the DVLA. Failure to do so can result in a £1,000 fine, invalidate their licence and lead to possible prosecution if the person is involved in an accident. Nurses can help to ensure that patients adhere to these rules. If you have any reason at all to suspect that the injury will affect a patient’s ability to drive you should tell them this and provide the number for the DVLA Drivers Medical Group. Headway provide a booklet called *Driving after brain injury* which you and the patient should find helpful.

**Headway services**

Headway has a network of over 100 Groups and Branches throughout the UK, which patients and their families should be made aware of as soon as possible. A wide range of services are available including rehabilitation programmes, family support, social reintegration, community outreach and respite care. Services vary depending on the region and you can find contact details of your local Group or Branch at www.headway.org.uk/in-your-area.aspx.

The Headway nurse-led helpline provides information, advises on sources of support and offers a listening ear to anyone affected by brain injury. You can contact the helpline yourself to discuss individual patients or any of the issues raised in this factsheet. You can also refer patients to the service. Contact us on 0808 800 2244 or helpline@headway.org.uk.

Further information on all aspects of brain injury, including freely downloadable factsheets and details of our other publications, is available on the Headway website at www.headway.org.uk.

**Conclusion**

This is a time of enormous upheaval in the health and social care system. The strains on each area of the NHS can mean that brain injured patients do not receive appropriate referrals when they are discharged. Ward nurses are under great pressure and we do not expect you to take full responsibility for every aspect of patient care. However, if you do have the opportunity to facilitate more efficient referrals then we hope the information in this factsheet can help you.
The important thing to remember is that what may seem like a simple discharge could in fact be complex due to the subtle cognitive effects of brain injury.

**Clinical guidelines**

Several UK clinical guidelines have been produced to outline the ideal standards required for the assessment, treatment and rehabilitation of people after brain injury. These emphasise the need for timely, specialist rehabilitation and support.

The following are freely available online:


Further reading

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


To discuss any issues raised in this factsheet, or to find details of our local groups and branches, please contact the Headway helpline free of charge on 0808 800 2244 (Monday - Friday, 9am-5pm) or by email at helpline@headway.org.uk.

You can also find more information and contact details of groups and branches on our website at www.headway.org.uk/supporting-you.
Online directories

Association of Speech and Language Therapists in Independent Practice
www.helpwithtalking.com

Brain Nav – The National Brain Injury Service Directory
www.brainnav.info

British Association of Behavioural and Cognitive Psychotherapies (BABCP)
www.babcp.com

British Association of Brain Injury Case Managers (BABICM)
www.babicm.org

British Association for Counselling and Psychotherapy (BACP)
www.bacp.co.uk

British Psychological Society (BPS)
www.bps.org.uk

Chartered Society of Physiotherapy
www.csp.org.uk

College of Occupational Therapists Specialist Section – Independent Practice
www.cotss-ip.org.uk

College of Sexual and Relationship Therapy (COSRT)
www.cosrt.org.uk

Counselling Directory
www.counselling-directory.org.uk

Find a Therapist - UK and Ireland Directory of Counselling and Psychotherapy
www.cpdirectory.com

Physio First
www.physiofirst.org.uk

Relate – the relationship people
www.relate.org.uk

Royal College of Speech and Language Therapists (RCSLT)
www.rcslt.org