



Management of acquired brain injury: a guide for GPs

Introduction

There are estimated to be at least 1 million people in the UK living with the effects of acquired brain injury (ABI)¹. 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
- Anoxia, such as from heart attacks, carbon monoxide poisoning and near drowning
- Brain abscess
- Metabolic disorders (e.g. liver and kidney diseases and diabetic coma)
- Other forms of poisoning and infectious disease

Many of these people receive little or no provision of rehabilitation or other support services after discharge from hospital. In these cases, the GP is the primary source of support and referral to specialist services. This factsheet is designed to assist GPs in providing the best possible support to ABI patients.

The 'hidden disability': undiagnosed brain injury

It can be all too easy to miss a previous ABI as the primary cause of a patient's difficulties. 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'. This is even true in many cases of traumatic brain injury, when the external wounds have healed well.

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 history it can be easy to focus on the wrong thing². The patient may also lack insight and awareness of their own problems and fail to report relevant information, therefore complicating matters further².

In some cases, injury to the brain may not even have been previously diagnosed. This is particularly the case after minor head injuries (see *Minor brain injury: a guide for GPs*). However, there are many other conditions where this can occur. For example, a patient



may have sustained multiple injuries in a car accident and the primary diagnosis may have been something else. Also, if someone has had a cardiac arrest or carbon monoxide poisoning, the fact that their brain may have been starved of oxygen can be neglected.

Even if a CT or MRI scan has been performed and shown no injury, there may still be problems³. CT and MRI scans do not show damage at a microscopic, cellular level, and widespread disturbance of neurons can occur without being visible^{4 5}. Many recent studies have shown that white matter abnormalities are associated with post-concussion symptoms after minor brain injuries. These subtle deficits are only apparent on diffusion tensor MRI scans and these are not commonly performed⁶.

Many studies have looked at the prevalence of post-concussion symptoms after minor brain injuries and have found up to 40% of people meet diagnostic criteria for post-concussion syndrome (according to DSM-IV) as much as 12 months after injury⁷. Other research has observed persistent symptoms after one year in 84% of patients⁸. If a patient has had a head injury at any time and presents with any of the symptoms described below, it is important to refer to relevant specialists.

Effects of brain injury

The effects of brain injury can range from very subtle to very severe. The fact that someone has a brain injury is often not obvious to others. Even seemingly minor problems can significantly affect people's lives and, importantly, those of their loved ones.

Effects include:

Physical problems:

- Contenance 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 (blurred vision, double vision, sensitivity to light)
- Dizziness and balance problems
- Fatigue, often severe
- Hormonal imbalances
- Movement and co-ordination problems
- Neuropathic pain
- Sexual dysfunction
- Speech difficulties
- Weakness or paralysis



Cognitive problems:

- 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 problems:

- Anger
- Apathy and loss of motivation
- Impaired insight and empathy
- Irritability
- Personality changes
- Anxiety
- Depression
- Impulsivity and self-control problems
- Mood swings
- Restlessness

Social, personal and practical problems

- Difficulties performing routine domestic activities
- Employment problems, e.g. inability to carry out previous duties effectively, slowness in carrying out tasks, finding work more tiring
- Inability to cope with family demands
- Loss of driving licence
- Personal and sexual relationship problems
- Reduced independence
- Self-esteem problems
- Social interaction problems



Brain tumours

In most cases, when a GP is faced with a brain injured patient they aren't in life threatening danger. Usually it will be the short or long term difficulties they are having that you will need to deal with. However, sometimes a patient will present with symptoms that may indicate a brain tumour. In these cases, prompt and accurate diagnosis and referral is of life saving importance.

Estimates of actual incidence rates for brain tumours vary but there are over 20,000 admissions to hospital with primary diagnosis of brain tumour in England each year⁹. Brain tumours can be very difficult to identify immediately because the symptoms overlap with many other conditions. They can also present in a variety of ways depending on their location in the brain.

The most common symptoms are headaches and seizures. Although these symptoms more commonly indicate other conditions, it is important to consider tumour as a possible cause. Severe headaches, especially when not usually experienced, increasing frequency of headaches and headaches and sickness together are danger signs. Headaches indicating tumour may be worse in the morning and get better during the day.

Other symptoms suggesting tumour in different areas of the brain include the following:

- Apathy and lethargy
- Dizziness
- Fits and strange feelings, auras or déjà vu
- Incontinence
- Loss of co-ordination
- Memory problems
- Muscle weakness
- Problems with sight, hearing, taste, smell or touch
- Changes in personality
- Difficulty speaking or understanding
- Hormonal problems
- Irritability and aggression
- Loss of feeling in part of the body
- Movement problems
- Planning and organisation problems

If you suspect a brain tumour then it is important to refer to a neurologist as soon as possible. You can find excellent further information on brain tumours at www.cancerresearchuk.org and www.thebraintumourcharity.org. A diagnostic aid for GPs is available at www.gpnotebook.co.uk. *Oxford Handbook of Neurology* is also an excellent guide to identifying and treating brain tumours and other neurological conditions and can be purchased from the Headway Amazon shop at www.headway.org.uk/headway-amazon-shop.aspx.



Referral guide

If the patient has a previous diagnosis of a traumatic brain injury, or another diagnosis indicating a brain injury, such as stroke, brain tumour, meningitis, etc, then you could contact their neurologist, or previous consultant, and discuss the situation. The patient may benefit from a regular review of their case and the consultant may be able to refer to rehabilitation services you can't.

If you suspect a patient has a previously undiagnosed brain injury, a referral should be made to a specialist. This could be any of the following, depending on the nature of the problems and service provision in your area:

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

Provision of neuropsychology and neuropsychiatry is limited in many regions so you will need to investigate referral options. Such services may only be available on the NHS if the patient is first referred to a neurologist. If no NHS referrals are available then it may be necessary to look into a private appointment. A directory of chartered psychologists in private practice is available on the British Psychological Society website, www.bps.org.uk.

Other rehabilitation professionals can help people to overcome their everyday problems. Services you should consider referring to include:

- Cognitive behavioural therapists
- Community brain injury services
- Counsellors and therapists
- Neurophysiotherapists
- Occupational therapists
- Physiotherapists
- Social workers
- Speech and language therapists



Rehabilitation may involve developing strategies to help compensate for memory, attention, fatigue and concentration problems, advice about adapting a person's employment situation so that they can continue to work, or help in boosting confidence and regaining self-esteem. 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.

It is important, where possible, to access professionals with specialist expertise in acquired brain injury. However, if such specialist services are unavailable then any support is better than nothing. For example, counselling and psychological therapy through Improved Access to Psychological Therapy (IAPT) services could be extremely beneficial. Cognitive behavioural therapy is widely available through IAPT services and this approach is highly favoured for the treatment of behavioural problems after brain injury. Additionally, some local memory clinics may have brain injury specialists who can assess memory problems and provide memory aids and strategies.

It is important to remember that, even if a patient has been living in the community for some time, it isn't too late for referral to long-term inpatient rehabilitation or residential care. If a patient would benefit from intensive support or their family cannot cope with looking after them full-time, then you might want to consider appropriate inpatient units. The long-term well-being of both patient and family are the primary concerns when making this decision.

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

- Epilepsy nurse specialists
- Epileptologists
- Neurologists
- Neurophysiologists

On some other occasions you may need to consider referral 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 also occur due to tumours, strokes and other conditions affecting the pituitary gland and hypothalamus (see <https://www.headway.org.uk/brain-injury-research-into-neuroendocrine-dysfunction.aspx>)



Ophthalmologists or neuro-ophthalmologists:

For eye conditions caused by injury to the brain and central nervous system

Dizziness and balance problems are often related to the vestibular system. If you suspect this is the case then you could consider 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. Rehabilitation professionals will often work with family members as well in order to help them to cope with the situation.

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 insurance and lead to possible prosecution if the person is involved in an accident. GPs have a vital role to play in ensuring that patients adhere to these rules¹⁰. 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 published a booklet called *Driving after brain injury* which you and the patient should find helpful.

Ongoing support

The effects of brain injury impact on social, work and family life and problems are likely to manifest themselves in different ways as a patient's life progresses. It is important for the GP to provide ongoing support and referrals⁹. Even just providing information and a listening ear can have a significant effect on a patient's wellbeing after brain injury.

It is also important to be aware that patients may not always find the problems easy to talk about, especially if there are sexual and relationship difficulties. It may be appropriate to ask if there are any general issues in this area, even if the patient hasn't mentioned them.



Headway services

Headway has a network of over 100 Groups and Branches throughout the UK. A wide range of services are available including rehabilitation programmes, family support, social re-integration, community outreach and respite care. Many Groups and Branches provide services for people with minor injuries and often have connections with rehabilitation professionals and counsellors who provide in-house therapy. 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 or refer patients to the service. Contact us on **0808 800 2244** or helpline@headway.org.uk.

Final word – other things you can do

2013 is a time of enormous changes in the health and social care system. The advent of clinical commissioning groups in England has placed greater pressures and responsibilities on GPs, while changes to the GP contracts in England sees general practice facing new targets and additional workloads. Headway is greatly aware that GPs have to consider every injury, disease and health condition and have limited resources to focus on brain injuries.

We hope that the information in this factsheet can help you to identify and refer patients with greater efficiency and that you can use the available resources to provide the best care available for patients. We also hope that GPs with commissioning powers can start to make these resources more readily available as widely as possible.

There are steps that you can take to improve the situation. The United Kingdom Acquired Brain Injury Forum (UKABIF) makes the following suggestions for healthcare professionals in their 2012 acquired brain injury manifesto¹:

- Ensure that your clinical commissioning group has a named neurological lead; if not request one
- Review the information and support available for people with an ABI in your area

The national Headway organisation and our local Groups and Branches are here to help. Please visit the GP information section of the Headway website for a range of resources, including Headway publications, academic references, assessment tools, clinical guidelines and useful links. These include the Rivermead Post-Concussion Symptoms



Questionnaire (RPCQ), a valid and reliable measure of post-concussion symptoms, and the Sport Concussion Assessment Tool 3 (SCAT 3). The measures can be administered by GPs in order to give you a firm idea of a patient's problems.

Go to www.headway.org.uk/gp.aspx.

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 and the role of GPs in facilitating this.

The following are freely available online:

British Society of Rehabilitation Medicine. *BSRM Standards for Rehabilitation Services, Mapped on to the National Service Framework for Long-Term Conditions*. BSRM, London 2009. Available from www.bsrn.co.uk/ClinicalGuidance/ClinicalGuidance.htm.

National Institute for Health and Care Excellence (NICE). *Head Injury: Triage, assessment, investigation and early management of head injury in infants, children and adults*. National Collaborating Centre for Acute Care: 2007. Available from <http://guidance.nice.org.uk/CG56>.

Royal College of Physicians and British Society of Rehabilitation Medicine. *Rehabilitation following acquired brain injury: national clinical guidelines* (Turner-Stokes, L, ed). London: RCP, BSRM, 2003. Available from <http://bookshop.rcplondon.ac.uk/details.aspx?e=14>.

Scottish Intercollegiate Guidelines Network (SIGN). *Brain injury rehabilitation in adults*. Edinburgh: SIGN; 2013. (SIGN publication no. 130). [March 2013]. Available from: <http://www.sign.ac.uk>.



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

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



References

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3. Levin HS, Amparo E, Eisenberg HM. (1987) Magnetic resonance imaging and computerized tomography in relation to the neurobehavioral sequelae of mild and moderate head injuries. *J Neurosurg*, 66:706-713.
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5. Metting Z, Rodiger LA, Stewart RE, Oudkerk M, De Keyser J et al. (2009) Perfusion computed tomography in the acute phase of mild head injury: regional dysfunction and prognostic value. *Ann Neurol*; 66: 809–816.
6. Smits, M., Houston, G. et al (2011) Microstructural brain injury in post-concussion syndrome after minor head injury. *Neuroradiology*; 53: 553 – 563.
7. Røe, C., Sveen, U., Alvsaker, K. & Bautz-Holter, E. (2009) Post-concussion symptoms after mild traumatic brain injury: influence of demographic factors and injury severity in a 1-year cohort study. *Disability and Rehabilitation*; 31 (5): 1235 – 1243.
8. van der Naalt J, van Zomeren AH, Sluiter WJ, Minderhoud JM. (1999) One year outcome in mild to moderate head injury: the predictive value of acute injury characteristics related to complaints and return to work. *J Neurol Neurosurg Psychiatry*; 66: 207–13.
9. NHS Information Centre for Health and Social Care, 2013.
10. Gibson, J. (2008) General practitioners and long-term neurological conditions. *Disability and Rehabilitation*; 30 (25): 1956 – 1958.



About Headway

Headway - 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, advises on sources of support, finds local 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
- Producing a range of publications on aspects of brain injury
- Lobbying for better support and resources to be made available by statutory health and social care providers
- Campaigning for measures that will reduce the incidence of brain injury
- Accreditation of UK care providers through the Approved Provider scheme

Make a donation

I wish to help Headway - the brain injury association to improve life after brain injury by making a donation £

Your personal details

Mr/Mrs/Miss/Ms

Full name

Address

Postcode

Daytime tel. number

Email

Your payment details

I enclose my cheque for £ made payable to Headway - the brain injury association

Please debit my Visa / Mastercard / Diners / Maestro card number:

Security code*:

*3 digits on reverse of card

Expiry date:

Start date:

Issue no. (Maestro only):

We (Headway - the brain injury association) hold the information you supply to us on our database. From time to time we may send you information regarding other services and products we provide. If you do not wish to receive such information, please tick this box.

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I confirm I have paid or will pay an amount of income tax and/or capital gains tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities and Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and council tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given.

Donate by phone or online

- To make a donation by phone, call: **0115 924 0800**
- To make a donation online visit: **www.headway.org.uk**

Completed forms should be sent to: The Fundraising Team, Headway - the brain injury association, FREEPOST RSGU-CSKS-CSJS, Bradbury House, 190 Bagnall Road, Old Basford, Nottingham, NG6 8SF