Headway
the brain injury association

GP's guide

to management of acquired brain injury

This publication is written to assist GPs in providing the best possible support to patients with suspected or confirmed acquired brain injury.

This publication has previously been endorsed by the Royal College of General Practitioners.

www.headway.org.uk
0808 800 2244

Contents

Introduction 1
The 'hidden disability': undiagnosed brain injury 2
Effects of brain injury 3
Brain tumours 5
Referral guide 7
Family support 10
Driving after brain injury 10
Ongoing support 11
Headway services 11
Final word – other things you can do 12
Clinical guidelines 12

Introduction

Every year, around 350,000 people are admitted to hospital with a brain injury related diagnosis in the UK. 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 publication 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. Research suggests that if someone has a complex medical history 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.

In some cases, injury to the brain may not even have been previously diagnosed. This is particularly the case after minor head injuries (see GP's guide to mild head injury). 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 (such as orthopaedic injuries). 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 problems. CT and MRI scans do not show damage at a microscopic, cellular level, and widespread disturbance of neurons can occur without being visible.

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 performed.

Many studies have looked at the prevalence of post-concussion symptoms after mild 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 injury. Other research has observed persistent symptoms after one year in 84% of patients. 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:

- Continence problems
- Dizziness and balance problems
- Epileptic seizures or absences
- Fatigue, often severe
- Headaches, often severe and persistent

- Hormonal imbalances
- Loss of taste and smell
- Movement and co-ordination problems
- Nausea/ vomiting
- Neuropathic pain
- Sensitivity to noise
- Sexual dysfunction
- Sleep disturbance
- Speech difficulties
- Tinnitus
- Weakness or paralysis
- Visual disturbances (blurred vision, sensitivity to light)

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

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

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 license
- 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 just over 30,000 admissions to hospital with primary diagnosis of brain tumour in England each year. 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
- Changes in personality
- Dizziness
- Difficulty speaking or understanding
- Fits and strange feelings, auras or déjà vu
- Hormonal problems
- Incontinence
- Irritability and aggression
- Loss of co-ordination
- Loss of feeling in part of the body
- Memory problems
- Movement problems
- Muscle weakness
- Planning and organisation problems
- Problems with sight, hearing, taste, smell or touch

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.

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.

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.

Opthalmologists or neuro-opthalmologists: 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 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 . Headway's publication Driving after brain injury may be helpful to yourself and the patient.

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 referrals. 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 120 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/supporting-you.

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

We hope that the information in this publication 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.

Further information and guidance for GPs and patients is available on our website.

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 guidelines from www.bsprm.org.uk/resources/guidelines.
- National Institute for Health and Care Excellence (NICE) guidelines from www.nice.org.uk/guidance.
- Scottish Intercollegiate Guidelines Network (SIGN) guidelines: www.sign.ac.uk.

We hope that this has been a helpful resource. Please consider sharing your feedback with us by scanning the QR code or by visiting our publication feedback survey https://uk.surveymonkey.com/r/hwpublications.

Learn more and support our work at www.headway.org.uk/get-involved.

This information was last reviewed in 2023.

We're here to listen.

If you need support, or have a question about brain injury, contact our free nurse-led helpline:

0808 800 2244
helpline@headway.org.uk

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