The acute phase – in hospital

*Includes glossary of terminology



The Child Brain Injury Trust is a national charity supporting anyone affected by childhood acquired brain injury. The following information has been developed to help the reader understand more about brain injury and some of the associated issues. Every effort has been taken to ensure the information is accurate and up to date. If you require advice, information or wish to make a referral please visit: https://childbraininjurytrust.org.uk/how-we-help/advice-information-referrals/

In addition to the information contained in our Factsheets, the Child Brain Injury Trust also have a range of freely available e-Learning sessions covering a broad range of topics to support professionals and families alike. Once you have registered to view the eLearning you will be able to access all sessions without charge, and no further registration is required. Please follow the link below:

E-Learning Library - Child Brain Injury Trust



In addition to our e-Learning and this Factsheet, we also have an App **CBIT in Hand** that is downloadable by visiting the App Store or Play Store on your mobile device. This App will guide you through support appropriate to your current situation.

The acute phase - in hospital

Suddenly being thrust into the complexity of a hospital environment when your child is very poorly, can be overwhelming; you will suddenly be faced with a sea of new faces, language, terminology and decisions.

This Factsheet explains some of the language and terms used by professionals involved in your child's care. It also provides some advice about how to look after you and your child in hospital.

Acquired brain injury can happen to anyone at any time. It is unexpected and impossible to prepare for. If a child should sustain an acquired brain injury, it can be life changing for the child and the entire family. It is hard to imagine how it feels. Many parents feel unprepared, not knowing what to do. It takes over their life and everything else gets pushed into the background.

Parents often feel guilty and may regret not acting sooner or not noticing what had happened. It is impossible to avoid such feelings and important to remember that acquired brain injuries can happen unexpectedly.

As well as dealing with their own emotions, parents can find that an acquired brain injury has an impact on the whole family, turning it into a life-changing experience. Parents are encouraged to accept help from friends and family who offer.

The number of doctors and nurses involved can be overwhelming and it may be difficult to understand what their different roles are. This might be explained at the time but with so much happening it is important to remember that the healthcare professionals may be unable to explain things fully and the language used by professionals can also be confusing. The following list explains some of these terms:

Acquired Brain Injury	An injury to the brain that has happened AFTER birth – i.e. after a period of NORMAL development	
Acute	Develops suddenly and often of short duration	
Audiologist	Someone who tests your hearing	
Care Plan	Identifies the care your child will need and who will be providing it	
Clinic Letter	A letter resulting from a hospital appointment	
Clinical Psychologist	Someone who works within the health service and has studied thinking, behaviour and emotions. He/she works with individuals and families to help them to cope better	
Cognition	The mental process involved in thinking, perceiving, intelligence, understanding, reasoning, judging and remembering	
Coma	A state of unconsciousness and unresponsiveness to stimuli, unlike sleep (see also Glasgow Coma Scale)	
Community Nurse	A nurse working in the community	
Concussion	Immediate and temporary loss of brain functioning resulting from a head injury, and often accompanied by sickness or nausea, headaches and double vision (see separate Factsheet on Concussion)	
Consultant	Senior doctor	
Contre Coup	The head is hit from one direction and the brain is jolted on to the skull on the opposite side, which can cause damage	
Contusion	Bruising on the brain	
Convulsion	A fit or seizure	

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CT Scan	'Computerised Tomography' scan, a series of x-rays which show pictures of the skull and the brain from different angles	
Discharge	Official permission to leave hospital, usually granted by the clinical team looking after the child or young person, in consultation with the <i>discharge planning team</i> or <i>MDT(Multi-Disciplinary Team)</i>	
Discharge Planning Meeting	See 'Planning Meeting'	
Educational Psychologist	Works within the school/education system and will organise additional support for children at school if it is needed	
Focal Damage	An injury to one specific area of the brain, as against a DIFFUSE INJURY which affects several areas of the brain	
Glasgow Coma Scale (or 'GCS')	Scale used to assess level of consciousness after head injury. Lower scores indicate more time spent in an unconscious state	
Haematoma	An accumulation of blood within the tissues which clots and forms a swelling	
Haemorrhage	Bleeding	
HDU	High Dependency Unit	
Intracranial Pressure	Pressure inside the skull caused by swelling of or bleeding into the brain	
MRI Scan	'Magnetic Resonance Imaging', a scan used to get a better picture of the brain using a magnetic field	
Multidisciplinary	Where professionals of many disciplines or specialities are involved; often shortened to MDT	
Named Nurse	A nurse that is allocated to your child	
Neurologist	A doctor dealing with the brain and the nervous system, but not a surgeon	
Neuropsychologist	A specialist Clinical Psychologist (see above) who looks at what the brain can and cannot do, e.g. memory, visual perception, reasoning, attention and speech, and uses this information to help to understand a child's behaviour, thinking and emotional difficulties	

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Neurosurgeon	A brain surgeon	
Neurosurgery	Operations on the brain	
Occupational Therapist	Provides on-going assessments and advice regarding the skills and dexterity to be as independent as possible, both at home and at school. Can give advice on therapeutic programmes, specialised equipment and adaptations to support learning and development	
Ophthalmologist	A doctor who deals with eyes	
Orthopaedics	Treatment of bones	
Paediatricians	Doctors who specialise in the care of children	
Paediatric Neurologist	A paediatrician with extra training in neurology	
Physician	A doctor who is not a surgeon	
Physiotherapist	Provides advice and treatment for children with physical difficulties to help them to achieve independence	
Planning Meeting	A meeting held at the hospital before your child is discharged in order to plan the services and support that will be required. Everyone who will be involved or working with your child should be invited to this meeting	
Post-Concussion Syndrome	Can happen in the weeks or months after a mild or minor head injury. Symptoms can include headaches, dizziness, poor concentration, memory problems, speaking or listening difficulties, emotional and behavioural problems (see also Factsheet on Concussion)	
Post Traumatic Amnesia	Shortened to PTA, this term refers to the length of time someone is disorientated or confused directly after an injury	
Radiography	Using techniques involving radiation (such as x-rays) to build up pictures of the body	
Referral	A request for a service to be provided	
Social Worker	Employed by the local authority to co-ordinate services for people who need support	

Speech and Language Therapist	Assesses speech and understanding of language and communication and may be involved early on with swallowing and feeding difficulties
Subdural Haematoma	A blood clot within the skull that presses on the brain tissue
Ventilator	Equipment that helps with breathing

Glossary of common terminology used in reference to an ABI.^{i ii}

Other terms you may have heard relating to head injury are mild, moderate or severe. People can use these terms loosely, but there are definitions:

- *Minor*: a momentary loss of consciousness, with a Glasgow Coma Score of 14. Treatment is not needed although 48-hour monitoring is required. Serious complications and mortality from such an injury are rare.
- *Mild*: a head injury causing unconsciousness for less than 15 minutes, with a Glasgow Coma Score of 13 to 15. May involve Post Traumatic Amnesia usually lasting less than 7 days.
- *Moderate*: remaining unconscious for between 20 minutes and 6 hours, with a Glasgow Coma Score of 9-12. Post Traumatic Amnesia of over a week.
- **Severe**: unconscious for more than 6 hours, with a Glasgow Coma Score of 3-8 (3 is the lowest possible GCS). Post Traumatic Amnesia may last for considerably longer than a week.
- *Very severe:* unconscious for over 48 hours. Any ABI with a grading above severe requires hospital treatment. A few patients may develop complications requiring surgery, while others can go home after 48 hours.

Additional injuries are likely to complicate the condition and may increase the seriousness of the overall outcome.

Generally speaking, the less severe the head injury, the better the outcome. However, it is important to remember that some children who have had a very severe injury go on to achieve much more than was first predicted and those with relatively mild injuries may experience considerable difficulties. There are a number of reasons why the severity of a head injury does not always give a clear indication of what can be expected, for example how a child was before or treatment.^{iii.}

If your child is in hospital

Things can be very confusing and disorienting for children in hospital. They may have been assessed, treated or had some surgery. They may be feeling unwell, unhappy and emotional.

As a parent or carer you may wish to:

- Keep the area where the child is quiet and calm. They may find it difficult to remember things in the early stages, so it's important to keep the environment as peaceful as possible. Try to limit the amount of activity, noise, TV, music and movement.
- An acquired brain injury can affect the way a child processes what's going on around them so they may feel overwhelmed if there are too many visitors.
- Try to avoid discussing your child's condition with others at their bedside.
- They may be **very** tired and need time to rest, relax and to heal.
- You may have to remind your child where they are and what has happened to them.
- Try to make sure there isn't more than one thing going on at a time.
- Remember to talk to your child calmly and allow plenty of time for them to reply.
- Tell them who you are and who is there with you; don't be afraid to hold their hand and comfort them.
- Tell your child what's going on at home and what you are doing.
- If your child is unable to speak they may be able to communicate with you in other ways, such as eye contact, or gestures, pictures.
- If allowed, bring in some of the child's things from home, such as a favourite book or toy or even bedding. It can be helpful for siblings to visit, not least because they still need to be around their parents too.
 - The decision to bring siblings to visit is often a difficult one; if they don't visit they may
 not understand what is going on, why everyone seems so anxious and eventually perhaps
 why their brother or sister may be different when they come home. Equally if the
 decision is made for them to visit, you may be worried that they will be frightened by
 how their siblings looks, all the wires etc. It can be a hard decision to make and only you
 will be able to make it. Whatever you choose rest assured it will be the right one for
 you and your family.

You may also benefit from viewing other Factsheets freely available via our website using the following link:

Factsheets - Child Brain Injury Trust

Looking after yourself

Being at hospital with your child can be a demanding and exhausting experience. It can have a physical effect as well as an emotional one. Parents and carers may not get much rest or sleep, they may not eat

as well as they could and they may not have access to things they depend upon at home such as a washing machine, a private space, etc.

So it's really important that parents and carers try to take regular breaks for food and rest. (See our Factsheet on Looking after yourself)

MAKE A DONATION TODAY

The Child Brain Injury Trust relies on grants and donations to enable us to continue our work supporting families affected by childhood acquired brain injury.

Please help us to continue our work by making a donation today – $\underline{CLICK \text{ HERE}}$ to make a one off donation or set up a monthly donation.

Thank you – your donation does make a difference.



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ⁱ The British Medical Association – Peter M. *Illustrated Medical Dictionary*. 2nd Edition. London: Dorling Kindersley Limited; 2007

ⁱⁱ Martin E. *Oxford Concise Medical Dictionary*. 7th Edition. New York: Oxford University Press; 2007.

^{III} Cowen TD et al .*Influence of early variables in traumatic brain injury on functional independence measure scores and rehabilitation length of stay and charges*. <u>Arch Phys Med Rehabil.</u> 1995 Sep;76(9):797-803