Acquired brain injury in children

How to help
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This information pack has been produced by the Children’s Neuro-rehabilitation Team in Leeds.

It is aimed at everyone that may have contact with a child who has had an acquired brain injury (ABI).

The term ABI means any brain damage, however slight, that occurs in children as a result of an accident or illness. This booklet explores some of the longer-term difficulties the children can have and gives advice about how to help.

We hope that you find this booklet useful and that it increases your awareness of the many difficulties a child with a brain injury may face.

We have tried to cover the main topics that will be relevant to the child.

This booklet has been written by members of the Leeds Neuro-rehabilitation Team. Further information about the team and their work may be obtained from:

Department of Paediatric Neurology
F Floor
Martin Wing
Leeds General Infirmary
Great George Street
Leeds
LS1 3EX
0113 392 6903

Specific contact details for individual children may be provided with this booklet.
The Hospital and Early Rehabilitation Pathway

The Acute Phase

Brain Injury Occurs

Child arrives at local hospital

Transfer to Leeds Children’s Hospital

Scans and X rays

Beginning of Rehabilitation

Paediatric Intensive Care Unit may have other injuries

Transfer to Children’s Neurosciences Unit, Clarendon Wing, Leeds Children’s Hospital

Neurorehabilitation team

Physiotherapists

Doctors

Occupational therapists

Dietitian

Speech and language therapists

Nurses

Clinical Psychologist

Teacher
Planning for Discharge

Planning for discharge

Local hospital to continue rehabilitation

Leeds General Infirmary

- Home visits - weekend leave
- Neurosciences Unit during week for rehabilitation; attend hospital school

Planning discharge meeting

Aim: -

- Establish pre accident / illness information
- Hospital & school liaison
- Preparation for discharge
- Planning & assessment re: support

Phased Reintegration Into Own School

- All therapists
- Doctors
- Nurses
- Education Team
- Own school
- LEA
- Parents
- Psychologist
- Social worker

Regular review in outpatients; input from health, social services and education

Return to school (with support)

Regular review in outpatients; input from health, social care and education
Myths and Facts About Brain Injury

Not all brain injuries are the same

Parents and teachers may be unfamiliar with the effects of brain injuries. Misunderstandings can create barriers in developing effective educational programmes for children with acquired brain injuries.

<table>
<thead>
<tr>
<th>Myth</th>
<th>Fact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Since the child looks good physically, everything must be OK.</td>
<td>A child with an acquired brain injury may show no physical signs of disability. However, the ability to learn may have changed.</td>
</tr>
<tr>
<td>A child who has a severe acquired brain injury will have a serious and permanent disability.</td>
<td>The severity of the brain injury does not always predict long-term outcome. Recovery from a brain injury is very different from a broken bone. Children with more minor brain injuries can have serious disabilities and those with serious injuries can have good recoveries. Each injury is different.</td>
</tr>
<tr>
<td>The younger the child is when injured, the better the recovery.</td>
<td>The younger the child the shorter time they have had to develop. Therefore the impact of the injury may only become apparent years later when they are doing more complex tasks.</td>
</tr>
<tr>
<td>Myth</td>
<td>Fact</td>
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<tr>
<td>-------------------------------------------</td>
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</tr>
<tr>
<td>After six months, a child with an acquired brain injury won’t get any better.</td>
<td>There is no timetable for recovery. Changes may be most rapid during the first year after injury, but progress may continue for many months and years.</td>
</tr>
<tr>
<td>An acquired brain injury erases memory.</td>
<td>Many children have post-traumatic amnesia and can’t remember events right before or after the injury. Memory deficits are common and learning new information can be a common problem. Memory can be patchy.</td>
</tr>
<tr>
<td>Children after an acquired brain injury are unmotivated.</td>
<td>After an acquired brain injury, children fatigue easily and need more rest. They are less able to concentrate and pay attention.</td>
</tr>
</tbody>
</table>

Rehabilitation is a lifelong process
Attention and Concentration

Following a brain injury, many children are unable to resume normal school activities quickly. There can be considerable differences in the definition of attention and concentration in reports of teachers, parents and psychologists, all compounded by a child’s individuality.

One example is that the child cannot concentrate on instructions given in the classroom but can for example watch television over an extended period of time. This is because there are many different components to being able to concentrate, and a child’s abilities are highly related to both interest in the topic and whether there are any associated thinking or learning problems.

The harder a child finds it to do something, the more difficult they will find it to concentrate and pay attention. The degree of difficulty a child has is probably related to the severity of the acquired brain injury and how long since the injury.

<table>
<thead>
<tr>
<th>Common Problems</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focussing attention is a very active process and concentration is made more difficult when asking a child to divide their attention between two or more tasks</td>
<td>Try to keep the child on task by keeping the task simple and focussed</td>
</tr>
<tr>
<td></td>
<td>Use short prompts and cues</td>
</tr>
<tr>
<td></td>
<td>Break down tasks into achievable chunks</td>
</tr>
<tr>
<td></td>
<td>Use one-to-one teaching particularly when presenting complicated material</td>
</tr>
<tr>
<td>Common Problems</td>
<td>Strategies</td>
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<tr>
<td>--------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Children who are having difficulty with remembering and recalling prior</td>
<td>Reduce distraction within the classroom as much as possible, (both auditory and visual distraction)</td>
</tr>
<tr>
<td>information particularly find it difficult to concentrate and stay on task</td>
<td>Look at the positioning of the child within the classroom. Where would there be fewer distractions?</td>
</tr>
<tr>
<td>within a busy noisy classroom</td>
<td>Be aware that short periods of concentration are better than long periods.</td>
</tr>
<tr>
<td>Attention is also closely related to memory difficulties and fatigue</td>
<td>Recognise the attention span of the child and compensate for it</td>
</tr>
<tr>
<td>(See relevant sections 6 &amp; 9)</td>
<td>Try and catch the interest of the child by using varying teaching styles</td>
</tr>
<tr>
<td></td>
<td>Use privacy boards/learning zones</td>
</tr>
<tr>
<td></td>
<td>Eat and drink adequately when at school</td>
</tr>
</tbody>
</table>
Memory

Memory is the ability to take in, store and retrieve information. It is not one thing or one skill on its own. It should be thought of as a number of skills working together. Memory involves all senses. Working memory is the ability to remember and manipulate information for 30 seconds or so. Long-term memory is a store of information and / or knowledge held from a few minutes to years such as information about ourselves linked to time and place, general knowledge, the learning of facts and knowledge of how to carry out activities.

<table>
<thead>
<tr>
<th>Common Problems</th>
<th>Strategies</th>
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</thead>
<tbody>
<tr>
<td>An inability to immediately recall information heard or seen</td>
<td>Reduce distractions when trying to remember information</td>
</tr>
<tr>
<td>Drawing solely on previous learning from before the injury, may mask their difficulties with new learning</td>
<td>Identify strengths and weaknesses</td>
</tr>
<tr>
<td>Reduced insight into their memory difficulties, which can affect their ability to learn and use different / new strategies</td>
<td>Provide multi-modality learning opportunities e.g. hear, see &amp; touch</td>
</tr>
<tr>
<td>Difficulty in recalling new information</td>
<td>Encourage use of planners / diaries / checklists / Dictaphones / personal organisers</td>
</tr>
<tr>
<td>Difficulty holding conversations</td>
<td>Talk through lessons / instructions to check that they have remembered key aspects</td>
</tr>
<tr>
<td>Common Problems</td>
<td>Strategies</td>
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<tr>
<td>--------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>May fill in gaps in memory with “stories” -confabulation</td>
<td>Provide written instructions or worksheets to back up verbal instructions</td>
</tr>
<tr>
<td>Poor carry over of information from one situation to another</td>
<td>Provide opportunities for over learning (repetition with variation, use novel ways of reinforcing procedures e.g. ICT)</td>
</tr>
<tr>
<td>Fluctuating memory from day-to-day</td>
<td>Give graded work presenting information in small blocks</td>
</tr>
<tr>
<td>Difficulty following and remembering instructions for homework</td>
<td>Use cue cards / graded prompts</td>
</tr>
<tr>
<td>Unable to follow a book, film or story</td>
<td>Use a ‘buddy’ system to help with getting to classes with the right books</td>
</tr>
<tr>
<td>Difficulty remembering stages involved in new tasks</td>
<td>Use DVDs, CDs, written support, storyboard material, drama to reinforce structure</td>
</tr>
<tr>
<td>Difficulty route finding around school, finding their locker etc</td>
<td>Provide differentiated school-work</td>
</tr>
<tr>
<td>Difficulty getting to right lesson with correct books at the right time</td>
<td></td>
</tr>
</tbody>
</table>
Perception is the gathering of information by all the senses, and putting this together with past experiences, to make a meaningful and functional whole. Following acquired brain injury, children can experience specific difficulties with perception that affect their ability to carry out activities of daily living. These difficulties can be apparent immediately after the injury, or emerge as the child grows older and their skills are challenged, particularly at school.

<table>
<thead>
<tr>
<th>Common Problems</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spatial awareness</td>
<td>Approach tasks in a consistent, routine manner</td>
</tr>
<tr>
<td>Getting clothes the right way round when dressing</td>
<td>Provide verbal prompts for dressing tasks, fastenings may need adapting</td>
</tr>
<tr>
<td>Negotiating around obstacles when walking</td>
<td>Adapt the environment by reducing the number of objects on a surface to help the child locate what they want</td>
</tr>
<tr>
<td>Transferring information from 2D to 3D in technology / science lessons</td>
<td>Provide differentiated worksheets which are not “busy” with information. Use a larger font size</td>
</tr>
<tr>
<td>Figure - ground skills</td>
<td></td>
</tr>
<tr>
<td>Difficulty finding belongings in their tray at school</td>
<td></td>
</tr>
<tr>
<td>Difficulty finding the right information on a busy worksheet</td>
<td></td>
</tr>
<tr>
<td>Common Problems</td>
<td>Strategies</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Copying from the board in class</td>
<td>Provide multi-sensory learning experiences e.g. write a new letter; look at the letter; trace the shape with your finger; copy the letter saying its name / sound aloud; write the letter from memory</td>
</tr>
<tr>
<td>Recognising objects regardless of the position they are in, this includes difficulty with shape recognition, letter recognition</td>
<td>Keep the key objects / materials in the same location in the classroom</td>
</tr>
<tr>
<td>Reduced awareness on their affected side and of that side of the environment</td>
<td>Use a red line at the extreme edge of the page and verbal prompts to help scanning left to right</td>
</tr>
<tr>
<td>Bumping into objects, banging their weaker arm / leg</td>
<td>Use a reading window</td>
</tr>
<tr>
<td>Difficulty reading / scanning left to right</td>
<td>Use multi-coloured lines to guide children when writing</td>
</tr>
<tr>
<td>Dressing one side of their body</td>
<td></td>
</tr>
<tr>
<td>Poor motor planning due to a lack of awareness of parts of their body in relation to themselves and the environment</td>
<td></td>
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<tr>
<td>Colour recognition</td>
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</tbody>
</table>
Executive Skills

Difficulty with executive skills greatly affects a child’s abilities in social and educational settings, and can impact on their ability to reintegrate within their peer group. Executive skills cover areas such as:

- Formulating realistic goals and planning ahead
- Organising activities
- Initiating tasks / communication
- Flexible problem solving (divergent thinking)
- Monitoring their actions and acting on feedback
- Using judgement
- Coping with more than one task at a time
- Being aware of the impact of their own behaviour on others, and be able to alter it
- Ability to focus attention
- Self directing skills
- Speed of processing information

A child may have any combination of difficulty in these areas after acquired brain injury
<table>
<thead>
<tr>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identify strengths and weaknesses</td>
</tr>
<tr>
<td>Break down tasks/activities into manageable chunks</td>
</tr>
<tr>
<td>Prompt to focus attention on task and to switch attention when multi-tasking.</td>
</tr>
<tr>
<td>Give graded prompts over a period of time</td>
</tr>
<tr>
<td>Encourage time awareness and budgeting time effectively</td>
</tr>
<tr>
<td>Encourage the use of a diary, watch or a timer for specific tasks</td>
</tr>
<tr>
<td>Make time allowances and adjust pace of work</td>
</tr>
<tr>
<td>Provide aids to assist with organisation skills e.g. timetables / homework books / checklists</td>
</tr>
<tr>
<td>Provide regular 1:1 time to plan and structure work, as well as give feedback</td>
</tr>
<tr>
<td>Provide advance information - being told of the expected learning outcome will help a child value the information that they are being given. Let them know what they will be doing next in the school day</td>
</tr>
<tr>
<td>Make careful consideration of choice and number of subjects at Key Stage 4 and beyond, as certain subjects can be extremely challenging</td>
</tr>
<tr>
<td>Assist with setting realistic goals and establish clear expectations for the child</td>
</tr>
<tr>
<td>Provide step-by-step approach to problem solving</td>
</tr>
<tr>
<td>Consider the use of “buddy” systems</td>
</tr>
</tbody>
</table>
Fatigue

Following brain injury, children’s capacity both physically and mentally is markedly reduced. This is because the amount of energy they have to expend in order to carry out tasks (however simple) is much greater. When the brain has been injured, a child will not return immediately to their pre-accident levels of being able to concentrate, think and learn. They tend to switch off, needing to concentrate for shorter periods of time and require frequent rests. Fatigue is common, and persists for a considerable time after the brain injury. Physical as well as mental fatigue is a very real issue and children may also get clumsier as they get more tired. Children can also have disturbed sleep patterns after a brain injury and this will contribute to tiredness during the daytime. Sleep will be discussed during reviews in the clinic, and in some children it may be appropriate to consider a trial of medication (melatonin) to help.

<table>
<thead>
<tr>
<th>Common Problems</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties in attention, learning and memory mean by the end of the school day, the child is more tired and exhausted than before their ABI</td>
<td>Recognise that the child will perform better in the morning. Be aware of times that the child is more prone to tiring. If possible plan the timetable so that topics which require more concentration happen earlier in the day</td>
</tr>
</tbody>
</table>
### Common Problems

- Mental and physical fatigue may arise from trying to meet apparently normal challenges such as producing homework on time.
- The brain-injured child will use greater effort to perform tasks that used to be simple and automatic.
- Fatigue produces greater distractibility which may lead to a further decline in performance.
- They are likely to be less able to play or less willing to socialise, particularly towards the end of the day.
- Fatigue in turn could lead to children responding aggressively or present as being more frustrated when challenged.
- Fatigue will also become more marked towards the end of the week.
- Headaches

### Strategies

- Try to incorporate rest periods during the day. It may be important to provide somewhere where the child can be totally quiet and recover.
- Recognise that fatigue can fluctuate and some days the child may fatigue more easily than others. This doesn’t mean they are being unco-operative.
- Structure verbal instructions far more carefully and simply when one recognises the child is tired because processing verbal information is much more difficult when the child is tired.
- Establish sleep pattern.
Behaviour

Behavioural difficulties associated with acquired brain injury include:

- Lack of initiative and poor motivation
- Reduced spontaneity
- Immaturity, impulsiveness, rushing and ‘over the top’ reactions
- Tactlessness, aggression, lack of inhibition and inappropriate behaviour
- Reduced insight

It should be emphasised that behavioural difficulties should not just be seen as disruptive or aggressive. Being withdrawn and quiet can be just as troublesome for that particular child, leading to problems with learning and social relationships. Children with acquired brain injury may behave inappropriately because of their damage and are not being deliberately ‘bad’ or ‘naughty’.

It is important to recognise a change in their behaviour from before the injury. A child may be disruptive in class due to difficulty concentrating, which along with comprehension problems will make understanding teachers’ instructions difficult. This may lead to frustration, low self-esteem and consequently undesirable behaviour.
Understanding the problem

It is necessary to monitor closely any behavioural problems and identify whether they are due to disorders of conduct or due to problems with learning, vision and attention.

Observe the behaviour and consider the following:

- What triggers the behaviour?
- What does the child do typically?
- What happens as a result of the behaviour?

Careful observation must be done before any intervention to change behaviour is attempted. It should be long enough to be able to see some pattern emerging, for example, you may find that outbursts tend to occur at the end of the day. The child could be fatigued and unable to control his / her behaviour at this time. It may also occur in certain lessons, which the child is finding especially difficult.
Social Skills

Social skills are the way we act and speak in different situations. Following a brain injury, children can often have difficulty in judging the best way to act in social situations.

Appropriate skills are essential for children to be able to make friends. The types of skills necessary for this are:

- Listening
- Showing an interest in people / conversations
- Taking turns
- Asking and answering questions

Children who have had a brain injury may also find it hard to alter their behaviour in different situations i.e. acting differently in school assembly from in the playground. Stressful or competitive situations can make the problems worse. Difficulties with social skills can present very differently from child to child; one can appear aggressive whilst another may be quite withdrawn.

<table>
<thead>
<tr>
<th>Common Problems</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being rude, silly or immature</td>
<td>Talk about class / school rules and appropriate behaviour</td>
</tr>
<tr>
<td>Use of inappropriate swearing, comments or laughter</td>
<td>Establish specific rules for behaviour in certain places</td>
</tr>
<tr>
<td>Common Problems</td>
<td>Strategies</td>
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</tr>
<tr>
<td>Problems understanding or using body language and facial expressions</td>
<td>Identify behaviours leading up to an ‘outburst’ and intervene before it happens</td>
</tr>
<tr>
<td>Poor understanding of ‘social space’ i.e. not standing too close to who you are speaking</td>
<td>Don’t react in a confrontational manner. Try to avoid arguments with the child</td>
</tr>
<tr>
<td></td>
<td>Try verbal or non-verbal cues to try and discourage the behaviour</td>
</tr>
<tr>
<td></td>
<td>Praise appropriate behaviour</td>
</tr>
<tr>
<td></td>
<td>Talk about what would have been a better way to behave</td>
</tr>
<tr>
<td>Difficulty in taking turns</td>
<td>Work on sharing and taking turns in small group situations</td>
</tr>
<tr>
<td>Poor use of eye-contact</td>
<td>Use social skills groups e.g. circle time</td>
</tr>
<tr>
<td>Difficulty understanding humour or sarcasm</td>
<td>Avoid using jokes or sarcasm</td>
</tr>
</tbody>
</table>
The potential range of communication difficulties following a brain injury is very wide. Children may have difficulties in understanding spoken language, their own use of language, or both.

Speech production may also be affected due to motor problems acquired from the injury. Communication difficulties post brain injury can be easily missed. Many children will go on to speak once more in (apparently) lengthy sentences. Further attention to these will reveal language lacking in detail and clarity. Children will also frequently forget or misunderstand what has been said to them. Again, this may not be initially apparent, as they will often act as though they have understood.

<table>
<thead>
<tr>
<th>Common Problems with the Understanding of Language</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor listening and attention skills reduce the child’s ability to understand information</td>
<td>Allow extra time for discussions and explanations</td>
</tr>
<tr>
<td>Slowed speed of language processing</td>
<td>Reduce any auditory / visual distractions to aid concentration in listening tasks</td>
</tr>
<tr>
<td>Difficulties following verbal information e.g. directions / facts / questions</td>
<td>Slow the speed of your speech down</td>
</tr>
<tr>
<td>Particular difficulty with processing lengthy verbal instructions / details</td>
<td>Keep your language simple and try to only give one instruction at a time</td>
</tr>
<tr>
<td>Common Problems with the Understanding of Language</td>
<td>Strategies</td>
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<tr>
<td>--------------------------------------------------</td>
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</tr>
<tr>
<td>Repeat instructions. Also, encourage the child to ask for instructions to be repeated</td>
<td></td>
</tr>
<tr>
<td>Use of picture communication symbols</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Common Problems with the Use of Language</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Slow verbal responses</td>
<td>If the child cannot ‘find’ the right word can they</td>
</tr>
<tr>
<td>Slowed ability to access specific words</td>
<td>- Describe it?</td>
</tr>
<tr>
<td>Inaccurate naming of items / people etc.</td>
<td>- Use gestures or pointing to help?</td>
</tr>
<tr>
<td>Frequent use of non-specific descriptions e.g. “that thing”</td>
<td>- Visualise a picture of the word or spelling of the word?</td>
</tr>
<tr>
<td>Poor organisation and clarity of spoken language</td>
<td>Or can you</td>
</tr>
<tr>
<td>Lack of detail and depth to a conversation</td>
<td>- Give the child the initial sound of the word?</td>
</tr>
<tr>
<td>Difficulty expressing needs / emotions</td>
<td>- Give the child a sentence to complete e.g. “you write a ...”?</td>
</tr>
<tr>
<td></td>
<td>- Describe some things about the words?</td>
</tr>
<tr>
<td>Common Problems with the Use of Language</td>
<td>Strategies</td>
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<tr>
<td>-----------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Try to avoid using difficult words with the child</td>
<td></td>
</tr>
<tr>
<td>Try and clarify if he/she has understood what has been said</td>
<td></td>
</tr>
<tr>
<td>Use verbal / non-verbal clues to stop the child from ‘rambling’ (you’ll need to discuss these cues with the child)</td>
<td></td>
</tr>
</tbody>
</table>
Family

A brain injury will affect the way of life experienced by the child and family from the time of illness. Even if complete recovery occurs, there can still be far reaching effects upon the family, affecting every day routines, hopes, ambitions and the relationships both between the family members and the outside world, including school.

Things that affect one member of the family usually have a knock-on affect on other family members and this may take time to become apparent. Responses to illness are highly variable and charged with emotions. The ability of families to deal with these experiences is variable. A brain injury can precipitate dramatic changes in roles, relationships and goals.

<table>
<thead>
<tr>
<th>Common Problems</th>
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</thead>
<tbody>
<tr>
<td>Parents and siblings may become overprotective</td>
<td>Find out about the family structure and how it need to adapt</td>
</tr>
<tr>
<td>Relationships may become strained</td>
<td>Be aware of possible complicated family structures</td>
</tr>
<tr>
<td>Stress for the family, such as adapting to new roles and a different lifestyle</td>
<td>Encourage normal routine for both the child and for the siblings if they are in school</td>
</tr>
<tr>
<td>Siblings may have been ignored or have become jealous</td>
<td></td>
</tr>
<tr>
<td>Common Problems</td>
<td>Strategies</td>
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<tr>
<td>--------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Coping with the stigma attached to having a less able child.</td>
<td>Be non-judgemental</td>
</tr>
<tr>
<td>Social isolation can occur and family activities may become restricted</td>
<td>Allow the child and family members to express his / her frustrations</td>
</tr>
<tr>
<td>Loss of control, helplessness, dependence on others</td>
<td>Involve the school nurse for support and advice</td>
</tr>
<tr>
<td>Grieving for a child they once knew if he / she has not returned to their previous state.</td>
<td>Involve whole family in the decision making process</td>
</tr>
<tr>
<td>Worry about schooling, future aspirations and career prospects</td>
<td>Provide regular feedback about the child to the parents - don’t forget the positives</td>
</tr>
<tr>
<td>Medical-legal implications may linger for many years</td>
<td>Establish ground rules with the child, for example, expectations regarding homework or behaviour and ensure the family are aware of these</td>
</tr>
<tr>
<td>Financial implications. Parents may have had to give up work to care for their child</td>
<td>Social Care may be able to help with financial advice / benefits</td>
</tr>
</tbody>
</table>
Physical Skills

Most children will experience some level of physical difficulties after brain injury. Their problems will vary widely and may fluctuate both on a daily basis and at different periods during the day.

These problems may affect the child’s performance at school in many different ways. The school environment is very busy and crowded and often serves to exacerbate any physical problems encountered in the school environment.

Transport to and from school

The child is likely to physically tire much more quickly than their peers. Speed, stamina, strength and balance may all be affected. Walking or public transport may be too much for the child to cope with or may tire the child to the extent that performance in school may be compromised. It may be necessary for the child to have special transport arrangements to and from school to minimise tiredness during the day. This may be a temporary or permanent arrangement.

Movement around school

Due to physical problems, the child may need extra time to move around school. They may have difficulties carrying bags, books etc from class to class and so assistance in this area is often required. The greater distance between classes, the more the child will struggle or tire and these issues should be considered when organising rooms and timetables. The child may need permission to leave class a little bit early to allow time to reach their next class when the corridors are less busy. A “buddy” system may be appropriate.
Stairs

Stairs may be particularly difficult for the child. They may need to be avoided or appropriate assistance given. Handrails are often necessary and extra time should be allowed for movement if required. If possible, keep lessons on the ground floor or avoid several level changes in one day.

In the classroom

It may be necessary to place the child’s desk nearer to the front of class or by the door to reduce the amount of walking and allow easy exit for the next class. In some cases it may be important for these children to have correct supportive seating to minimise physical effort. Tiredness, both physical and mental, will drastically affect the child’s performance in class. Fluctuations will be seen both day to day and throughout the day. You are even likely to see a change in the child during a single lesson. It is necessary, therefore, to minimise physical exertion to reduce the effects of tiredness in class. The child may need to have rest periods during the day or shorter school days. The more tired a child is the more difficult they will find physical tasks and the more pronounced their physical problems will be.

Lunchtime

The child may need extra time or help to get to the canteen. It is better for them to be first rather than last as queuing for any period of time may be too tiring. They may require assistance to carry trays etc to their seat and they may also need more time to eat their food.
In the playground

Some children are likely to have some level of impaired balance and co-ordination and therefore tend to fall more often. The more tired the child is the more this will be a problem. Close supervision is often necessary in a busy playground environment. If the child has particular difficulties, it may be a good time for a rest or a quiet period.

PE Lessons

Many children feel very self-conscious in PE lessons. They may have physical scarring from their accident or may be embarrassed at their decreased physical skills. It may be necessary to adapt PE and Games appropriately (or allow the child a rest period / alternative lesson at this time, or they may have a therapy programme to carry out at this time). Obviously each child is different - some don’t like being singled out or they would rather join in if possible. Assess the situation and discuss with the child’s physiotherapist if you feel you need further advice. A school visit will normally be arranged and this may include observation of a PE class.

Wheelchairs

Often children return to school with wheelchairs. They may be required all-day or just at particular times to reduce physical exertion. It is important not to assume that because they can walk they do not need the chair. The child will require assistance as self-propelling a wheelchair is hard work. Extra space may be required both in the classroom and in the corridors. It may be necessary to allow the child to leave class a few minutes early to avoid the rush. In this situation, a lift is necessary to move between floors.
**Activities of Daily Living**

After acquired brain injury, a child can have difficulty with everyday tasks due to loss of physical, cognitive, perceptual and psychosocial skills.

<table>
<thead>
<tr>
<th>Eating &amp; Drinking</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child may</td>
<td>Provide physical assistance to carry trays / open packaging</td>
</tr>
<tr>
<td>• be unable to cope with the noisy canteen</td>
<td></td>
</tr>
<tr>
<td>• not be able to carry food on a tray to the table</td>
<td>Use a buddy system to ensure they eat / drink at appropriate times</td>
</tr>
<tr>
<td>• be unable to manipulate their usual cutlery</td>
<td>Use positive encouragement when a child has loss of appetite and liaise with parents / carers to explore interesting meal options</td>
</tr>
<tr>
<td>• not be able to open packaging</td>
<td>Ensure they have access to appropriate feeding and drinking equipment. The Occupational Therapist will be able to advise on this</td>
</tr>
<tr>
<td>• not remember to eat / drink</td>
<td>Modified food / fluid textures and consistencies</td>
</tr>
<tr>
<td>• have a loss of appetite</td>
<td>Assist with money management when appropriate</td>
</tr>
<tr>
<td>• take longer to eat</td>
<td>Support the child gradually to enable reintegration in to the school canteen</td>
</tr>
<tr>
<td>• have difficulty managing food and / or fluid orally</td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>Strategies</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>The child may be unable to</td>
<td>Allow extra time getting changed for PE lessons</td>
</tr>
<tr>
<td>• sequence dressing</td>
<td>Provide support / prompts to ensure he/she dresses correctly</td>
</tr>
<tr>
<td>• get clothes the right way round</td>
<td>Adapt fastenings and provide easier clothing to increase child’s level of independence</td>
</tr>
<tr>
<td>• dress at speed</td>
<td>Provide assistance to put on and fasten aprons / overalls</td>
</tr>
<tr>
<td>• manage fastenings (buttons, zips, laces)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal Hygiene</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child may be unable to</td>
<td>Provide verbal prompts to wash hands at appropriate times during the day</td>
</tr>
<tr>
<td>• remember to wash hands</td>
<td>Provide assistance to wash as and when required</td>
</tr>
<tr>
<td>• wash effectively if they have reduced hand function in one or both hands</td>
<td></td>
</tr>
<tr>
<td>Toileting</td>
<td>Strategies</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td>The child may be unable to</td>
<td>Ensure they have access to appropriate equipment for</td>
</tr>
<tr>
<td>• transfer on / off the school</td>
<td>toileting. The Occupational Therapist will be able to</td>
</tr>
<tr>
<td>toilet safely</td>
<td>advise on this</td>
</tr>
<tr>
<td>• manage clothing</td>
<td>Provide assistance with toileting</td>
</tr>
<tr>
<td>• clean selves after toileting</td>
<td>Provide prompts to go to the toilet in break times</td>
</tr>
<tr>
<td>• remember to go to the toilet in</td>
<td></td>
</tr>
<tr>
<td>break times</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Managing Periods</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>The child may be unable to</td>
<td>Have a designated member of staff for the child to go</td>
</tr>
<tr>
<td>• cope emotionally with their</td>
<td>for feminine hygiene materials</td>
</tr>
<tr>
<td>periods following their acquired</td>
<td>Prompt by a sensitive member of staff to change their</td>
</tr>
<tr>
<td>brain injury</td>
<td>feminine hygiene materials at regular intervals</td>
</tr>
<tr>
<td>• remember to bring in any</td>
<td></td>
</tr>
<tr>
<td>feminine hygiene materials</td>
<td></td>
</tr>
<tr>
<td>• remember to change feminine</td>
<td></td>
</tr>
<tr>
<td>hygiene materials</td>
<td></td>
</tr>
</tbody>
</table>
Continence, Gastrostomy and Tracheostomy

Continence
Maintaining normal bladder and bowel function may be a problem for some children following an acquired brain injury. Whilst in hospital they will have been immobile and consequently may be prone to constipation. Once the child becomes mobile, this problem usually resolves. However some children may require medication to enable them to have their bowels open and are typically prescribed lactulose. It is also important to promote a healthy diet and encourage oral fluids, as this will help the bowel to function normally. During the acute and rehabilitation phase some children may not be able to control their bladder and bowel function and are nursed in nappies. During the rehabilitation phase, toileting skills are relearned.

It is important to allow the child to visit the toilet when they ask. They may not be able to wait until a more convenient time.

Gastrostomy Feeding
Some children following an acquired brain injury may no longer be able to feed normally. An alternative way of providing a child’s nutrition needs to be used and this is often via a gastrostomy. A gastrostomy is an opening into the stomach through the abdominal wall where a tube is surgically placed. Nutritionally complete milk based feeds are administered into the gastrostomy tube via a feeding pump. A dietician will see your child to ensure they meet their nutritional requirements.
For most children the gastrostomy will be a temporary way of feeding and once they take sufficient oral dietary intake the gastrostomy will be removed. A small circular scar will be visible on the abdominal wall where the gastrostomy was inserted and some children will be conscious of this scar.

**Tracheostomy**

In the acute phase following brain injury, some children require a tracheostomy to enable them to breathe. A tracheostomy is an incision into the windpipe that forms a temporary or permanent opening. A tracheostomy tube is inserted to allow the passage of air and the removal of phlegm. The tracheostomy is effective as an alternative airway.

When the tracheostomy is no longer required, it is removed and the opening in the neck covered to encourage it to close. Occasionally this may require stitches. What may be observable now is the scarring on the neck and the child may be conscious of this. There may be some issues for the child about body image due to this scarring.

**Careers Advice**

Careers Advisers start seeing school students in Year 9 (13 / 14 years). Those with additional support needs should receive an individual guidance interview. Through Years 10 and 11, all schools offer a Careers Education and Guidance programme that is designed to give students the information they need to make informed choices. Careers Adviser interviews continue through this period and into the 6th form if appropriate. All those leaving Year 11 should have a place to go to (staying at school, college, training or employment) but if not they can call at the careers centre for further help.
It is important that Careers Advisers have relevant information on how a brain injury affects each individual. Some medical information is provided to Careers Advisers but parents are often the best source for this. In addition, some of the careers guidance delivered in schools may not be relevant to young people with a brain injury. Therefore, it is important that appropriate individual guidance is offered.

It is a good idea to meet the Careers Advisers in Year 9 - and at all times when key decisions are being made. In some cases, it will be a good idea to meet with a Specialist Careers Adviser who will have more experience of working with young people with disabilities and access to extra information.

Those who stay at school for the 6th form can continue with any support they had before this. Those who go to local colleges should discuss their support needs during the application process - possibly even before this. Colleges can provide extra help. Where local colleges cannot provide the extra support needed then residential colleges can be considered - some have direct experience with students who have an acquired brain injury. There are also special programmes to support people with disabilities into employment and training. Connexions / Careers Advisers can help with all this - please use this service!

Further information can be obtained from your school or the Connexions / Careers Service.
Leeds Children’s Neuro-Rehabilitation Team Contacts

Contact will vary from hospital appointments, home and nursery / school visits. Members of the team will often arrange to see children together.

<table>
<thead>
<tr>
<th>Service</th>
<th>Contact Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant:</td>
<td>0113 392 6903</td>
</tr>
<tr>
<td>Medical Secretary:</td>
<td>0113 392 6903</td>
</tr>
<tr>
<td>Hospital Teacher:</td>
<td>0113 392 3711</td>
</tr>
<tr>
<td>Occupational Therapy Team:</td>
<td>0113 392 3612</td>
</tr>
<tr>
<td>Physiotherapy Team:</td>
<td>0113 392 6361</td>
</tr>
<tr>
<td>Regional Child &amp; Family Support Co-ordinator, Yorkshire &amp; North East of England</td>
<td>0791 775 7960</td>
</tr>
<tr>
<td>Speech &amp; Language Therapy Team:</td>
<td>0113 392 3727</td>
</tr>
<tr>
<td>Dietetics:</td>
<td>0113 392 3507</td>
</tr>
<tr>
<td>The Children’s Trust Brain Injury Specialist</td>
<td>0780 351 7916</td>
</tr>
<tr>
<td>Paediatric Neuropsychology and Psychology:</td>
<td>0113 392 6796</td>
</tr>
<tr>
<td>Careers advice: (Leeds Connexions)</td>
<td>0113 220 4850</td>
</tr>
</tbody>
</table>
Feedback Questionnaire

Acquired Brain Injury in Children - How to Help
We would value your feedback on our booklet so that we can improve future versions.

Please could you take time to fill this in, and post it to the address at the bottom. Write any additional comments on the back.

Your name:

........................................................................................................................................
(This is voluntary and you can leave blank if you would prefer)

Relationship to child with ABI:

........................................................................................................................................
(e.g. parent / teacher / therapist / etc)

What were the three most useful or helpful parts of this booklet, and why?

1) ........................................................................................................................................
2) ........................................................................................................................................
3) ........................................................................................................................................

What three things could be improved and how?

1) ........................................................................................................................................
2) ........................................................................................................................................
3) ........................................................................................................................................
Is there anything missing from the booklet that you think should be added?

........................................................................................................................................
........................................................................................................................................
........................................................................................................................................

Please rate the following:

1 = very good / useful through to 5 = poor / not helpful)

- Readability and clarity

  1  2  3  4  5

- Practicality / usefulness of strategies

  1  2  3  4  5

- Improved understanding of child’s difficulties

  1  2  3  4  5

- Improved ability to explain child’s difficulties to another person

  1  2  3  4  5

Comments

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........................................................................................................................................
........................................................................................................................................

Many thanks for taking the time to fill this in.

Please post to: Dr Rajib Lodh Room 35, F Floor, Martin Wing, LGI, Great George St, Leeds LS1 3EX
## Useful Contacts

<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone Number</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability Net</td>
<td>0800 269 545</td>
<td><a href="http://www.abilitynet.org.uk">www.abilitynet.org.uk</a></td>
</tr>
<tr>
<td>CBIT (Child Brain Injury Trust)</td>
<td>0186 934 1075</td>
<td><a href="http://www.childbraininjurytrust.org.uk">www.childbraininjurytrust.org.uk</a></td>
</tr>
<tr>
<td>Contact a Family</td>
<td>0808 808 3555</td>
<td><a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a></td>
</tr>
<tr>
<td>CSIE (Centre for studies on Inclusive Education)</td>
<td>0117 353 3150</td>
<td><a href="http://www.csie.org.uk">www.csie.org.uk</a></td>
</tr>
<tr>
<td>Headway</td>
<td>0808 800 2244</td>
<td><a href="http://www.headway.org.uk">www.headway.org.uk</a></td>
</tr>
<tr>
<td>The Children’s Trust for children with brain injury</td>
<td>0173 736 5000</td>
<td><a href="http://www.thechildrenstrust.org.uk">www.thechildrenstrust.org.uk</a></td>
</tr>
</tbody>
</table>