

# Childhood Acquired Brain Injury: The hidden disability



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# Childhood Acquired Brain Injury: The hidden disability

A quick guide to understanding and supporting  
children with acquired brain injury

by Louise Wilkinson, Head of Information and Learning,  
Child Brain Injury Trust

This guide aims to:



- + Introduce childhood acquired brain injury (ABI) and how it is acquired
- + Identify why this neuro-disability is often overlooked or misdiagnosed
- + Provide some practical school-based support strategies
- + Share the perspectives of young people, parents and academic research

## What is an acquired brain injury?

**ABI – Acquired brain injury** is an umbrella term for describing an injury to the brain that happens after birth, after a period of normal development.

**TBI – Traumatic brain injury** is a brain injury acquired by a blow to the head – see below. A TBI is also sometimes referred to as head injury.

Cohorts for research studies on brain injury are usually those who have suffered a TBI, as it is usually known when, how and why their injury occurred, relevant data can then be analysed accordingly. Therefore, throughout this guide you will see the term TBI used in relation to research studies, and ABI in the general narrative.

## PONDER POINT

**'But we have no children in our school with a brain injury'**

**Many children and young people whose learning is impaired because of an ABI may not have any kind of formal diagnosis. Equally the majority of children with an ABI will have no physical sign of their disability.**

**How many young people in your school have learning difficulties that you 'just can't quite put your finger on'? Could it be an ABI?**

**Don't be afraid to ask the question.**

Children may acquire a brain injury from any of the following events:

- Traumatic injury (TBI) to the brain caused by falls, road accidents (as a pedestrian or passenger), sports injuries, non-accidental injury (shaken baby), near drowning etc.
- Illness such as stroke, brain tumour or epilepsy
- Metabolic disorders such as liver or kidney or diabetic coma
- Infections such as meningitis or encephalitis
- Medical procedures such as surgery for removal of a tumour, or the effect of drugs or radiation to treat leukemia or similar.

The key point is that it is an injury to the brain after a period of **normal** development; the child was not born with the injury but acquired neurological

injuries after birth. The injury can change the way a person thinks, feels and responds to the world around them. The World Health Organisation ranks traumatic brain injury as the leading cause of disability and mortality in children and young adults worldwide. A Swedish long term study of 1.1 million individuals found that TBI was an absolute risk of over 10% for low educational attainment, and concluded that consideration needs to be given to review the cognitive, psychological and social development of all children and adolescents who sustain head injuries.<sup>2</sup>

As shown in the table below studies in the UK have shown that the prevalence of TBI in the general population is higher than other more widely acknowledged and understood neurodevelopmental disorders.

## Neurodevelopmental disorder

Reported prevalence rates amongst young people in the general population.



<sup>1</sup> TBI excludes brain injury acquired as a result of illness (meningitis, epilepsy or measles), tumours, strokes, poisoning, and lack of oxygen

<sup>2</sup> McKinley et al, 2008; McGuire et al, 1998

Data Source – “Nobody made the connection” Report for Children’s Commissioner October 2012

## **PONDER POINT**

**'Surely parents will know if their child has a brain injury?'**

**Not every child who has a bump on the head will attend an A&E Department. Equally, even if the child is admitted to hospital for a traumatic brain injury or illness, often when the child is being discharged the medical team will advise parents of a 'full recovery'; this may be the case medically/clinically, but what about the ongoing development of the child's brain – how do we know what damage may have been done until their brain is fully matured around age 25yrs?**

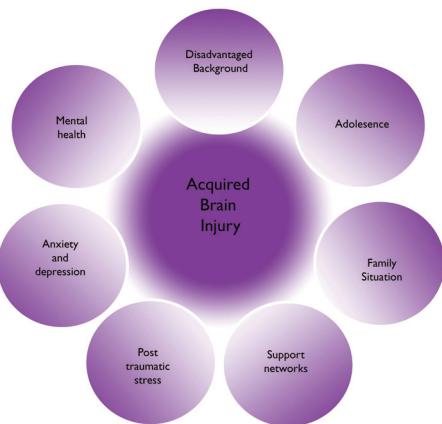


...being exposed to a mild TBI was associated with a range of adverse outcomes, including... low educational attainment. Greater injury severity was associated with poorer functioning outcomes and age at first TBI moderated the effects of long term outcome.<sup>2</sup>

## **Complexity of ABI**

Many children and young people affected by ABI present with a mixed set of difficulties, which could potentially include mental health or developmental delay issues. These may initially be seen as the core of their problems, however, often

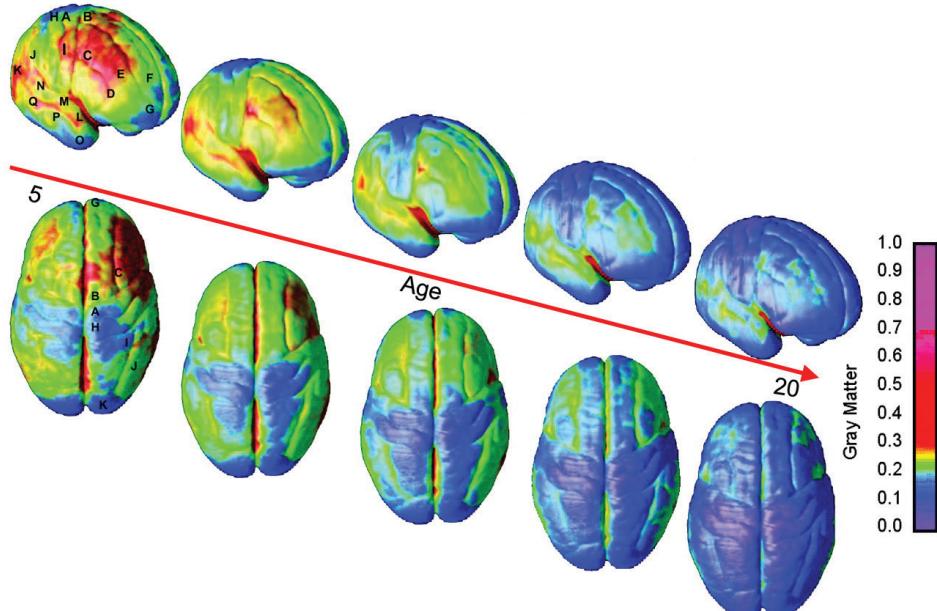
children and young people affected by ABI have a complex history and background, which may mask the direct cause of their difficulties. For example, research has shown that boys from lower socioeconomic backgrounds have a higher risk of ABI<sup>12</sup>. Combine the sometimes turbulent behaviours of adolescence and you could be presented with a highly complex set of difficulties, each potentially masking the other.



## **Types of change following ABI**

Acquired brain injury can lead to two types of change, direct and indirect, and these may not be easy to distinguish. Loss of limb or damage to brain tissue are direct injuries, whereas reduced mobility and memory loss or depression are examples of indirect changes. Some of the changes immediately after injury are transient, others become longer term or even permanent, or may emerge over time as the brain continues to develop and greater demands are made on the young person.

## Brain development and maturation



Gogtay et al (2004)<sup>5</sup>

The image above shows the mapping of grey matter over time, and helps to clarify that the human brain is not fully developed until a person is in their mid twenties. So for children and young people there is a 'sleeper effect' on some of the issues that are yet to appear from their initial injury.

In the face of ongoing problems both at home or in the classroom or general school environment, it is important to ascertain if there is a prior history of ABI. If this is the case, it is important to remember that it may not be a question that the child or young person WON'T do something, it may be that their brain CAN'T do it.

### **It should be remembered that:**

- 1 The vast majority of problems faced by a child with an ABI are initially invisible.
- 2 Problems may emerge with time (sometimes years).
- 3 Behaviour problems can emerge as a direct result of injury to the brain, or indirectly arising from the child being unable to cope with their physical, cognitive, social and emotional problems.
- 4 Just as each child is different, so is the manner in which an ABI presents for any given child; no two injuries will be the same.



A US study highlights the impact of behaviour ratings of impaired executive functioning [EF] and verbal memory deficits on educational outcomes following paediatric TBI. Behaviour ratings of EF appear to be a critical, unique predictor of educational outcomes in adolescents who have suffered a TBI.<sup>7</sup>



If TBI results primarily in a reduction of the rate at which work is accomplished, a detrimental effect on scholastic attainment might become apparent only gradually as the child's increasing chronological age begins to outstrip his reduced rate of school progress.<sup>8</sup>

## Physical and physiological impairment

Depending on the nature of the ABI, in some cases there may be a degree of physical and physiological impairment, caused by damage in the parts of the brain responsible for movement and motor skills. Because the brain is responsible for everything we do then there is a possibility that any aspect of human functioning may be affected.

**Major physical impairment** including difficulties in walking or gross disturbance of movement.

The visibility of these impairments enables staff and pupils to moderate their

expectations. However, in mainstream schools children with physical impairment may be subject to bullying.

## Problems with co-ordination, control and balance

which may only appear in certain situations:

- Perhaps less obvious than physical impairment, leading to tremulous movements which may increase with effort, poor hand-eye co-ordination and some clumsiness. (Potentially leading to misdiagnosis of dyspraxia alone)
- Motor co-ordination which becomes worse as the child becomes more tired.

**Visual and motor difficulties** – for some children this may mean that they have proprioceptive difficulties, and may be awkward and ungainly; this is due to the brain not being able to process where limbs are in relation to the rest of the body. This can lead to a number of issues in sports and PE, or activities that may require precise co-ordination.

## 'Unseen' physiological problems

As mentioned earlier in this miniguide, our brain is responsible for everything we do and therefore there can be some unexpected effects following ABI that can include any of the areas detailed below.

**Fatigue** is one of the most common disabilities following ABI. Think of the brain as a road network of connections and because some of those roads are now blocked, the child has to use alternative,

sometimes slower and longer, detours to achieve the desired outcomes; this uses more energy and ‘fuel’ causing debilitating and overwhelming fatigue. Typically seen as:

- Overwhelming tiredness and decline in functioning as the day, week or term progresses, despite sleeping well at night
- Extra effort required for cognitive processing or overcoming physical problems. This can vary depending on what has been required of the child that day or on the preceding days, causing good days and bad days
- The child perceived as lazy or unmotivated to engage in lessons or activities.

**Vision** can become impaired as a result of ABI, this can range from double vision or partial loss of sight, to problems with depth perception. Such issues may not be obvious as the child may compensate automatically, but may be apparent in terms of motor co-ordination. If a child has acquired their injury under the age of two, they may have no cognition of any impairment, as they their vision has ‘always been like this’.

**Hearing** can also become impaired following ABI. Hearing difficulties may give rise to poor attention in class and should be investigated and ruled out in the case of inattention. Damage that causes hearing problems may also affect the part of the ear that regulates balance, so be aware of activities where sense of balance is important, especially sport and PE.

**Taste and Smell** are other sensory impairments that can affect the child or young person following ABI, which can be devastating and dangerous. For example, the inability to smell gas and the loss of smell leading to loss of appetite and enjoyment of food.

### **Control of other bodily functions**

such as bladder control issues can mean the need to use the toilet more frequently or urgently, or both. If these issues are not explicitly known then children (and especially young people) can become embarrassed about having to ask to go to the toilet in class. This is where pre-planning and person-centred arrangements are helpful.

**Weight** A rapid weight increase can sometimes follow ABI. This can be due to injury to the part of the brain that controls appetite, leaving the child with little sense of satiation and leading to potential overeating. Combined with any gross motor impairments which lead to a less active day to day life, weight becomes difficult to manage and can lead to obesity.

### **Growth and sexual development.**

The hypothalamus and pituitary gland are parts of the brain responsible for secreting hormones. Occasionally these can be damaged as a result of ABI which can cause problems with hormone secretion.

**Growth hormone replacement therapy** may be needed if there is a lack of physical growth in a child or young person. Equally some children

may secrete too much growth hormone and be very large for their age.

**Sex hormones** are secreted from the pituitary gland and ABI can lead to early onset of puberty with secondary sexual characteristics emerging earlier than expected; for example young boys may develop pubic hair and voice changes, and in girls there can be early onset of menstruation as well other usual features of female sexual development. In contrast, there may also be delayed onset of puberty and exceptionally impotency in adolescent boys which can continue into adult life.

These issues can lead to:

- Bullying and mental health and/or wellbeing issues in relation to self-esteem and confidence for the young person
- Heightening self-consciousness, as the overall impact of these changes/differences will be readily apparent during changing time for sports, swimming, PE and so on. It is not surprising that those affected could be reluctant to participate in this type of activity. These changes perhaps have greater potential than previously described physical disabilities for heightening self-consciousness
- Greater vulnerability for some young people who have experienced severe ABI, as they may go on to have sexually disinhibited behaviours which can cause isolation from peers and friendship groups, as well as making them more potentially vulnerable generally in society.

**Epilepsy** can become an issue following traumatic brain injury, even if there was no prior history of seizures or absences. The majority of these young people will be on anti-convulsant medication which, in turn, has side effects such as occasional drowsiness or unusual behaviour.



*In one study of children conducted at a paediatric rehabilitation facility, the five highest ranked categories of sexual behaviors from a sample of 24 students were (1) masturbation, (2) sex talk, (3) attempted or actual 'petting/fondling', (4) attempt to solicit sex, and (5) verbal sexual threat.<sup>4</sup>*

## Intellectual and educational consequences

For many children the issues above do not occur unless there has been a very severe injury. It is far more common for those who have any degree of ABI to have consequential difficulties affecting cognition and learning. The ways in which the consequences of ABI become apparent in academic progress and attainment will vary, depending upon the severity of the injury, age at injury and the individual themselves.

Children affected by ABI are likely to have a constellation of cognitive and executive functioning issues; it is unlikely that their injury will affect just one area outlined in this section. Rather, the child may have any combination of severe issues in one or more areas, with lesser difficulties in others.



A study of TOMAL (Test of Memory and Learning) indicated that children who sustain moderate and severe head injuries have markedly impaired memory in both visual and verbal modalities. Specifically, TBI child demonstrates difficulties in the immediate recall of both verbal and visual material and remembering verbal information after a 30 min delay. Attention and concentration, as well as sequential, associative (i.e. cued), and free recall, are problematic for the moderate and severe paediatric TBI.<sup>6</sup>

### Speed of information processing

An ABI can affect processing speed.

Whilst this may be observed in movement and perhaps speech, more subtly it may impact on the speed at which the child can process and respond to information. Over time this may improve but there may be residual effects that have a cumulative effect on progress:

- Speed of writing is compromised leading to unfinished work
- Continually asking for things to be repeated
- Slow when changing lessons.

**Attention and concentration** are prerequisites for learning and academic attainment for any child or young person. Difficulties in maintaining concentration and being distracted by visual and auditory information are among the most common difficulties following ABI. Even if this was an issue pre-injury it is likely that after ABI the difficulties will be more noticeable.

It is important to be aware that what appear to be attention and concentration issues can actually be difficulties with other areas of functioning caused by ABI –

- For some children, changes such as a different classroom or initiating a new task can result in behaviour that manifests as attention difficulties, but is in fact the child unable to cope with the change or finding the task too complex. Loss of attention may reflect failure to understand the task due to processing difficulties and then lead to poor motivation and further inattentiveness
- Depending upon the demands of the lesson, some pupils may struggle to attend and then may fail to remember what has been taught, thus limiting progress and attainment.

**Learning and memory** – According to one study on ABI and memory – ‘memory is not a single function or entity, but an array of cognitive processes involving the acquisition, retaining, and retrieving of information’ (Gross & McIlveen, 1999).

In the context of this miniguide we are discussing memory generally, and it should be noted that there are different types of memory. Each is held across and between different areas of the brain so, for example, a child may have difficulty with working memory, but have no problems with recalling what happened during the summer break.

- Pupils affected by ABI may forget lesson content and/or instructions. As a result, homework may be forgotten, incomplete or wrong

- The child may forget where they have left something and genuinely believe that the item was stolen. The child with an ABI may not appear to recognise their own difficulties and so is likely to construct a sequence of, what seems to them, sensible events
- For most pupils affected by ABI, learning and memories secured pre-injury may remain largely intact. It is new learning that is hard to recall and integrate with prior learning. A child may be able to remember what they were taught previously, but could struggle to recall the lesson taught yesterday. Whilst seemly unusual, this source of confusion is a typical pattern for pupils with ABI and memory issues.

## **PONDER POINT**

***'How can I tell if the child has memory issues as a result of an ABI?'***

**It is hard to tell if a pupil is showing signs of functional disorder or motivational non-compliance, especially if the pupil is able to cover issues with compensatory strategies. It is acknowledged that distinguishing between memory and attention and other reasons for problems in the classroom can be hard. If the pupil is being consistently inattentive or forgetful, memory difficulties should be ruled out through appropriate assessment.**

**Speech and higher level language skills** can be impaired following ABI. It is possible that pupils with an ABI may have difficulties with articulation of speech due to impaired motor function of the physical elements that produce speech – the words and sounds. It is important to remember that the use of speech and language, and thereby conversation, is also dependent upon memory, attention and concentration and appropriate processing speed.

Other speech and language issues to consider are:

- Age at time of injury:  
– A child injured aged 3 or 4 may have issues coping with complex grammatical structures as this speech and language capability is not generally fully formed until a child develops to age 5 or 6 years. Similarly, injuries acquired after 10 years of age may result in problems with abstract thought and reasoning as these skills are generally not developed before this age
- Difficulties in finding the right words to express themselves
- Sustaining a basic conversation can be difficult especially if there is more than one other participant. In particular, this can cause difficulties in keeping track of extended classroom discussions.



## CASE STUDY

Matt had a brain injury from a skull fracture as a result of a fall from his high chair when he was a baby. He was taken to hospital at the time and sent home with the ‘bump on the head’ letter. Matt’s brain injury was finally confirmed when he was 6. His Mum sought a diagnosis through neurological support services and ABI charities, together with a neuropsychology report from a regional hospital. Mum felt that his educational needs were never properly met because, although Matt needed a lot of prompting with attention, concentration and behaviour, he was very bright. Because of his behaviour, Matt was placed into learning units where the academic ability of his peers was much lower. This had a detrimental effect on his self-esteem and progress.

## Emotional changes

Considering the profound and life-lasting changes that can occur even in the case of mild ABI, it is not surprising that emotional changes can occur:

- Rapid and often intense mood changes are not uncommon. The presenting features of the emotional impact can include: irritability, low tolerance to frustration, general moodiness and a tendency to react with out of proportion intensity
- Fear and anxiety may develop in pupils previously not affected by them. This may be due to concerns about an illness reoccurring or post-traumatic stress.

- Emotional reactivity, such as tearfulness or being quick to temper may be heightened as the child or young person comes to terms with their ABI prognosis and the potential personal, social and educational consequences
- As well as coming to terms with their changed abilities, it is possible that secondary symptoms of clinically high levels of anxiety and depression can also occur, together with low(er) levels of confidence, self-esteem and identity. Loss of interest and apathy may become apparent, which, in turn, may be misconceived as deliberate disengagement by the child
  - These clinically significant mental health issues can often be seen as the primary cause for changes in behaviour rather than the ABI itself.

## Ponder Point

***'This child was previously known to us for having social, emotional and behavioural difficulties, so what is the difference now?'***

***ABI may change the way a child or young person processes information, behaves and responds to the world around them. Consider how the child was prior to their ABI and how they present now; have their usual levels of social, emotional or behavioural difficulties changed?***

## **Changes in Behaviour, Self and Personality**

Personality changes can be bewildering for the parent, teachers and peers of a child following ABI; they somehow seem "different". Individuals who were once conscientious, friendly and sensitive can become indifferent and impulsive. Equally, independent and lively children can become dependent and lose initiative and self-confidence. Some of the most common elements of noticeable 'personality change' are:

- Affective instability
- Marked shift from normal mood to irritability
- Recurrent outbursts of aggression or rage that are out of proportion to precursory events
- Markedly impaired social judgement
- Uninhibited acts and verbalisation
- Perseveration (the repetition of a particular response [such as a word, phrase, or gesture] regardless of the absence or cessation of a stimulus).



*Personality change due to traumatic brain injury is characterised by a persistent personality disturbance that is thought to be related to the direct physiological effect of traumatic brain Injury (TBI). The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning [learning]. Personality change is a relatively common and critically important syndrome that complicates paediatric TBI.<sup>1</sup>*

## **Ponder Point**

### **'Isn't this ASC or ADHD?'**

**Many of the manifestations of ABI are similar to those found in children with Autistic Spectrum Conditions (ASC) and/or those with ADHD. It is possible for a child or young person to have secondary ADHD (sADHD) characteristics as a result of ABI. Has that child with the ASC and/or ADHD characteristics actually had an ABI in earlier life?**

**Neurodevelopmental diagnoses have their place and can support access to services and educational support – but they can equally mask the story of ABI and therefore possible wider long-term (developmental) implications, and hinder forward planning particularly in the context of significant transitions. So where possible try to unpick the story.**

**Self-image** can be an issue. In relatively few instances of ABI, the child or young person will have little or no insight into the changes of self following the injury. They will have little cognisance of the loss or changes in their abilities and skills. This lack of self-awareness can cause difficulties, as the pupil may not believe or realise there are issues or inappropriate functioning that need to be addressed in order to support their academic and social development.

Many pupils who are aware of the changes since their ABI (in their own ability and the way others perceive them) may start to have negative self-thoughts which intrude on their sense of self.

Other potential outcomes from poor self-image and others' jokes, are negative self-perception, sensitivity and emotional reaction. This maybe seen as normal classroom banter, but it can have a negative impact on self-esteem and confidence, and in some cases lead to angry outbursts in retaliation.

The pupil may begin to avoid tasks, become self-deprecating or behave disruptively. They may also be very reluctant to ask for help, as they see this as a failing on their part.

There may also be pupils with undiagnosed ABI, who have issues with self-confidence and self-esteem because they feel 'different' to their peers and are aware that they may not function cognitively in the same way. This can become most apparent following transition to Key Stage 3 (KS3), when organisation and planning skills should be developing.

**Behaviour** issues are the most common of all issues following ABI and can manifest in a manner of ways. Challenging behaviour can be as a direct result of the injury to the child's brain (the hypothalamus, which sits behind the frontal lobe, controls mood, anger, and libido) or an indirect consequence

of frustration, anger, and dismay at the difficulties the child or young person is facing.

## Ponder Point

**'This pupil has no issues after their injury.'**

**Not every child who has an ABI may present with negative behavioural issues, sometimes they are the model pupil. Just because they are the model pupil doesn't always mean they are performing to their full potential – could you be underestimating their progress and attainment potential because they appear to have no problems?**

**Where a child recognises their changed ability** they may become more easily frustrated and unable to see or accept their new limitations. Typical behaviours may include:

- Irrational outbursts and erratic temper
- Impulsivity
- Lack of insight and empathy
- Social disinhibition
- Ignoring acceptable social and moral conventions.

Some of these behaviours may emerge over time (sometimes years) as the cumulative effects of specific learning difficulties become apparent. As noted earlier, the transition to KS3 can be a particularly challenging time for pupils with ABI, and children who exhibited exemplary behaviour in KS2 may start to show increased and unacceptable

behavioural issues as more demand is placed on their reduced ability.

**Adolescence and ABI** can be a volcanic mix as during adolescence any direct impact of the brain injury on self-regulation may negatively interact with normal adolescent development, sometimes causing very challenging behaviour. It is during adolescence that over-sexualised and disinhibited sexual behaviours may become more apparent and problematic. (This could lead to safeguarding issues as a vulnerable young person may, by virtue of their vulnerability and disinhibition, put themselves or others at risk).



A study of clinically significant behaviour and executive function issues during the initial 18 months following injury in a cohort of children aged 3-7 years, showed significantly more externalising behaviour problems and executive function problems following injury that persisted through the 18-month follow-up. Minimal social competence difficulties appeared at the 18-month follow-up, suggesting a possible pattern of emerging deficits rather than a recovery over time.<sup>9</sup>



## CASE STUDY

Elliot was adopted when he was a baby having been taken into care by social services. Elliot struggled to keep up with other children in the class at school, almost from the start. When he was aged 8 it was diagnosed, through neurodevelopmental assessments, that he had acquired a brain injury as a 'shaken baby'. (Adoptive parents are not usually given any information about potential abuse prior to the child going into care).

Elliot's primary school was amazing. They had not had any experience of a child with an ABI but learnt all they could from his parents and worked closely with a coordinator from the Child Brain Injury Trust, who came to school and explained to the staff about Elliot's difficulties and what they could do to support him. Elliot's peers were also given an awareness session to help them understand why Elliot sometimes behaved differently to other children in the class, and why he would often just shout out inappropriately. His class teacher and SENCO put strategies in place to support his needs and offered differentiated learning for him.

When it was time to transition to KS3 Elliot had a 'gold standard' transition. The SENCO from the new school went and observed him in class, she also attended training about children with



ABI, so she was prepared to support him fully. Because of his memory problems, Elliot had additional taster days at his new school, and had an album of photos of his new teachers and classrooms, as well as a map of the school, to look at through the summer holidays.

After transition, the school arranged for Elliot (who had difficulties socialising) to attend a lunch time drawing club (set up just for him) to which he could bring two friends each day. The drawing club also supported the development of his fine motor skills.

Elliot's school also arranged for daily communication with home and, if he had one of his escalated behavioural outbursts, they would call mum for advice and gradually learned what his trigger factors were and how to de-escalate the situation.

These are just a few of the ways in which Elliot's schools sought to understand and support the needs he had as a result of his ABI. He has now progressed very well and is expected to achieve really good results in his exams; this is due to Elliot's hard work, his family having a meaningful input and the 'gold standard' approach of the school and its staff to help him progress and achieve the highest possible academic and social outcomes.



## Changes in social relationships

Friendships can be a key issue after a child has an ABI. Occasionally, established friendships can dissipate after the initial acute hospital phase is over. Sometimes the skills needed to maintain existing friendships and build new friendships may have been affected directly by the injury to the brain; this could include things such as:

- Listening skills
- Empathy
- Insight
- Ability to follow conversations.

It is not uncommon for new friendships to be with younger or older individuals, or those who have social or emotional difficulties. Due to lack of insight, adolescence can also be a difficult time, as described above, as the vulnerable young person may be more susceptible to the use and effects of drugs or alcohol. The changes in a young person might make it difficult for their friends to understand or relate to them because they are 'not who they used to be'. This can also lead to a decreasing friendship circle, loneliness and isolation.



Children with severe /moderate TBI demonstrate selective, long term deficits in their social problem-solving skills that may help account for their poor social and academic outcomes. Children who sustained a severe TBI between the ages of 6 and 12 years demonstrated less developmentally advanced social problem-solving on average four years post-injury than children with orthopaedic injuries not involving the brain. In addition, the developmental level of children's social problem-solving skills was related to important aspects of their adaptive functioning, including both social and academic outcomes.<sup>11</sup>

## Ponder Point

**'Some difficulties observed, such as social difficulties, can be the same as for children on the autistic spectrum.'**

**Many of the manifestations following brain injury are quite similar to those presenting in children with Autistic Spectrum Condition (ASC). This can relate to social skills and other behaviours and functioning such as perseverance and obsessive behaviours. However, it is important to understand that the behaviours are as a result of the injury to the brain and that other issues may become apparent over time. Therefore, is it possible that some children and young people have been wrongly diagnosed?**

## **Changes in family relationships**

**Siblings** often have a hard time adjusting to family life when a brother or sister has an ABI. Their lives have suddenly changed too, and can be affected in a number of ways:

- They may have been present at the event that caused the brain injury and could be affected by survivor guilt, or post-traumatic stress
- Often siblings are unconsciously sidelined during the acute hospital phase, leaving them feeling unloved and uncared for which can lead to mental health issues later on
- Siblings may also be required to become an additional carer within the home to support parents in caring for their injured brother or sister
- They may also find the change of personality difficult and disruption to home life hard to cope with and could be reluctant to ask friends to come to their home because they feel embarrassed, and then feel guilty for having these thoughts.

**Parents** will be going through a period of major adjustment. The life-changing instant that a child acquires a brain injury may have a profound effect on the whole family, and turn their world upside down.

Typical impact may include:

- Being a carer for their now disabled child
- Becoming their own child's 'best friend'
- Greater level of supervision required for their, perhaps, more vulnerable and immature child

- Taking on the role of expert and advocate to get the best therapeutic and educational support possible for their child
- Possible reduction in their financial circumstances
- Having less time for themselves which puts added stress on adult/partner relationships
- Guilt about the event that caused the injury, or even anger and blame relating to the cause of the ABI.

### **Ponder point**

#### **'Parents need your support too'**

**Sometimes parents enter a phase of denial after their child has an ABI. They are not yet prepared to accept that the dreams they had for the future may not be achieved. This, in addition to trying to cope with their changed circumstances, the extra strain on their time, relationships and additional medical appointments, can cause them to appear to be very demanding in their communication style with schools and teachers. As with any parent, they still want the best for their child, and their relationship with the school and their child's teacher(s) is even more important and needs to be nurtured, even where this can be challenging.**

It is important to understand that the range of impairments following ABI can make children and young people

'difficult to teach'. Equally teachers, and occasionally even parents, may not be fully aware of the nature or extent of the child's difficulties, especially considering that some may become worse over time as the brain is developing.

Good communication between home and school is vital for securing the best possible educational progress and attainment.



*Children with more severe injuries and lower pre-injury adaptive abilities, and whose families are coping poorly, are at greatest risk of long-term impairment in day-to-day skills, even several years post-injury.<sup>10</sup>*

## Practical steps

There is much that can be done to support a child with an ABI in school, many strategies will be part of the SEN toolkit in your school. The following basic information should be shared with the school staff team, in particular that:

- 1** There can be behavioural changes directly relating to ABI in children who are apparently coping, which may only emerge sometime after the initial injury.
- 2** Cognitive changes can emerge with time and children will often struggle more as the time since their injury increases, and they and their brains continue to develop and mature.

Special Educational Needs Coordinators, learning support staff and teachers can do much to assist the child in both special and mainstream schools. Among the

many things that schools can do are:

- Put appropriate strategies in place as soon as the child returns to school; do not wait to see how the child settles in as this can only exacerbate difficulties
- Allow a flexible approach to teaching, perhaps considering a differentiated and even occasionally reduced curriculum, where necessary
- Colour-code material and books to assist with organisation and planning
- Cue the student by name and check for attention when key information is given
- Consider what can be done to support sensory problems and minimise their impact
- Provide written instructions for tasks for the child to refer to
- Ensure homework tasks are explicit and clear, checking for full understanding.
- Allow additional time for processing of information and tasks
- Schedule frequent monitoring of progress and attainment to ensure that teaching is appropriately paced
- Encourage alternative strategies to deal with difficulties, especially for memory and organisation
- If appropriate, make special arrangements for examinations.
- Provide frequent encouragement
- Understand and deal with difficult behaviour by considering the context; understand the antecedent and adapt the learning and social context accordingly
- Check for and deal with any bullying; some forms may appear mild, but when it is constant and incipient it can be overwhelming.

- With the family's approval, provide peer awareness of the child's issues and difficulties, and seek their understanding and support for their classmate.

And finally – it is important to plan ahead for key transitions (pre-school to primary; primary to secondary; secondary to further education and beyond); and by implication to identify long-term possible challenges for the child or young person across their school career and to put in place suitable strategies of support as required.

### Final Ponder Point

**For the majority of children who have had an ABI, school will be their main source of rehabilitation once they are well enough to return; relearning about the world around them and how they fit in. How well equipped are you to provide this ongoing rehabilitation and support?**



## **Further Information**

The Child Brain Injury Trust is a national registered charity that supports families affected by childhood acquired brain injury, no matter what the cause of injury.

### **Learning and Information**

An extensive library of information and learning is available:

- Regional Workshops, often offered without charge to education professionals

<https://childbraininjurytrust.org.uk/events/categories/workshops>

- On demand E-learning webinar library, with over 30 topics covered, also offered without charge

<https://childbraininjurytrust.org.uk/how-we-help/e-learning-library>

- A range of Factsheets looking at a variety of issues faced by children and families following ABI

<https://childbraininjurytrust.org.uk/factsheets>

- In-service training for up to 16 delegates

- <https://childbraininjurytrust.org.uk/how-we-help/in-service-training>

For more information please email [learning@cbituk.org](mailto:learning@cbituk.org)

Or call 01869 341075

### **Family Support**

Any family affected by childhood ABI can receive practical and emotional support from the charity. It is easy to self-refer, please just contact:

Information, Referral and Advice Line

Or call 0303 303 2248

## Mini Guide References

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- <sup>3</sup> Residual Attention Deficits Following Childhood Head Injury: Implications for Ongoing Development. Anderson & Pentland (2010)
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- <sup>10</sup> Understanding Predictors of Functional Recovery and Outcome 30 Months Following Early Childhood Head Injury. Anderson et al (2006)
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## About nasen

nasen is the leading UK professional association embracing all special and additional educational needs and disabilities. The organisation promotes the education, training, development and support of all those working within the special and additional educational needs and disabilities sector. Membership of nasen is an invaluable source of advice, offering an exclusive and vital range of benefits to support teachers, governors, teaching assistants and the entire education support network in the delivery of high-quality inclusive practice.

Visit [www.nasen.org.uk](http://www.nasen.org.uk) for more information about what nasen can do for you.

## Child Brain Injury Trust

In addition to supporting children and families affected by childhood acquired brain injury, the Child Brain Injury Trust also delivers Workshops, online webinars, downloadable Factsheets and other information resources for education staff, to enable greater awareness of this under acknowledged disability.

If you would like to learn more please connect with us:  
[www.childbraininjurytrust.org.uk](http://www.childbraininjurytrust.org.uk)

Advice, Information and Referral Line  
0303 3032248

Email: [learning@cbituk.org](mailto:learning@cbituk.org)

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