Meningitis Research Foundation

Meningitis now

Emotional and behavioural effects of ABI caused by meningitis and septicaemia

The experience of being seriously ill and in hospital is likely to be very stressful for a child and also for their parents and siblings; research has shown that stress and anxiety can lead to changes in behaviour [1 - 3]. For many children, these changes will be temporary, lasting for several weeks or months, but usually improving over the year after the illness.

Some of the common difficulties that can occur in the early recovery period:

- **Tiredness** is very common in the first few weeks of recovery and can lead to changes in behaviour. Older children may want to return to their usual activities as soon as they feel well, but it is important that they have enough rest in order to recover properly. Returning to school on a part-time basis at first is often a good idea. Younger children may not be able to explain or understand their tiredness and can become irritable or restless. It is really important that you talk to your child's school or nursery about what has happened and how your child can be helped to return.

- **Changes in behaviour** are quite common in the early recovery period. Temper tantrums, bed wetting, nightmares, mood swings and concentration difficulties are probably due to a combination of the physical and psychological effects of the illness, and tiredness often makes them worse.

- **Anxiety** about the time spent in hospital and the fear of possibly being ill again can affect some children in the early recovery period. If your child is old enough, it is usually helpful to encourage them to talk about their worries and concerns. Parents can sometimes find this difficult as it is a reminder of the traumatic experiences that they have also had. If anxiety persists, for the child and/or the parents, it can be beneficial to talk to someone outside the family or to therapists such as counsellors. For children who find it difficult to talk, or for young children who are not able to explain how they are feeling, art, play or music therapy can be used to help these children express their thoughts and anxieties.

Although these problems are usually temporary, it is important to discuss any concerns you have with the paediatrician 4 – 6 weeks after discharge from hospital, or with your GP if you have concerns after this time.

Longer term problems

Meningitis and septicaemia can be a cause of acquired brain injury (ABI). This is an injury to the brain that has happened after birth.

If a child has an ABI as a result of meningitis or septicaemia behaviour changes may persist, or new difficulties that were not evident in the early months of recovery may become apparent later on. These can have a significant impact on a child's ability to settle back into school and social life.

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If you are concerned about changes in your child's behaviour, it is important to talk about them with your GP, health visitor or child's teacher. It may be necessary to refer your child to specialised services that can provide more appropriate treatment and support.

Common longer term behavioural difficulties that can happen after ABI:

- **Apathy, lethargy, dependency and poor motivation** can be caused by damage to the brain mechanisms that are responsible for arousal and initiation of activity. There can be an assumption that children behaving in these ways are lazy and disinterested, particularly in school. However, because these behaviours are unlikely to cause disruption in the classroom, they can be overlooked by teachers and result in these children not being properly supported to reach their full potential, both academically and socially.
- **Anger, irritability and aggression** can be caused by damage to brain mechanisms that control behaviour, but can also be exhibited as the child's response to being ill and having difficulty in understanding what has happened.
- **Impulsivity, disinhibition and sexual inappropriateness**. As a child gets older, impulsivity and disinhibited behaviour can put them at risk of harm. A lack of insight into the consequences of such behaviour can cause friction between the child and their parents, teachers or peers. These behaviours can also isolate them from friends because they cause embarrassment.
- **Obsessive behaviour and inflexibility** can make it difficult for children to cope in different or varied situations as they find it hard to be adaptable or flexible. This can have a significant impact, particularly in social situations.

Common emotional difficulties that can happen after ABI:

- **Loss of confidence** is very common and children will need lots of encouragement and understanding to help them cope with the variable impact of the ABI.
- **Mood swings** can be difficult to understand. The child may laugh or cry very easily, and suddenly switch from one emotional state to another.
- **Depression, anxiety and a sense of loss are common**. Depression and anxiety may be due to physical injury to the parts of the brain that control emotion, but they may also be due to an understanding of the impact that meningitis or septicaemia has had on their life and an insight into the long-term, permanent difficulties there will be coping with the after effects.

After ABI, long term changes in behaviour rarely remain stable. Children may grow out of certain behaviours and develop more appropriate ways of responding, or the behaviours may be replaced by other inappropriate, but different ones. There can be different reasons for behavioural and emotional changes and an understanding of these can help to manage them effectively.

Reasons for behavioural and emotional change following ABI

Neurological damage to the brain can result in direct behavioural and emotional changes. The frontal lobes are responsible for the ability to self-regulate behaviour. If this area of the brain is damaged then children may lose the ability to regulate or control some aspects of their behaviour. As the brain takes over 20 years to fully develop, some changes may be evident immediately after the illness and others may appear at a later stage as the various functions of the brain mature.

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- **Psychological reactions to disability or life changes** can affect behaviour. Although neurological damage to the brain can directly cause changes in behaviour, many changes are actually due to the child's reaction to their initial illness and the consequences of it. If a child has been left with after effects as a result of meningitis and septicaemia (whether they be behavioural or physical) they can suffer significant loss: the loss of independence, previous academic or sporting ability, friends and social status. This can have an impact on their self-image and emotional state, leading to feelings of failure or frustration.

- **Cognitive and communication difficulties** can happen as a result of ABI and cause a high level of frustration for a child. This can lead to changes in behaviour as the child struggles to communicate their frustration and distress. "A child's behaviour is a way of coping with the world and its frustrations. Children with ABI frequently have communication deficits, along with a range of cognitive difficulties, and these are exacerbated by fatigue, anxiety and confusion. Whenever any of these negative feelings are experienced, it is often not possible for the child to talk fluently enough to express this, or to say what he would like to have changed. Behaviour is often his only language; he does not necessarily choose to misbehave but may not possess any other skills in certain situations." (Walker and Wicks, 2005)

- **Pre-injury behaviour** can have an impact on behavioural and emotional difficulties that happen after ABI. A child's personality and behaviour before the illness, and also the family dynamics, can influence behaviour following ABI. It is important for parents and teachers to take this into account, and consider if behaviour or reactions to situations have changed since the child's illness.

- **Environmental factors** can have an impact on a child's ability to cope with changes following ABI. A positive and supportive home and family environment is even more important to a child with ABI. The parents may need extra support to deal with new behavioural and emotional changes, especially if they themselves have other problems or stressful situations to cope with.

- **Medication**, for example, anticonvulsants, may affect a child's behaviour and also their learning ability. If changes are noticed that could relate directly to medication, it is important that these are discussed with your child's doctor.

How to get help for your child

It is really important to report any concerns about your child's behavioural or emotional difficulties to your GP, health visitor or child's teacher as soon as possible. Make sure you mention that your child has previously been ill with bacterial meningitis and septicaemia and take a copy of your guide and journal with you along with this factsheet when explaining your concerns.

If difficulties continue, ask your GP for a referral to Child and Adolescent Mental Health Services (CAMHS). Children, young people and their families can be referred to CAMHS if they are finding it hard to cope with family, school or social life.

CAMHS are specialist NHS services. They offer assessment and treatment when children and young people have emotional, behavioural or mental health difficulties. Clinical psychologists can offer a wide range of help regarding ways to manage your child's behaviour. If the problem is serious then your child may need to see a child psychiatrist.

It is usually your child's GP that will make a referral to CAMHS, but your child's school can also do this. At school an educational psychologist can assess the needs of a child with ABI and help to ensure that the child's specific needs are met through an individual education plan (IEP). It is usually the head teacher at your child's school who will make this referral.

Please see our fact sheet "Education – your child's rights" for further information.

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Further sources of information and support

The **Brain Injury Hub**, written by The Children's Trust, contains an extensive amount of information on all aspects of brain injury, including emotional and behavioural difficulties:

http://www.braininjuryhub.co.uk/

Headway is a charity that provides information and gives support to people affected by brain injury:

https://www.headway.org.uk/Emotional-and-Behavioural.aspx

The **Brain and Spine Foundation** is a charity committed to providing reliable information and support to people living with neurological conditions across the UK. Within their website is a site specifically for children and young adults who are living with ABI:

http://www.aboutbraininjury.org.uk/problems_an_ABI_may_cause.aspx

The **Child Brain Injury Trust** is a charity providing non-medical services to families affected by childhood ABI across the UK. These services include training for parents and teachers on understanding the needs of children following ABI:

http://childbraininjurytrust.org.uk/

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Brain Injury Hub **http://www.braininjuryhub.co.uk/**

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