

Understanding and Managing Fatigue

The Child Brain Injury Trust is a national charity supporting anyone affected by childhood acquired brain injury. The following information has been developed to help the reader understand more about brain injury and some of the associated issues. Every effort has been taken to ensure the information is accurate and up to date. If you require more immediate support or assistance please contact our **Helpline 0303 3032248** or email helpline@cbituk.org where we will be able to respond to your specific enquiry and offer support.

Fatigue

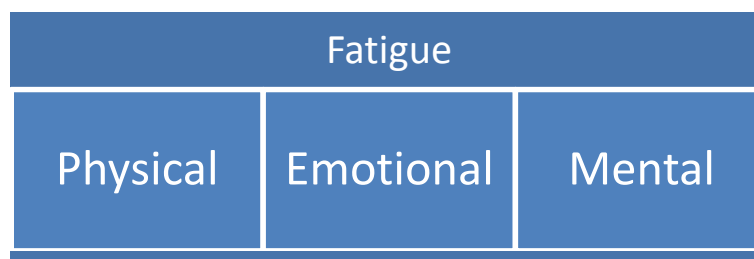
This Factsheet is to help you understand why your child may be very tired (fatigued) following an acquired brain injury (ABI), and what can be done to support them.

What is fatigue?

Fatigue is an overwhelming feeling of weariness, tiredness, exhaustion and lack of energy and is common after acquired brain injury. The severity of the levels of fatigue and its impact can, like an ABI itself, vary from person to person.

Why is fatigue common after a brain injury?

Acquiring a brain injury, like any other major illness, will require the body to work hard to try and replenish resources and regain fitness. However with an ABI there is a more complex reason for fatigue.



- **Physical**
 - Muscle weakness following illness or injury may mean that physical movements require greater levels of energy to complete simple tasks
 - This type of fatigue is likely to improve over time as physical strength is regained
 - Getting tired after physical activity
 - PE at school, playground games, going out with friends, getting dressed, feeling more tired after school, at the end of the day or toward the end of the week
- **Emotional**
 - Feeling overloaded and overwhelmed by the enormity of what has happened and sometimes with the effort to process the world around you
 - Getting more irritable and frustrated and having less patience

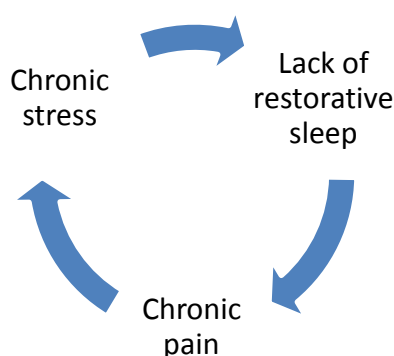
- **Mental**

- A lot of young people after a brain injury have slower speed of processing: difficulties concentrating and remembering things and difficulties with planning and organisation. These challenges will impact on thinking skills and how tired a child’s brain feels, leading the child to experience:
 - Headaches and feeling exhausted after concentrating
 - Information overload and feeling ‘blank’
 - Being unable to think quickly enough, a bit like a mental “fog”

Once physical, emotional and mental reserves are used, fatigue sets in. The experience of fatigue is a very subjective issue and will be felt differently from person to person and even over the course of a day. As one young person said *“How can I get anyone to understand all this [fatigue] when I have no proof of how I feel?”*

Signs that a young person is suffering from fatigue may typically be:

- Getting very tired after physical exercise
- Struggling to get out of bed in the morning
- Getting headaches and feeling exhausted after concentrating, even after short periods of time
- Information overload and feeling ‘blank’
- Slurred speech
- Blurred vision
- Being less coordinated
- Being irritable and having less patience
- Being different on different days
- Delays in processing and responding to information



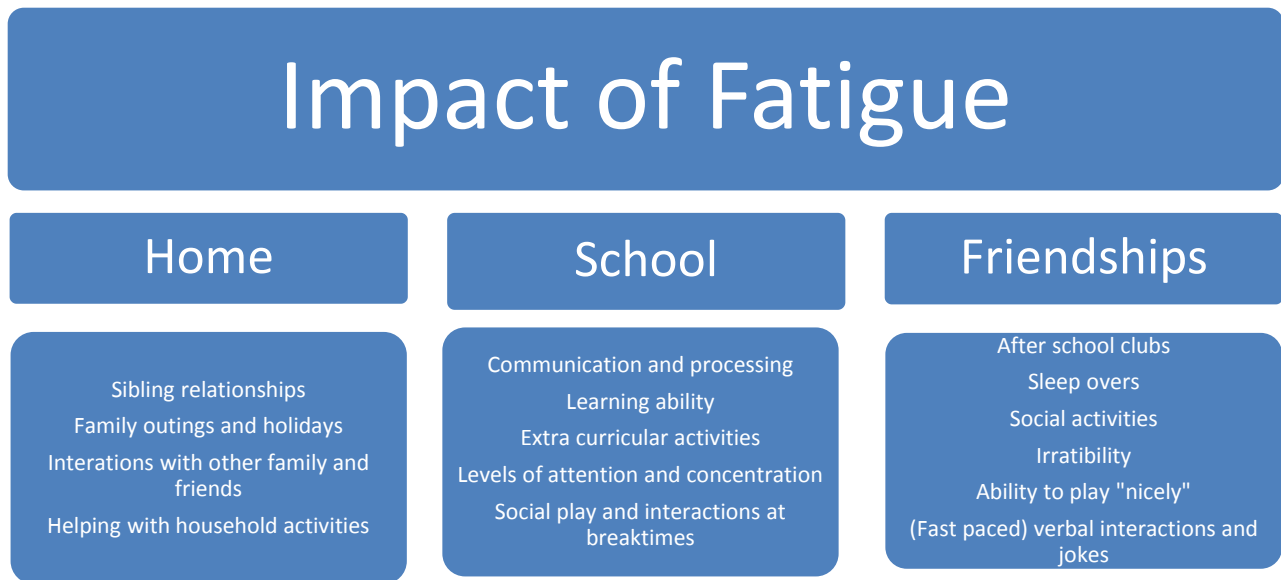
Fatigue can also be caused by other factors which may feed into one another and are not necessarily directly related to an ABI such as:

- Lack of regular and restorative sleep
 - Common after ABI
- Chronic pain
 - As a result of their illness or injuries
- Chronic stress
 - Such as fear of returning to school
 - Exams
 - Domestic situation

Sleep and fatigue

Fatigue is often aggravated when your sleep is poor. After a brain injury it is often difficult to get to sleep - or you wake and struggle to get back to sleep during the night and then feel unrefreshed in the morning (see Factsheet on Sleep issues).

Impact of fatigue



Sometimes issues related to fatigue can be mistaken for the child lacking motivation to engage in tasks and activities, or perceived by others as just being "lazy".

Often in school parents are told that their child "must try harder".

But they are simply just fatigued.

What can be done to assist fatigue?

Keeping an *Activity Rest and Sleep Diary* can help to understand any specific causes of fatigue. The list below are all the things that could potentially impact on the child or young person's fatigue:

- A physical injury, specific activities, environmental factors (climbing stairs for example)
- The child or young person's ability to know and understand when they are tired and to stop and rest
- Specific lessons in school
- New medicines

An Activity Rest and Sleep Diary could also highlight:

- What makes fatigue better or worse?
- How is the young person's sleep and/or mood across a day or a week?
- Are they in pain?
- And whether a specific event has affected fatigue levels; for example, a big family event at the weekend.



Keep a diary for a few weeks and see if any patterns or trends appear; this will help to decide what can be done to help reduce levels of fatigue.

Once you have identified any patterns or specific causes or difficulties with fatigue, agree with your child one or two goals that they would like to try and work towards, for example:

- To be able to complete a whole lesson/day/week at school
- To be able to join afterschool club such as Scouts, Brownies...
- To be able to have the energy to go and meet their friends
- To be able to play with their siblings without getting tired and irritable

Think with your child about how to achieve the goal. In particular think about who needs to be part of the plan (e.g. family members, friends, teacher(s), the child themselves) and what they need to do to work to achieve the goal.



With any area of difficulty following an ABI, there is a simple rehabilitation cycle that can be followed, this ensures overcoming difficulties following an ABI can be constantly reviewed and changed when appropriate.

This is the basic framework that the healthcare professionals supporting your child should be working to and you can use it at home too.

Strategies to help manage fatigue

Don't try to fix everything at once - You and your child need to decide what problems or issues are most important, you can't fix everything at once, so focus on the things that are either easiest to overcome or will make the biggest difference.

Good days, bad days - Try to remember that your child may have good days and sometimes not so good days and take account of this when you are encouraging them to achieve their goals.

Plan ahead - Plan the week as a whole, both home and school activities, and take in to account things like family gatherings and holidays.

Support within the family - Help siblings to understand about potential fatigue and how to support their brother/sister when they get tired and don't want to play or are irritable.

At school

Using a timetable, ask the child/young person to write down all the things they do in a week at school, and use a highlighter pen to show:

- When they are feeling tired, remember to include school subjects, times of day, places, people and situations. You might see a bit of a pattern and it is useful to show teachers/parents.
- Look at where they can make changes to their weekly timetable to save energy.
- Have a discussion with the teacher about whether it would be possible to drop particular activities or make changes to when the activities take place across the week. Also where possible include more time for relaxing and fun things and if needs be some 'quiet time' at key times of low energy / high fatigue in the school day.

Other strategies for school:

- Graduated return to school post illness/injury
- Have a “timeout” card, so that when the “reserves” have been used up (or preferably before) your child can have a “brain break”
- Provide differentiated work to reduce the amount of writing, language processing and allow more time
- Provide homework via email or on USB stick
- Chunk (combine a small group of tasks or activities) information and allow rest time in between sections
- Reduce the amount that has to be physically carried around school
 - Perhaps have two sets of reference books, one for school and another set at home
 - Use a locker for items not required for each lesson
- Ensure plenty of food and drink is made available
- If possible group lessons/classrooms physically closer together

Friendships and social life

Fatigue can have a huge impact on many other difficulties following acquired brain injury and one area that can suffer is friendships and social life. This is because children and young people may be just too tired to get involved in social play and activities. Also it takes a huge amount of concentration and processing to hold onto conversations with friends, most of which are fast paced, tangential (going in one direction and then another) and full of banter and jokes. A lot of young people with brain injury simply zone out from these conversations, finding it too difficult to keep up with the topic of conversation.

- Encourage them to choose their friendships carefully and have friends who understand that they may not always be able to keep to social arrangements or feel like going out and being friendly.
- Help the young person to explain to friends that they may have difficulty with keeping up to speed during fast flowing chatty conversations if they are tired, especially when they have late nights and are in noisy environments.
- Try to keep some energy in reserve for social activities – it is an important part of growing up – perhaps just as important as school.

General Strategies:

- Try to include physical exercise across the week (although it is difficult when you are constantly tired, if they are activities that your child naturally enjoys, it may not feel like such a battle).
- Remember to chunk all activities with rest at home as well as at school.
- Sometimes young people with an ABI lack the insight to know when they are tired; help them to recognise the signs of fatigue and know when to stop for a rest.
- Encourage restorative sleep patterns.
- Remember some medications may have a sedative effect and take this into account as well when planning the day/week.
- Try to ensure stress levels are managed within the home and at school.

Chill out and relax

Being able to chill out and relax is an important strategy to help reduce fatigue and aid restorative sleep, so make sure you also include this as part of your fatigue management strategies.

- Help to chill out by:
 - Lying on a bed and listening to music
 - Taking a bath with relaxing bubbles and aromas
 - Simply just lie down in the bedroom
 - Go for a walk and take in the world around you
- Learn relaxation techniques
 - *Relaxing from Head to Toe.* Scrunch up every muscle in your body from the tips of the toes to the top of the head; then, gradually relax each tiny set of muscles starting at the tips of your toes, through the feet, into the ankles, the calf muscles, knees, thighs.....right through to the muscles in the face and the top of head....
 - *Mindfulness.* This is a method where a person tries to block out all the input from their surroundings – noises, sights, etc, and concentrate purely on breathing, and reducing the speed of their breathing, blocking out all other thoughts.

For some children their fatigue will reduce over time as their rehabilitation continues and they regain their physical strength, although sometimes the effort in finding new routes to do the things the child used to do, may always cause mental fatigue.

For further help and support on issues relating to fatigue please contact the Child Brain Injury Trust **Helpline 0303 3032248** or email **helpline@cbituk.org**

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