



Helping children live well with brain tumour-related fatigue

brainstrust information sheet

Know Hows are published by *brainstrust* to help people living with a brain tumour to understand current topics. They are produced with input from relevant scientific and clinical experts and are written in a way that should help you to understand often complicated topics. This Know How has been specially created for parents and caregivers of children with a brain tumour.

If you have an idea for a Know How, then please let us know.

If you have any queries, don't forget you can talk to one of our support specialists on **01983 292 405** or email **hello@brainstrust.org.uk**.

Why do we need this Know How?

We know that one of the most frequent and distressing problems described by people living with a brain tumour is fatigue. But brain tumour fatigue is different. It occurs with emotional, cognitive and behavioural problems, and it can be due to neurological dysfunction, treatments, mood disturbances or supportive medications.

What do we mean by *fatigue*?

Fatigue is a physical, emotional and/or mental tiredness that does not go away completely. It is often experienced as overwhelming. It is very different from everyday tiredness, because it lasts longer and can come on without warning. It has a big influence on everyday activities and can make even small chores or routine tasks seem impossible.

Fatigue can last for a very long time (months to years), even after completing treatment for a brain tumour. Fatigue is known to be one of the most difficult side effects of brain injury and cancer treatment.

Strategies to support your child

We were kindly provided some insight about how to manage fatigue by the head occupational therapist at Royal Marsden Hospital, Maria Denise Pessoa. Occupational therapists hold a wealth of information to help your child live well beyond a brain tumour diagnosis. Get in touch with your clinical team to organise an appointment to see an occupational therapist.

Unfortunately, we cannot cure brain tumour-related fatigue, but we have some tools to manage it. One of the strategies that may work for you or your child is using the 5 Ps of energy conservation:

Planning

Planning actually means writing up a plan or schedule of the activities that are intended to be accomplished on a given day. When writing the activities down, it is useful to try to identify which activities will demand more or less energy. It is helpful to keep in mind that activities that include standing up, moving around or

maintaining concentration for long periods of time are the ones that demand more energy.

Prioritising

There is no secret to this one. Prioritising actually means choosing the most important activities from your plan. This means focusing on the most important tasks and perhaps identifying the ones that may be postponed or delegated to someone else to do or help with. When prioritising, remember that the most important activity for you may not be the most important activity for your child. The more motivated the child is to perform a certain task, the more likely they are to be inclined to complete it.

Pacing

Pacing has two different aspects in fatigue management. One of them is indeed not rushing and allowing the child to take their time to complete a certain task, explaining to them that it is okay to do tasks more slowly and to not complete a certain task as quickly as their siblings or friends. The second aspect of pacing is to introduce regular breaks and time for recovery, especially during longer activities, such as going out to the park or attending school. If your child is struggling to accept that they need to stop and recover, try implementing some routine in which rest is reframed as a fun task, such as yoga time, a meditation session or playing 'sit still like a frog' with eyes closed.

Positioning

Positioning is all about being aware of which position your child will adopt when performing a certain task. Opt for positions that involve sitting down rather than standing up and those that offer support to other areas of the body, such as their back and arms. When we choose supportive positions for a certain task, the child is able to focus more energy on the task itself rather than waste their energy trying to maintain their position standing up or walking around. If your child wants to do some baking, for example, it

is a good idea to have them sitting at the table with all ingredients within their reach. This way, your child will focus on the activity and direct their energy to the tasks rather than waste energy standing up and walking around the kitchen to fetch ingredients. Your occupational therapist can help you with identifying which equipment might benefit your child and help them save energy in everyday activities, such as showering and going to school.

Permission

Permission also has two different aspects when it comes to energy conservation. One of them is understanding that it is okay to ask for help and for your child to allow themselves to be assisted by someone else. The other aspect of permission is having a chat with your child and explaining that they are allowed to have a rest and break times, and that they are not expected to perform or be as quick as other kids or their siblings.

Ask your child

- What are you struggling with the most?
- What do you need help with?
- What can I help you with?
- What activity do you want to do today?
- What helps when you are really tired?

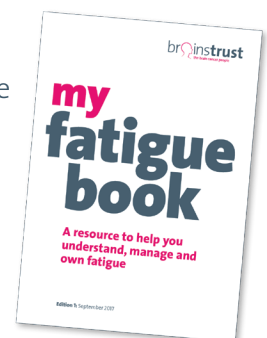
Contact

You can call, write, type, text. Email for help and support: hello@brainstrust.org.uk.
Telephone: **01983 292 405**.

Other helpful links

Our fatigue toolkit is a great resource for parents to understand a little more about fatigue and learn some strategies. You can download a copy online via the link below or get in touch with *brainstrust* to order a hard copy.

brainstrust.org.uk/fatigue



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