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Ask the Expert Information Sheet

Helping Your Child Understand What is Happening and Providing a Sense of Control

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For additional Information Sheets or to learn more about other brain tumour topics, visit www.BrainTumour.ca

Brain Tumour Foundation of Canada Information Sheets are provided as an informational and educational tool and are not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute for medical care. We urge you to seek specific medical advice on individual matters of concern.

Brain Tumour Foundation of Canada is generously supported by individuals, corporations and employee groups. It is through the tireless dedication of donors that help is available for anyone affected by a brain tumour, including patients, survivors and their loved ones.

Being in the hospital removes a child from the familiar surroundings that often help them feel comfortable, confident and in control. Loss of this control may result in your child feeling confused, worried, scared, withdrawn, frustrated or angry. As your child's caregiver, there are things that you can do to ease your child's anxiety. Preparing him or her before treatments and procedures may help your child cope with the anxiety, and may even relieve some unrealistic fears he or she may experience. It is important to give accurate, honest and age-appropriate information to your child, not only to maintain trust, but also to help him or her cope with upcoming treatment(s).

You know your child the best and how your child will cope with new information. Many times, children benefit from knowing what will happen in advance. You decide how much time your child needs to be emotionally prepared. Some children need a lot of time to absorb and understand, while others become anxious when learning the information too far ahead of time. Let the health care professionals know what strategy works best. Child life therapists are available to help prepare your child in a way that fits best with his or her needs and level of understanding. If a child life specialist is not available, ask your health care team who can help.

Therapeutic play is a useful way to explain information and prepare children for medical procedures, surgeries and treatment. Child life specialists use hospital supplies, doctor play kits and body outline dolls to help teach and support children. Older children can benefit by seeing photographs, a demonstration on a doll and/or talking about what they will see and experience.

It's important to frame questions that empower your child to exercise control and respect their choices. For example, offer choices such as, "Do you want your pink medicine or the white medicine first" instead of "Let's take your medicine, OK?" This last question is not really a choice. Some children would like to "help" during small medical procedures, such as bandage changes. This allows them to feel valued in the choices they have made while minimizing their distress.

Encourage your child to participate in his or her self-care as much as possible. An example would be to keep up your regular home routine and expectations for cleanliness and oral hygiene. This helps to empower your child. Another strategy is to create a schedule that can be placed in the room or on your hospital door. Family and health care professionals can fill in the schedule, so that you and your child will know,

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you are **not** alone

as much as possible, what events are planned for the day, e.g. meals, rest, family time and therapies. This schedule provides structure for the day and enables everyone to know what is happening.

Preparation for Surgery

Prior to surgery, your child's primary doctor or a delegate will explain the surgical procedure and any risks/complications involved. Be prepared to have a list of your questions regarding your child's surgery. You will be asked to sign a consent form after your doctor has explained things, once all your questions have been addressed and you have an understanding of the surgery.

There may also be questions related to your child's past surgery and anesthetic history. Pre-operative blood work and urinalysis is usually required. Your child's nurse or physiotherapist may also explain about special deep breathing exercises that will be necessary after surgery. The nurse may show you where you may first visit your child once surgery is over.

The anesthesiologist may visit prior to surgery. He/ she may ask questions concerning your child's general health and any specific problems. He/she will answer any concerns or help you deal with anxieties you may have with regards to the anesthetic.

An IV may be started shortly after admission to the hospital in order to administer anti-inflammatory medications, such as corticosteroids, to reduce any swelling around the brain. The IV will also be used for hydration as your child will be fasting leading up to the surgery.

The night before the operation your child will not be allowed to eat or drink after midnight, as this would interfere with safe anesthetic care. If your child eats or drinks during this time, the operation will be postponed to another day.

Your child may have some hair removed at the operative site at the time of surgery. Care will be taken to remove only what is necessary.

Preparing Your Child for Surgery

You will be prepared for your child's surgery by your health care team. Your child may look to you for reinforcement of what has been told to him/her as well as for constant support. Look for cues from your child if he/she wants to discuss the procedure with you further. Encourage your child to talk about the operation and ask questions and then give simple explanations using words he or she understands.

Remember that a description of what will happen when your child wakes up from surgery is also important. Be careful of using terminology that could have more than one meaning such as saying: "put you to sleep" instead of the preferred "a special kind of sleep." Most children need to know that they will not wake up during the operation but when it is over. Be honest in your explanations but do not give preconceived notions about what your child will feel. Words such as "pain," "hurt" and "scary" need not be used unless your child vocalizes them.

Additional support, information and education offered by Brain Tumour Foundation of Canada:

Adult, Pediatric and Non-Malignant Brain Tumour Handbook available in English and French

“A Friend in Hope” children’s storybook available in English and French

20+ Adult Support Groups across Canada (in-person and virtual)

Toll-free information and support line

BrainWAVE Pediatric Support Program

Print BrainStorm Newsletter
Email Newsletters:
• E-BrainStorm
• Peace of Mind

“Grey Matters” Blog

All patient resources are available free-of-charge in Canada. Call 1-800-265-5106 or visit www.BrainTumour.ca for additional details and information.

Fear of the unknown is usually much worse than the actual truth. By preparing your child for surgery, in partnership with your team, you will help make the experience less stressful for you and your child.

ABOUT THE AUTHORS:

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