Brain Tumour Australia Information

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Kids Corner

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Understanding the topic of brain tumours can be challenging for both adults and children. Learning the differences between the term primary tumour or secondary tumour can be even more confusing. Like any other tumours or cancer, they can usually be treated. However, sometimes they cannot be cured.

Facing a diagnosis of a brain tumour is daunting enough.

But for some families there is additional trauma because the news has to be shared with children.

The child may be the person diagnosed with a tumour or they may be the sibling of another child with a brain tumour diagnosis. Or they may be the child in the family where a diagnosis of a brain tumour has been received by a parent, a grand parent or a special adult in their life.

When reaching the decision to speak with children about a brain tumour and how the diagnosis and subsequent treatment may effect the person with the diagnosis and the family as a whole, the first step is to make sure you feel comfortable talking about the diagnosis.

You know your child better than anyone else. You can recognise some of their fears and concerns. If this task seems daunting then seek professional help. Through communication your child can better understand that brain tumours are like any other disease. This is an important aspect in assisting children cope if a family member has symptoms or problems associated with a brain tumour.

When a Child is diagnosed with a Brain Tumour

Childhood brain tumours

- Childhood brain tumours are a diverse group of diseases characterized by the abnormal growth of tissue contained within the skull.
- Brain tumours can be benign (without cancer cells) or malignant (contains cancer cells).
- Other than leukaemia and lymphoma, brain tumours are the most common type of cancer that occurs in children.
- Treatment may be different for children.
- There are many types of brain tumours that occur in children.
- Treatment and chance of recovery (prognosis) depend on the type of tumour, its location within the brain, the extent to which it has spread, and the child's age and general health.

Various community programs exist to provide support, either by peers or sessions with professional counsellors to aid in children obtaining understanding about the brain tumour journey. Whether personally diagnosed with a tumour; or if the brain tumour diagnosis occurs for a family member eg. Parent or sibling; children have special needs .

Talking to a child about their brain tumour diagnosis

Being told that your child has a brain tumour diagnosis is perhaps the most difficult news a parent will ever have to face.

Depending on the age of the child, parents have to decide

- When should a child be told?
- Who should tell a child?
- What should a child be told?

Historically children may have been kept in the dark about their diagnosis, even the treatment and the prognosis may not have even been mentioned between parents. Even today in 2006 well meaning family and friends will offer a wide range of `advice' in relation to speaking to children about their brain tumour diagnosis, some of it good and some of it not so `good'.

Children are incredibly perceptive. Even toddlers have been heard to ask questions and make statements about their health, treatment and life and death issues.

There is a vast amount of documented evidence that show that most children are aware that they have a serious illness and also are aware when adults try to protect them from learning about that illness.

Not feeling well, falling over, not being able to do things that they would normally enjoy, all are signals to any child that something not quite right is occurring. When visits to the doctor, scans, MRI's, scans, blood tests or other medical procedures happen or are scheduled to happen, it usually does not take long for a child to ask some pretty serious questions. Children also are prone to sense the anxiety, stress and fears of family members, health professionals and friends.

Whispering or speaking ceasing when a child enters the room, extra phone calls, conversations behind closed doors, frequent tears and anger can all signal a child that something pretty serious is happening.

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Helping a Child to cope with having a Brain Tumour

Children who are not told about their illness may use an over-imagination and fears to seek explanations to the life changes or events. These incorrect explanations may lead to nightmares, the child believing they are being punished for previous inappropriate behaviours, guilt and anxiety.

Having knowledge and education about their diagnosis can decrease distress and even lead to a better level of cooperation during treatment.

Who should tell a child?

This is a very personal decision. This is not an easy task. Both parents may decide to tell your child. A parent may find it less confronting to do the task on his or her own. There may only be one parent in the family; there may be no parents and other family members may be given the task. A decision may be made to speak to the child with the child's doctor or a counsellor in attendance - different circumstances may be called to play to suit individual needs and situations. The most important thing to remember is deliver the information with honesty, support and love. Parents and families usually have a pretty good idea of how to communicate with their child. If you want professional help, organise it through you treatment centre where a social worker or a psychologist may be available to assist. Making notes, rehearsing, discussion with another may provide some direction or guidelines prior to speaking with your child.

When should a child be told?

There is no right time to have this discussion, however, if surgery is planned or if the child is experiencing personal changes or events such as seizures, a discussion cannot be delayed too long. It is usually best to discuss it as soon as possible after a diagnosis has been received. You will recognise mood changes, and behaviour changes, so try to choose a time and place where you have privacy. Avoiding the discussion will allow the child's imaginings to grow out of control

What should a child be told?

Firstly obtain all relevant information from the treatment team. When your child asks questions, you will be better prepared and be able to provide some of the answers. Children feel more secure when they are provided with honest information. How much you tell the child and the manner in which you share the information depends on the age and development of the child.

Initial diagnosis

Overwhelming feelings of helplessness occur. Various medical professionals will provide an initial explanation of the child's brain tumour and the treatment to be offered. However, parents/families in a state of shock may not be able to process all the information given. Confusion at this time is common, so taking notes, asking questions and re-asking questions is beneficial to gain a clear understanding of the overall situation.

This is a time for serious decision making so clarity of thought is critical.

During the clinic appointments with the treatment team the following questions may be raised:

- What type of brain tumour does the child have?
- What does this mean for the child?
- How did the brain tumour occur?
- Could the brain tumour have been prevented?
- Is it hereditary?
- How long has the brain tumour been growing?
- What is the treatment for this type of brain tumour?
- Can it all be removed?
- What does surgery involve?
- What do other treatments involve?
- Can the child have the same type of treatments that adults have when diagnosed?
- How long is the treatment for?
- What happens after treatment finishes?
- Are there any side effects of the treatment?
- What will/could happen to the child?

Acknowledging the Diagnosis

Some parents become angry at everyone and anyone; themselves, the doctor, God, their sick child for becoming ill or at their other children or their partner. This is normal. However, these responses need to be recognised and understood so that others in the family may be given the opportunity to support each other during these difficult times.

It should be remembered that nothing parents do, or haven't done, has caused their child's diagnosis.
It is important for parents to be able to talk to others, in the family, relatives, friends and the treatment team, so that emotional responses are known and understood appropriately and coping strategies can be developed.

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Acknowledging the Diagnosis cont.

Parents are concerned with protecting their children so instinctively they may react to the brain tumour diagnosis with an over cautious response to not discuss the reality of the diagnosis, the treatment, or its side-effects. Sadly this may effect the child's feeling of security.

It is important for the child, particularly older children/ teenagers to be given a chance to talk about his/her diagnosis, what it means to him/her and how he/she feels. If a child senses that a parent finds it difficult to talk about the brain tumour diagnosis, they may in turn try to protect their parents further by withholding their own fears and concerns.

A child who may find themselves in this type of situation, loses an aspect of their most important outlet for support; honesty, leading to an increase in their own fears that their diagnosis or prognosis is much worse than it actually is.

A second opinion can be obtained to reassure parents that the advice they have received is the best option for their child. This can be organized for you by your general practitioner or consultant.

However, seeking second opinions may delay essential treatment and may reflect a parent's extreme difficulty in dealing with the diagnosis.

Alternative forms of treatment for cancer, and a whole range of suggestions may be received from other family, friends, neighbours and even acquaintances - it is important that these issues be discussed with your doctor prior to embarking on other types of treatment.

What to tell your child about the diagnosis and treatment

Historically, children were kept in the dark about issues that may have serious consequences however; it is generally felt that children should be told as much about her/his illness as their age allows them to understand.

Most children know something is happening even though they have not been told directly.

Even 4 or 5 year olds, pick up pieces of information either from:

- Overhearing discussions
- Observing adults crying
- Hearing conversations stop completely or conversations occurring in whispered tones when they are in earshot
- Extra adult visitors arriving
- Sensing parental concerns and stress
- Having questions about extra restrictions and attention, treatment and medicines
- Being kept away from school
- Not being able to play with friends
- Hearing inaccurate versions of the `truth' from other children who may have had other adult communication on their health issue.

The Important Question:-
Is NOT whether or not you should tell the child about the diagnosis and treatment

BUT what and how to tell them.

An open honest approach is essential:

- It's better to say `I don't know but I will find out' than to say nothing, avoid answering or make up an answer
- Remember it is important to talk with children only to the extent that they are able to listen
- Lying only leads to distrust and presents issues as the child commences treatment that may require hospitalisation, medication or affects self image eg. Hair loss, surgical scars or results in the child feeling incredibly unwell
- Be mindful because a child has not spoken about their diagnosis, and fears related to it does not mean that they don't have any questions
- The issue of their own mortality, including issues of dying may be of the utmost concern to them, and they deserve an opportunity to voice these concerns
- What you tell the child will depend on their age, maturity and your personal attitudes and feelings.
- Some parents like to tell their children by themselves at the hospital, others prefer to wait until they go home
- Some may wish to have the support of either a doctor, a social worker or a psychologist when it is explained to the child

Whatever is most comfortable for you and your child is the most important.

Talking to a Child about a Brain Tumour Diagnosis

What to tell a child if they have been diagnosed with a brain tumour or if a family member has been diagnosed with a brain tumour?