

## WHEN MUMMY HAS A BRAIN TUMOUR

A brain tumour is a mass of tissue in which cells grow and multiply out of control, which can cause pressure on the brain. The tumour can damage nerves and healthy brain tissue.

### Symptoms

Headaches, vomiting, unsteadiness or loss of balance, seizures, double vision problems, sleepiness, weakness on the one side of the body, irritability and changes in behaviour.

### How can my family, my loved ones, and I cope with my brain tumour?

A family in which someone has a brain tumour is constantly challenged by changing circumstances, and yet must also strive to be caring and supportive throughout the entire process of diagnosis, treatment, and recovery.

Being aware of some of the different ways in which illness may affect you and your loved ones can help in finding the best ways to cope with these changes. People may respond in various ways. Common reactions can include physical symptoms such as fatigue, nervousness, impaired sleep or appetite; emotional reactions such as fear, shock, depression, anger, guilt, mood swings, or crying; cognitive symptoms that may include difficulty concentrating or forgetfulness; and spiritual responses such as searching for meaning, or an increase or decrease in spirituality. These are all normal responses to stress. Recognising these common issues can guide everyone struggling with the challenges brought about by a brain tumour diagnosis.

Brain tumour patients will often have a primary caregiver, the main person who assists the patient and cares for his or her needs. Communication between family members about changes in roles and responsibilities may become more difficult. How a family copes with these changes is affected by the ability to communicate. Families may need to identify outside sources of support to assist with this process, such as a counsellor, psychologist or mental health professional.

Identifying individual family members and friends who are committed to helping can provide needed support to the patient and help with difficult transitions. Including others who are looking for a useful role to play can promote a sense of community and reduce the feeling for caregivers and patients that they are alone. Creating new, flexible solutions to changing circumstances can also serve as a way to help cope with the changing nature of the illness. Recognising that the old way of doing things may no longer be useful can help families to come up with new and innovative ways of dealing with change.

It is difficult to summarise a single approach to coping, because every patient, family, and disease is different. But it is important to recognise how stress is affecting you. If your response to stress feels extreme or persists over time, consider consulting your doctor or a counsellor.

Many people rely on family and friends or their spiritual community for support. Medical social workers can connect you with local resources. Support groups,

including internet-based groups, can often provide contact with other people in a similar situation. There are organisations with resources available to help patients and their families cope with the disease.

### **Why should my children be told?**

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- A brain tumour affects the feelings and emotions of the whole family and a child has a right to know about anything that affects the family.
- Children can sense when something is wrong, because they are very sensitive to tension and stress. If you try to protect them by saying nothing, they may fear that something even worse is happening. Not talking about the brain tumour may suggest it is a subject too terrible to be discussed, and can make children have an exaggerated fear of brain tumours or illness later on.
- Children may find out the truth from someone else, or get misleading and frightening information from TV, the internet or other sources.
- Children can feel isolated if they are not told. They might feel they are not important enough to be included in an issue that affects all the family.
- Children are good at noticing things but may be mistaken in their interpretation of what they mean. For example: 'Grandad died in hospital. Now Dad has to go into hospital. He is going to die too.' Or 'I was cross with Mummy when she told me to pick up my toys. Then she was ill. Maybe I made her ill.'
- Children who know the situation can be a comfort to you. You won't need to watch what you say all the time or feel secretive and isolated in your own family. Openness can help all of you to feel closer.
- Children have an ability to deal with the truth that adults often underestimate. Not knowing things can make them feel anxious. Even very sad truths will be better than the uncertainty of not knowing what is happening. We cannot stop them feeling sad, but if we share our feelings and give them information about what is happening we can support them in their sadness.
- Dealing with a brain tumour in the family can be an opportunity for children to learn about the body, tumours, treatment and healing. They can learn about how strong people can be during hard times and how to deal with difficult feelings.

### **Who should tell my children?**

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- As a parent or carer, if you feel able to tell the children, it is usually best for you to do it. This is a very difficult thing to do and there is no easy way of saying it. It is all right to get upset or cry. Seeing you cry gives your children permission to cry too, and crying together can feel very supportive as you are sharing your feelings. You will know if you can be the one to tell them.
- If you do not feel able to tell the children, your partner or a close relative such as a grandparent could do it. A nurse or your doctor or a member of the professional staff looking after you can also be involved. It is important that you know what has been said to your children, and it may be helpful for you to be present when they are told.

### **When should I tell my children?**

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- After being diagnosed, it is helpful to explain what is wrong. You don't have to tell everything at the same time. You can give a bit of information at a time.
- Before treatment begins and when you are being treated, you can explain the treatment and how it is given. You can also talk about the side effects and about any changes in treatment, whether things will be different at home or how you feel. Some treatments such as chemotherapy or radiotherapy can make you feel very tired and possibly irritable. It is helpful to explain this to your children so that they know that the treatment may affect how you behave and relate to them.
- Try to keep information relevant to the current situation. It can be best to give children warning that something is about to happen, such as a scan or treatment, shortly beforehand, but not too far in advance.
- After you finish treatment, explain to your children that you will tell them about your health and about any changes.
- Be willing to talk whenever your child asks questions or seems concerned about your condition.

### **Where should I tell them?**

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- There may be particular places where you feel more able to talk to your children, or they may be more likely to discuss things with you. An example is when they are in the bath.
- Often, children may talk about things or ask questions when they are in bed and settling down to go to sleep. It is very important to answer any questions that they ask at this time. However, this may not be a good time to start a conversation that could be difficult, as the child may then have a long time on their own to think about the situation or may not be able to sleep. If they do ask questions at this time and you talk to them, it is important to spend time with them to make sure that they feel supported before they go to sleep.

### **How should I tell my children?**

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- You can talk to your children as a group, or individually (if they need to know different things because of differences in their ages or how grown up they are).
- You may want to practise what you will say and anticipate the questions that the children will ask. It is important to talk in a language and at a level that each child understands.
- It is helpful to create an environment in which your children feel safe and in which they feel able to ask questions, even if they feel sad and upset. Set aside plenty of time, when you know that you will not be interrupted, and let the children know that you have plenty of time to discuss the situation with them.

### **How much should I tell my children?**

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Children need to be told information in a way that they can understand.

- Tell them what has happened, such as some details about the brain tumour.
- Explain what will happen next, such as how it will be treated.

- Leave them with feelings of hope that even though you are upset now, there will be better times.
- Assure them they will still be loved and cared for. Tell them who will look after them, if necessary.
- Listen to them – it lets you know what they can cope with.
- Answer their questions simply.
- Ask them what they think a brain tumour is. Explain it as well as you can.
- Ask them if they are worried about anything in particular.
- Correct any misunderstandings they may have.
- Be honest.
- Let them know how the situation affects your feelings and emotions, as well as giving factual information about the brain tumour and treatments. An example is that you can say you may feel more sad than normal, or may be more easily irritated.

### **Some suggested ways of saying things**

'I have an illness. It is called a brain tumour. The doctor is giving me medicine to help me get well. Sometimes I will feel ill or tired and sometimes I will feel fine. Dad/Mum will help me to take care of you until I feel better.'

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- Simple and straightforward language is the most helpful, for example: 'Some of the cells in my brain have grown too quickly and have made a lump that is sore. The doctors have taken the lump out during an operation.'
- 'Being ill makes me feel sad. You are a help. But it's all right for you to feel sad (or angry or happy or whatever). Our feelings change but Mummy/Daddy and I will always love you.'
- 'A lump was growing in my head that wasn't supposed to be there. It is called a brain tumour. The doctors took it out in the operation I had. Now I will have treatment so that it doesn't come back. If you have any questions about the tumour, you can ask me. Sometimes you hear frightening things about brain tumours, but there are lots of different kinds of brain tumours. I will tell you what we know about my tumour.'

### **Some don'ts**

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- Don't lie.
- Don't trouble them with complicated medical details, money problems (except when it will affect them), or your worries about waiting for the results of tests, etc.
- Don't make promises you may not be able to keep. (Say 'I think I will be able to...' or 'I'll try to...')
- Don't be afraid to say 'I don't know'.
- Don't push children to talk if they do not want to.

### **Talking to children and considering their feelings**

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If you never show how you feel, the chances are your children won't either. Trying to hide strong feelings can be very difficult and may cause even more problems. Covering up strong emotions can mean that the emotions build up. A child can become frightened of his or her own feelings instead of accepting them as normal.

You are likely to be very sad about what has happened. Don't be afraid to express it. If you can let the sadness out and cry together, the tension is likely to ease and this can be very supportive for everyone.

### **Children may feel other things**

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- Some children will feel sorry for themselves when a parent is ill, then feel guilty because they think they should feel sorry for the parent.
- Some children will try to make up for these guilt feelings by being especially good and setting impossibly high standards for themselves.
- Some children will cling to you too much, afraid that something will happen if they are not there.
- Some children will withdraw from you, unconsciously trying to become more independent in case something else happens to you.
- Some children will resent the fact that they need to help you when the opposite was true before.
- Some children will laugh and behave badly to cover up their real feelings or their lack of understanding (especially in awkward situations).
- Some children will pretend to be ill to get attention or because they want to be with a parent. They might make a big fuss about a minor illness.
- Some children may be afraid that they will get a brain tumour too.
- Some children will have physical effects such as loss of appetite, stomach ache or stress-related headaches.
- Other children may show their distress in other ways such as lack of concentration, sleeplessness, bedwetting or babyish behaviour.

These things will pass with time, but let your children know that you understand and accept them as they are.

### **Dealing with uncertainty**

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The uncertainty of what may happen is what makes brain tumours especially difficult to cope with. Living with uncertainty is part of having a brain tumour and it can be hard to accept that. There are some questions you will not be able to answer. It can be helpful to tell your children that things are uncertain and acknowledge how difficult it can be to cope with that.

Find out all you can about the brain tumour and its treatment, to make the unknown more familiar. You can also find out about symptoms of the brain tumour, or possible side effects of the treatment.

### **Changes**

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Everyone in your home will be affected by your brain tumour, even if they don't all show their feelings. There may be changes in how you look and there may be changes in what you are able to do.

You will want to try to keep things as normal as possible. Be there as much as you can for your own and the family's sake. Keep as many things the same as you can. A daily routine is important. Make sure that the necessary things get done.

## Getting help

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Another family member may have to take over some of the things you usually do. Children will learn that this is part of what it means to be a family. Get outside help if necessary, especially if you have side effects from repeated treatment that make it difficult to cope with a home and family.

It is also best, if possible, to have the same person helping, especially when there are young children who need consistent care. The social worker at the hospital can give information on local childcare facilities and also help with finding payment for childcare, if necessary.

## Who can help?

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If you find that problems continue, let your GP and the hospital know. Your GP may be able to refer you to someone who can help and support you and your family. Don't hesitate to ask for professional counselling. It may be possible for the whole family to be counselled together. It is helpful to tell your child's school about your situation so that the staff there can support your child.

It could be useful to join a brain tumour support group in your area as it can be comforting to talk to someone in a similar situation. Ask your local library if there are any videos or books that may be helpful.

## Physical changes

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You may look different due to the illness or treatment: for example, you may put on or lose weight. Some treatments may make your hair fall out. Children are often more able to accept body changes than adults, however it can help to let them know it is OK for them to talk to you about it. You may also feel tired and may not be able to do as much as you usually manage. You can give a brief explanation of why you look or feel the way you do, and leave it at that.

## Other children

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There may be gossip among the local children. This may be your chance to help them to understand something about brain tumours, if you feel able to. On the other hand your children may not want to admit that anything has changed in your home. Let them know you are willing to talk to their friends if they would like you to, and if you feel that you would be able to. It is also helpful if you let your children know that it is OK for them to talk to their friends, other adults or health professionals about these changes and how they feel.

## Dealing with change

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Be flexible – sometimes changes make it necessary to declare a 'state of emergency' when everyone in the family has to adjust their plans at short notice. Try to be relaxed if changes must be made, although sometimes you may feel overwhelmed by many changes happening at once. Try to involve children as much as you can in the new plans. Children respond differently to situations according to their own nature and personality and have different needs at different ages.

## Support for children

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If children seem to need additional help and support ask the hospital or GP about child psychologists or other help that may be available locally. Very young children may benefit from seeing a play therapist. Your GP, hospital specialist, hospice or social worker can arrange these services for you.

## Discipline

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Maintaining discipline during times of stress and illness may be difficult because children can behave badly in order to get the attention they feel they are missing. A breakdown in discipline can send signals to a child that something is very wrong at home and so it is important to set consistent and familiar limits and find ways to enforce them.

Let the children know you understand, love and accept them, but not their misbehaviour. Reward good behaviour and let them know that you especially appreciate cooperation now.

The information in this section is general - each child will have different needs at each stage. You and your children may have similar feelings and emotions.

Helping children to understand your experience needs sensitivity and a good sense of timing. Your children may go through some of the feelings that you may have, such as disbelief, anger, uncertainty, hope, fear and acceptance. They may have special needs because of their ages, and these may change at different stages of your illness.

## Fives and under

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- The youngest children fear separation, strangers and being left alone. If you are in hospital, arrange for a familiar person to stay with them. Talk to them and assure them you are coming home from hospital soon and that you think of them when you are apart. If they come to visit you, suggest they bring a well-loved toy with them. You can give them something special (such as a toy or a blanket) that they can keep with them when they are at home, to remind them that you are thinking of them and that you care about them.
- Young children often feel they have magical powers and that what they wish will come true. They may feel guilty that a parent is ill, or that they have had bad thoughts about a parent. Assure them that nothing they have done, said or thought could have caused your illness. They may also worry that they too will get a brain tumour, and it is helpful to let them know that tumours is not 'catching'.

## Ages 6-11

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- Children between six and eleven may be very concerned about a parent's health. It is important not to put pressure on them or worry them with details.
- Many children of this age have a basic knowledge of body parts and their functions, and can understand simple explanations about the brain tumours and its effects on the body.
- Children may show their worry or concern through disturbances in eating, sleeping, schoolwork or friendships. Children at any age may start behaving like younger children. Sometimes it is just their way of saying 'I'm here too'.

- Let the children's teachers and school nurse know about your condition, as their suggestions and understanding will help if there are any problems. You could also ask your child if there is anyone they would like you to tell about the brain tumour, such as their brownie or Cub Scout leader or their friends' parents.

## Teenagers

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- Teenagers can have an especially hard time – adolescence is not an easy phase in any case. Their emotions are sometimes complicated and troublesome. They may find it hard to talk to you or to show you how they feel, and at times their behaviour may be difficult for everyone to deal with.
- At a time when they are probably struggling to be grown-up they may feel that it will be seen as childish to show their emotions or to ask for help. They may stop talking to you because they are trying to appear strong for you, or are worried that they will be misunderstood.
- It may help to reassure them that talking about their feelings and worries is a positive way of coping and is how adults often deal with stressful situations. If they are finding it hard to talk to you, encourage them to talk to someone close who can support them, such as a relative or family friend.
- Your illness may mean that they are asked to take on more responsibility than they had before. This can be a positive experience for them if they feel that their efforts are helpful and recognised. However, difficulties can arise if they feel overburdened with responsibility to the point of not having their own needs met. Teenagers need to be included and consulted as adults, but will continue to need guidance, support and reassurance.
- Boys may have difficulty dealing with women's cancers due to self-consciousness around the time of puberty, and girls may worry that they will develop the same type of cancer.
- Girls may have difficulty dealing with men's cancers, such as prostate, testicular or penile cancer. Boys may worry that they may develop the same type of cancer.
- Keeping to any rules that you had before your illness is also important. Teenagers need to know that a normal life matters even more than before.

## Sharing experiences with children, good and bad

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However long you may have to live, time with your children is very precious. It may be difficult to enjoy quality time with them when you are feeling the effects of the brain tumour or its treatments. Some of these suggestions may help:

### Being together

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Plan for laughter. Laughter is good medicine for all of you. You are still going to have fun together. You may enjoy each other even more.

If you need to, think of things to do together that do not need much energy – read, watch TV or videos/DVDs together, write a story about your family and share it with them. Have plasticine or play dough and other creative materials to use to work out some frustrations that you and the children share.

## At home

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- When you are at home, even a small child can be involved in bringing you your meals, or the paper or books to read. Do as much as you can yourself so that the children do not begin to resent running your errands. Allow them to have enough free time for themselves.
- Read a book together about the body. Point out where the brain tumour is and what is happening physically.
- With younger children, use role-play. Act out what is happening to you by using a doll. Use other dolls for other members of your family. Children often express what they are really feeling in their play. Listen carefully to them.
- Encourage your children to draw pictures about the experience of having an ill parent. This is also a good way to express emotions. Write a story together about 'When I became ill'.
- Select stories about other people who have had brain tumours and read them with your children.
- Get together with other parents and families who are coping with a brain tumour. Arrange for your children to meet other tumour survivors.
- Share poems and songs that mean a lot to you with your children.
- Make up or find a slogan to help all of you. Make posters, mobiles or badges using the slogan for inspiration.

## Benefits of sharing

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You can make a difference by how you choose to respond to your tumour. Despite all the difficulties, your situation may introduce positive things that can lead to benefits in the future.

- Spend more time with your children and actually feel closer to them. Sharing emotions can really strengthen the bond between parents and children.
- Children can grow in their ability to face other difficult experiences in life. They can grow in independence and self-confidence. They may become more responsible. They may become more sensitive to the needs of others and more able to understand and love another person.
- A brain tumour can bring out the best in people. Take pride in your children's ability to deal with problems and find new solutions.

The whole family may discover reserves of love and inner strength that will enhance the rest of your life together.

Parkinson, C.S. (1991) Excerpt from *When Mummy has a brain tumour* Rochester, NY: Park Press