

Talking to Your Family & Friends about your Brain Tumor



Telling your family or friends that you have been diagnosed with a brain tumor can be one of the most difficult conversations you will ever have. You have to inform family members, including your spouse or partner, parents, children and close friends, and you may also realize that you have a much larger circle of friends than you ever imagined.

Many will have more questions than you are prepared to answer, or even have answers for at this time. All of this makes keeping everyone informed a potentially daunting task and one particularly difficult when you are yourself trying to come to grips with life-changing news.

The first thing to realize is that *you don't have to personally tell everyone*. You can get help, most likely from a trusted friend or family member. This could be your spouse/partner, but it could also be someone else you know can handle this assignment.

Things to think about in communicating with your Spouse or Partner:

- Understand that you and your partner may have different needs/feelings/views. Listen and respect one another. Be honest regarding your feelings. Practice or write down in advance what you want to say.
- Agree on what to tell your children and others. Have a consistent message.
- Discuss what types of support and encouragement you need.
- Talk about treatment options/plans. Come to decisions together.
- Use a code/signal if you need visitors to stop a certain topic of conversation or if you need them to leave.



- Discuss posting of pictures - which ones are okay to communicate, and which ones are not.
- You don't always have to talk about your tumor/cancer. Talk about normal/everyday things. Humor may relieve stress and help you both deal with your diagnosis. Remember, "Laughter is the Best Medicine."
- Schedule specific times to talk with each other.

We Can Help!

Talking to your Children

Should I talk to my children? Should I let them know? Children are smart. They probably know something is going on and not talking only makes things worse. Many children feel relieved when they are given some information regarding your illness.

Decide who you would like to have with you when you tell your children. Do you want your partner, another adult/family member there? Should you talk to your children individually, in groups of the same age, or all together?

Toddlers/Preschoolers do not need a lot of information. You can show them where your “owie” is by pointing to your head, or use a doll or stuffed animal. Tell them they cannot “catch” the owie from you. Ask them if they have questions, and answer only what they ask. Use simple words and keep conversations very short.

With School-Aged Children a stuffed animal, doll, or picture can help in the communication. After you tell them, they may just go off and play. They may respond later by being extra quiet or angry instead of using words.

Older Elementary School Children and Teens will require a lot more details. Tell them the name of the cancer. Talk about your treatment plan. Let them know the tumor/illness is not contagious and they did not do anything to cause the cancer/tumor.

Teenagers are much more aware of cancer than younger children. The internet is widely available to them. Find out and ask them how much they know about brain cancer. Find out if what they know matches your condition. What have they heard from family members, neighbors, friends, classmates? Tell them you are still learning, have a lot more to learn and that it would be great to compare notes on what all of you have learned. Share your treatment plan with them. Share as much information as you think they can deal with.

Be prepared for emotional responses. Let your children know it is okay for them to have painful thoughts and feelings. You can admit you are scared too. Do not hide things from them. Their teachers and school nurse need to be told, if only so that they can be prepared and be on the look out for any unusual behavior. This will allow them to be sensitive to your child’s needs and give you feedback regarding any changes in mood and behavior.

Let them know there will always be people to take care of them - family, friends, their teachers at school - that you all care about them and are there for them whatever they need. Tell them you love them! No matter what happens, you love them!

Parents can be a tremendous support!

Talk openly to your parents about what you are thinking and feeling and ask them to speak openly to you. It will help you work together and solve problems and issues easier. Parents can help you with:

- Finding information/doing research
- Assisting you with doctor appointments and taking notes
- Organizing medical and insurance records/statements
- Doing household chores, fixing meals, picking up the kids from school
- Answer questions/telephone calls from other family/friends

Parents may ask you many questions, and give you “advice”. It is a parent’s instinct to protect you; try to understand they are also going through their own emotions about your diagnosis. If you feel they (or your spouse/partner) becomes too controlling you may want to meet with a counselor or family therapist.

Talking to your close friends

You will probably want to have these conversations in person or via telephone. For couples, you can have your spouse or partner make the call. In visits from friends, make sure you tell them when topics are off limits (things like religion or other people with cancer) or you would rather talk about something else.

Talking to people outside your immediate family and close friends

You may not want to share the same detail of information, especially with coworkers. Be prepared for offers of help, and what your response will be. If you are open to their offers of help, give them a task!

Keeping everyone updated

This is usually best done electronically so that everyone gets the same message, once the initial word is out. Email or CaringBridge can be used for updates as well as Facebook groups. You can also use Facebook to share the fun events such as outings or celebrations.

Keep in mind.....

- Many people want to see you. You control who sees you and when. It is ok to say no.
- There are many different types of communication.....face-to-face, telephone, email, social media, Skype. Use any or all of it, but make sure that it fits the person.
- Have a person intercept calls for you. For instance, they could say you are resting right now but I’m sure he would like to see you and tell them to be sure and bring their lawn mower, famous casserole, or whatever.
- People want to help but they need to know what you need. This is a great way of letting them know. For the super-organized, CaringBridge and other sites can be invaluable. But the Doodle Poll does not work for everyone.
- You can have as many (or as few) talks, visits, or Skype chats as you want. It’s all about YOU!

