

When your child is diagnosed

Making Decisions and meeting with your treating team.

During this difficult time at diagnosis, it is also the time where you will be asked to make a number of decisions about your child's treatment. Below are some reminders that might help you to make these decisions.

- ✔ Don't be afraid to look for information from a variety of different sources, including your oncologist, medical literature and reputable websites. If you are searching on the internet, please be sure that the site you are on is one that has support from the medical community, as there are a number of websites that give incorrect or out-of-date information.
- ✔ Try to have more than one person at meetings to help take in all the information.
- ✔ Write questions down in a notebook prior to the appointment. Often we forget what we wanted to ask in short appointments.
- ✔ Record all the answers to your questions in the appointment or shortly after, as well as other important information that will be useful to remember.
- ✔ Try not to focus on statistics or numbers – sometimes these can be misleading.
- ✔ Be aware that there may not always be definite answers and you may not always get the answer you were hoping for.
- ✔ Continue to ask questions when you are unsure (and keep asking, if it still does not make sense).
- ✔ It may be useful to ask the doctor to give you a drawing or visual representation of what they are talking about. People learn differently, and it might make more sense to you visually.
- ✔ Talk to people whose opinion you value and trust about what is going on.

What should I tell my child?

This is a common question and concern for parents. What you tell your child and their siblings is a personal matter, and a number of factors will come into play, including cultural, family and religious beliefs.

- ✔ It is important to be open and honest. Sometimes when children are not told about their illness, they can imagine things that are not true. For example, they may believe that they got sick as a punishment for doing something wrong.
- ✔ Who tells them about their diagnosis is also a personal decision. You do not have to explain everything by yourself, and members of your treating team can assist with this.
- ✔ If someone else is explaining about the diagnosis, it is important that you are present, as your child will need someone whom they love and trust when hearing the diagnosis.
- ✔ Consider your child's developmental age and capacity, and try to tailor the information to their level. Brief and simple explanations are often best. Below is a list of general guidelines of what children of various ages are likely to understand. Remember these are just guidelines and that every child is different.

Infants

- ✔ They have no sense of time or understanding of their illness, so it is difficult to explain
- ✔ The main worry at this age is being away from parents and loved ones.
- ✔ Biggest concern is what is happening in the present moment.
- ✔ Important to be honest about trips to the hospital and procedures that they need to go through, as this helps your child trust you and the treating team.

Pre-schoolers

- ✔ This is an age where children are starting to seek independence, and developing a number of new skills, such as walking, talking, and toilet training. It is also the common age for 'temper tantrums'.
- ✔ Use simple words to explain the illness e.g. need to have medicine so you can be well, and play without being so tired.
- ✔ Important to give your child appropriate choices e.g. if medicine needs to be taken orally, you might ask how they would like to take it, with water, or apple juice. This way the child has a choice and some control over their medication, whilst ensuring that the choice is not whether they take it or not.

School-aged Children

- ✔ You can use more details when explaining cancer to older children, e.g. discussing how the body is made of up of different types of cells, with different jobs to do, and that the cancer cells get in the way of the work of these cells doing their job. Treatment will help get rid of the cancer cells, so the other cells can do their job properly.

Adolescence

- ✔ At this age, young people are acquiring a much more complex and abstract view of the world, and cancer can be explained in much more detail.
- ✔ Be open to ongoing questions and discussion that your child may wish to have. Be prepared that you may not have all the answers.
- ✔ Talking about cancer as a family and how to manage it, may help to bring the family closer together.
- ✔ It may be helpful to explain that there are many different types of cancer, and that this cancer may be different to the ones that they have heard of. Many people are afraid of the word cancer, because they believe that people always die from this.
- ✔ Try to use words that the child will encounter in hospital (e.g. leukaemia, tumour, cancer, mass, growth), so that they will not be surprised or worried when people use another term.
- ✔ Reassure your child and their siblings that cancer is not contagious and that they did not and cannot catch it from someone.
- ✔ Reassure them, that they did not cause this.
- ✔ There are a number of books and other resources available to assist with talking to your children about cancer. Please read any books that you might like to use first, to ensure that you are comfortable with the content. It is most useful reading the book with your child, so that you are able to answer any questions that might arise.
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