

SPEAKING UP FOR YOUR CHILD

A tip sheet for parents and carers,
written by parents who have cared
for a child with cancer



Being an advocate for your child means speaking up for them. This can take considerable courage. There are many reasons why you may wish to speak up for your child while he or she is receiving treatment. It is always important that you do so. These tips have been developed by parents for parents and carers, to help make the experience a little easier.

1

Trust yourself when you speak for your child. No one knows your child as well as you.

2

Your child's care will not be compromised if you inform the hospital about a problem you or your child is having.

3

Understand your child's treatment plan when you give consent. This will give you confidence when talking to your child's treating team.

4

Ensure that the **doctors and nurses are aware of your child's wishes** about their treatment. Your child may be too young, or too shy to speak up. It is up to you to do this for your child, so their wishes are not ignored.

5

Ask questions

- No question is too small or silly
- Asking questions will help you to be well-informed when giving consent to treatment
- To help you remember the answers, write them down.
- Ask questions as many times as you need to so that you understand the answer
- If you still do not understand, ask the same question to different doctors or nurses. People explain things differently.

7

Understand the proposed medical treatment. The doctors should always explain the risks and possible side effects, including what may happen if you decide not to allow any part of the treatment. If you don't understand, ask the question again.

8

Ensure that the doctors and nurses are aware of any **religious or cultural beliefs or customs** that are important to your child and family.

PRACTICAL TIPS

1

Talk to the most senior available doctor or nurse at the time of your concern. Try to be mindful of the time you choose to do this. Ask if it is a good time to talk and if not, return at a more convenient time.

2

Try to stay calm, and talk slowly and clearly. Staff will be more open to your concerns when you are respectful. Share your ideas with the staff, and the action you would like. Asking 'how can we solve this problem?' can be a good way to approach the conversation respectfully.

3

Write it down! It is helpful to write down (or ask the clinician to write down) all of your questions, the responses and the actions decided upon so you have a record of your issues and what the plan is. It's too easy to forget details when you are in a stressful situation.

4

If you don't feel confident talking on behalf of your child, you can have another person speak for you, such as a relative, friend or trusted health care worker.

5

If you have a problem with your child's care which is not fixed after 'speaking up' ask a staff member about the hospital complaints procedure.

6

Care for yourself. To be able to care for your child and family you need to care for yourself. Please refer to the 'looking after yourself while you are caring for your child' tip sheet.

Further information for families can be found at www.pics.org.au/families

This tip sheet has been written by the Children's Cancer Centres Parent Advisory Group (PAG) with the support of the Paediatric Integrated Cancer Service (PICS). The PAG are a group of parents of cancer patients and staff representatives who work together to improve the care of children with cancer.

Disclaimer: For education and information only. Content is accurate at the time of publication, however over time information may change. Always get advice from your health care team for answers to your medical questions.

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