

Tips for parents from parents

This tip sheet has been written by parents who have cared for a child with paediatric cancer for parents currently caring for an unwell child. When caring for a child who is unwell, it is common to experience a wide range of emotions. Some general tips on how to look after yourself are listed below.

- 1 Do what you need to get through each day. Sometimes that's enough.
- 2 Don't be afraid to ask questions.
It's okay to say 'I'm not sure I understand, can you tell me more...' or 'What does that mean?'.
Medical language takes a little while to learn and occasionally medical staff need to be reminded of this!
- 3 Don't feel pressured to tell everyone everything. Re-telling information is exhausting and often time consuming. Friends and family should understand this.
- 4 Ask your consultant how things are going. Sometimes we are too polite to ask and are left wondering and worrying in our silence.
- 5 At the introduction of a new treatment drug ask your consultant:
 - What do we need to be worried about?
 - What do we need to look out for?Forewarned is definitely forearmed.
- 6 'I've walked a mile in your shoes.' Families affected by paediatric cancer seem to have a natural empathy with each other, which is wonderful. Remember, however, that every experience is unique and each family is allowed to travel the road in their own way and own time.



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'Let me know if there's anything I can do...' is a phrase you will hear a lot.

Graciously accept the offer and be specific. Ask them to walk the dog, mow the lawns, drop off a meal every Monday, pick up notices from school, get video blogs from your child's friends.

If every person who asks does just one thing, it's not too much of a burden to them, but a wonderful way of shortening your to-do list.

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Tell someone in your medical team if you are feeling very worried about your child's treatment or an upcoming test result. Generally speaking they will respond with sensitivity and haste to your anxiety.

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Do something kind for yourself **whenever** you are able. We all know it is hard to find the time in among the demands of caring for a child with cancer, but even something small can help you recharge a little.

A friend gave me a lovely hand cream so I made it a point to put that on every day. The aroma reminded me to stop for just a second and breathe a little each time.

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Find a support system and lean on them as often as you need to. If you don't have family or friends nearby then make contact with some of the organisations that offer support to families. The first phone call can be difficult but most parents report it being well worth it.

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Remind yourself that you are doing a remarkable job in the most challenging of situations. You have probably discovered that you are stronger and more capable than you even knew and it is important to acknowledge this.

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Print off and/or email this tip sheet to the people who are supporting you to offer them some additional ideas.

This pamphlet has been compiled by the Children's Cancer Centres Parent Advisory Group (PAG) with the support of the Paediatric Integrated Cancer Service (PICS) as part of the Cancer Australia 'Supporting People with Cancer' Grant initiative, funded by the Australian Government. The PAG are a group of parents of cancer patients and staff representatives who work together to improve the care our children receive.

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. Published June 2014.