

Here for you

Things you might like to discuss with the palliative care team about care at the end of life



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An electronic version of this document is available at:
eprints.qut.edu.au/127639

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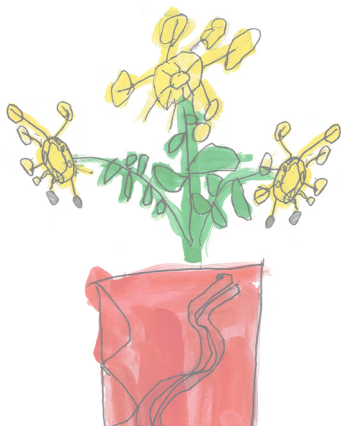
Artwork supplied by Queensland Children's Hospital Junior School

Purpose of this booklet

This second booklet deals with topics you might like to discuss if your child's illness progresses. There may also be relevant topics in the first booklet.

The role of palliative care is to improve a child's wellbeing in the context of serious illness. We understand that you may have questions or concerns about meeting the palliative care team. You may find this booklet helpful to think about topics you wish to discuss, or questions you have for the team. This booklet may include topics you are already wondering about, or may be helpful to consider in the future.

We understand that families have unique knowledge about their child that informs care. We aim for our discussions to respect the important role families play in shared decision making. Different families are likely to have different questions, concerns, and needs. Some of the content of this booklet may not be relevant for your circumstances.



Paediatric Palliative Care

Palliative care is an approach that improves the physical, emotional, social, and spiritual wellbeing of children. Palliative care focuses on improving quality of life for the child, managing symptoms, and providing support for the whole family.

The paediatric palliative care team provides an extra layer of support for your child, alongside your other care teams. Rather than solely focusing on your child's illness or condition, we hope to focus on your child's needs, goals and wishes, and how we can best support your child and your family. Symptoms can affect the overall wellbeing of children, and the palliative care team has the expertise and experience to help with this.

Paediatric palliative care can also support families (including siblings). Care can be provided in different places to suit your situation, including your home and your hospital. In some areas a children's hospice may be available.

How to use this booklet

Take some time to read through this booklet, use the content as a guide, and consider what is important for you to discuss with the paediatric palliative care team.

There is space to write down notes during meetings, so you can remember the information later. There is space at the end of the booklet for you to write down other questions or topics you might like to discuss.

If you would like, simply tick the items you would like to discuss and give this booklet to the healthcare professional. They will then know what you want to discuss.

You can keep this booklet for future use as different topics become relevant for your child's care.

Preparing for my child's end of life care

1. What might happen to our child over the next days/weeks/months?

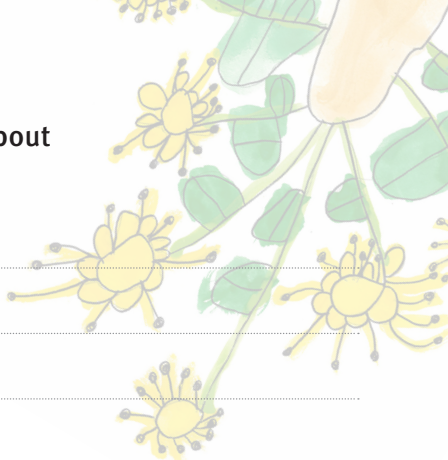
2. How will we know when our child's life is nearing the end?



4. Will there be time to prepare?



6. What happens if we change our mind about what we want for our child's care?





A series of horizontal dotted lines spanning the width of the page, intended for handwriting practice. There are 18 lines in total, evenly spaced.

More information and resources can be found at
<https://palliativecare.org.au/children>

