Here for you

Things you might like to discuss with the palliative care team

For more information contact:
Email: ppcsrg@qut.edu.au

An electronic version of this document is available at:
eprints.qut.edu.au/127752

The development of this document was supported by a grant from Gilead Sciences Europe Ltd

Published by the Queensland University of Technology
August 2019

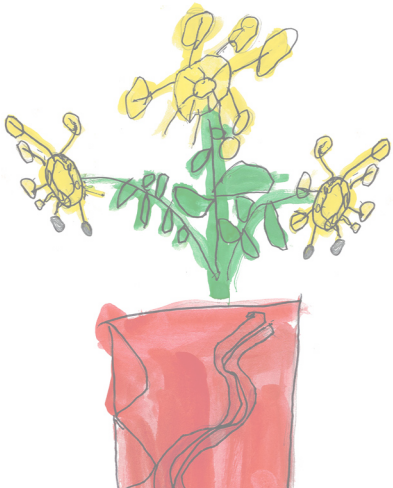
Endorsed by Paediatric Palliative Care Australia and New Zealand (PaPCANZ) and Palliative Care Australia (PCA)

Artwork supplied by Queensland Children's Hospital Junior School

Purpose of this 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, and so you may wish to focus on topics that are the most important for you at this time.



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. You may also write down other questions or topics you wish 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.

There is a second booklet available about topics that may be helpful to discuss if your child's illness progresses.

Understanding Palliative Care

1. How can palliative care help our child and family?

2. What can palliative care help us achieve?
(You might like to list some of your goals below.)

3. How does palliative care work with our child's other health care teams?

4. How can we keep in contact with the palliative care team?

Making Decisions

5. How can we, and our child, be involved in making decisions about their care?

6. What decisions about our child's care may we need to make in the future?

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

Family Concerns

8. **How can the palliative care team support us to talk with our child, their brothers or sisters, or others about what's happening?**

9. **We'd like to talk to the palliative care team about things that are important to our family.** (Examples of things you might like to discuss are your culture, beliefs, or family structure. You may like to list particular topics below.)

10. How can we balance the care that our child needs with the needs of the rest of the family?

Understanding our options for maintaining wellbeing

11. How can palliative care help us to support our child's wellbeing?

12. **How can the palliative care team help to keep our child engaged in important activities?** (Examples of activities you might like to discuss are school and social activities. You may like to list additional activities below.)

Managing Symptoms

13. **Are there symptoms that our child may experience over time?**

14. What are our options for managing our child's symptoms?

15. What are the possible side effects of treatment and/or interventions?

16. What can be done if symptoms don't settle?

17. What do we do if our child is not able to take their usual food, fluid or medications?

18. **What role can holistic, complementary or alternative therapies play in our child's care?** (Types of complementary therapies might include: specialised diets or supplements, herbal treatments, naturopathy, homeopathy, meditation, hypnotherapy, massage, reflexology, and multivitamins.)

Resources and Support

19. **How can we access support, resources or equipment in our local community?**

20. Where can we seek emotional support?

21. Who can we speak to if we need help with financial matters or paperwork related to our child's care?

Understanding our choices for location of care

22. Where can we care for our child and what is available to support this?

23. Can we change our mind about where we are caring for our child?

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

QUT

Paediatric
Palliative Care
AUSTRALIA & NEW ZEALAND

PalliativeCare
AUSTRALIA