



PALLIATIVE CARE FOR MITO KIDS

WHAT IS PAEDIATRIC PALLIATIVE CARE?

Paediatric palliative care is care and support provided to children who have a progressive, life limiting illness. It is a holistic approach which supports the physical, emotional, social and spiritual needs of your child and your family.

Palliative care aims to improve your child's quality of life and help them live as well as possible by reducing the amount of symptoms they feel. Palliative care is a family-centred model of care, meaning that family and carers also can receive practical and emotional support.

Palliative care for children involves:

- ensuring your child is comfortable and in the best possible condition so that they can do things that are important and fun (e.g. going to school or kindergarten)
- supporting and helping you and your family with difficult decisions
- helping you to support your child with any worries or questions they might have
- helping you support siblings of your unwell child
- providing practical help with equipment, medications and respite care

PALLIATIVE CARE IS NOT ONLY END OF LIFE CARE

Palliative care can raise anxiety for you and your family because it is associated with care in the last days of life. However, palliative care can help manage your child's mito symptoms so they can continue to live life while dealing with their illness. You may have an on-off rotation with palliative care through periods of your child's wellness and illness. Some families are involved with palliative care for months or even years.

Depending on your medical needs, palliative care may help your child be cared for at home, rather than in a hospital. Many families feel more comfortable at home where they can control their daily routine and have the opportunity for family and friends to assist with their care.

WHO PROVIDES PALLIATIVE CARE?

A palliative care team may include a number of different health care professionals including your GP, palliative care specialist doctors, occupational therapists, physiotherapists, grief and bereavement counsellors, pastoral care workers and volunteers. The involvement of these professionals will be based on your child and family's needs.

HOW TO ACCESS PALLIATIVE CARE

For help and information about which services are available and how to access them ask your:

- Doctor
- Hospital Liaison Officer
- Nurse

Or visit: <https://palliativecare.org.au>

PAEDIATRIC PALLIATIVE CARE ASSESSMENT

Palliative care for children involves a holistic assessment to determine the needs of both your child and your family.

This assessment is a time to explore your child and your family's goals, hopes and concerns and usually includes input from a multi-disciplinary team. The primary goal of this assessment is to provide the best possible arrangement for the family.

The assessment may provide an opportunity to discuss:

- Preferred place/s of care
- The health needs of your child
- Education
- Social activities
- The emotional, cultural and spiritual needs of your family

***“Palliative care teams changed our lives, and if we could give advice to any parent of a child with a rare disease/ life limiting illness it's don't be afraid to involve them. They have a wealth of knowledge, not just for end of life but for managing and making life comfortable in the time that you have.*”**

As there is no treatment for mito having specialist and palliative care to help symptom manage is imperative. They are also one of the best supports in the sense of understanding and the emotional side, as they are about the closest in understanding what you are dealing with as they deal with special children like Tyler every day.”

Abbey-Lee Flaskas, mum to Tyler who sadly passed away from mito in July 2018

HELPFUL HINTS FOR FAMILIES

- Let your child's treating healthcare team know when you are ready to talk about your child's mito progression, symptoms, timing of death and other related issues
- Look after yourself; build some 'me time' into the daily routine
- As a family, try to openly discuss how you are going to manage the many changes that are ahead
- Share your feelings, thoughts, fears, concerns, hopes and expectations with a trusted person
- Create memories of your child. This can be achieved through special times together, photos or videos
- Many people feel the greatest help they receive is the care and support given to them by their family and friends. One of the best things you can do at this difficult time will be to accept the help and support offered by the people closest to you

Your GP or palliative care services can help with accessing a bereavement counsellor or social worker. Below are some organisations who can provide information and support:

Australian Centre for Grief and Bereavement

1800 642 066

<https://www.grief.org.au/>

Beyond Blue

1300 224 636 (available 24 hours a day)

<https://www.beyondblue.org.au>

Kids Helpline

1800 551 800 (available 24 hours a day for young people aged 5 to 25)

<https://kidshelpline.com.au/>

Lifeline

13 11 14 (available 24 hours a day)

<https://www.lifeline.org.au>

MensLine Australia

1300 789 978 (available 24 hours a day)

<https://mensline.org.au/>

Parentline

1300 301 300

<http://www.parentline.org.au>

Content sourced from Palliative Care Australia and Royal Children's Hospital, Melbourne.