Do you have a child with a life limiting illness?

Does your child experience pain or other difficult symptoms relating to their illness or disease progression?

Would you like more professional help in planning for the care of your child?

Do you want to give your child and family the best possible quality of life?

#### Do you experience any of the following?

- Isolation
- Anxiety
- Depression
- Exhaustion
- Feeling trapped
- Family life stress factors:
- Financial stresses
- Loss of work
- Time away from home and other children
- Difficulties navigating the health system



## Paediatric Palliative Care Facts For Families



## rainbowplace.co.nz

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Hospice Waikato

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# Rainbow Place supports families/whānau through a child or young person's illness

Caring for a child or young person with a life limiting illness can be a difficult time for parents, siblings, grandparents and other involved carers.

Rainbow Place Care provides support for families/ whānau caring for a child with a life limiting condition. Care is tailored to each family's unique situation and individualised needs to help make decisions about the planning and delivery of care throughout a child's illness. This can reduce some of the fear and anxiety experienced during this difficult time.

Rainbow Place's paediatric palliative care is different from adult palliative care. When children are diagnosed with a rare medical condition it can be difficult to predict how an illness will progress. Some children may be a patient in our care over many years.

#### What do we provide?

- Ongoing communication to support your family (home visits, telephone calls, video conferencing and emails).
- Paediatric Nursing support including: Assessment and management of pain and other difficult symptoms your child may experience during their illness.
- Education and support to help administer unfamiliar drugs that may be prescribed to care for your child at home.
- Coordination of care to link your child and family/ whānau with your local professionals and community services (including rural areas).
- Creative, music and massage therapies.

- Loan of equipment and liaison between occupational therapists.
- Coordination with all health care professionals involved in the care of your child.
- Psychosocial support for siblings and other family members.
- Mana Awhina support services.
- Support to establish your goals of care (including advance care planning).
- Care and support during end-of-life care.
- Bereavement care for parents, siblings and other extended family members.

All our services are provided on a needs basis and are free of charge.

#### Where can Rainbow Place care be provided?

In many situations' families can choose where they would like to care for their child.

Most care is provided at home, however as an illness progresses, it may become necessary to spend more time in hospital. Rainbow Place palliative care services can help by coordinating care across these locations to help ensure that families are supported wherever they wish to be.

Respite symptom management and end-of-life care are provided on site at Rainbow Place, Cobham Drive Hamilton. Children and young people with life limiting condition can use our respite room to receive nursing care, to give carers and family members a break, family members are also able to stay on site.

### When is a good time to access Rainbow Place Care?

A referral to our palliative care service can be made at any time during your child's illness. It is often difficult to predict the progression of many childhood illnesses. It is a good idea to think about a palliative care referral early, even at the time of diagnosis when medical treatment is given to treat or cure and illness.

A referral to our service does not mean that you have given up hope. In fact, it allows for more time to plan your child's care and provide the best possible support for you and your family.

#### How do l organise a referral?

If you think paediatric palliative care could be helpful for your child and family/whānau. You may self-refer however we will need to access you child; medical records before your referral is accepted. Talk to one of your child's doctors or healthcare professionals and an appointment can be arranged. Including a tour of our facilities.

#### What are Rainbow Place's contact details?

Rainbow Place 334 Cobham Drive, Hamilton 3240 Phone 07 8591260 www.rainbowplace.co.nz Refer online - it's quick and easy to submit. www.facebook.com/rainbowplacehospicewaikato/