Victorian Paediatric Palliative Care Program
and
Very Special Kids

Mapping Paediatric Services

Palliative Care: Extending the Reach
7th Biennial State Conference

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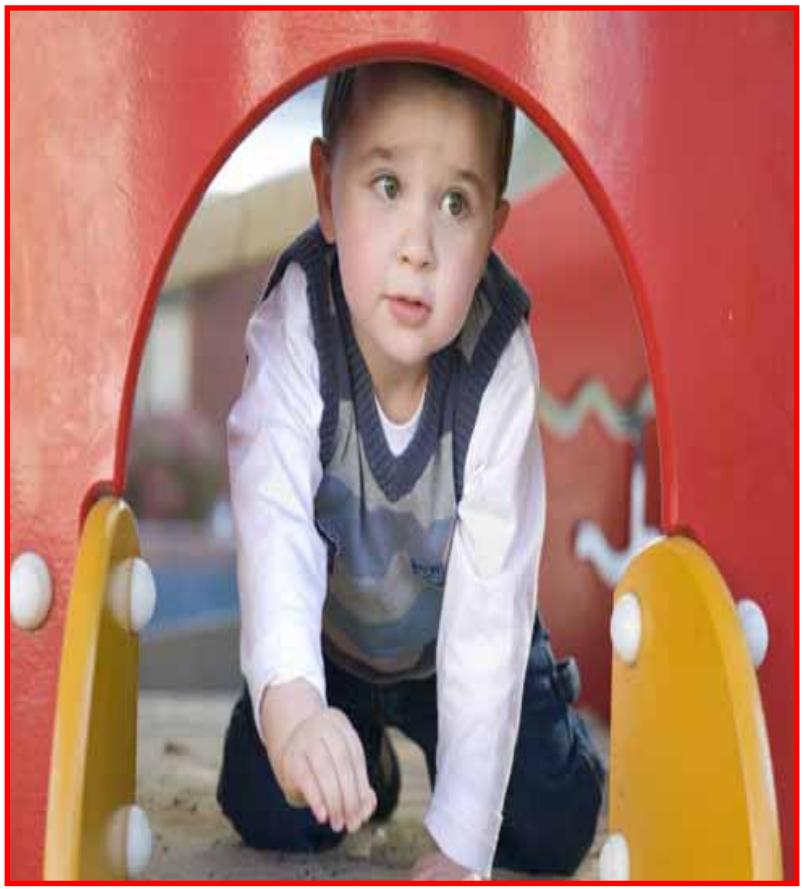
Very Special Kids

- Statewide non-profit organisation
- Supporting over 850 families who have children with life-threatening illnesses (350 bereaved)
- Continuity of care from point of diagnosis through to recovery or bereavement
- Registered families can access any of our services, as required (no cost to families)



Family Support Team

- Counselling & emotional support
- Referral and advocacy
- Facilitation of programs
- Sibling support programs
- Bereavement support program
- Family camps and activity days
- Newsletters



Very Special Kids House



- Australia's first and Victoria's only children's hospice
- Established in 1996



- Planned and emergency respite
- Step down care
- End-of-life care
- Parent Accommodation

Very Special Kids Paediatric Palliative Care Model

- An active and total approach embracing physical, emotional, social and spiritual elements
- Focuses on enhancement of quality of life for the child and support for the family
- Services provided from the point of diagnosis through to bereavement
- Services include family support, respite care, symptom management, end-of-life care and bereavement support
- Care is delivered across hospice, hospital and family home



Victorian Paediatric Palliative Care Program

- Consultation-liaison program
- Alliance between RCH, Southern Health & VSK
- Commenced in 2000
- Paediatrician/Consultant Dr's
- Liaison Nurses
- Case Management Liaison /Social Work - part time
- Occupational Therapist- part time

Consultation-liaison

- Health professionals within the state, nationally
- Families
- Community sector

Provision of education

- General
- Specific
- Development and provision of resources
- Help families with decision making

What is Paediatric Palliative Care?

"Palliative care for children and young people with life-limiting conditions is an *active* and *total* approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of *respite* and care through death and *bereavement*."

(Royal College Paediatrics and Child Health, UK)

The Family's Experience of Illness

- The family's experience of grief begins with a diagnosis of illness or disability

- The family ride a rollercoaster of emotions

- Changes
  - in their child's health
  - in their relationships with medical, nursing and allied staff
  - in their lifestyle
  - in their relationships with friends, family and the community

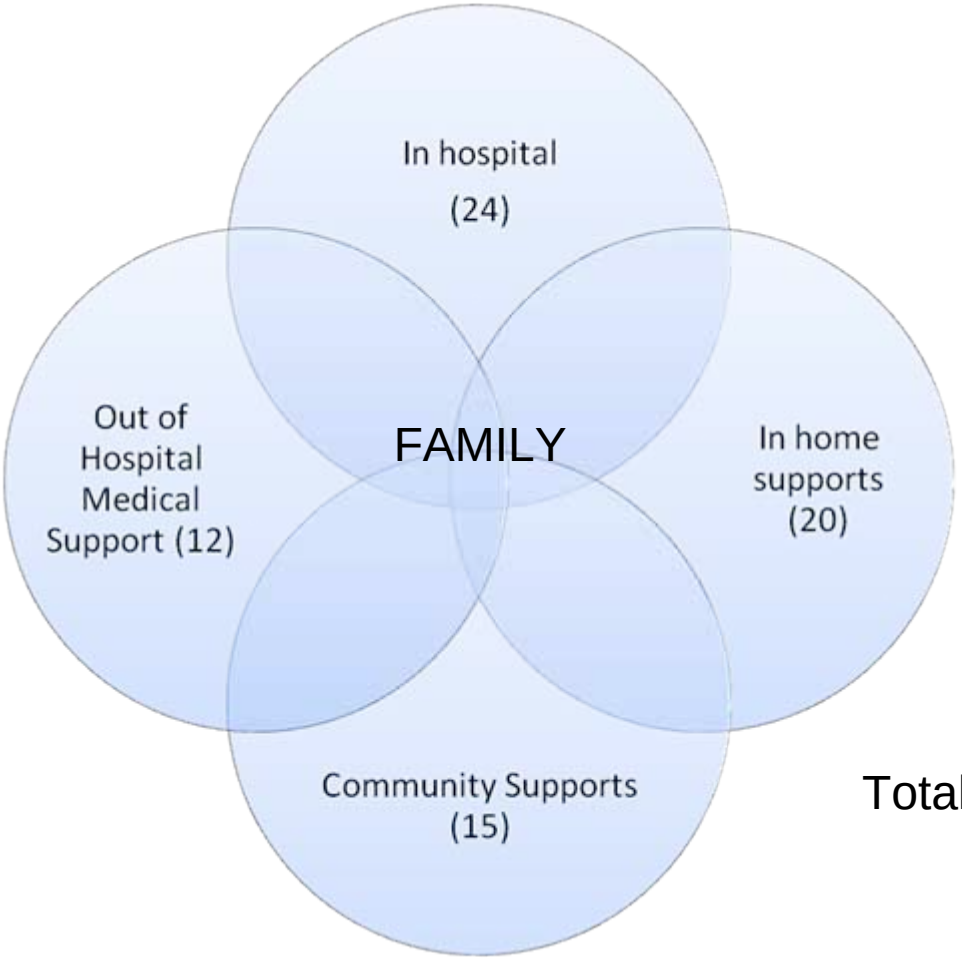
- Men and women may respond differently and have different needs and responsibilities. This can put further emotional and financial strain on the couple

The Family's Experience

Parents' Perspective:

- Understand complex medical terms
- Make decisions about treatment for their child
- Know the decisions will impact the whole family
- Tell the child and siblings about the illness and discuss death and dying or NOT
- The family's wishes may conflict with other family members, staff or community practices and beliefs

The Support System



Total = 71 supports

A Family's Ability To Cope

Family Crisis: Illness – ensuing grief

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Concurrent Stressors

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Family Resources

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Family Perception Of Event

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Positive Outcomes

Increased:
Closeness
Understanding
Respect
Problem Solving Skills
Empathy
Sharing

⇩

Strengthening Of Relationships

Negative Outcomes

Exacerbation of previous problems
Accentuation of previous tensions
Incremental grief

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Weakening Of Relationships

Source: "Dying And Grieving Lifespan And Family Perspectives" Cook & Oltjenbruns 1998

How to support the child and family?

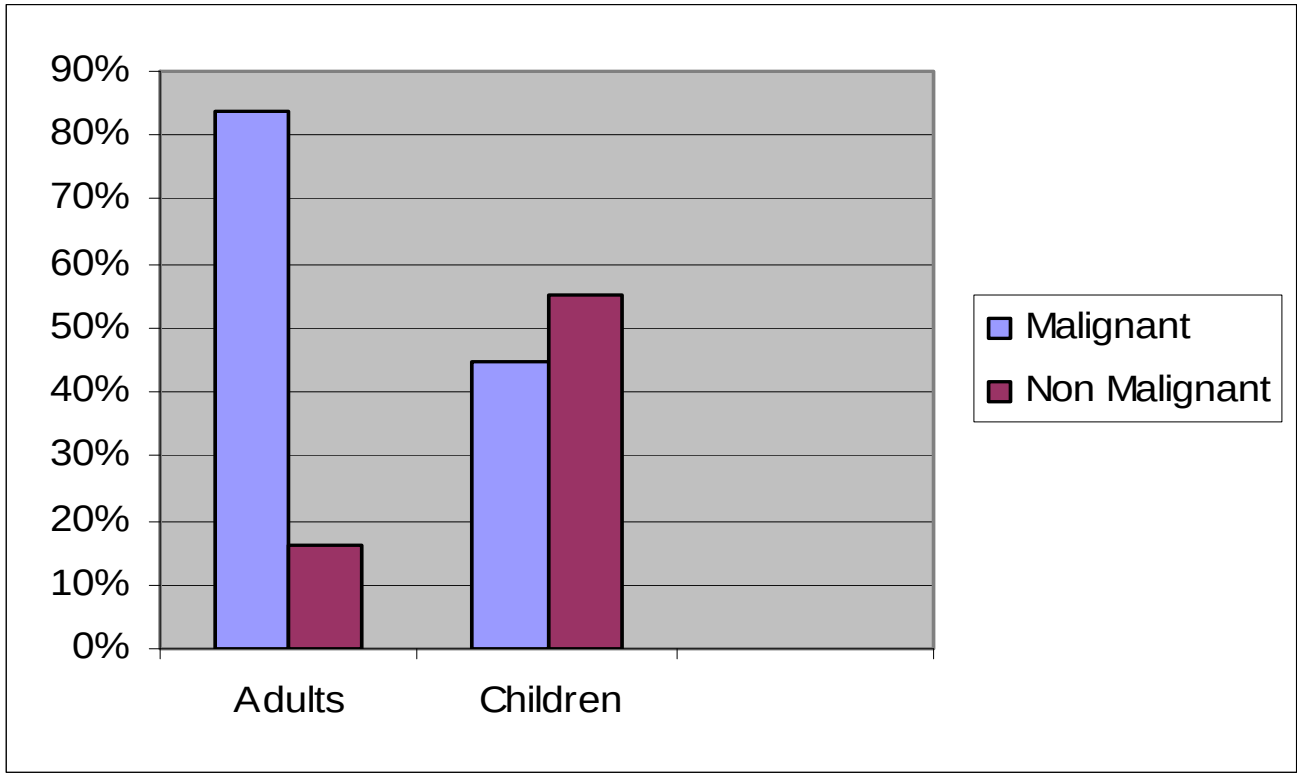
Give back control

- Slow processes down
- Involve family
  -parents, children and extended family and friends
- Provide information
  Processes
  Verbal and written Options

Case Study - Lily

- Born in 2000
- Parents are consanguineous (married cousins)
- Presents to local hospital unwell
- Multiple referrals made to various services
- A firm relationship forms between the family, VPPCP and Very Special Kids with regular respite at *Very Special Kids House*

A Comparison of The Frequency of Malignancy in Adults and Children



2007-2008, Mercy Palliative Care and VPPCP shared project

Other Comparisons

- Different focus on whole family
  - parental responsibility
  - more hands on, must learn medical treatments
  - make difficult decisions
  - parents can choose not to tell child, siblings
  - multiple children in family with condition
  - stigma of genetics, disability

- Different medical paradigm
  - consultation with GP in end stage
  - chronic deterioration, sometimes unclear end stage
  - child may choose to stay in supported environment

- Different cultural paradigm
  - photos, footprints, handprints