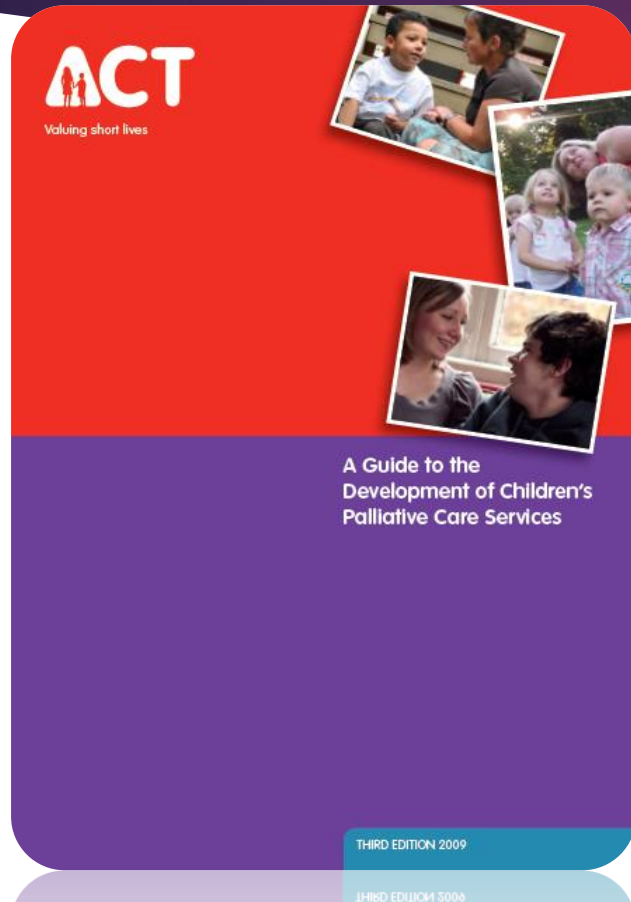


End-of-life care for children with life-threatening illness and medical complex condition in Hong Kong

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Definition of paediatric palliative care



- ◆ For children and young people with *life-limiting or life-threatening conditions*
- ◆ It is an *active and total* approach to care, *from the point of diagnosis* or recognition, throughout the child's life, death and beyond
- ◆ It embraces *physical, emotional, social* and *spiritual* elements and focuses on the enhancement of *quality of life* for the *child/young person* and support for the *family*
- ◆ It includes the management of distressing *symptoms*, provision of care through death and *bereavement*

A Guide to the development of Children's PC Services, Association of Children's Palliative Care (ACT) UK 2009

- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, in children's homes and even in special schools.



Paediatric Palliative Care is



Child-centred



Family-centred

Enhance quality of life

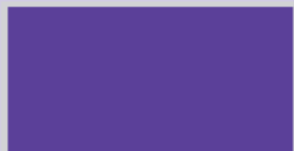
Who needs paediatric palliative care?



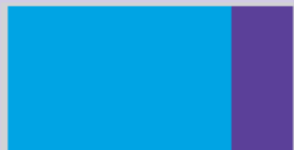
As the illness progresses the emphasis gradually shifts from curative to palliative treatment.



Highly technical invasive treatments may be used both to prolong life and improve quality alongside palliative care, each becoming dominant at different stages of the disease.



No cure is possible and care is palliative from the time of diagnosis.



At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation dawns.



Curative



Palliative

01 *Cancer, irreversible organ failures*

02 *Duchenne muscular dystrophy, cystic fibrosis*

03 *Genetic, metabolic disorders*

04 *Cerebral palsy*

Why needs paediatric palliative care?

There can be few greater tragedies for a family than the death of their child. The circumstances surrounding their child's death can have huge impact on family members and can imprint memories which may last a lifetime.

Sister Frances Dominica

Paediatric Palliative Care development in Hong Kong

1999

CCF set up children's palliative and home care service to end stage cancer children in 5 children cancer centers



兒童癌病基金
Children's Cancer Foundation

2011

CCF Started pilot service for non-cancer child patients

2015

HA commission training on paediatric palliative care



醫院管理局
HOSPITAL
AUTHORITY

2017

Hong Kong Society of Children's Palliative Care set up



The Hong Kong Society of Children's Palliative Care
香港兒童紓緩學會

2018

Children's Palliative Care Foundation set up



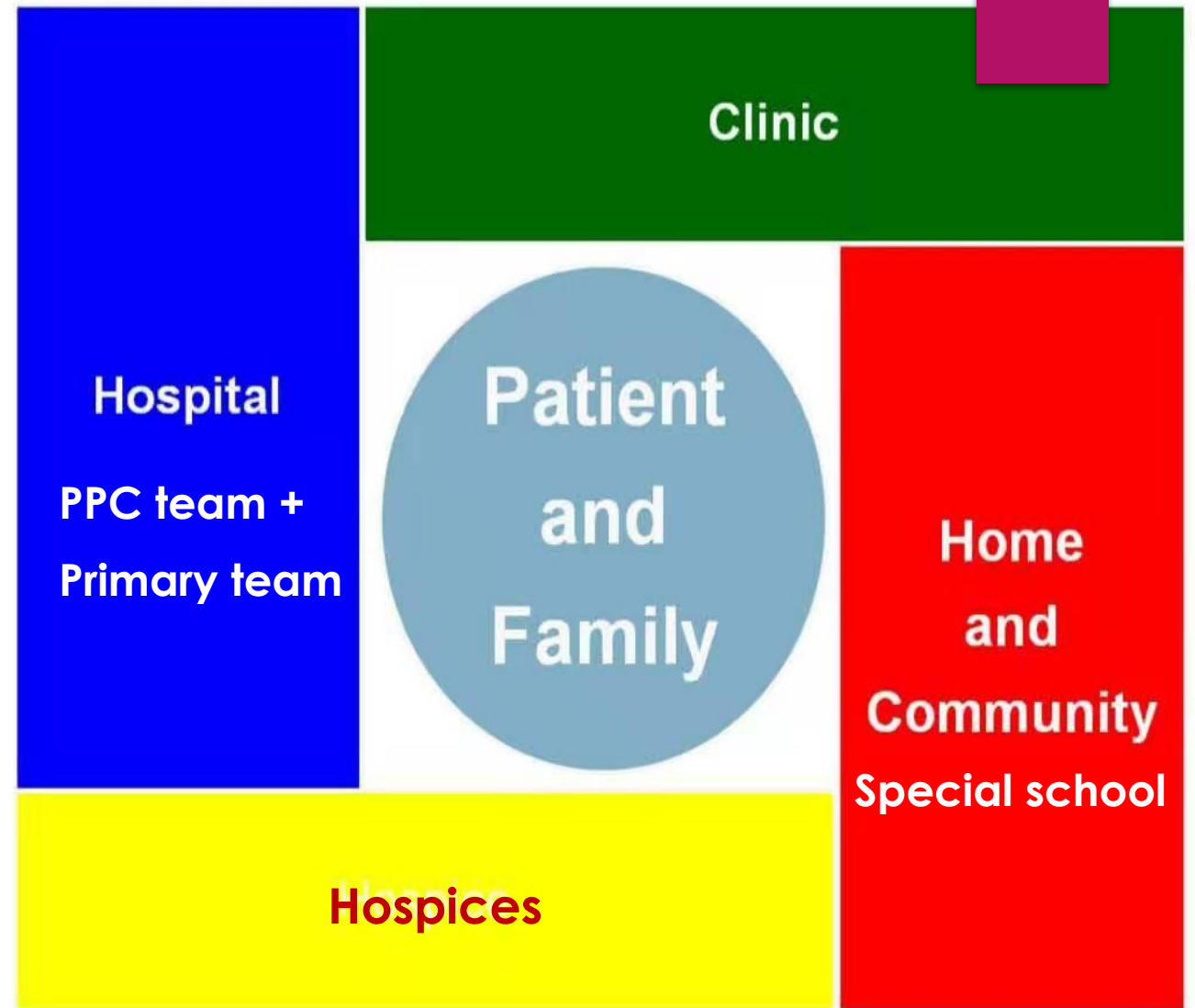
兒童紓緩服務基金
Children's Palliative Care Foundation
高麗兒童癌病基金 An entity owned by Children's Cancer Foundation

2019

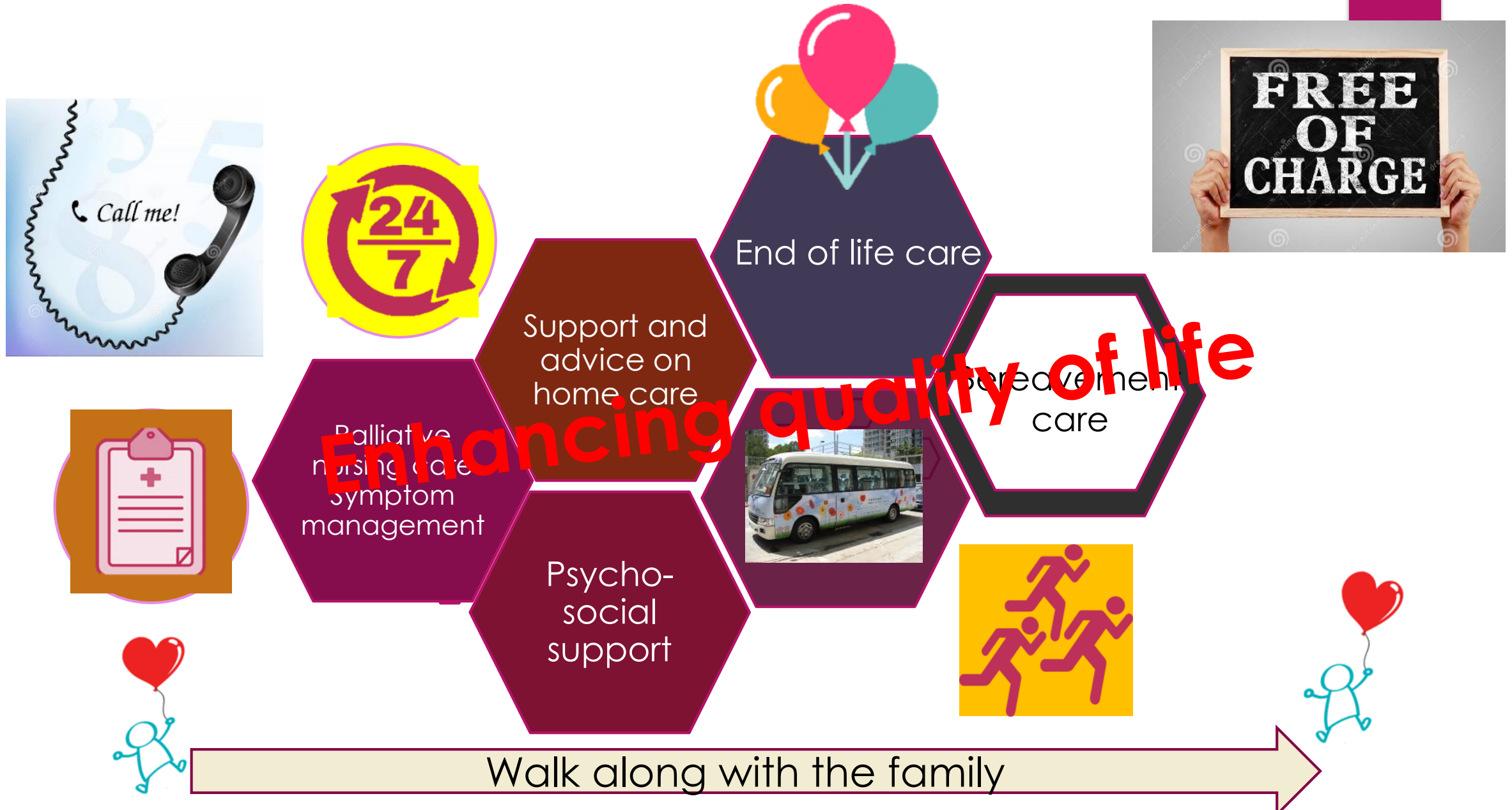
Paediatric Palliative Care Team in HK Children's Hospital

香港兒童醫院
Hong Kong Children's Hospital

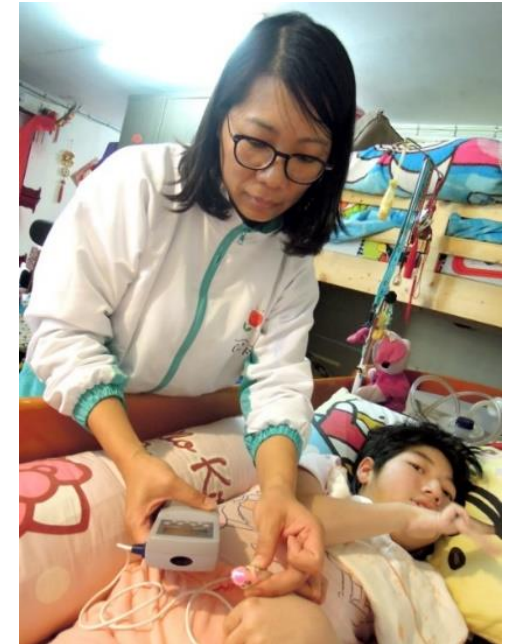
Shared care model



Scope of community-based services



Symptom management and nursing care consultative services at home





Visiting
patient in
special
school



Rehab bus service facilitates patients to go into society



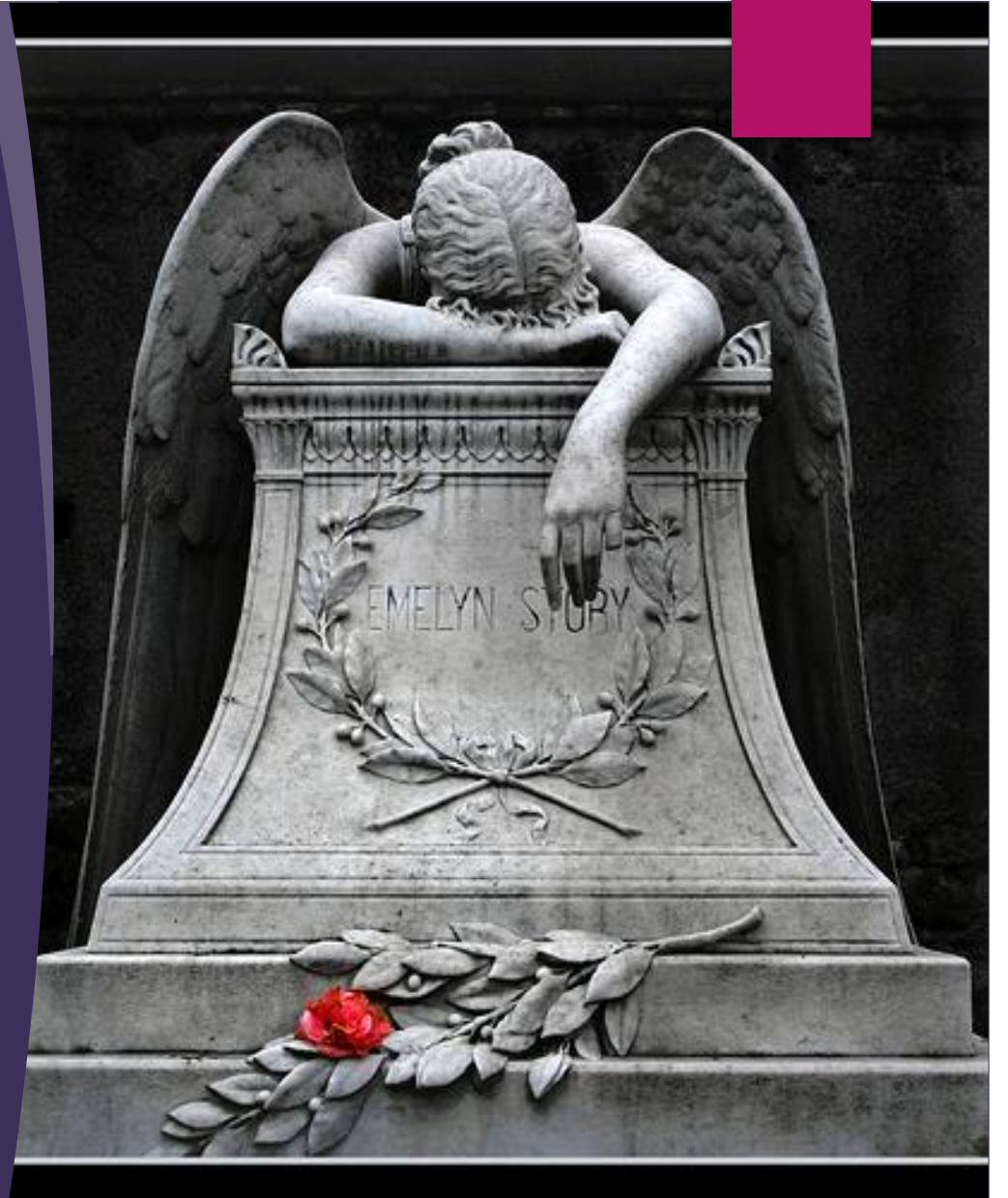
This is my special chair with all the equipment. I can go home.

When life comes to end

- Focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition.
- This includes care during and around the time of death and immediately afterwards.
- It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.
- It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

Bereavement care

Bereavement frequently starts at the moment of diagnosis, so support should be provided throughout the illness. This includes the need to continue and possibly provide intense support to the whole family, during the time of the child's death and beyond.



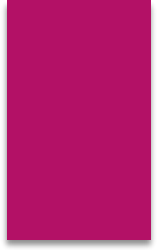
Activities for bereaved families



Memorial program









We are
family
forever

Perinatal Palliative Care is



- The support offered to parents who find out during pregnancy that their baby has a life-limiting condition.
- For parents who choose to continue their pregnancies, this support is provided from the time of diagnosis through the baby's birth and death.
- To help parents embrace whatever life their baby might be able to have, before and after birth.

Neonatal Palliative Care is

- ▶ The planning for and provision of supportive care during life and end of life care for the newborn baby and his or her family when diagnosed with a life-limiting condition.
- ▶ most frequently occurs in a Neonatal Intensive Care Unit (NICU).



Transitional care is



- the term used when the child is moving from childhood into adulthood.



- the transfer of service provision around this time should be well planned and ensure as little disruption to the young person and their family as possible.

Palliative care for children is special in several ways

- The number of children who passed away is small, compared to that of adults'
- It's difficult for parents to accept the illness and impending death of their child
- The signs and symptoms of children with life-threatening illness and their response to medication are different from that of adults'
- Care embraces the whole family. Parents and siblings are especially vulnerable, and parents bear a heavy responsibility for personal and nursing care

Palliative care for children is special in several ways

- Provision of teaching and play for sick child is essential
- A characteristic of childhood is the continuing development - physical, emotional and cognitive, which is reflected in their communication skills, and which affects their understanding of their disease and death.

Some primary care paediatricians never acknowledge death in children. They may be unfamiliar or uncomfortable with counseling or managing a child and family in palliative care, given the infrequency of death in most practices.

Many life-threatening and -limiting illnesses in paediatrics are rare. It is difficult to diagnosis. Medical professionals are lack of knowledge in treating and predicting the prognosis.

The taboo around child death, without an open and honest approach in dealing with child death. No hospices here and without adequate children's palliative care options.

Challenges to develop Paediatric palliative care

Challenges to develop Paediatric palliative care

- ▶ A lack of understanding about what children's palliative care is.
- ▶ Families should not have to choose between life-prolonging care and palliative care, when they can go hand-in-hand.
- ▶ The disease trajectory of children who are life-threatening and -limiting with medical complex conditions is prolonged that makes referral at right time and long-term PPC services provision challenging.
- ▶ There is insufficient research and evidence-base on the use of medication to treat pain and other symptoms and psychosocial issues related to end-of-life care for children and families.
- ▶ Adult hospice and palliative care personnel often have no paediatric expertise. Many of the conditions that are common in paediatrics are virtually unknown in adult palliative care.



THANKS