

The background of the slide is a photograph of the Hong Kong Children's Hospital building, a large, modern multi-story structure with a colorful facade of blue, green, and yellow panels. The building is set against a bright, slightly hazy sky with some tree branches visible in the upper right corner. The text is overlaid on this image.

Palliative care service in Hong Kong Children's Hospital

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Palliative Care in HA in the past

Adult

- Palliative medicine as a medical specialty in 1998
- Structured specialist palliative care teams in 16 HA hospital
- Subspecialty training
- Well established cluster/hospital based referral networks

Paediatric

- By respective paed depts (no structured program)
- No subspecialty training
- Limited community support
- Lack of structured transition care

Drive for development of Paediatric Palliative Care

- 1999, Children's Cancer Foundation started the first PPC service in HK
- 2015, first commissioned training for paediatric palliative care held in HA
- 2011, Pilot programme by CCF to support non-cancer patients with PC needs
- Some paediatric department set up limited PPC service in their hospital without additional resources
- 2016, formation of concern's group to push end-of-life care for children
- 2017, establishment of The Hong Kong Society of Children's Palliative Care
- 2017 Annual Plan bidding for PPC service approved by HA (government)
- 2018, establishment of HK Children's Palliative Care Foundation



The Hong Kong Society of Children's Palliative Care

香港兒童紓緩學會

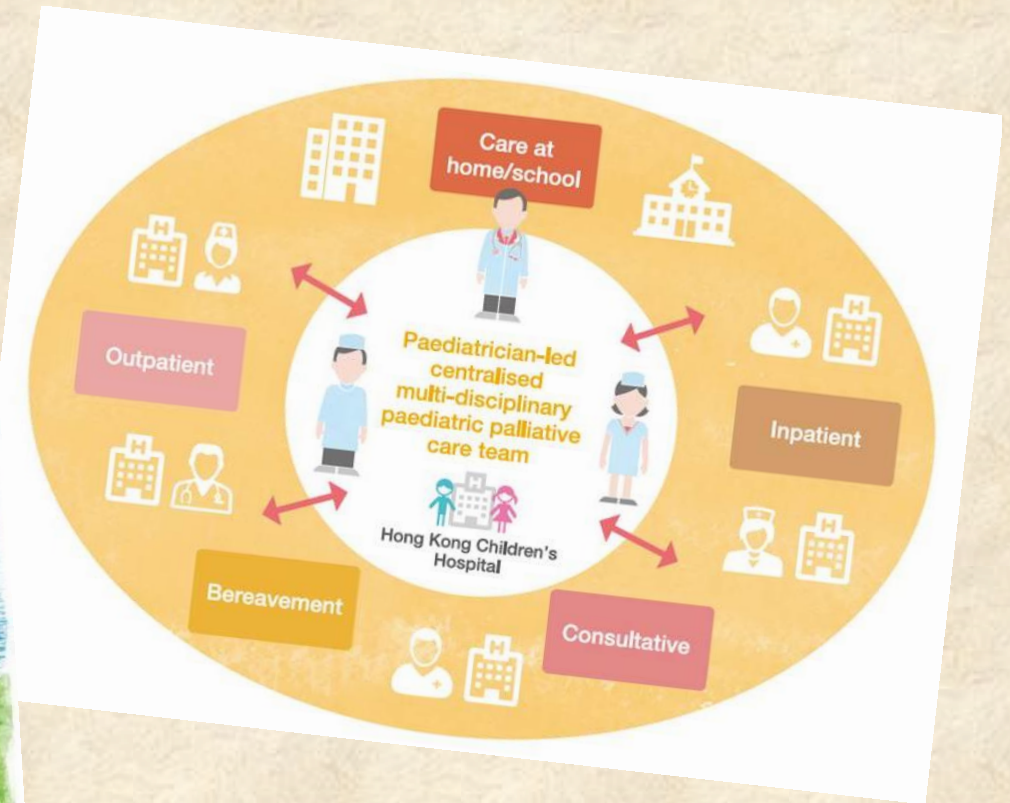
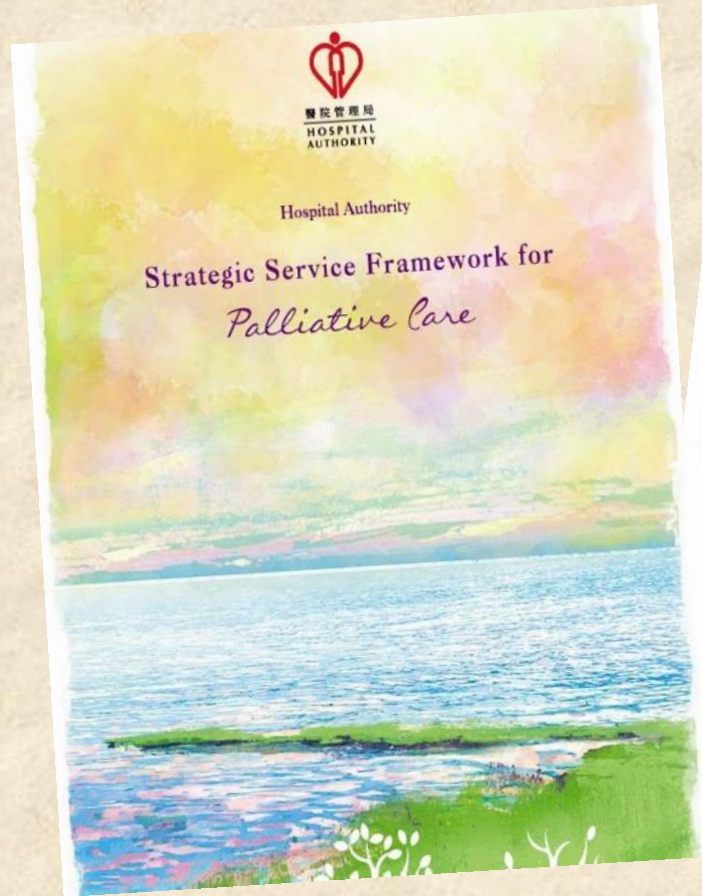
Medical staff opinion: urgency for improvement

Factors needing improvement with level of urgency

Factors needing improvement	Level of urgency (Mean)*
Availability of manpower	4.20
Linkage between hospital service and community service	3.76
Sufficient resource support	3.75
Recognition of the importance of paediatric palliative care	3.70
Bereavement service for patients' families	3.69
The knowledge of palliative care among patients' families	3.68

*Range from 1 to 5, higher score means more immediate improvement is needed. Mid-point is 3.

HA Strategic Service Framework (2017)



HA's Vision on Palliative Care

“All patients facing **life-threatening and life-limiting** conditions and their families/carers receive timely, coordinated and **holistic palliative care** to address their physical, psychosocial and spiritual needs, and are given the **opportunities to participate in the planning** of their care, so as to improve their **quality of life** till the end of the patients’ **life journey.**”

- Covering both **adults and children** with **cancer or non-cancer** diseases.

(HA Strategic Service Framework for Palliative Care, 2017)

Paediatric Palliative Care

Palliative care for paediatric patients can take place at **Any Stage** of a serious illness



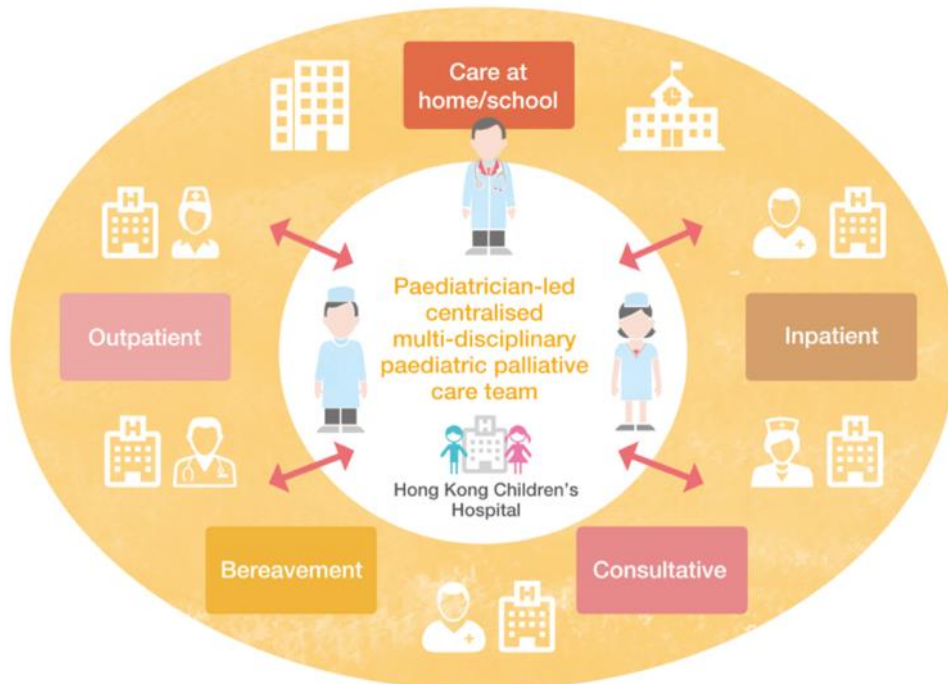
Provided in **Different Settings**, ranging from tertiary care facilities to the patients' home



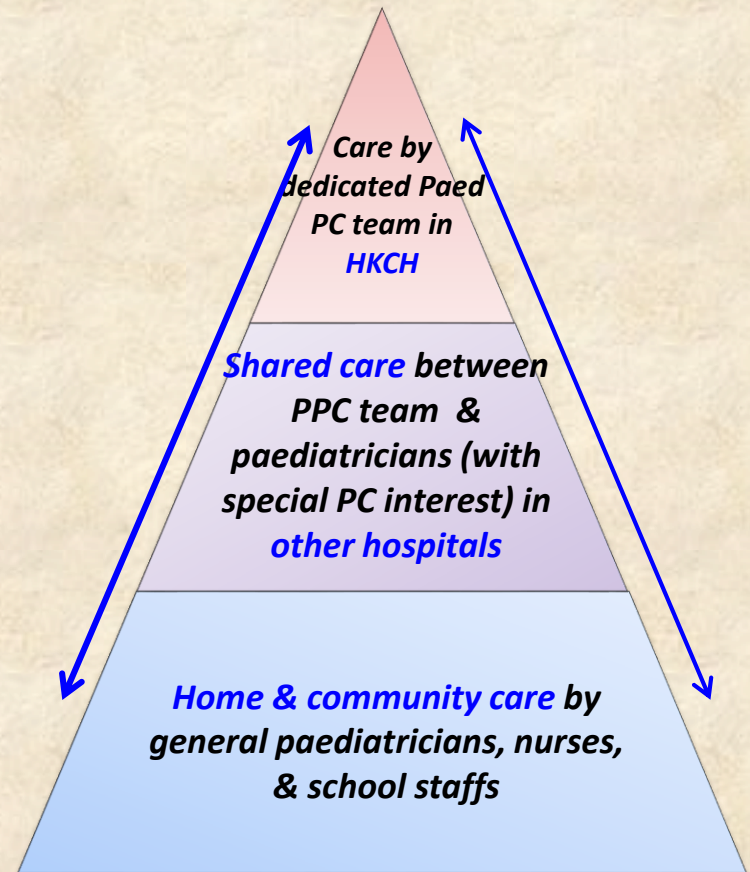
Families include parents, siblings, carers and significant others who matter to the patients

Paediatric Palliative Care Services in HA

Figure 12. Future Service Model of Paediatric Palliative Care in HA



A **centralised paediatric PC team** works with the designated care team of doctors and nurses at **regional level** to provide a continuum of **territory-wide** palliative care services from hospital to community under a **single clinical governance**



Hong Kong Children's Hospital



HKCH paediatric palliative care team

- Paediatrician
- Nurses
- Social worker
- Executive assistant



Children with life-limiting and life-threatening conditions

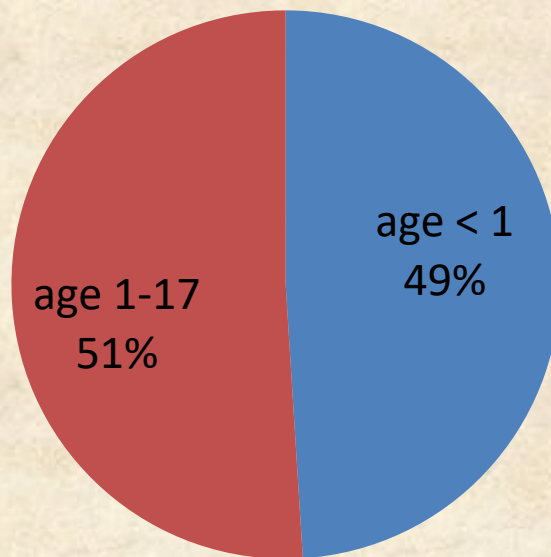
Association for Children's Palliative Care (ACT)/Royal College of Paediatrics and Child Health (RCPCH) categories :

1. **Life-threatening conditions (LTC)** for which curative treatment may be feasible but can fail.
 - cancer, irreversible organ failures of heart, liver, and kidney
2. **Conditions where premature death** is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.
 - DMD
3. **Progressive conditions without curative treatment** options, where treatment is exclusively palliative and may commonly extend over many years.
 - mucopolysaccharidoses, neurodegenerative disease
4. **Irreversible but non-progressive conditions causing severe disability** leading to susceptibility to health complications and likelihood of premature death.
 - severe cerebral palsy, multiple disabilities following brain or spinal cord injury

Paediatric Palliative Care

No. of registered death in HK (2014): **45 718**

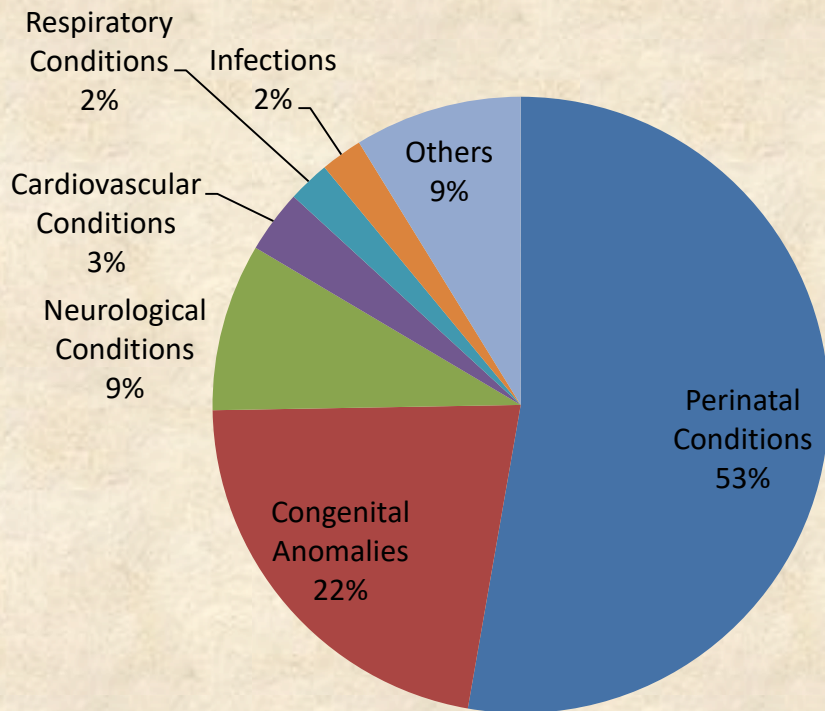
- **< 1 %** (256*) are of **age < 18**
- Of which, **212 (83%) deaths occurred in HA**



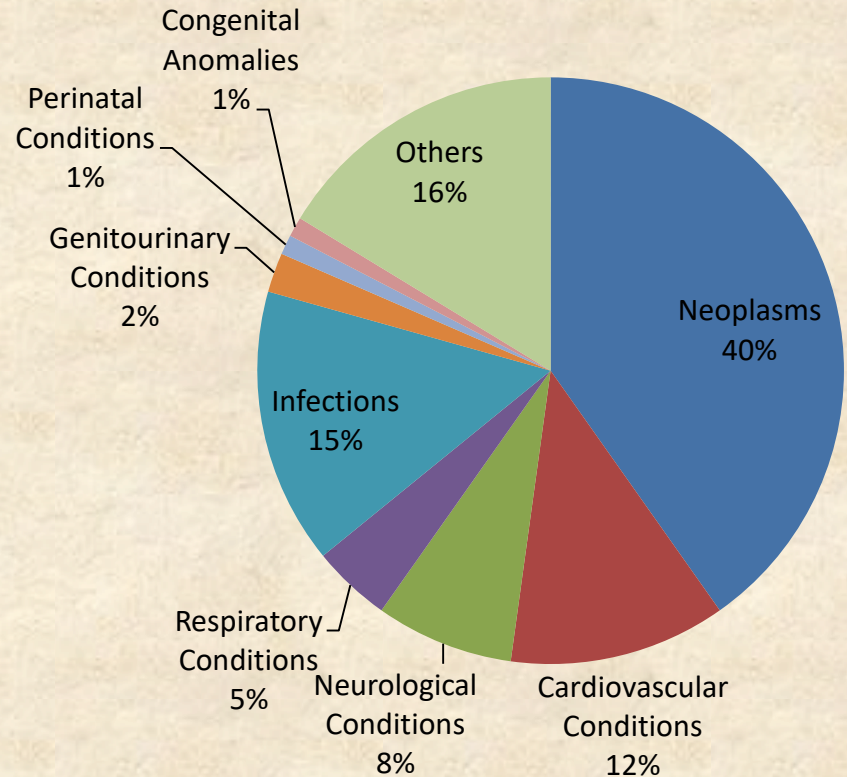
***Half of them occurred
before the age of 1***

Paediatric Palliative Care

Death in Age Group < 1 (2014)



Death in Age Group 1 to <18 (2014)



According to the principal diagnosis of death episode in HA

HKCH paediatric palliative care service

- Symptoms control
- Psycho-social /spiritual support
- Discussion of advance care plan or other ethical conflicts
- Home care support
- End of life care
- Bereavement care
- Complex care co-ordination
- Collaboration with NGO

HKCH Palliative Care Services

- Intervention for symptom palliation & psychosocial problems
- Consultative service for shared care with parent team

Inpatient Care & Consultative Service

- Continuity of palliative care of discharged patients
- Management of less acute & complex symptoms

Outpatient Care

- Support patients and families in grief
- Identify persons at high risk of psychological morbidity

Bereavement Care

Care at Home, School & Residential Home

- Optimize symptom control & rehabilitation
- Provide psychosocial care for patients and their families in the community

Consultation

- Start with HKCH patients
- Territory wide support by phases
- Share care with parent team to formulate unique management plan for each patient and family

 醫院管理局 HOSPITAL AUTHORITY		HKCH Palliative Care Team Consultation Form		 香港兒童醫院 Hong Kong Children's Hospital	
Patient FULL label					
Name					
Sex					
DOB					
Address					
Reasons for consultation:					
<input type="checkbox"/> Symptoms control <input type="checkbox"/> Psychosocial/ spiritual support <input type="checkbox"/> Support at critical moment (e.g. break bad news, sudden deterioration) <input type="checkbox"/> Discussion of ACP or other ethical conflicts <input type="checkbox"/> Home care support <input type="checkbox"/> Complex care coordination <input type="checkbox"/> Collaboration with NGO <input type="checkbox"/> End of life care <input type="checkbox"/> Bereavement care <input type="checkbox"/> Other:					
Details:					
Patient summary					
Now at <input type="checkbox"/> Home <input type="checkbox"/> Hospital/ward: <input type="checkbox"/> Special school:					
Contact person		Name:		Relationship with patient:	
		Tel :			
Medical history:					
Diagnosis:				Date of diagnosis:	
Disease trajectory:		<input type="checkbox"/> New diagnosis	<input type="checkbox"/> Stable	<input type="checkbox"/> Relapse	<input type="checkbox"/> End Stage
		<input type="checkbox"/> Deterioration			
Infectious disease:			If yes, precaution:		
			<input type="checkbox"/> Contact <input type="checkbox"/> Droplet <input type="checkbox"/> Airborne		
Parents' consent for consultation		<input type="checkbox"/> Yes <input type="checkbox"/> No			
Doctor In Charge		Hospital/ unit		Signature	Date
Please fax this referral form to 35127644					
For palliative team use					
Date of assessment		Date of consultation received		Assigned key worker	
HKCH PPC consultation form updated on 13 March 2019					

Family

PPC team

Parent team
Allied Health professional
Other health care provider

Community

Tailor made management and follow up plan

In-patient support

Community support

Bereavement service

Home care support

Palliative care clinic

Palliative Care Clinic

Facilitates children and families



Home care support

- Designated home care team
- Telephone consultation
- Home visit service
- Collaborations with NGOs



Bereavement Support

- Loss of a child can be traumatic for parents and the whole family
- Bereaved family whose child died in HKCH
- Known case of Paediatric Palliative Care Team (Territory wide)
- *Individual/family bereavement counseling*
- *Bereavement group*
- *Memorial camp*
- *Debriefing session for health care providers/ volunteers*



Share care with regional hospital

By phases



Enhance Community Support

- Enhance palliative care support for **Special Schools**
- Strengthen **Community Partnership** on Paediatric Palliative Care



Way forward

- Transition to Adult Palliative Care Service
- Education and Training
- Research
- Cultural Change



Contact

HKCH intranet ->

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An architectural rendering of a modern, multi-story building with a colorful glass facade. The building features a grid of windows with varying colors (blue, green, yellow) and a prominent red heart logo on the upper left corner. The scene is set against a bright, slightly hazy sky with some foliage visible in the foreground and background. The overall tone is bright and optimistic.

Thank you