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## 2 Paediatric Palliative Care Team



紓晴家





## Team Members

Paediatric Palliative Care Team (紓晴家) Paediatricians

Nurses

**CCSP** 

Link Nurse









### **最治療**謬課

謬誤: 紓緩治療 是放棄所有治療, 以及 不能再轉回腫瘤科等治療

澄清:醫護人員會與病人商 討治療選擇。病人如有需 要,可以轉回所需專 科如腫瘤科治療。

> 謬誤: 紓緩治療 代表留院直至死亡

澄清:病人留院是因症狀嚴重,或有複雜心理問題。很多病人在家体養,透過門診及家訪跟進。

謬誤: 紓緩治療 等同安樂死

澄清:安樂死在港不合法,在紓緩治療中,醫護 人員不會刻意加速或延 遲病人死亡。

> 謬誤:接受紓緩治 療代表很快死亡

澄清:何時接受紓緩治療視 乎病人需要。近年國際上鼓勵 紓緩治療早期介入,當病人被 診斷患不可治癒癌症後12 周內,便可開始提供治 療服務。

資料來源:香港紓緩醫學學會主席吳常青



https://hk.news.appledaily.com/local/daily/article/20190113/20589933







#### Caritas Medical Centre Department of Paediatrics & Adolescent Medicine



#### 兒童紓緩治療齊認識問答 (活動前)

請在適當的空格內加上✓

職位:	醫生□	護士□	病房助理□	其他 □

	問題	是	否
1.	在香港,預設照顧計劃 (Advance Care Planning) 是不可隨時更改的		
2.	兒童舒緩治療服務對象只是瀕臨死亡或癌症的兒童		
3.	當兒童的疾病沒法根治時,舒緩治療才應該介入		
4.	在香港,家長可為兒童作出預設醫療指示(Advance Directive), 制定		
	的預設醫療指示是有法律約束力		
5.	使用嗎啡很容易引致上癮及呼吸受抑制		
6.	在香港,兒童不能選擇在家離世		
7.	適當處方嗎啡,能夠延長接受舒緩治療兒童的生命		
8.	不作「心肺復甦術」是等於「安樂死」		
9.	在香港,為未成年病人制定的預設照顧計劃(Advance Care Planning)是		
	有法律約束力		
10.	兒童舒緩治療服務與善終服務是相同的		
$\vdash$			







#### Who We Are

What we do

The Paediatric Palliative Care Team (PPCT) is a team of health care professionals including physicians and nurses. We work closely with other professional staff in the hospital, like clinical psychologist, chaplains, hospital play support children with life-limiting and/or lifethreatening conditions and their families.

#### 我們是誰

**紓晴家是由醫生護士組成的團隊。我們也與其** 他專職醫療例如臨床心理學家, 醫院遊戲師, 醫務社工與及牧靈部合作無間, 為面對危疾的 兒童及家人提供協助。

#### Department of Paediatrics & Adolescent Medicine 明愛醫院兒童及青少年科



Enhance communication between your child, family members, and healthcare providers

Assist you to make decisions that best reflect your child's and your family's values and preferences

Work alongside with your existing health care provider by advising on pain and symptoms control, psychosocial/spiritual issues

Liaise with other services in hospital and community to provide best possible care for your child and family

提升兒童, 家人以及醫護人員之間的溝通

協助您做出最能反映您孩子和您家人的價值觀 和偏好的決定

與您的醫護團隊緊密合作, 提供方案緩解疼痛 和其他令人痛苦的症狀, 減輕因疾病所引致的 身體、心理、社交以至實性上的痛苦

與醫院和社區的其他服務部門保持聯繫。為您 的孩子和家庭提供最適切的護理





#### 舒緩治療 ≠ 放棄治療

#### 根據世界衛生組織的定義 兒童紓緩治療

是一種對兒童身體、心理和精神的整體積極治 療, 並包括為家庭提供支援。

它始於做出診斷之時, 並一直延續下去, 而無 論兒童是否接受疾病的針對性治療。

許多人認為接受紓緩治療就是「甚麼都不做」、 「等死」。其實、舒緩治療並不是「消極醫療」。 舒緩治療的重要將提升兒童及其家庭的生活質素 緩解疼痛和其他令人痛苦的症狀。

#### 哪些兒童需要紓緩治療服務?

第一類: 有生命威脅的疾病, 治療可能是有效 的, 但也可能失敗。如: 癌症、心、肝、腎 臟不可逆轉的器官衰竭。

第二類:過早死亡不可避免的疾病。如:杜興 氏肌營養不良症、脊髓肌肉萎縮症。 第三類:逐漸惡化且無法治癒的疾病。如: 粘

第四類。造成嚴重殘障,不可逆轉但也不持續

惡化的疾病。如:嚴重的腦痙攣、腦或脊髓損 傷後的多重残障。

#### Palliative care ≠ Giving up

#### WHO Definition of Palliative Care for Children

The active total care of the child's body, mind and spirit, and also involves giving support to the family.

It begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.

Not giving up. Focus on enhancement of quality of life. Manage pain and distressing symptoms

#### Who needs Paediatric Palliative Care?

1.Life-threatening conditions for which curative treatment may be feasible but can fail: e.g. cancer, irreversible organ failures of heart, liver, kidney.

2.Conditions where premature death is inevitable: e.g. cystic fibrosis, Duchenne muscular dystrophy, spinal muscular atrophy

Progressive conditions without curative treatment options: e.g. mucopolysaccharidoses.

severe disability, leading to susceptibility to health complications and likelihood of premature death: e.g. severe cerebral palsy, multiple disabilities such as





Department of Paediatric and Adolescent Medicine &

Developmental Disabilities Unit

#### Paediatric Palliative Care Series 经转



Date	Time	Time Topic		Venue	
5/11/2018	13:30 – 14:00	Introduction to Paediatric Palliative Care	Ms Tiffany Lam, RN	Wai Shun 9B Activity	
	14:00 - 14:30	DNACPR & ACP	Dr Stephen Chan		
12/11/2018	13:30 – 14:30	Respiratory symptoms management	Dr Stephen Chan		
19/11/2018	13:30 – 14:30	Neurological symptoms management	Dr Christine Lau	Room	
26/11/2018	13:30 – 14:30	Pain management	Dr Stephen Chan		







































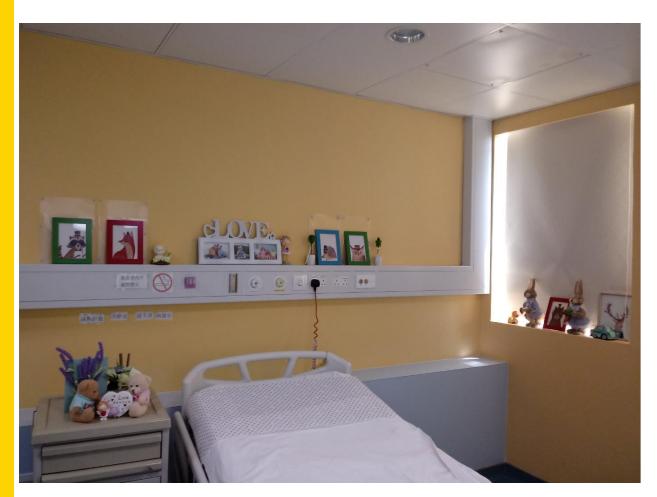








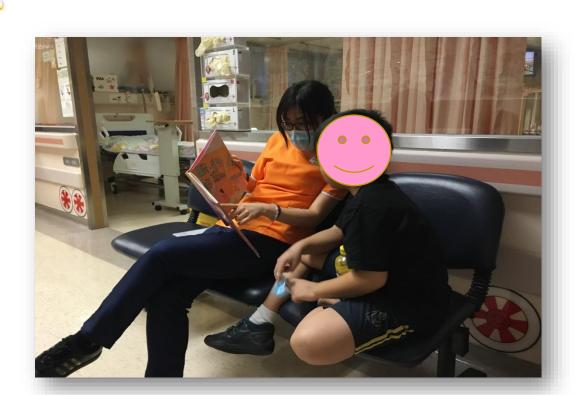








# Case Sharing



- 6 year old boy, Brain Tumor
- Terminal case, supportive treatment
- DNACPR
- Re-admit for fever and increase tone



遊戲師引導哥哥製作手工給弟弟,以表達對弟弟的思念和祝福

# Legacy Building





家庭成員的手掌印,創作手掌印畫,再配合紅十字老師的題字

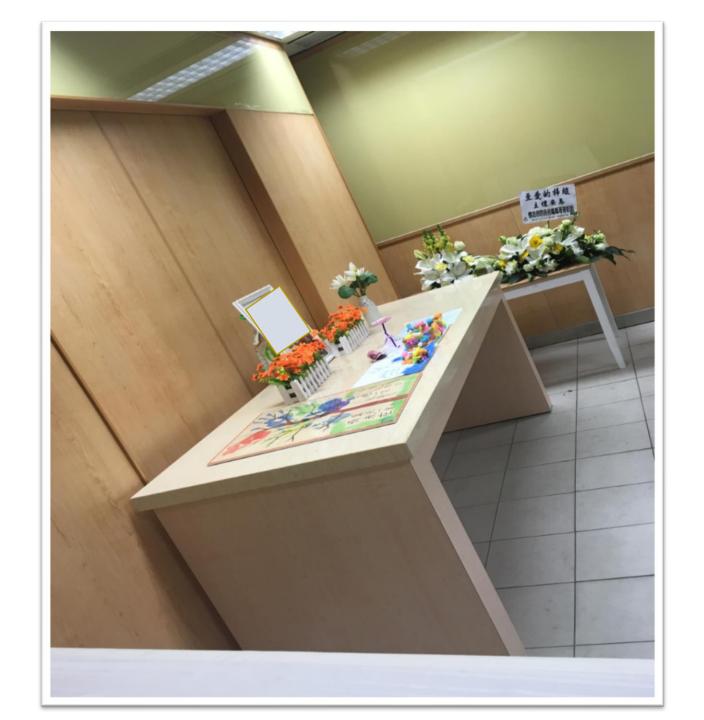








作品擺放在安息禮中



## 明愛醫院小禮堂: 寧佑軒



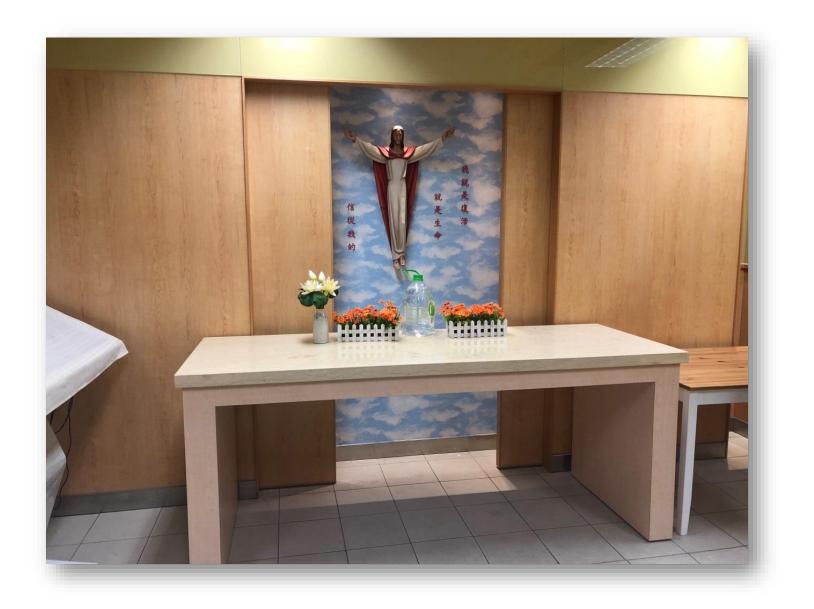








## 明愛醫院小禮堂: 寧佑軒







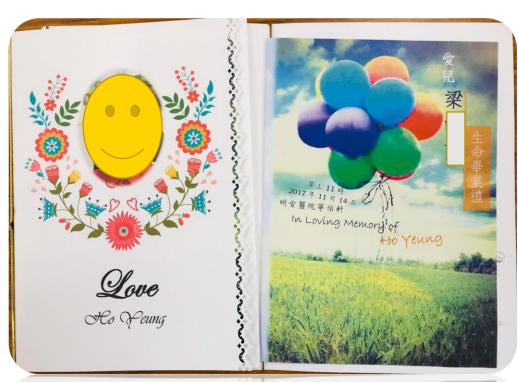


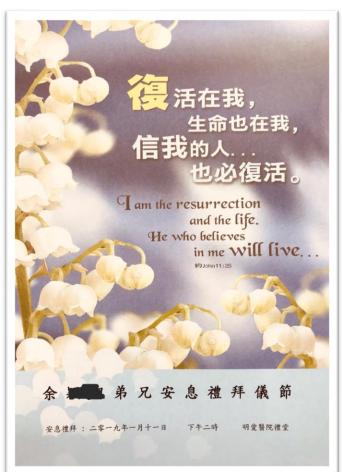






# Bereavement Support









## Bereavement Support





- 8 Ventilator Assisted Care Patients
- All on invasive ventilation





# Background

- 6 year old , girl
- Prematurity (gestation: 33+3 weeks) with multiple congenital abnormalities
- Upper airway obstruction since birth with emergency tracheostomy done requiring long term mechanical ventilation
- Severe neurological disability and development delay
- Feeding intolerance and poor oromotor effort, with laparoscopic fundoplication & gastrostomy done
- Musculoskeletal deformity: (1) Contracted elbows and wrists, (2) Extended and fixed knees while ankles are neutral (3) Bilateral hip dislocation, (4) Syndromal lordoscoliosis







# Family Background





Make a Wish







