

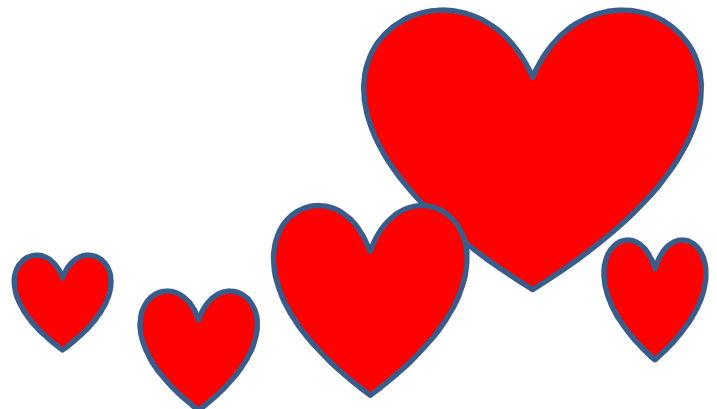
# Paediatric Palliative Care (PPC) in Nutshell Seminar

## PPC IN SPECIAL SCHOOL



P & AM APN Yam Wai Lin  
26 Oct 2019

Special School is playing a very  
important role for the PPC in  
Hong Kong



(2013-2015) 10 Severe MR Special Schools

57 students died



# Food for thought!

1. Who needs palliative care of our children?
2. Who are they?
3. Where are they?



# Who need palliative care of our children?

***Life limiting conditions, premature death is inevitable,***

*e.g. Duchenne muscular dystrophy, cystic fibrosis, HIV/AIDS, Chronic or severe respiratory failure, Renal failure, Severe short gut, TPN-dependent*

***Life-threatening conditions for which curative treatment may be feasible but can fail***

*e.g. Cancer, Complex and severe congenital or acquired heart disease, Trauma or sudden severe illness, Extreme prematurity*

***Progressive condition, no curative treatment***

*e.g. Progressive metabolic disorder, severe mitochondrial disorders, Severe OI subtypes, Trisomy 13 and 18*

***Irreversible but non-progressive condition, premature death is likely***

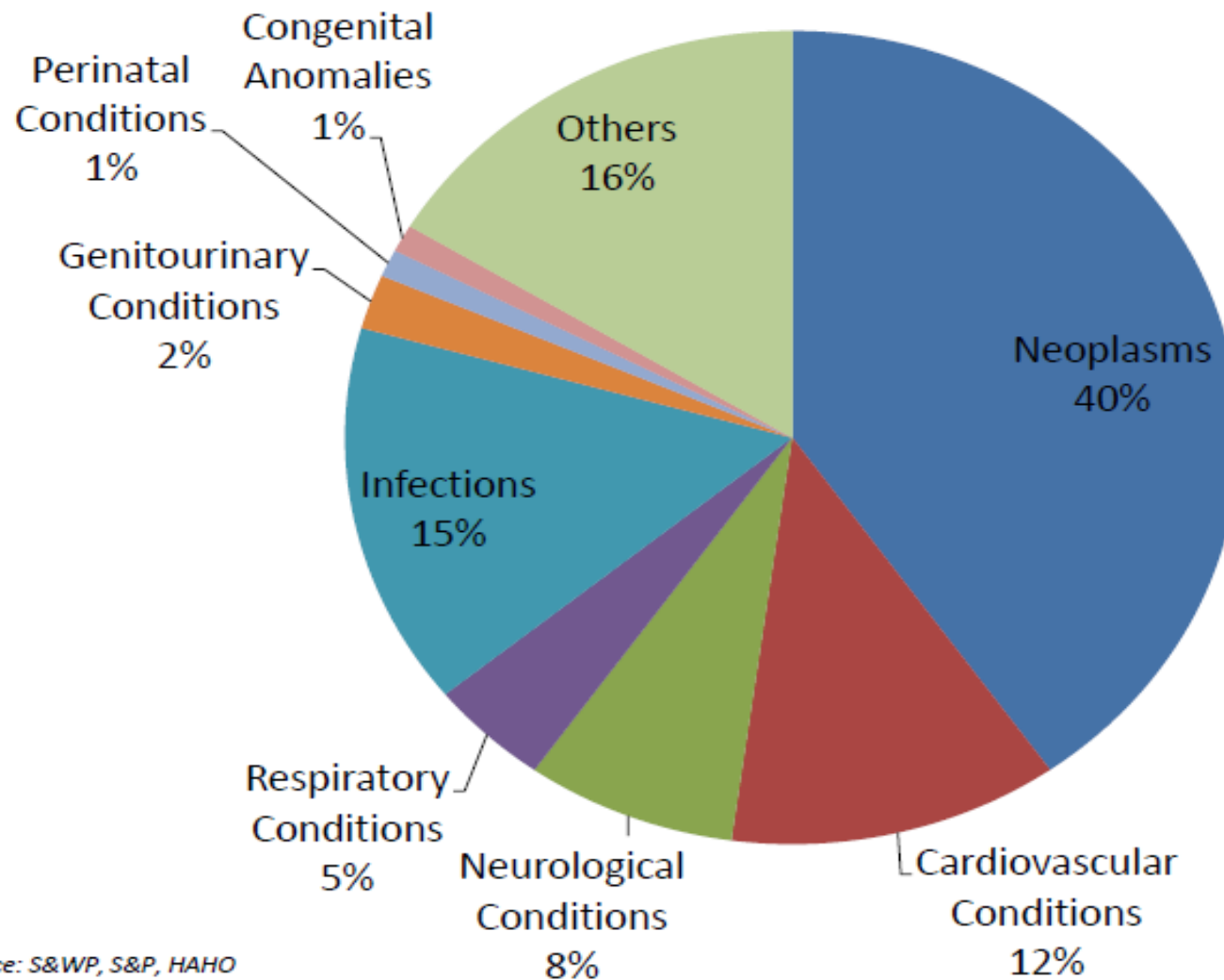
*e.g. Severe cerebral palsy, brain or spinal cord injury, anencephaly*



Standards of Practice for Paediatric Palliative Care and Hospice, National Hospice and Palliative Care Organization 2009.

# In Hong Kong

## Cause of Death in Age Group 1 to <18 (2014)



Remarks:  
According to principle  
diagnosis of the IP/DP  
death episode in HA  
No. of patient: 92

# Who are they?

- **30 to 40%** of our children requiring pediatric palliative care **are oncology** patients
- The **non-oncology patients are children with medical complexity** those mainly with neurological +/- respiratory problems



# Children with Medical Complexity (ChildrenMC)

1. One or more chronic clinical life-long severe medical condition

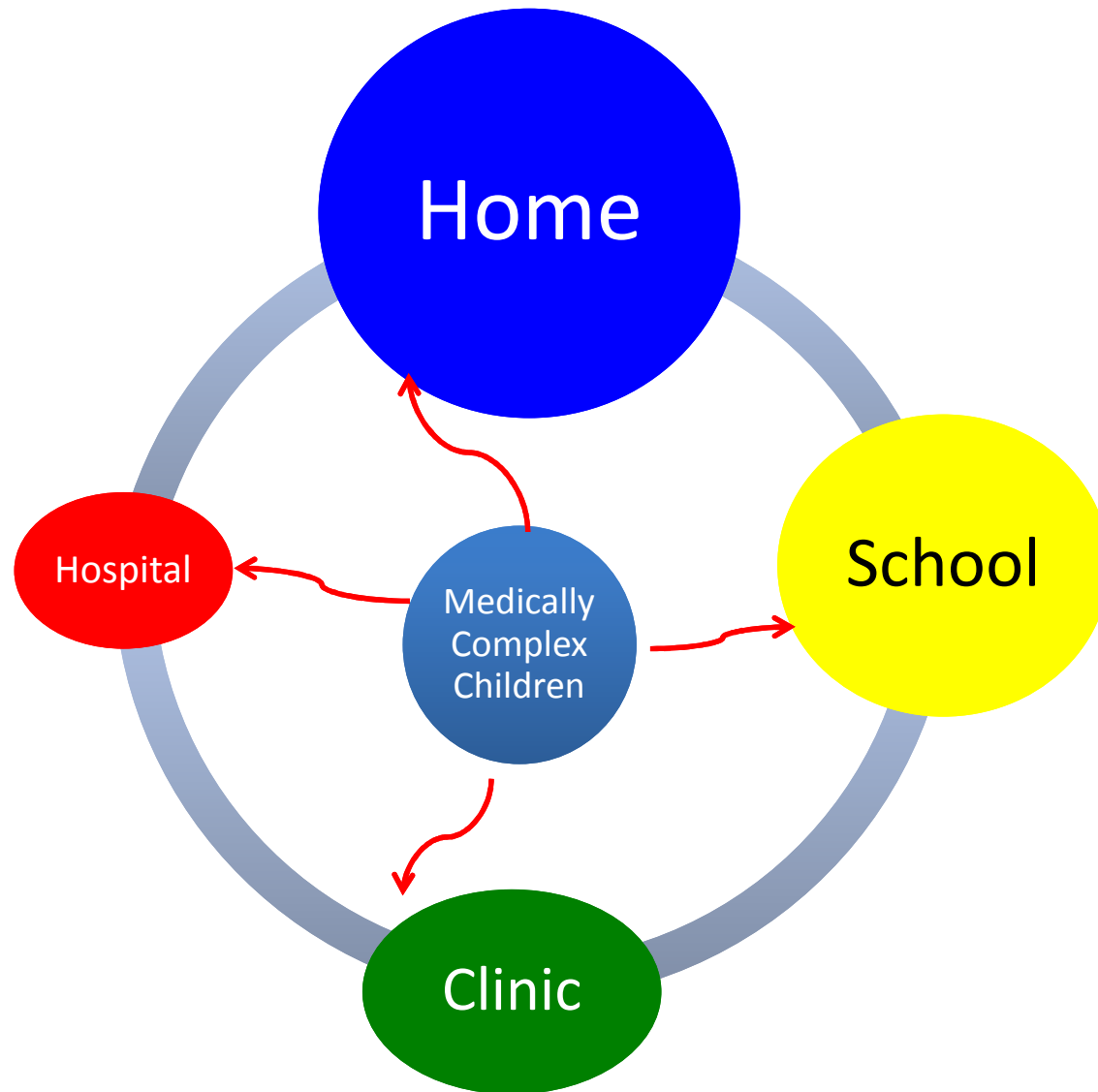
2. Severe functional limitations that require assistance from technology

3. Frequent health care users requiring repeated or prolonged hospitalizations.

4. Substantial needs including: medical care, specialized therapies and educational needs.



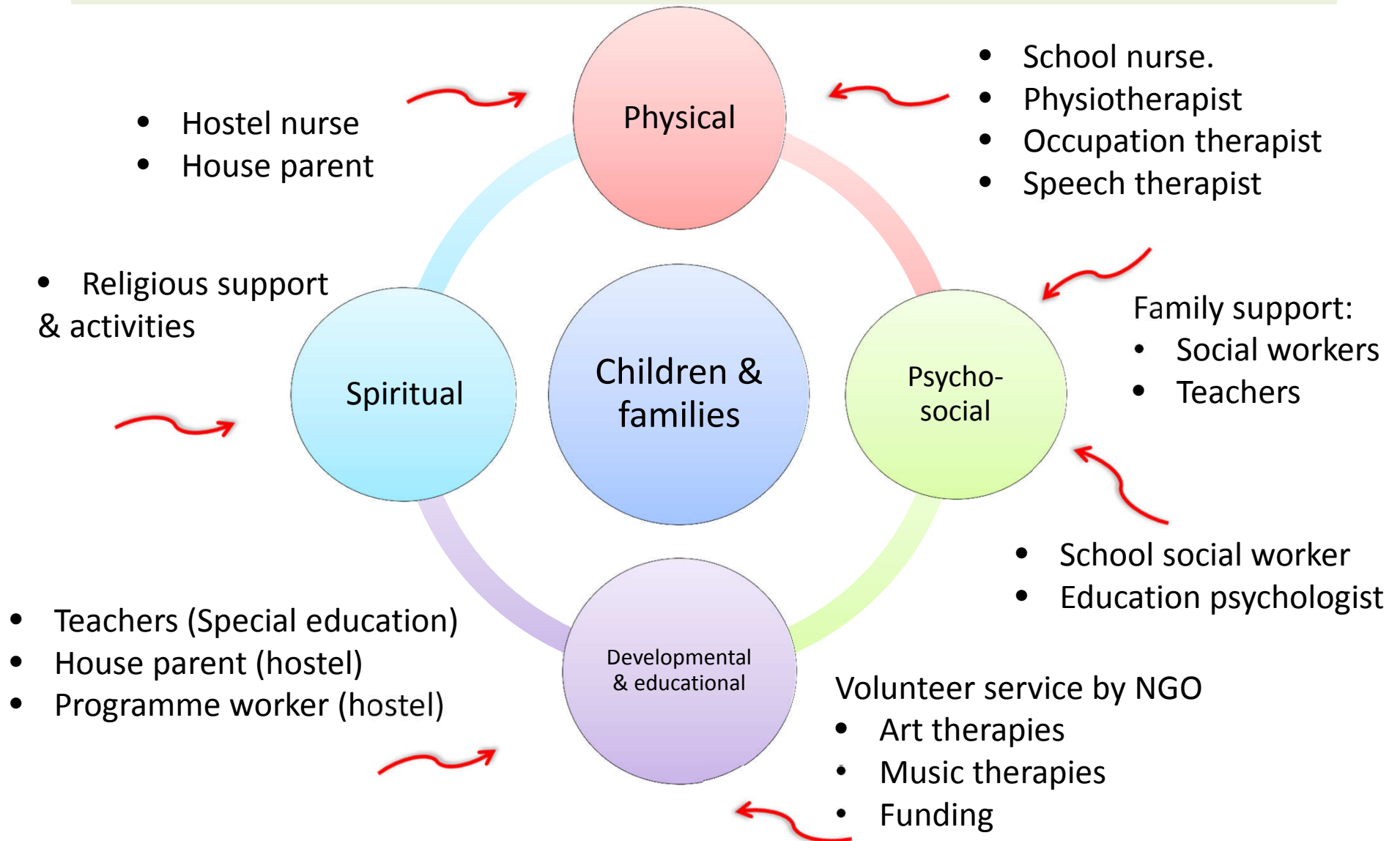
# Where are they?



The non-oncology patients are children with medical complexity mainly cared in special schools/ home/ residential homes



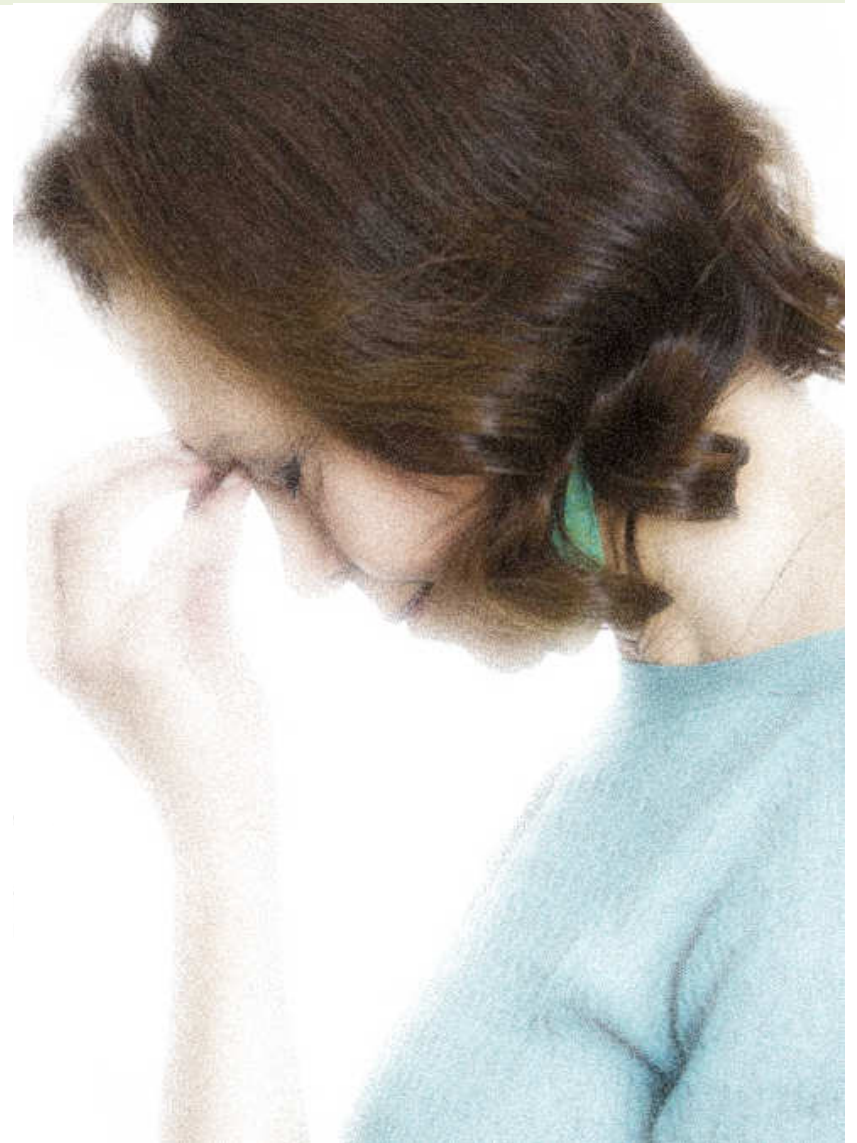
# Special Schools are providing Holistic Care for our children



# Special Schools are facing various of difficulties for taking care of our ChildrenMC!

- **Increasing** health care complexity of these children and **insufficient trained staffs** in special schools, which create **high carer stress**
- **Increasing demand** for discharge planning and **post-discharge support** for these children
- **Complex care tasks**, e.g. Behavioral problems, management of gastrostomy, feeding and tracheostomy, NIV, vesicotomy, etc.

survey by EDB, 2012



# Value of Paed Palliative Care in our Department





# Our strategies for the PPC !

Medically complex children – add life to days

Advocate on “Children’s Right”

<https://www.unicef.org/rightsite/files/uncrcchilldfriendlylanguage.pdf>



“Medical Home” model

Inter-disciplinary team approach, include parents

Set common goals of care & develop care plan

Community resources is essential

**PPC Frame work**

**BRight Project:**

P&AM, UCH

- Medical support promptly
- NGOs support home care

**CCF advanced home care program**

**Primary doctor/nurse**

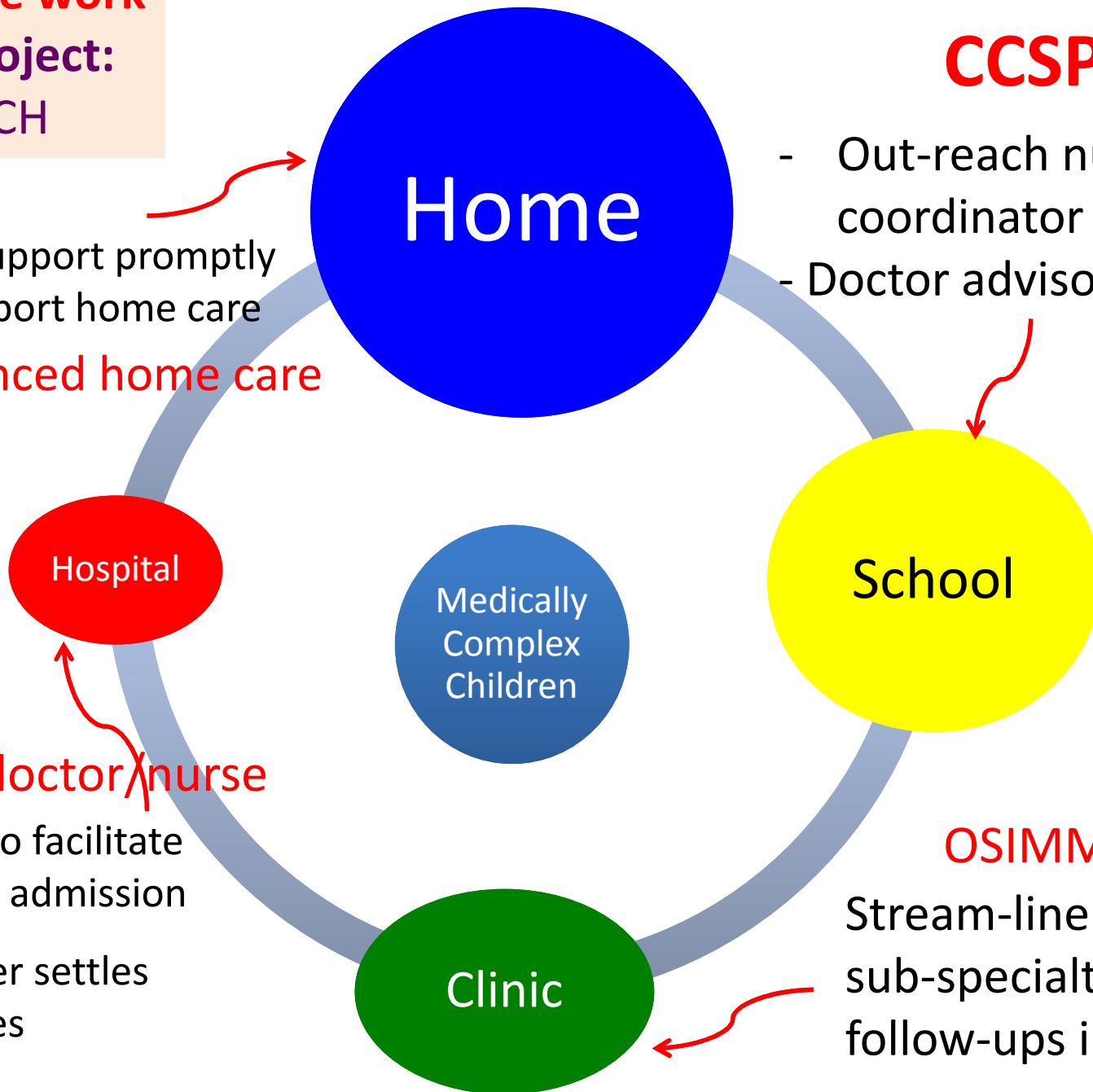
- Logistics to facilitate emergency admission
- Key worker settles minor issues

**CCSP**

- Out-reach nurse: coordinator
- Doctor advisor

**OSIMM**

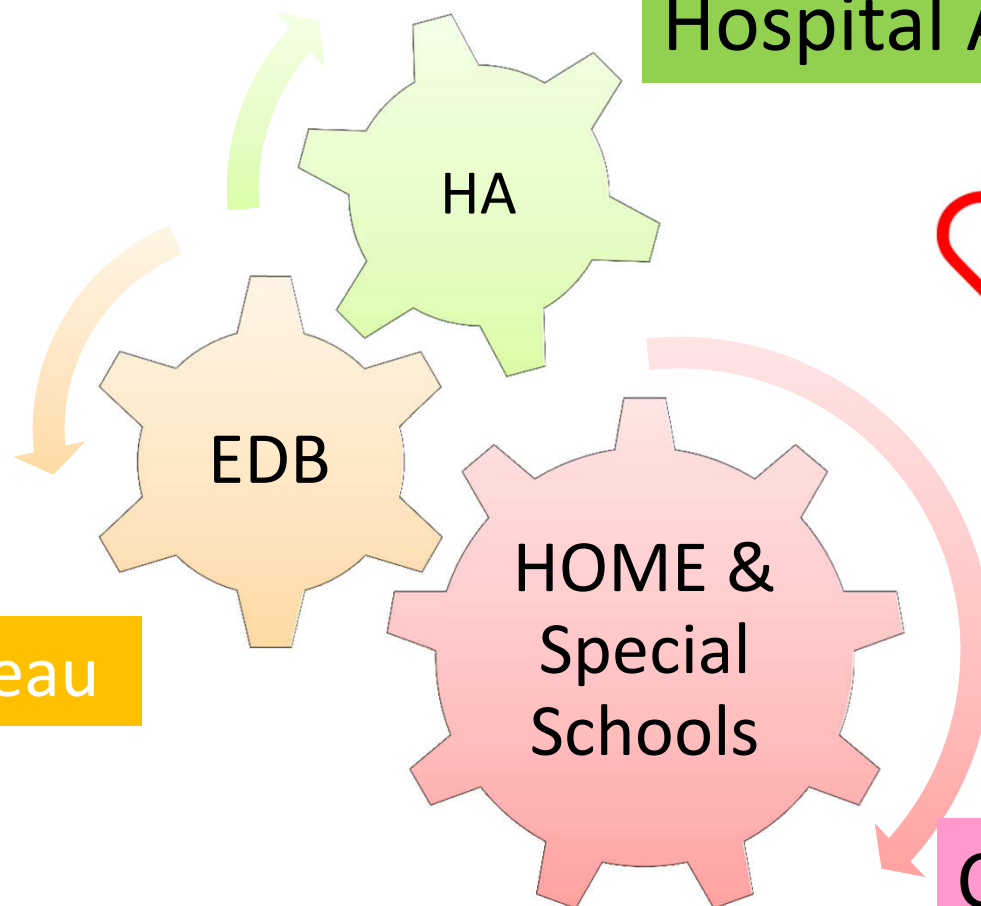
Stream-line all the sub-specialties follow-ups in one day



# Children with Medical Complexity Community Support Programme: (CCSP) A Collaborative Program since 2014

Cluster	Hospital
KEC	UCH
KWC	CMC
KCC	QEH,KWH
NTWC	TMH
NTEC	AHNH
HKWC	DKCH
HKEC	PYNEH

Hospital Authority



Education Bureau

Community

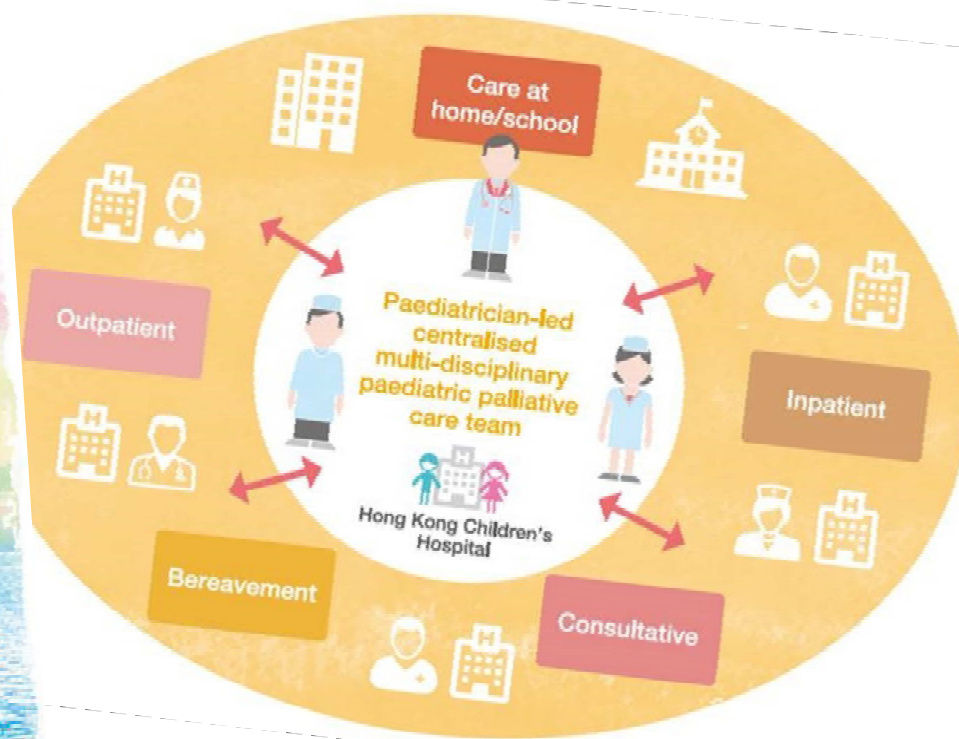


# Total 21 Special Schools under CCSP

Types of Special Schools	
Visual Impairment	2
Hearing Impairment	1
Physical Disability	4
Mild and Moderate Intellectual Disability	1
Moderate Intellectual Disability	4
Severe Intellectual Disability	9
<b>Total</b>	<b>21</b>

Total no. of boarders with medical complexity : ~282

# HA Strategic framework 2018



# Current Situation of Paediatric Palliative Care Services in HA

*What We Are Doing Now*

Support for the chronically or seriously ill paediatric patients in the community is also very limited because the existing paediatric services in HA focus on hospital care. Although paediatric nurses from a few hospitals provide home visits, they mainly deliver technical support to patients on ventilator and tube-feeding. Since many of the children with serious chronic illness are living in residential special schools, a Children with Medical Complexity Community Support Programme (CCSP) has recently been developed to support them, with paediatric nurses taking up the role as care coordinators. However, the nurses are not well equipped with the knowledge and skill-sets for addressing the palliative care needs of these patients.



# School Based Community Support Programme since 2014 in KEC



## Hong Kong Red Cross Princess Alexandra School

- Physical and Mental disability
- Primary & Secondary
- 230 students
- Boarders 93

## Sunnyside School

- Severe MR
- Primary & Secondary
- 100 students
- Boarders 38

# Our Mission!

Improving quality of life



↑ Family activities  
↑ School activities  
↑ Safety



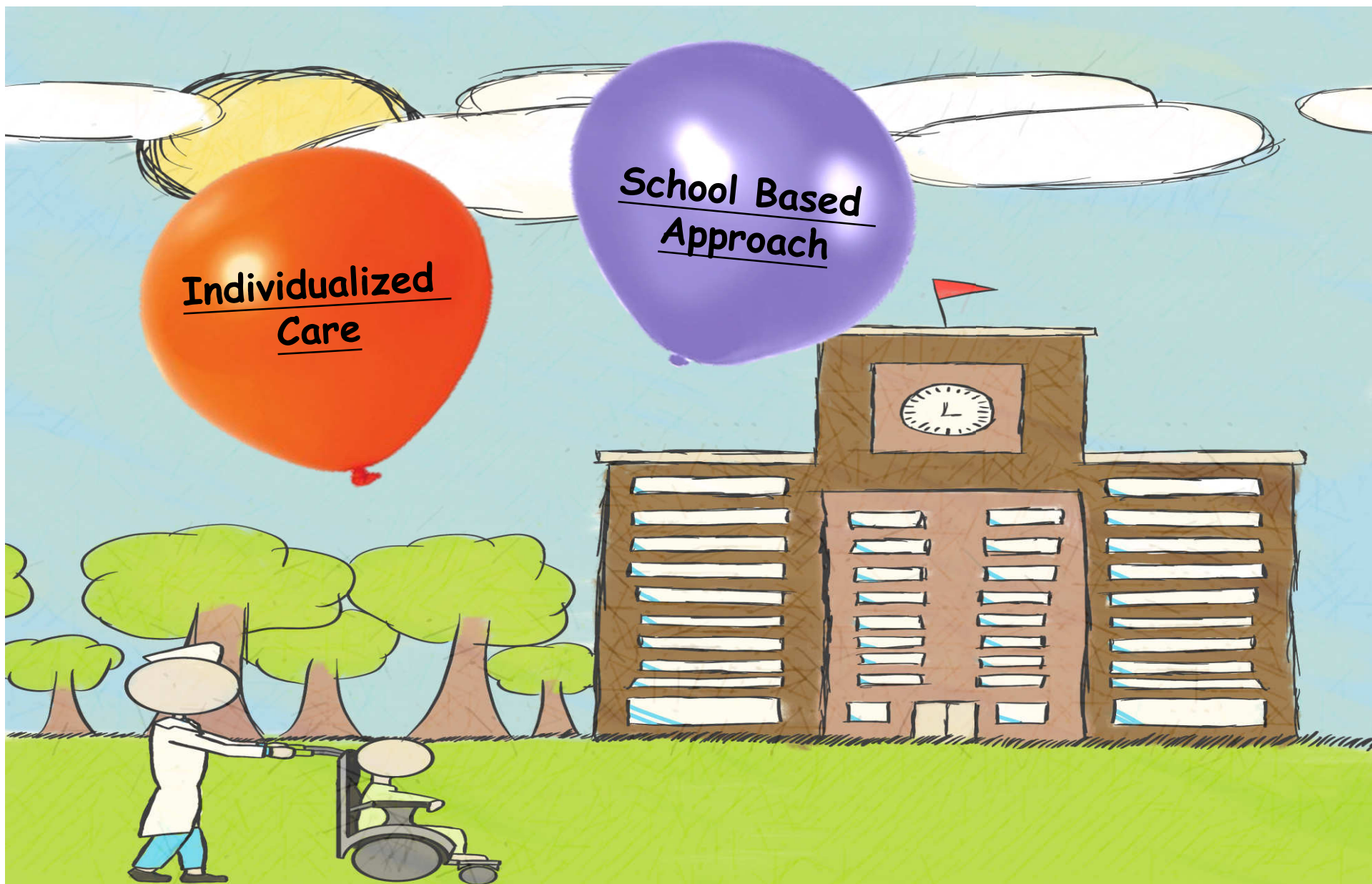
↓ absence from school  
↓ Length of hospital stay  
↓ Hospitalization  
↓ Re-admission

# Where are we now?

**BR**ight Project : Bright and be right!

We **advocate** for providing the **right care** at the **right time** in the **right place** by the **child** at the point in the context at the **child's family** life

# Our Care Model in the Special School



# What are we doing now?

## Individualized care



- Case meeting with parents
- Setting up care plan with interdisciplinary approach, 生涯規劃
- Collaboration with adult PC team for transition care (end of life care)
- Liaison between hospital and community
- Early Referral, e.g. hospital out-patient service, CCF, NGO, Make a wish, Yang's, PLK Community Support Service

## School Based Approach



- Empower school carers, e.g. infection control, Technology support training, 生死教育, ACP
- Caring round with doctor advisor team approach
- Proactive health education: infection control Hand Hygiene Campaign to reduce infection risk
- Coordinate outreach service, e.g. Paediatric care team, Orth, P&O



# What we do?

## Action

Hospital & School Visits  
Post Discharge FU

## Purpose

- Facilitating the continuity Care
- Enhancing communication



Enquiry Service

- Creating communication platform
- Allowing for Early Intervention
- Assuring the Safety of Children



Train-the-Trainer  
Program

- Increasing carers ' confidence
- Providing education & talks



Case Meetings involve  
family

- Bridging between hospital and community
- Setting up care plan with parents
- Ensuring prompt Intervention of care



# Inter-disciplinary team approach, include parents

P & C Round in the special school



CCF Home programme Quarterly Meeting in UCH



Family-centred Care approach



CCSP Case meeting with parent in school



# Facilitating Transitional Care!

1. Regular Neuro Team meeting
2. Liaise hospital and school
3. Case meeting
4. Transitional questionnaire
5. Interview child & family
6. Psychological support & counseling



# Facilitating the referring process consultation and treatment



# 20/1/2018 Podiatry foot health talk in Sunnyside School



# Orth outreach to special schools

Preparation by  
UCH Orth

The 4th Friday of  
the month pm

6 students/session

Preparation by  
Sunnyside School

23 Nov 2018

25 Jan 2019

22 Mar 2019

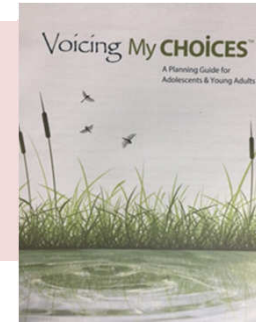
24 May 2019

27 Sep 2019

22 Nov 2019

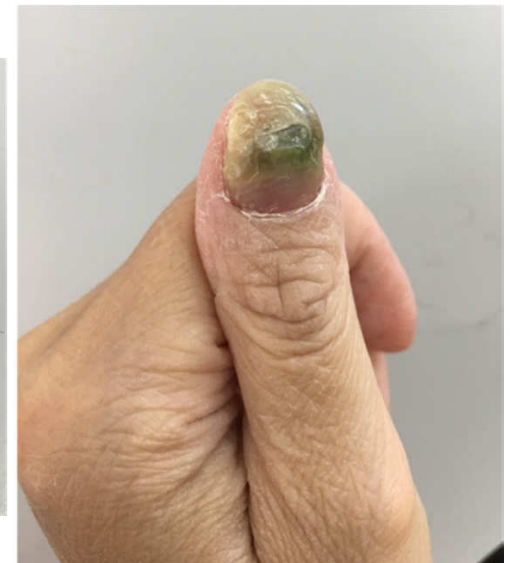


# Voicing out my choice!

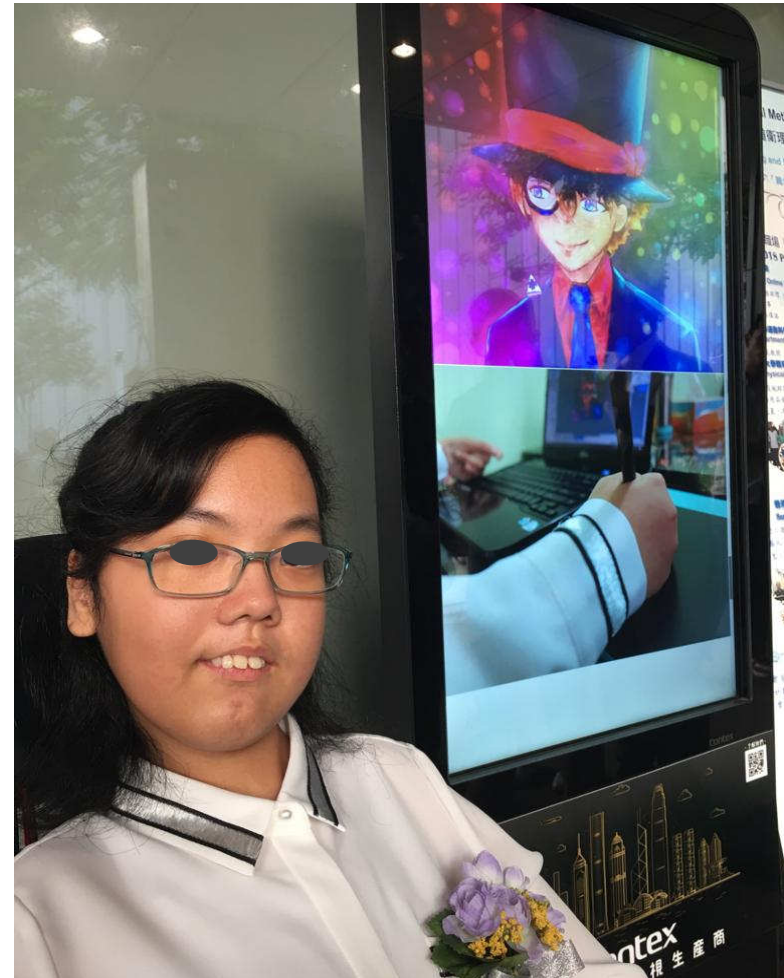


## BRight Project Care Team & School Care Team

1. 離校住宿
2. 在校讀書升班
3. 申請電物動輪進展
4. 慢性傷口不癒合及疼痛
5. My wishes



# Continuity support SMA II!





# My wishes



## 1. 可以繼續升學

- Open University
- 得到第一年學費贊助。

## 2. 安排入住院舍，十二月入宿。

## 3. 身體及營養狀況滿意

### 自我介紹

■ 陳華凡，自小就患有肌肉萎縮症，這個病會令我身體機能不斷退化，更會使我漸漸失去活動能力，雖然如此，但我不認為患有這個病是我的損失或缺陷，因為我身體的殘疾卻得到別人的協助及扶持，不單止是學校的教職員，還是一些熱心人士的幫助，所以我的人生經歷使我深深體會到「得中有失，失中有得」的道理。

我認為這張相片最能象徵著我自己。自小，我就喜歡接觸大自然，例如：行山、觀賞花草、觀星等，但礙於我身體的限制，我不能追求這個愛好，不過，我不會放棄每一個接觸花草樹木的機會，就好像這張相片，我與向日葵拍照。

我有著這個愛好，因為我認為年輕人需要活潑、外向一些，多些到戶外走走，不要整天呆在家中，例如：行山，這樣他們不但能擴闊視野及社交圈子，也可以使他們的人生觀、思維都會正面些，整个人生都會充滿正能量。



# Shan' wishes !

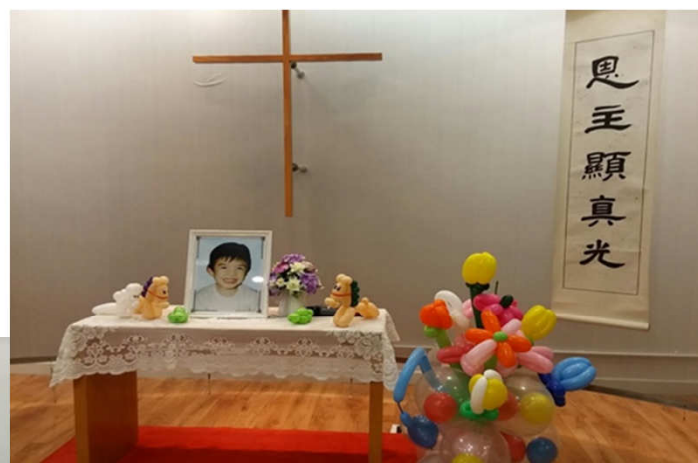


- ① 想一個適合自己的宿舍 (宿位)
- ② 想約一些相識的人去吃自助餐
- ③ 想約家人去飲茶
- ④ 想買部電腦(新)
- ⑤ 想買部電話(新)
- ⑥ 想學音樂(樂器)鋼琴、口琴、小提琴
- ⑦ 想去香港不同旅行 黃金海岸
- ⑧ 想裝修我的家
- ⑨ 想買部鋼琴 (放在家)
- ⑩ 想去旅行
- ⑪ 想做自己喜歡做的事 - 星星紙  
- 花





Memory making!



# 駿媽媽的話！



Microsoft Word  
文件

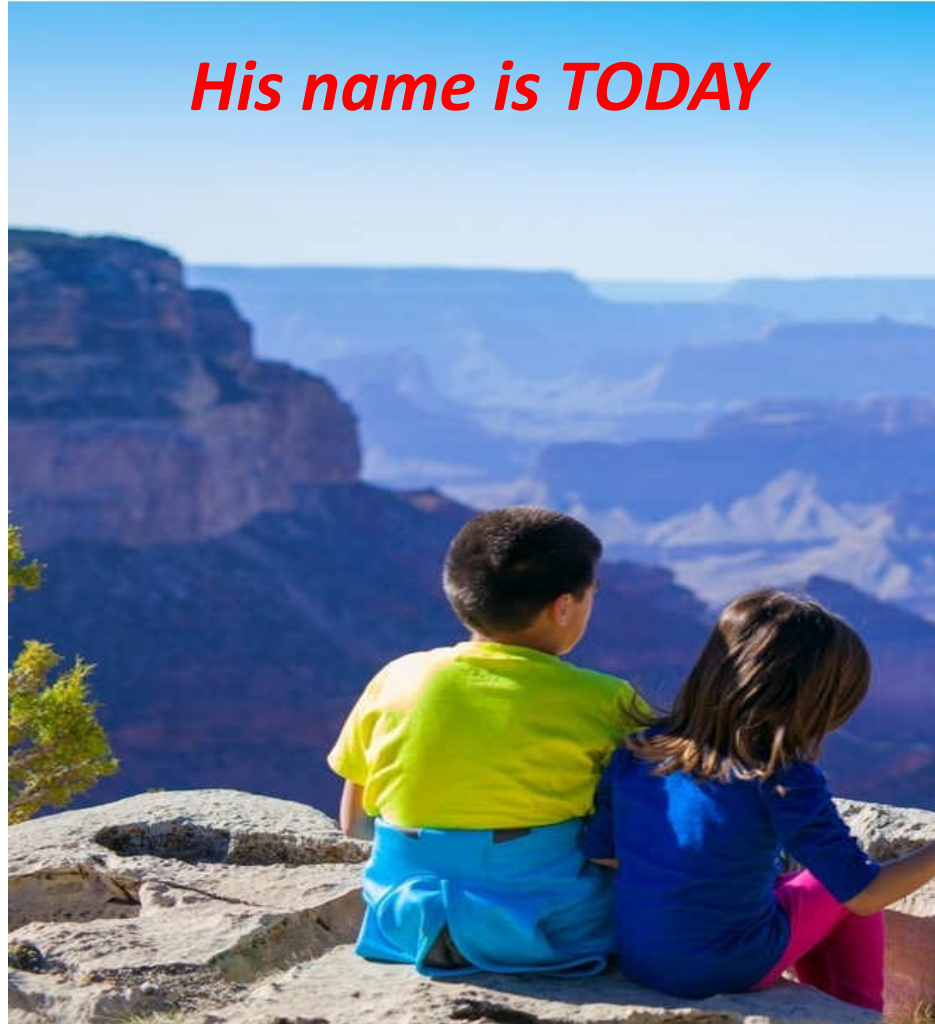
任姑娘您好！！

我愛兒駿駿的後事已經順利完成了。已經在上星期六做了骨灰的撒海儀式。非常感恩和寬懷！嘉駿他以後都可以在天父的懷裡，健康和自由了

！😊

雖然我們不是認識很久，但我覺得我們就像很熟悉和信賴的老朋友！妳對我們的關愛和幫助，我們十分感謝及窩心！在傷痛中給了我很大的愛和盼望！！多謝您！！❤❤

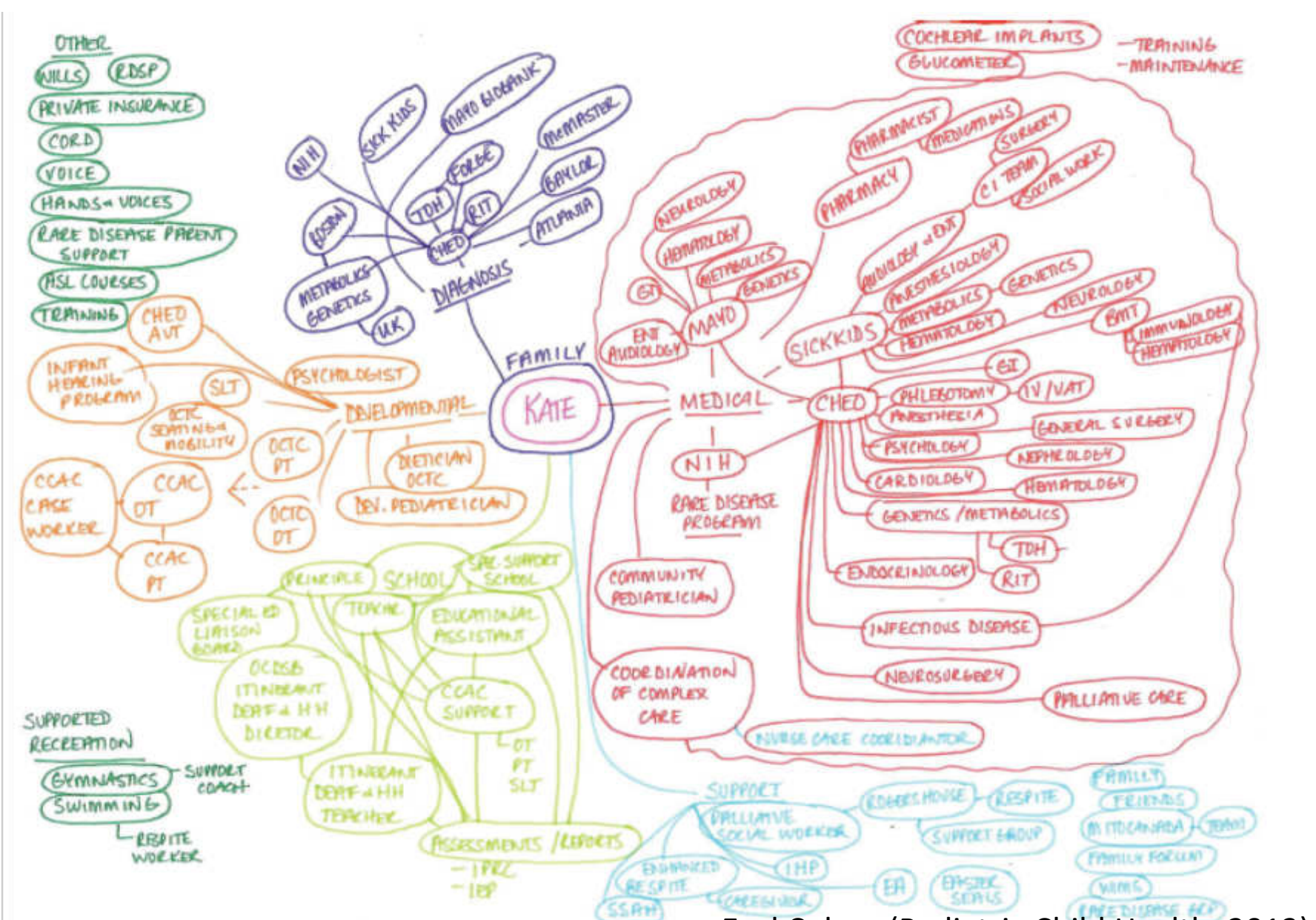
*His name is TODAY*



“Many of the things we need can wait, The child cannot wait”.....  
“To him we cannot answer ‘tomorrow’, His name is TODAY”

Gabriela Mistral  
Nobel Prize Winning Poet from Chile

# “Care Map” by a mother



Eyal Cohen (Pediatric Child Health, 2013)

# Early refer to Palliative Care Service

- Life-Long with severe medical conditions
- Deterioration with poor prognosis
- Severe Functional limitations
- Life-Limiting

Children's Rights  
Advocate!



# (WHO) Five Principle of the PPC

1

- Is the active total care of the child's body, mind and spirit and involves giving support to family (**Family-centered Care**)

2

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

3

- Healthcare providers must evaluate and alleviate a child's physical, psychological and social distress (**Holistic Care**)

4

- 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.**

5

- It can be provided in tertiary care facilities, in community health centers and even in children's homes (**In-hospital or Community**)

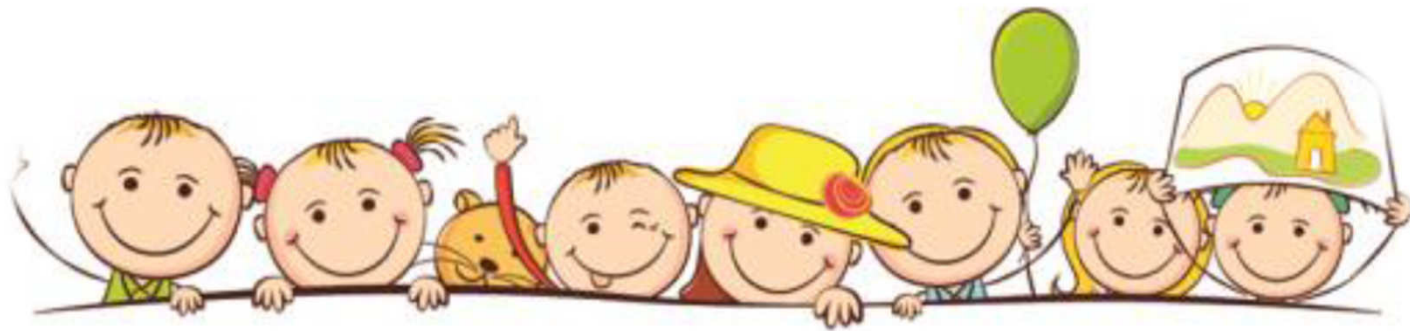
(WHO; 1998a)





The main thing is to make  
history, not to write it.

~ Otto von Bismarck



*Thank You*

# PPC Time Capsule!

