

Community-Based Palliative Program for Children with Complex Medical Disorders

Toh Teck Hock

MBS (Melb.), FRCPCH (UK), Dip Derm (Singapore),
 Chapter Com Child Health (RACP, Aust.), AM (Mal.)
 Paediatrician & Head of CRC, Sibul Hospital
 Community Paediatrician, Lau King Howe Memorial Children
 @ Agape, Sibul Divisional Health Office
 Professor, Faculty of Medicine, Nursing & Health Sciences, SEGi University







Outline of the Talk

- What's palliative care (in children)?
- Children who may benefit from palliative care
- What's Agape Centre and what do we do?
- Provision of palliative care for children with CMD in Sibul (Presentation by Nurses)
- Cases for consideration and improvement
- Moving forward (with thought-provoking ideas)

A common scenario during ward round:

- We have done everything we can, let's refer to the Palliative Care Team for further care.
- Aka: conservative, withdrawal

On the ground...

- Not sure what else to do, difficult to talk to parents/child, ...
- Not a job of a general doctor?
- Ahah (surprise) let's "empower" the volunteers and community
- Many are not trained to deal with death and dying.

What is palliative care (in children)?



ChatGPT



Palliative care in children is a specialized medical care approach aimed at improving the quality of life for children with life-threatening or life-limiting illnesses. It focuses on providing relief from the symptoms, pain, and stress of a serious illness, regardless of the diagnosis or stage of the disease. The goal is to support the child and their family physically, emotionally, and spiritually. Here are some key aspects of pediatric palliative care ↓

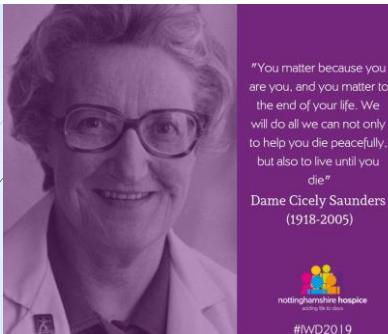
Palliative care in children

Keywords are:

- Life-threatening or life-limiting illnesses
- Quality of life
- Relief of symptoms, pain, stress
- Support – physical, emotional, spiritual

Thought-Provoking Ideas (1)

- Palliative care (in children) is **NOT** about:
 - conservative management, but "aggressive" care
 - withdrawal, but providing more specialised care
 - dying (only), but living



CURE SOMETIMES,
TREAT OFTEN,
COMFORT ALWAYS.
HIPPOCRATES

Who is palliative care for in children?

Palliative Care & Childhood Cancer

Home • Palliative Care & Childhood Cancer



Categories

- About Cancer
- About Charity
- Blog
- Childhood Cancer
- Common types of Childhood Cancer
- Cure for Cancer
- helping children with

The purpose of palliative care is to help a **child with cancer** live as comfortably as possible. The right approach to such care can also provide some peace of mind for parents and

Palliative Care for Children with:

- Diseases with relative known pathway / duration
- Examples:
 - cancer
 - prematurity / neonates with congenital lethal malformation, etc.
 - autoimmune diseases (e.g. SLE)
 - acute organs failure
 - trauma

Palliative Care for Children with:

- Severe neuro-disabilities from birth / very young age but living long
- Examples:
 - severe cerebral palsy
 - traumatic brain / spine injuries
 - degenerative disorder from neonate / infants
 - complex heart/lung/neurological disease
 - severe intellectual disabilities despite ability to walk

Palliative Care for Children with:

- Child initially well, with chronic diseases that take years to deteriorate
- Examples:
 - muscular dystrophy
 - end-stage kidney failure
 - metabolic disorders (MPS, storage diseases, etc)
 - degenerative neurological disorders (e.g. MELAS)
 - gastrointestinal issues (e.g. Crohn's, short bowel syndrome, etc.)
 - (trauma)

Thought-Provoking Ideas (2)

- Palliative care (in children) is **NOT**
 - only for those with cancer or terminal illnesses, but for many more.
 - the end, but the beginning of more comprehensive care
 - happening in isolation, but involve a team of professionals and parents
 - (only) about dying, but living with dignity

Who is Agape Centre (Sibu) for?

- Children & adults, with disabilities
- Include those with
 - intellectual / physical disabilities
 - learning difficulties/disabilities
 - complex medical disorders with neurodisabilities
 - neurodevelopmental disorders, e.g. ADHD, autism, etc.



Agape: Unconditioned Love



Agape Centre provides:

- Rehabilitation & medical treatment
- Education & early intervention program
- Social & sport activities
- Welfare support
- Employment training



Smart Partnership Initiative: Reaching Out for Children / Adults with Special Needs (Tan Sri Dr Noor Hisham (DDG, 2012))



Specialists Care



Physiotherapy



Occupational Therapy



Speech and Language Therapy ~11 Jan 2010

Dietitian Care for the Special Needs Children

Dental Services

- Weekly session during clinic days
 - dental education and screening
 - basic procedures
- Monthly dentist mobile clinic

Students Teaching

SEGi University
OT / Physiotherapy and
Nursing from MOH / Private
Institutions

Mobility & Rehabilitative Aids

Modified Wheel Chair Important in rehabilitation of children with Global Developmental Delay & Cerebral Palsy

Standing Frame (Prone Board)

To help child have sensory input lower limb, proper standing posture & stretch lower limbs.

Home Visit (Health) Team @ Agape

- PHN Yong Pei See
- SN Endun Jabu

Community Based Rehabilitation (CBR) Team



1 Sister, 2 PHN, 5 SN, 1 SJM, 1 PPK, 1 PA, 1 Driver

Paediatrician & Paediatric Medical Officer (on Rotation)



❖ Specialist In-charge – Dr Pau Kat Siong



❖ Medical Officer In-charge – Dr Vichard Lim

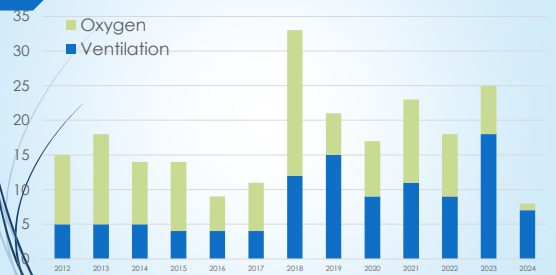
Therapists

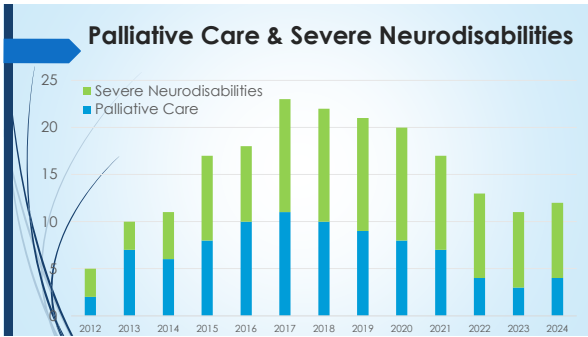


Workload of Home Visit



Home Ventilation & Oxygen Cases





Other Cases

- SCAN cases (Suspected Child Abuse and Neglect)
- Defaulter cases
- New cases (<5 y/o)
- Social concern
- School visit



Where Do We Get the Referral / Request?

- Sibu Hospital
- Other Health Facilities (Transfer In)



Preparation Before Home Visit



Activities During Home Visit




Activities During Home Visit





Bereavement support to family (after death)



What We're Proud Of?

- Provide nursing care according to plan and manage to come every visit.
- Catch up immunisation.
- Health education
- Family emotional support.
- Early referral to other bodies.



The Challenges



Challenges



Our Advice For People

- Team work
- Empathy
- Helpful
- Love



- Everything seems good, but...
- What might be happening in the real world?
- For consideration and improvement

Case 1

- a 5- to 6-year-old boy
- h/o albinism, chronic lung disease and recurrent infections requiring long term admission
- severe developmental delay, but able to stand/cruise
- single mother with low intellectual function, relying on social welfare funds
- DNR signed 3 years ago.
- last admission, about 1 year ago
- p/w respiratory distress requiring oxygen
- **Clerking Notes:** A child with DNR status ...

https://www.dailymail.co.uk/news/article-10346479/GPs-offered-teenage-patients-learning-di...

GPs offered teenage patients with autism and Down's syndrome 'do not resuscitate' orders during routine appointments at the height of the Covid pandemic – leaving some confused and upset, parents reveal

- Children with learning disabilities offered 'do not resuscitate' orders by GPs
- Shocked parents are worried orders could have been applied without knowledge
- NHS England wrote to doctors at start of pandemic reminding them of guidance
- Doctors take the final responsibility for issuing a Do Not Attempt Resuscitation

What does DNR means?

- ≠ "Do Not Treat".
- Only that CPR not be attempted.
- Other treatments (e.g. antibiotics, transfusion, dialysis, or use of a ventilator) that may prolong life can still be provided.
- Those that keep a patient free of pain and comfortable should always be provided.

Thaddeus Mason Pope, Mitchell Hamline School of Law, Nov 2023 (MSD Manual)

Thought-Provoking Ideas (3)

- Lives for children with CMD has **no limit**, but DNR has (time) limit!
- DNR Orders is **NOT**
 - a "leave it or take it" prescription
 - a KPI achievement!
- careful consideration of ethical, medical & practical factors.
- balancing benefits of resuscitation and the potential harm.
- decision aligns with the child's best interests and QOL goals.

Case 2

- A 3+ years old boy
- Born with severe hydrocephalus, parents from far
- Refused neurosurgical intervention, d/c home with palliative care
- Had VP shunt inserted eventually
- Regular home visit by palliative care team
- **Issues now:**
 - Severe cerebral palsy + developmental delay
 - Bilateral hips dislocation

Google refer

Dictionary
Definitions from Oxford Languages | Last 11,028

refer

"Refer" – what is it?

2. pass a matter to (a higher body) for a decision.
"the prisoner may require the Secretary of State to refer his case to the Parole Board"
- send or direct someone to a medical specialist.
"she was referred to a clinical psychologist for counselling"
- read or otherwise use (a source of information) in order to **ascertain** something; consult.
"I always refer to a dictionary when I come upon a new word"

Thought-Provoking Ideas (4)

- Let's **NOT** "referring" to palliative
- Instead,
 - **Continue** the excellent care by primary team (everyone can be a palliative care experts) – the **Rapport!**
 - **Bring in** the expertise of palliative care for more **supports** (to live, with good QOL)

Case 3

- A 10+ years old girl
- Goldenhar syndrome
- On PC & DNR Orders
- p/w cough on weekend
- h/o blindness, hearing loss, cleft lip & palate, on NG feeding, complex heart disease with usually saturation of 70%
- On home oxygen concentrator
- **Plan:** admit for observation



Thought-Provoking Ideas (5)

- Palliative care is beyond listening & talking therapy, relieving the symptomatic pain, &/or physical support (e.g. O₂ tank)
- But, **Tender Loving Care** + All Rounded **Support**
- Consider:
 - Respite care
 - Continuous home care (7/24 reachable contact)
 - Palliative-friendly practices
 - Schools, where the children should belong

Moving Forward

- Not a job of a single department / team / specialist / person
- Need human (and financial) resources
 - can not expect the horse to run and yet not giving the grasses
- More partners

Find **Partners** (keen People), make Friends

- ✓ Parents
- ✓ Professionals
 - ✓ colleagues in medicine, nursing and health
 - ✓ others: religious body, counselor, social worker,
- ✓ Public (NGOs, community keen people / leaders, entrepreneurs and corporates)
- ✓ Policy makers
- ✓ Press / media
- ✓ Politicians



Lau King Howe Memorial Children Clinic @ Agape Centre, Department of Paediatrics, Sibul Hospital and Divisional Health Office Sibul



"The Family"

Moving Forward

- Not a single department's job
- Need human (and financial) resources
 - can not expect the horse to run and yet not giving the grasses
- More partners
- Getting the terminology correct

Palliative (Palliate)

Origin



late Middle English: from late Latin *palliat-* 'cloaked', from the verb *palliare*, from *pallium* 'cloak'.

Oxford Language:

make (a disease or its symptoms) less severe without removing the cause

Thought-Provoking Ideas (6)

- Palliative care (in children) is **NOT** only about **terminal care** (临终关怀)
- ChatGPT re Chinese Translations:
 - China: 姑息疗法、缓和医疗
 - Hong Kong: 纾缓治疗
 - Macao: 缓和医疗
 - Taiwan: 安宁疗护

Moving Forward

- Not a single department's job
- Need human (and financial) resources
 - can not expect the horse to run and yet not giving the grasses
- More partners
- Getting the terminology correct
- More research – not much is available on children's palliative care

Conclusion

- Palliative care** for children with **CMD**
 - a multifaceted, compassionate and comprehensive approach
 - aimed at enhancing the QOL for both the child and family.
- Heterogenous** group of children that may benefit from improved care and wellbeing.
- Address physical **symptoms**, providing emotional **support**, facilitating **communication**
- Offer **end-of-life care** and **bereavement** support.
- Sibu way, **local approach** - require more support, involvement of all, for improvement.

Acknowledgement

- Colleagues in the Department of Paediatrics & Clinical Research Centre, Sibuhospital & DHO Sibuhospital
- Staff and friends in Agape Centre
- SEGi, Sunway, UNICEF, etc.
- The Community in Sibuhospital

