



What is Children's Palliative Care: Benefits and Challenges

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What is Palliative Care?

- The word “**palliate**” comes from the Latin word “**pallium**” which means **cloak**.
- **Symptoms** are ‘cloaked’ with treatments whose primary aim is to provide **comfort** even if cure is not possible.

“May you be wrapped in tenderness my brother, as if in a cloak” the Qur'an



Who is a Child?

- From the peri-natal period
- Neonates
- Infants
- School –aged children
- Adolescents and Young Adults (AYA)
- Upper Age? 10/12/17/18?





WORLD HEALTH ORGANIZATION'S DEFINITION OF PALLIATIVE CARE FOR CHILDREN



Palliative care for children is 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. Health providers must evaluate and alleviate a child's physical, psychological and social distress. 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 and even in children's [own] homes.

WHO 2002

It is a '*Philosophy*' of Care

- CPC should be provided across the continuum of care
- CPC can be provided from diagnosis through into bereavement
- PC can help the child's illness and provide support for the family.
- PC **must** be an integral part of care not an optional extra
- PC is about living



Palliative care can:



- Ease the child's pain and other symptoms
- Provide emotional and social support that respects the family's cultural values.
- Help a child's health care providers work together and communicate with one another
- Start open discussions about options for care.

In some countries



- Even where cure is theoretically possible, it is often not realistic owing to:
 - Uneven distribution of services
 - Children presenting late
 - Expense
 - Awareness
 - Technical skills and expertise
- Therefore children's palliative care is even more important

What are the Benefits?

1. Principles of CPC
2. Continuum of Care
3. Pain and Symptom Management
4. Emotional Support
5. Social Issues
6. Spiritual Issues
7. End-of-Life Care
8. Transitions
9. The family and significant others
10. Financial issues.....



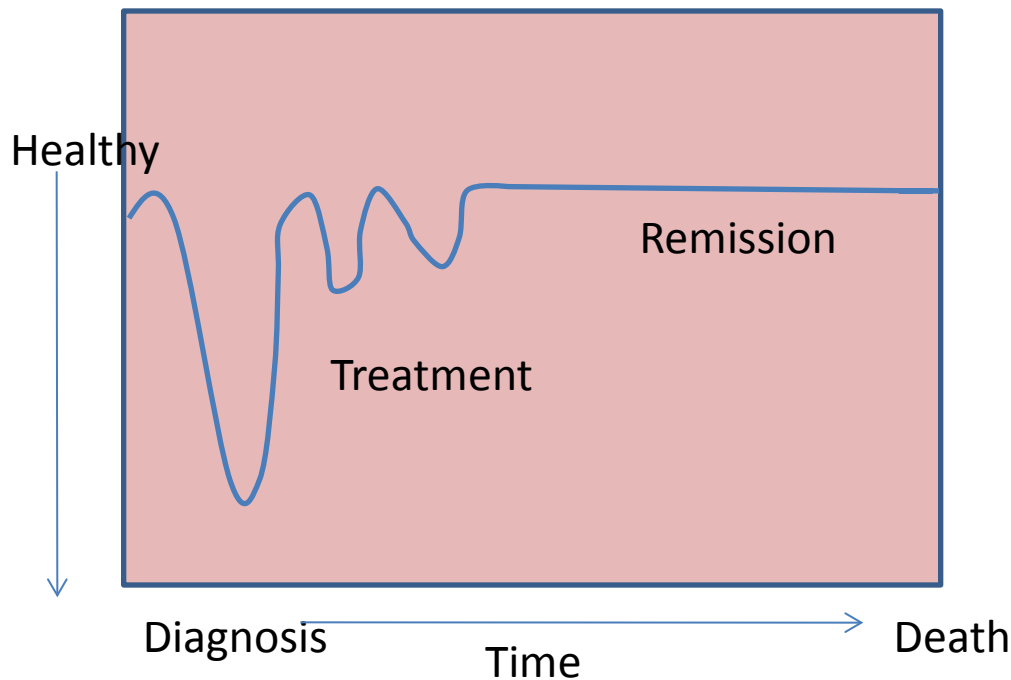
1. Principles of CPC

- Provides relief from pain and other distressing symptoms;
- Affirms life
- Intends neither to hasten or postpone death
- Offers a support system to helps children live as actively as possible until death
- Helps the family cope during the child's illness and in their own bereavement.
- It uses a team approach to address the needs of patients and families.
- It will enhance quality of life, and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life (WHO 2002)
- Is applicable wherever the child needs care

Categories of life-limiting and life-threatening conditions
(Together for Short Lives) (Wood et al 2010, Downing et al 2015).

<p><u>Category 1</u> Life-threatening conditions for which curative treatment may be feasible but can fail</p>	<p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
<p><u>Category 2</u> Conditions where premature death is inevitable</p>	<p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, duchenne muscular dystrophy.</i></p>
<p><u>Category 3</u> Progressive conditions without curative treatment options</p>	<p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: batten disease, mucopolysaccharidoses.</i></p>
<p><u>Category 4</u> Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death</p>	<p><i>Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event of episode.</i></p>
<p><u>Category 5</u> Neonates with limited life expectancy <u>Category 6</u> Members of a family having unexpectedly lost a child from a disease, an external cause or during the perinatal period</p>	<p><u>Additional proposed categories (Wood et al):</u></p>

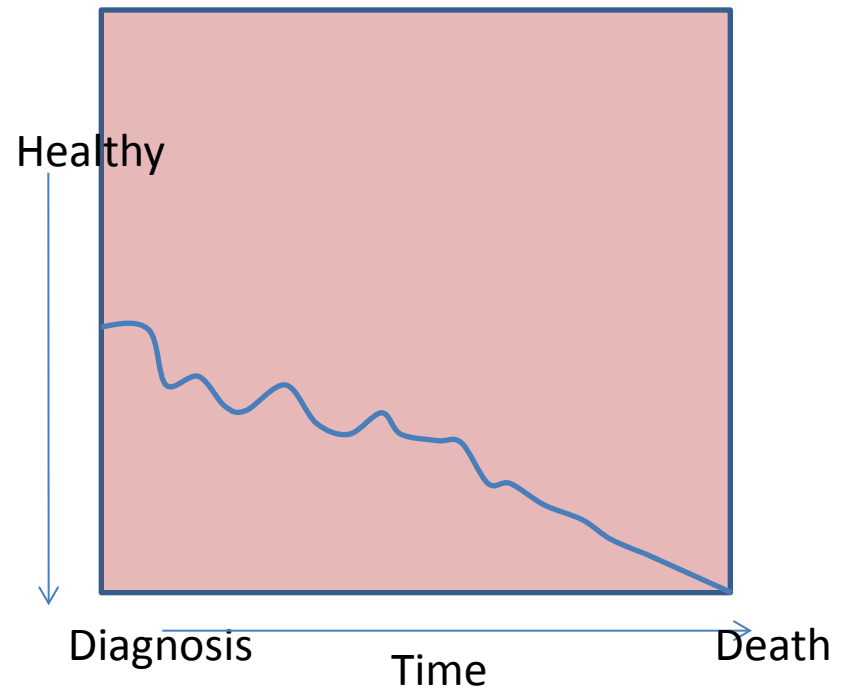
Category 1



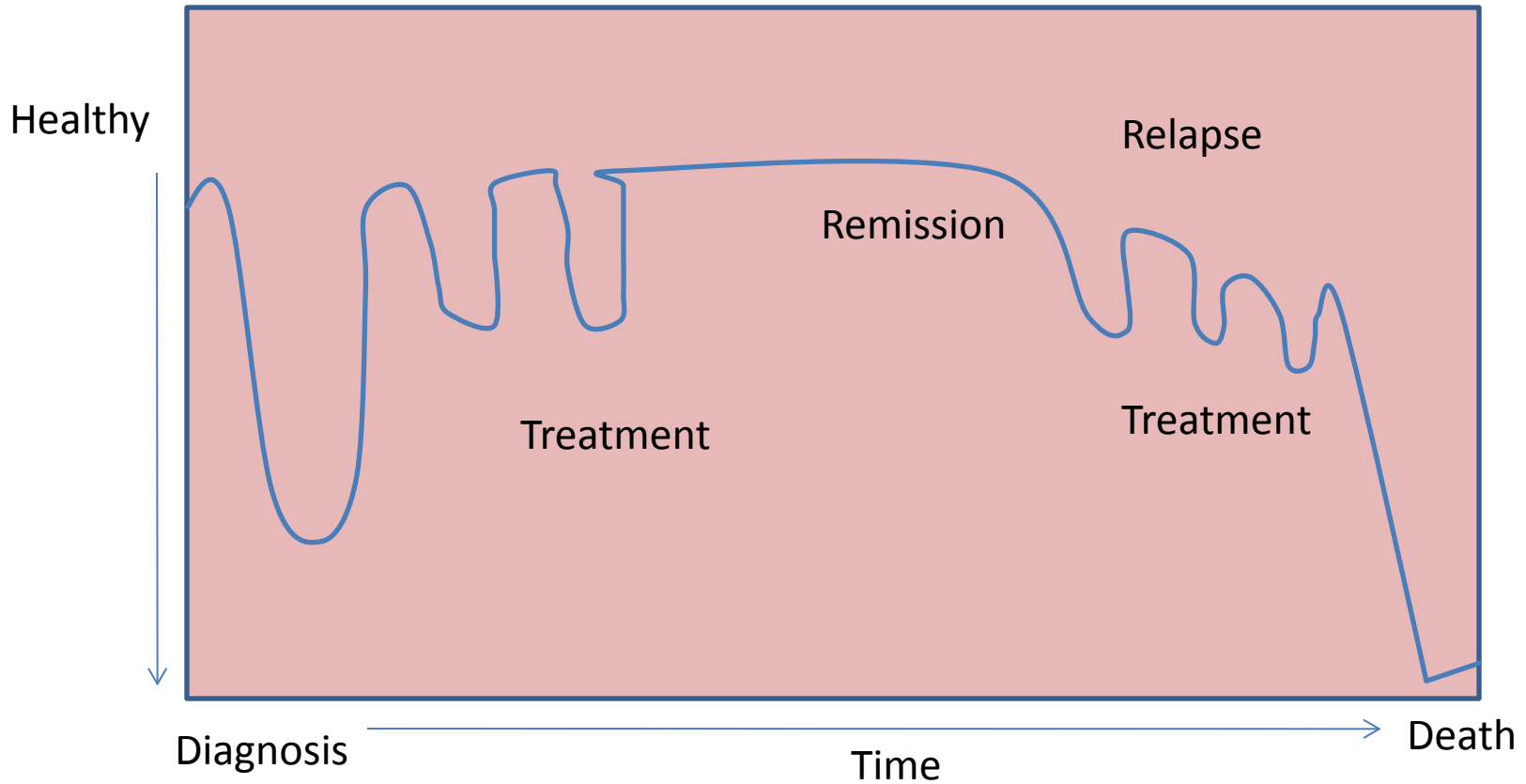
- **Advanced or progressive cancer or cancer with a reasonable prognosis**
- Irreversible organ failures of heart, liver, kidneys
- Complex and acquired heart disease
- Severe malnutrition
- Pulmonary TB, XDR and MDR TB
- Head injury post MVA

Category 3

- Batten disease
- Mucopolysaccharidoses
- Down's Syndrome with severe congenital heart disease
- Adrenoleukodystrophy (ALD)
- Trisomy 13 and 18
- Renal Failure - no dialysis available
- Irreversible organ failure – no possibility of a transplant



Category 1 → Category 3



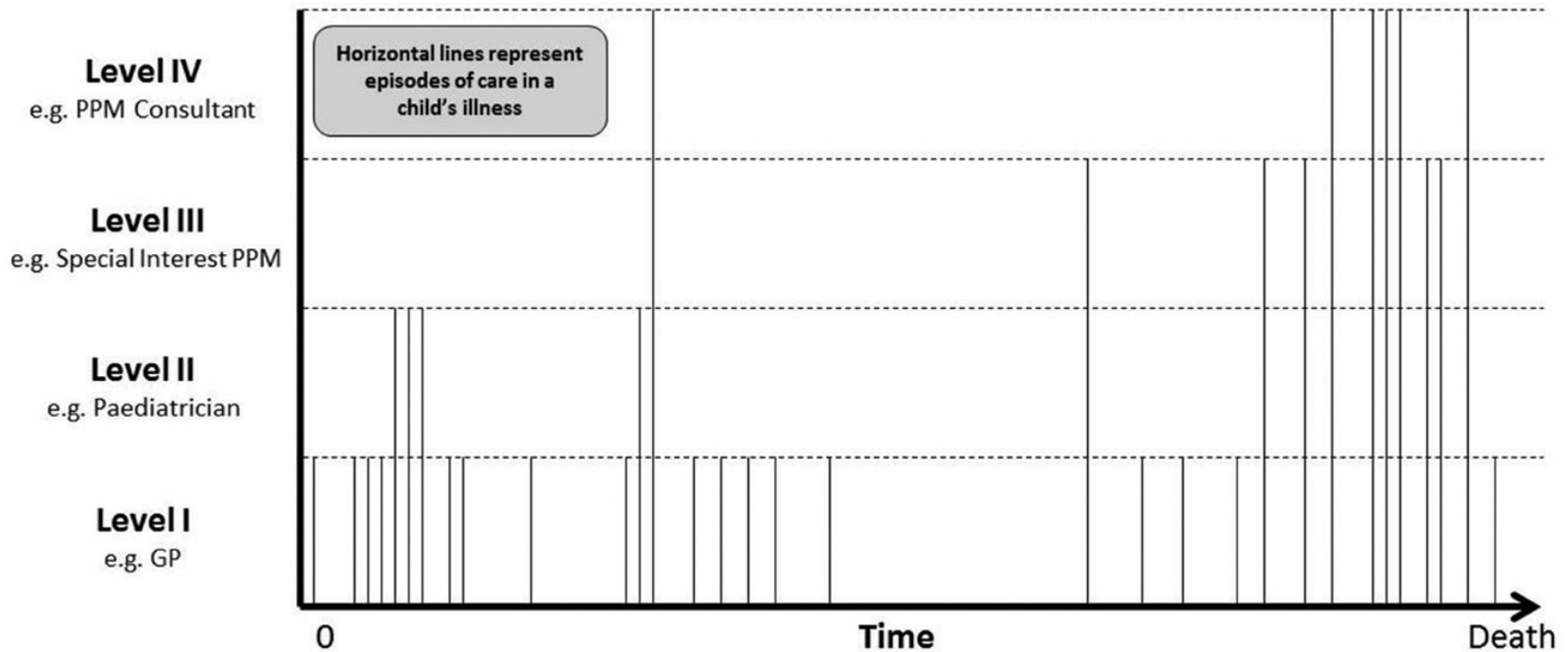
2. Across the Continuum of Care



- From diagnosis through to death and into bereavement
- Across the variety of care settings
- Whenever the child and their family would benefit from it
- Should not be seen as a last resort but an essential component of care

Generalist vs Specialist CPC

Child 1



3. Pain and Symptom Management



- An essential component of care
- Not just related to the cancer, but to treatment as well e.g. procedural pain
- Pharmacological and Non-pharmacological
- Important from pre-diagnosis onwards

4. Emotional Support



- For all children, regardless of age
- *'Friendship'* groups with other children with cancer
- Important for the child and their family
- Need to be open and honest in our communication
- Address Collusion

5. Social Issues



- Importance of peer support
- Loneliness and isolation
- ‘Stigma’ and impact on the families
- Inability to continue with ‘normal’ social activities
- Schooling is important

6. Spiritual Issues



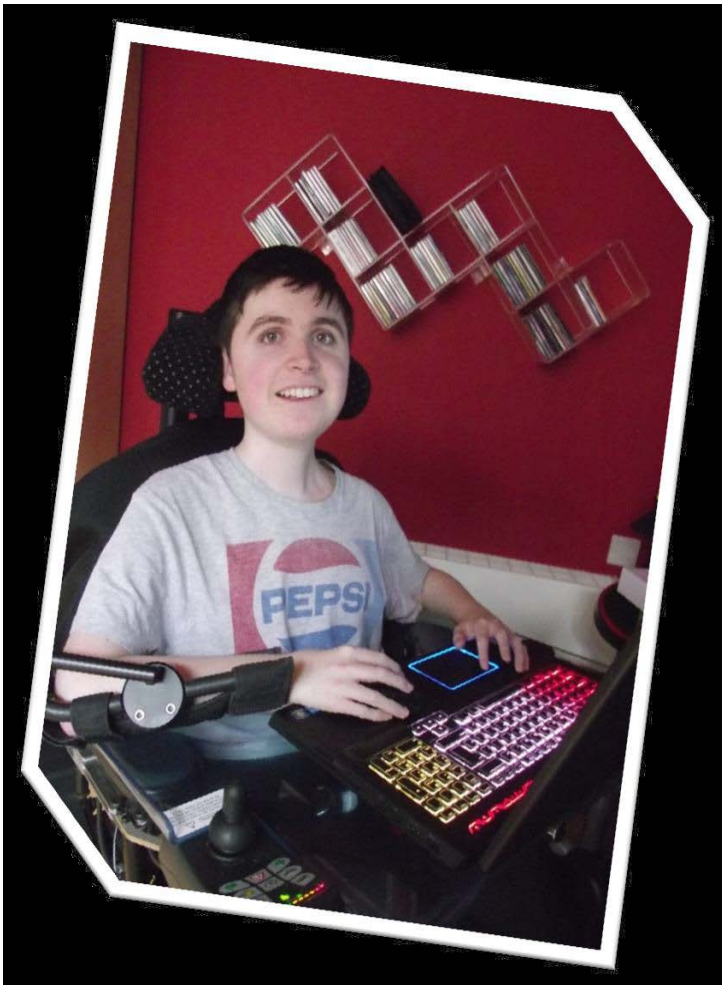
- Existential issues are important in CPC
- Often hard for us to talk to children about such issues
- Useful concepts:
 - *Hope*
 - *Transcendence*
 - *Meaning*
 - *Acceptance*
 - *Connectedness/Relatedness*

7. End-of-Life Care

- Dying is a process
- Teamwork is essential in order to support the family
- Don't forget the siblings
- Encourage openness between members of the family
- Support re decision making is key
- May have a advanced care plan
- Think about where they will receive care e.g. at home, the hospital etc.



8. Transitions



- *“With an increasing number of young people surviving with life-limiting or life-threatening conditions into adulthood, understanding their palliative care needs during transition and into adult services is paramount”.*

9. The family and significant others

- Need support throughout the course of the illness
- Particularly at the end of life and into bereavement
- Remember the whole family and significant others not just the parents
- Impact on relationships
- Siblings.....



10. Financial Issues

- Often not thought about or discussed
- Cost of being with the child in hospital
- Out of pocket expenses
- Cost of caring for the child e.g.
 - expensive equipment,
 - not being able to work,
 - care for siblings
- Spiral into poverty



Barriers and Challenges to CPC Development

- Lack of recognition of the need for CPC
- Lack of policies
- Lack of integration into health services for all ages
- Lack of access to:
 - *Education*
 - *Treatment*
 - *Trained professionals*
 - *Medicines*
 - Fear of the use of opioids
 - Lack of prescribers
- Lack of resources



The *'Elephant'* in the Room



Integrating palliative care and symptom relief into paediatrics

A WHO guide for health care planners, implementers and managers



www.elearnicpcn.org/course/view.php?id=7

International Children's Palliative Care Network: e-learning

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 - Overview
 - Introduction to Children's Palliative care
 - Final Activity
 - Where Next?
 - Evaluation Form
- Pain
- Communication
- Play
- Grief and Bereavement
- End-of-life
- Introduction aux SP de l'enfant

Introduction to palliative care in children

Your progress

Overview

This module will give you a brief introduction to children's palliative care. It will address issues around what palliative care is, which children need palliative care, the differences between adults and children's palliative care, and the global situation of children's palliative care.

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- Welcome
- Quick Navigation Guide
- Announcements

Introduction to Children's Palliative care

- Introduction to Children's Palliative care

Alleviating the burden of pain in palliative care and pain relief: an imperative of universal health coverage: the Lancet Commission report

Published online 12 October 2020

Executive Summary

In addressing unrelieved pain from long cancer, 50% of the palliative care services in Europe, Brazil, India, and the United States are not available. The lack of universal health coverage is a major barrier to the availability of palliative care services. The lack of universal health coverage is a major barrier to the availability of palliative care services. The lack of universal health coverage is a major barrier to the availability of palliative care services.

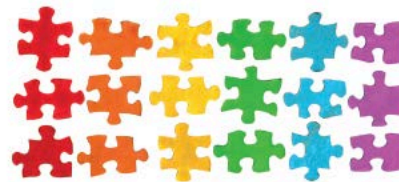
For people in all parts of the world the need for palliative care and pain relief is increasing. The need for palliative care and pain relief is increasing. The need for palliative care and pain relief is increasing. The need for palliative care and pain relief is increasing. The need for palliative care and pain relief is increasing.

A Guide to Children's Palliative Care

Supporting babies, children and young people with life-limiting and life-threatening conditions and their families

Fourth edition 2018

Edition 9.5, 2016



Basic Symptom Control in Paediatric Palliative Care

The Rainbows Children's Hospice Guidelines

www.togetherforshortlives.org.uk

A Really PRACTICAL HANDBOOK of Children's Palliative Care

for Doctors and Nurses Anywhere in the World

JUSTIN AMERY

Thank You!

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