Paediatric Palliative Care

Tuesday 13th April 2021

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For the next 30 mins

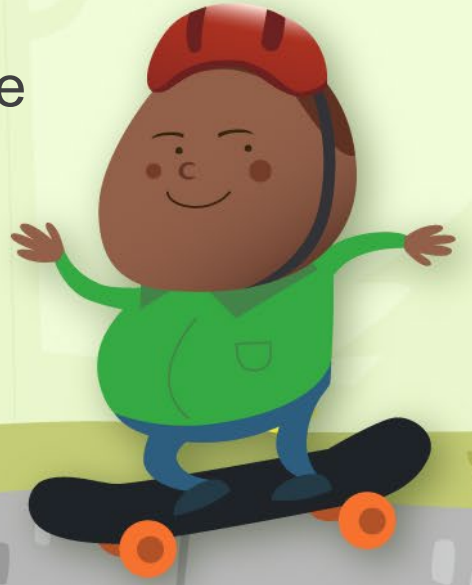
- Please feel free to ask questions – this is your learning
- First half
  - what children are referred to Paediatric Palliative Care (PPC)
  - Understand the differences in paediatric to adult in palliative care
- Second half
  - In depth case study

What is Paediatric Palliative Care (PPC)?

- PPC is not only about end-of-life care
- From diagnosis, dying and bereavement
- Children can be under PPC for years
- Common to be receiving curative treatment alongside PPC

As PPC nurses there are some key foundations to PPC

- Respect for the uniqueness of each family
- Empowering families
- Communication
- Community supports



Which patients are under PPC?

Life threatening conditions for which curative treatment may be feasible but can fail. Eg Cancer, organ failure

Conditions where premature death is inevitable. May have periods of intense disease directed treatment. Eg CF, Muscular dystrophy

Progressive conditions that are unable to be cured, such as metabolic storage disorders

Irreversible but non-progressive conditions causing severe disability, leading to susceptible to health complications. Eg severe CP, complex disabilities

What do we provide as a service?

- Management of symptoms to keep the child as comfortable as possible and enable the family to do the things that are important to them
- Co-ordinate care and liaise with other health care professionals – hospital and community based services
- Assistance with making informed decisions about treatment and care, including acute and advance care plans
- Grief and bereavement service
- Cover the South Island for clinically support
- Teaching and education to health care professionals

When & how to refer families to PPC?

- <u>Two key questions</u>
  - Does the child have a non-curative life limiting condition?
  - Would you be surprised if this child dies in the next 12 months?
- Any Health Care professional can contact us, we will then contact their primary consultant to confirm the appropriateness
- Early referrals are welcome

Referrals to PPC (Canterbury only) 2015 – 2020

- 70% Non oncology
  - Neurology
  - General Paediatrics
  - NICU
  - Metabolic
  - Cardiac
  - Perinatal
- 30% Oncology
  - Recurrent brain tumour
  - Treatment related AML
  - Relapsed neuroblastoma
  - Relapsed Leukaemia

Where do children die?

- Most children with life-limiting illnesses die in hospital
- Infants are more likely than older children to die in hospital
- Children with non-malignant disease are more likely to die hospital than children with cancer
- Home 45% (over half are oncology)
- Hospital 45% (over half are non-oncology)
- Hospice 10%

Different to adult palliative care

- Wide range of different conditions
- Pharmacokinetics and dynamics of drugs are different
- Many conditions are rare, parents become experts
- Length of illness can vary greatly from days to years
- Children may survive into early adulthood extending palliative care over many years
- Developmental issues – 6 month old, 6 year old or 16! Cognitive understanding of death
- Ethical dilemmas may vary, as kids cannot give consent

Case Study – Child A

- Diagnosed in July 2018 Infantile Neuroaxonal dystrophy secondary to PLA2G6 gene mutation.
- Gastrostomy inserted April 2019 as reduced effective swallow
- Family are very clear on a ceiling of care
  - No IV lines, no HDU/ICU. Oral antibiotics if required.
- Symptoms – irritability, lack of sleep, constipation
- Slow progression of disease.
- June 2020 – CSCI set up, just midazolam and morphine
- Mar 2021 – chest infection, recovered
- April 2021 – deterioration evident, weight loss, increase in seizures

The role of the nurse for Child A

Meeting with PPC nurse to talk about their wishes for Freya and establish goals of care

Symptom management – constipation, pain and irritability

Emotional support for the family

Medical support is mainly from the Paediatrician based at CPH, GP provides medication support and parental support

Daily visit from District nurses, twice weekly joint visit with CNS. Proved support for the DN and feedback to CPH team

Case Study- Baby A

- Born at 39 weeks C-Section for reduced fetal movements
- Born with poor respiratory function, apgars 2,7,9 admitted to NICU on CPAP. Noted to have seizures on day 1 (Wed)
- Day 2 (thurs) MRI confirmed HIE
- Day 3 (Fri) family meeting – Palliative care referral
- Day 7 (Mon) discharge home, NGT, Midaz & Morphine
- Day 25 (Sat) died at home with support from consultant on-call

Useful resources

- eGuidelines, hospital and community HealthPathways via intranet
- Starship https://www.starship.org.nz/health-professionals/paediatric-palliative-care-clinical-network
  - PowerPoint presentation available regarding pain management and irritability in non-verbal children

Keeping up to date

- Great network aimed at sharing knowledge and skills among nurses within child and youth
- Provides latest updates on research, education for all aspects of child health nursing
- Monthly emails with links to interesting articles
- Service development, and advocacy for children and nurses within child health
- Easy to join, just need your NZNO membership number
- https://www.nzno.org.nz/groups/colleges_sections/colleges/college_of_child_youth_nurses

Any questions??

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