Paediatric Palliative Care

North West Deanery ST 1 – 3 Regional Teaching

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Definition

“ …an active and total approach to care, from the point of diagnosis throughout the child’s life, death and beyond. It embraces the physical, emotional, social and spiritual elements and focusses on the enhancement of quality of life for the child or young person, and support for the whole family.”

[Together for Short Lives]

Principles of Paediatric Palliative Care

- Holistic care of the child and family
- Takes account of emotional, psychological, social and spiritual aspects of care.
- Person centred, individualised care that takes account of family needs.

Paediatric Palliative Care

- May be offered from birth (eg, chromosomal disorders, certain congenital anomalies)
- From time of diagnosis of a life shortening illness
- May be offered after a time of decompensation/recurrent hospital admissions
- Sometimes undiagnosed conditions causing severe impairment – lack of diagnosis meaning an unpredictable prognosis
- May come from a request from parents
- Prognostication about Life Expectancy difficult in paediatrics
- Sometimes new treatments arise – "*Game Changers*"

Epidemiology

- 2017: 3000 deaths due to medical conditions, 2351 due to known life limiting conditions or neonatal death (TFSL)
- TFSL Estimated 49,000 children aged 0 – 18 in UK living with life limiting/life threatening conditions.
- Approx 18,000 young adults aged 18 – 25 in UK living with life limiting/life threatening conditions
- Advances in medicine mean numbers increasing
- The number of children with “Exceptional Medical Complexity” is increasing too.

- [TFSL=*Together for Short Lives*]

Categories – RCPCH/TFSL

Category 1

Conditions which may be treatable – but treatment may fail, so the possibility of death is significant

Eg, cancer, congenital heart disease, liver, kidney, post organ transplantation, Long Term Ventilation.

Category 2

Children whose conditions will lead to premature death but there are long periods of intensive treatment aimed at prolonging life. They may be significantly disabled but have long periods of relatively good health.

(Palliative care needs not prominent, for long periods)

Eg, DMD, CF.

Categories – RCPCH/TFSL

Category 3

Progressive conditions without curative treatment options, treatment is palliative and may extend over years. Eg, Battens Disease, certain MPS, severe metabolic disorders, neurodegenerative disorders.

Category 4

Irreversible, non-progressive conditions causing severe disability, with susceptibility to health complications and likelihood premature death. Eg severe CP, complex disabilities following TBI or SCI.

May be exacerbations, episodes of hospital care, periods of compensation/decompensation, and stepwise decline.

“Hope for the best, but plan for the worst”

- Palliative care can be offered in parallel with treatments aimed at a cure or aimed at prolonging life.
- Parallel planning
- Involves thinking about a plan B… and C… and so on.
- Revising care plans to take account of complex and changing circumstances.

Multidisciplinary involvement

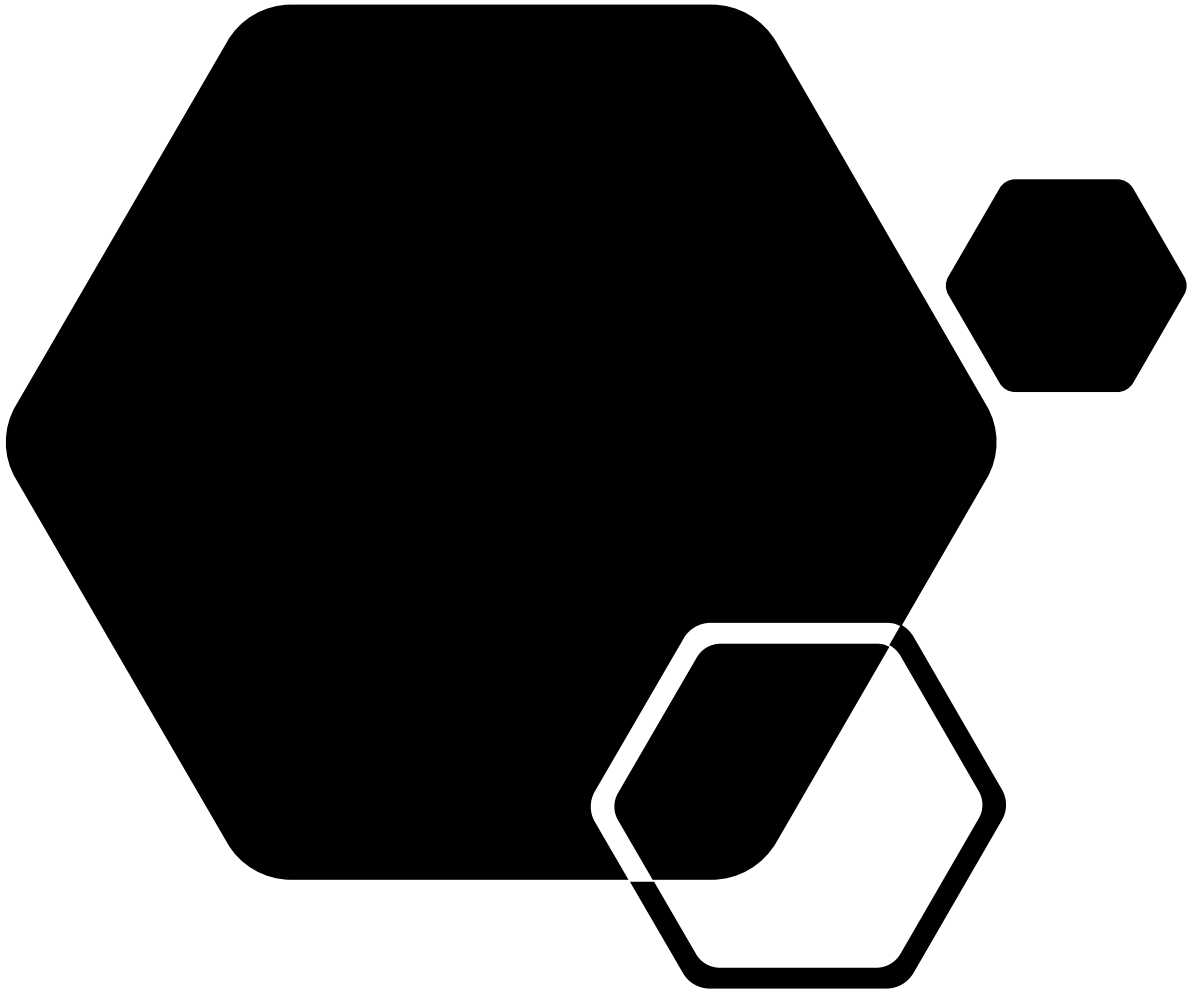
- For one child, the multidisciplinary team can be huge
- Communication essential
- Discuss with your neighbour – what would the MDT look like?

Discuss with your neighbour – 5 min

- What would the MDT look like for a child with palliative care needs?
- You may want to think about a child you have seen recently…
- How might this impact parents
- - positively?
- - negatively?
- Be prepared to feed back a short comment!

Research basis

Early involvement of Palliative Care services is the most effective and appreciated most by parents.



Spectrum of Palliative Care needs

University of Birmingham 2012

Shaw KL, Brook L, Randall D. The Spectrum of Children's Palliative Care Needs. The University of Birmingham, 2012. 65

Considering TFSL categories

Category 1

- Babies born extremely prematurely, severe NEC, congenital heart disease.

Category 2

- Certain chromosomal abnormalities, severe spina bifida, bilateral multicystic dysplastic kidneys, bilateral renal agenesis.

Category 3.

- Anencephaly, severe skeletal dysplasia, severe neuromuscular disorders

Category 4

- Severe HIE.

Neonatal period

- Palliative care involvement can begin antenatally
- TFSL has set out 3 stages and 6 standards –
- 1. Eligibility:
- 2. Ongoing care
- 3. End of Life and Bereavement care.

Together For Short Lives (TFSL)

- Stage 1 – Eligibility

(i) Sharing significant news, (ii) planning for choice in location of care – hospice? home? neonatal unit?

- Stage 2 – Ongoing Care

(iii) Multiagency assessment of family needs, (iv) coordinated multiagency care plans,

- Stage 3 – End of Life (EOL) and bereavement

(v) End of life care plan, (vi) continuing bereavement support and care.

Neonatal Period

- Prognosis can be very unclear
- The journey can be very unpredictable, “roller coaster”
- Consider best interests of baby
- Promote informed choice for parents.
- The ACP is a continuous process of engagement and not a one off event.

Discuss with your neighbour

- Think of a young child you have sent home from hospital with a life limiting condition.
- Who was involved?
- Did you use a template, guidance, discharge planning meeting?
- How long did it take?
- Could it be improved?

Pain

- Pain is subjective
- Multifactorial – not just the pathological, but psychological, emotional, spiritual components – interact.
- Physical pain complicated by psychological and emotional aspects of approaching end of life
- Assessment of pain (broader diagnosis and causation)
- Measurement (Quantification) – pain scales
- Objective and behavioural measures (parents)

APPM Formulary

- Association of Paediatric Palliative Medicine Master Formulary
- 2020, 5th Edition
- Available at https://www.appm.org.uk/guidelines-resources/appm-master-formulary/
- Speak to Pharmacy

WHO pain guidelines

- Step 1 - Analgesia for mild pain – Simple analgesics, paracetamol, NSAIDs.

- Step 2 - Analgesia for moderate pain – opioids as needed.
- Step 3 – Severe pain – opioids, starting dose of Opioids with breakthrough doses given 1 – 4 hourly. Incremental increase in background dose as determined by breakthrough.

Nausea and Vomiting

- Multiple physical factors
- Anxiety high
- Explore causation of nausea and vomiting – GI tract, including mucosal damage to GI tract, mechanical obstruction or reflux, blood toxins, liver damage, brain including raised ICP and psychological causes.
- Treat underlying cause where possible.
- Pharmacological includes:
- Gastritis or oesophagitis - alginates (gaviscon) omeprazole
- Toxic or systemic causes – cyclizine
- Levomepromazine

Constipation

- Inactivity due to condition or treatment
- Dehydration
- Reduced intake, abnormal diet
- Specific illness effects – eg hypercalcemia
- Psychosocial – embarrassment
- Anal tears
- Iatrogenic especially Opioid related.
- Treat the cause
- Consider stimulant laxatives, or softener laxatives, depending on cause
- Often an osmotic laxative regularly.

Excessive secretions

- Can be due to XS production of saliva , inability to retain saliva in mouth, or swallowing difficulties.
- Can lead to facial dermatitis, need for bibs etc, choking and coughing, aspiration, dysphagia and contribute to breathing difficulties.
- Common in CP and children with abnormalities of mouth, jaw or pharynx.
- Approaches include hyoscine patch, glycopyrronium bromide.
- Longer term solutions include botulinum toxin A, surgery.

Mouth care

- Very important part of care
- Parents can assist with this aspect
- Dry mouth can be due to dehydration, mouth breathing, unhumidified oxygen, drug side effect, hypercalcemia or hyperglycemia.
- Bleeding gums can be due to haematological conditions, poor oral hygiene, clotting disorders
- Oral candidiasis common
- Consider regular mouth care. Dental referral.

Emotional and psychological

- Anxiety – separation anxiety (hospitalisation), procedures, receiving bad news, fear of death
- Depression common
- Most children are aware of their condition at some level.
- Openly and compassionately telling the child reduces anxiety.
- Good communication
- Play therapy, music, art all known to be helpful in reducing anxiety
- Psychological referral – consider age of child
- Consider family psychological needs also.

Complementary approaches

- Aromatherapy, relaxation, massage
- Some hospices commission complementary therapies
- Visualisation, mindfulness

ACP

- A process of planning rather than a short task
- An ACP may be based on several assessments and discussions with the child and family.
- Social needs – not just about whether the child is known to social services!
- Nobody has “no social needs”.

Spirituality

- The wide variety of spiritualities and religious observance in the UK – and the non-religious
- Don’t assume. Ask informed questions.
- *What connects you*? *What is important to you*? (your sports team, your family, community, faith…)
- Not my spirituality – but *their* spirituality (*the patient and family’s*)
- Chaplaincies and hospice teams

We don't take away hop
and we won't discourag
your prayers.

Miracles do happen and we hope for the best

There is never "nothing more that can be done"

We will consider and offer support based on our understanding and clinical experience of the course of children's diseases.

"in our experience usually in this condition… this means that…this is what usually happens…"

We are hoping for a miracle
We keep on praying for him/her to recover.
We have heard of children who have overcome this.

Team care, self care

Looking after yourself and the rest of the team.

Questions – how are you doing?

Acknowledging emotions especially for those closely involved sometimes over months and years.

What are you going to do to rest/recharge?

Resources for further learning: Getting Started

- Look out for NW Palliative Care network – ACP awareness session (free)
- Neonatal nurses/midwives: “Monthly Mondays” – web based training led by Alexandra Mancini (free) Lead nurse for neonatal palliative care.
- Child Bereavement UK – online and face to face training on specialist topics related to child bereavement. Webinars eg – Supporting bereaved children and young people; Managing your own wellbeing, Islamic Perspective on death and bereavement.
- Association of Paediatric Palliative Medicine (Together for Short Lives)
- Advanced Communication Skills Training

Book recommendations

Paediatric Palliative Medicine OUP handbook (Hain, Jassal OUP 2016)

Neonatal Palliative Care for Nurses (Mancini, Price, Kerr-Elliott Eds 2020)

Oxford Textbook of Palliative Care for Children (Hain, 2021)

Resources for specialist training

- Specialist modules led by Edge Hill University, Coventry University
- Specialist Masters Courses – eg King's College London and Cardiff University
- SPIN training
- Paediatric Grid training
- Reflect, reflect, reflect….Your own reflection can be a rich vein of learning.

END

Any questions