How and when to refer a child for specialist paediatric palliative care?

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When to involve?

• Doctors’ uncertainty
  – ‘Not needed yet’
  – End of life care
  – Reluctance to share care
  – Upset the therapeutic relationship
  – Interference

• Families’ reluctance for referral
Adult Palliative Medicine

• 1967 Cicely Saunders St Christopher’s

• ‘An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’
Adult Hospice care

• ‘A place of rest for travellers and pilgrims’
• Half of all admitted to hospice return home
• End of life care and symptom management
• Illnesses
  – Malignancy
  – Degenerating conditions – MS, MND
  – Chronic illnesses – heart failure, COPD
Paediatric palliative care

- 1982 Helen House, Oxford
- 50 children’s hospices
- Together for short lives
- Subspecialty since 2009
Paediatric Palliative care

- Life-limiting conditions
- Active and total approach to care
- Physical, emotional, social, spiritual
- Enhance quality of life
- Family support and respite
- Care through death and bereavement
Paediatric Palliative Care

- Specialist respite care
- Symptom control
- Advance care planning
- Transition
- End of life support
- Bereavement care

“Sometimes, being the very, very best parent does not mean fighting to cure, but fighting to do the best you can for your child’s quality of life.”
Specialist Palliative Care Services
Tertiary specialist paediatric care and symptom control

Core Palliative Care Services
These form the majority of services required by children and young people with palliative care needs and their families, e.g. community nursing teams, hospices, bereavement services, sibling support

Universal Services
The foundations for a good palliative care service includes services which are available to all children and young people, e.g. GPs, education, playgroups
Which children?

- Life threatening conditions that may be cured
- Ultimately life limiting conditions but where intensive treatment may prolong life
- Progressive conditions with no prospect of curative or disease modifying treatment
- Stable neurological conditions with life threatening respiratory complications
Why are children different?

- Different range of illnesses
- Multiple professionals and sites of care
- Support the whole family, esp siblings
- Ethical issues: autonomy, parents’ roles
- Increasing technologies – ventilation
- Physical, emotional and cognitive development
- Increasing population at Transition age
- Children: different emotions
How many? – Fraser data

• 2011: 49,000 children in the UK
  – 32:10,000 prevalence
  – 123:10,000 prevalence under 1 year
  – Increasing in 16-19 year group (23:10,000)
• 2015: 95:10,000 children
• 5,000 children die per year
  – 3,000 children under 1 year
  – 2,000 could have benefited from palliative care
• GPs: a dying child once or twice in their career
• Hospital nurse: a dying child once every 2 to 3 years
• CCNs: a dying child once or twice a year
What families want

• Living with the likelihood of death
• A holistic family-centred approach
  – Care in the place of choice: community based
  – Relief of distressing symptoms
  – Respite care
  – Psychosocial support
• Flexibility to respond to changing needs
• ‘Constant struggle’ for key services
• Recognition of a life limiting illness
• Ongoing care: joined-up planning
• End of life and bereavement care
• Transition
• Neonatal
• Critical care choices
Children’s hospices

- Day care
- Hospice at home
- Specialist respite
- Terminal care
- Emergency care
- Contact/key worker
- Bereavement support to family, school
Physical symptom management

- Pain
- Nausea & vomiting
- Dyspnoea
- Constipation
- Irritable/restless
- Breathlessness
- Fits
- Fatigue

- GP involvement
- CCN teams
- DGH paediatrician
- Therapists
- Tertiary care
- Hospice
- 24-hour access to advice
- Planned, responsive
Psychological, emotional, spiritual support

• Psychological distress
  – Loneliness, anxiety, depression
  – Significant mental health problems
    54% mothers, 30% fathers

• Relationships

• Spiritual / religious support, ethics

• Loss of employment, reduced incomes

• Housing and social isolation
Advanced care planning

• Primary aim: shared decision making
• Explore different perspectives
• Appraise quality of life when relatively well
• Discuss aims of treatment centred on the child
• Discuss possible treatment benefits and harms
  – Covering all eventualities?
  – ‘A flavour of discussions’
  – The art of medicine
Fears

• Fear of conflict
  – ‘It will upset the relationship’
  – ‘I don’t want to destroy hope’
  – ‘Talking about death makes it more likely to happen’

• Personal sense of loss, failure, giving up
  – ‘I don’t have the skills / time / energy’
  – ‘It’s too emotional’
  – Potential for unrealistic expectations
‘Best interests’

- Ascertainable wishes, feelings and values
- Understand, weigh up proposed and alternatives
- Participate in decision making, with support
- Physical and emotional needs
- Risk of harm or suffering
- Background information: religious, cultural
- Making decisions on behalf of:
  - Likelihood, extent of improvement of proposed Rx
  - Prioritise options that maximise future choices
  - Risks from delayed or non-Rx (implications for family)
  - Views of parents and family
Quality of life

• Not just prolong life (quantity) but ensure that life meets certain criteria (quality)

• ‘Objective and subjective indicators of well-being in multiple domains’
  – Somatic sensation / pain
  – Cognitive function
  – Social, community
  – Personal factors: attitudes, culture, beliefs

• Who should measure?
  – Concrete, objective aspects, detect changes in domains
  – Nurses, carers over-estimate depression, anxiety, distress
  – Doctors consistently under-estimate symptom severity
Quality of life

• ‘Measure quantitatively and precisely’?!
  – ‘Health status’, not just survival statistics
  – Is an intervention worthwhile?
• A quantitative score to different domains
  – Is mobility equivalent to emotional well being?
  – 5 years of good quality or 15 years of less?
• Evaluation can never be fully objective
• Leads logically to ‘a life not worth living’
• Is ‘normal’ preferable?
• Can one life be intrinsically more valuable than another?
Evolving decision-making

• Safeguard life, not rush decisions
  – Time for consultation or assessment
  – Doubt about the severity of a condition
  – Doubt about the likelihood of recovery
  – Doubt about whether a particular Rx will benefit

• Review decisions and treatments:
  – May be withdrawn if ineffective or burdensome
  – More experienced opinion
  – Evolution of the clinical state
  – Collect factual information
  – Remediable causes excluded
Talking about death

- Communication skills
  - The art of really listening
  - Permission to talk openly
  - Family dynamics
  - Differing levels of understanding

- How can we promote choices at the end of life?
- What provision is available at the end of life?
- How can we journey with families?
Location death < 28 days E&W, 2009

- Hospitals: 2207, 98%
- Hospices: 5, 0%
- Home: 33, 2%
- Other: 9, 0%
Location death 28d-4y E&W, 2009

- Hospitals: 1301, 83%
- Hospices: 48, 3%
- Home: 182, 12%
- Other: 33, 2%
Location death 5y-14y E&W, 2009

- Hospitals: 428, 66%
- Hospices: 39, 6%
- Home: 144, 22%
- Other: 36, 6%
Location, all ages – disease specific

**Neoplasms**
- Hospitals: 119 (51%)
- Hospices: 24 (10%)
- Home: 88 (38%)
- Other: 1 (1%)

**Congenital malformations, chromosomal abnormalities**
- Hospitals: 321 (84%)
- Hospices: 39 (10%)
- Home: 15 (4%)
- Other: 7 (2%)
Place of end of life care

• Of children who had died at home
  – Stronger family relationships
  – More adequate coping abilities
  – Less residual guilt
  – Less depression, somatization or interpersonal problems

• Families who choose home have better outcomes
  – Is home better?
  – Do more able families choose home?

• Increased probability (RR 1.4) of a difficult moment of death

• Increase support with community nursing
  – Home deaths rose 30% to 75% (GOS)
Siblings

• Needs often neglected during child’s illness and after death
• Parents limited resources of energy, time, money, emotions
• Inform about illness and treatment
• Opportunity to participate in care, but not over-burden
• Maintain peer-relationships and activities outside family

• What do they know?
• What do they think is going to happen?
• What are their fears?
• What are their questions?
Children’s understanding

- Children tend to have precocious understanding
- Adults prefer to believe children cannot understand
- Children often join in pretence that they are unaware
- Communication: direct verbal, symbolic verbal, symbolic non-verbal language
- It is the process of dying, not the death itself that is most frightening
- Giving children the choice
Pre-bereavement

• Sowing seed thoughts
• Clarify questions: Why are you asking that?
• Tell the truth in stages: Check understanding
• How children are treated helps them to heal
  – Healthier adjustment if allowed to participate
  – Affects future development
  – Relate to others
  – Ability to cope with loss in the future
Building memories
Grieving is an expression of love

• Theory of bereavement
  – Framework for understanding
  – Emotions of loss
  – ‘Stages’: not so clearly defined
Kübler-Ross

1. Denial and isolation
2. Anger
3. Bargaining
4. Depression
5. Acceptance
1. Initial awareness of loss
2. Attempt to limit awareness
3. ‘Letting go’
4. Awareness of the depth of loss
5. A new perspective on the loss
6. Resolution of the loss
7. Reformulation of loss in a growth context
8. Transforming loss into new levels of attachment
The journey continues

• Re-orientation
  – Potentials given by the loss
  – Loss is a challenge to work through
  – Sense of integrity and wholeness
  – Loss changes relationships positively
  – Greater strength following loss
  – Increased capacity for growth
‘With opportunity comes responsibility’

Churchill