Care Journeys and Pathways Approaches

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Together for Short Lives Mission

“That all children and young people not expected to live to adulthood and their families have the best possible care and support in the place of their choice”
Our strategic priorities

1. Inform families of the services available to them and raise awareness of their needs

2. Work to achieve co-ordinated care for all children and their families

3. Promote the best quality of care across all services

4. Seek to secure sustainable funding for the full range of services needed by children and their families
What is the Palliative Care Journey?

From Diagnosis through
Living with the Condition to
End of Life Care, Death and into bereavement

Each care journey is unique – as each life is unique.
Children/Young People and their families want

Choices/options in all aspects of care, including therapies and death in the place of choice;

Coordination of services at home, where this is the chosen place of care, including provision of specialist equipment and access to 24-hour specialist advice and expertise;

Expert symptom management;
Children/Young People and their families want

Emotional, spiritual and practical support for all family members;

Short breaks, with medical and nursing input, when required

To be seen as a person 1st, their condition 2nd
Care coordination

Babies, children and young people with life-limiting/life-threatening conditions and their families live with that condition 24 hours a day 7 days a week,

Services across the UK are being challenged to provide coordinated care to these children and families.

The Core Care Pathway is a resource to support services in the delivery of coordinated care throughout the child’s care journey.
How have we tried to respond?

• Pathway series aims to fill a gap (policy to practice)

• Involved parents & young people & other “grassroots” experts from the outset, focus groups/use of email discussions

• Part of a series – style agreed – definition agreed

• Off-the-shelf version for personalisation
The Care Pathway Series


followed by the publication of a transition care pathway in 2007;

a neonatal pathway in 2009 and

an extubation pathway in 2011.
The Core Care Pathway

• The pathway is guided by key standards, based where possible, on evidence.

• The focus is on the child/family rather than the system

• The Pathway has 3 phases:
  • Diagnosis/recognition,
  • Ongoing care and
  • End of Life care
The key changes

- Overarching principles
- A New Bereavement Standard
- Language
- Emphasis on making the most of the time that the family has together.
- Focus on robust risk assessment
- Acknowledge the need for parallel planning
Overarching principles

- Best interests
- Spiritual support
- Multiple admissions
- Coordinated care
- Communication
- Uncertainty and losses
- Psychological support
- 24-hour support

A unique journey for every child and family
Ability to respond quickly and flexibly

Diversity and cultural issues

Parallel planning

Care for the team around the child.

Advance care plan

Consent and Confidentiality
The stages & standards

Within Stage one – Diagnosis or recognition:
1. The prognosis – sharing significant news
2. Transfer and liaison between hospital and community services

Within Stage two – Ongoing care:
3. Multi-disciplinary assessment of needs
4. A child and family care plan

Within Stage three – End of life:
5. An end of life plan
6. Bereavement support
Standard 1

Every family should receive the disclosure of their child’s prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.

Information should be provided for the child and the family in a form that they can understand.
Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.
Standard 3

Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.
Every child and family should have a multidisciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multiagency team should be identified in agreement with the family and use key working principles.

Wherever possible this should involve all agencies involved in supporting the child and family, including the child’s community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.
Standard 5

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.
Standard 6

Bereavement support should be provided along the care pathway and continue throughout the child’s death and beyond.
Multi-agency Integrated Care Pathways provides a guide to:

**What** we should do

Also need to establish:

**How** we can apply it to our individual areas and for individual families

Taking into account:

- differing & variable resources
- differing & mixed geography
Thank you