When Should Palliative Care Be Introduced?

Palliative care is often thought of as care at the very end of life. However, living with the threat that you or your child may die from a life limiting or life threatening condition turns the world upside down. These underlying conditions come from a wide spectrum of conditions with differing progressions in both time and manner. Many families find they need support in some aspects by palliative care services at times from the diagnosis onwards. This may be psychological support, symptom control etc. Palliative care offers an active and total approach to the child and families care. It is on this basis that Children’s Palliative Care Services are considered to have significant contributions to offer families with children with life limiting or life threatening conditions, from the time of diagnosis or recognition of the condition.

During the child’s palliative care journey, there are likely to be many challenges, with difficult ethical decisions to resolve and symptom control issues to face, for example. It is helpful for the family if they have had the opportunity to form a relationship of trust with their ‘palliative care team’, before such difficult decisions have to be made. Working through difficulties together in the earlier stages will pave the way for mutual respect in the latter stages, assuring the family that the team have their child’s best interest at the centre of all they advise and offer. It will also provide the opportunity to form a partnership of working together in a manner that enables the family to feel that they will be listened to and respected. Where teams from different care settings work together well from the beginning, the family are more likely to feel supported by their ‘virtual team’.

Referral to Palliative Care Services can therefore be made at any stage from the time of diagnosis or recognition of the potentially life limiting/life threatening condition. It may be helpful to contact the lead Paediatrician for Palliative Care and the Lead Nurse for Palliative Care within the child’s home location, to discuss what might be able to be offered. Including them in early discussions with the family, pre discharge, will help options to be explored that may benefit the family. Many children benefit from attention to symptom control at a local level and help with practical and nursing care, alongside the active treatment being progressed by their Specialist team. The child’s Specialist in their condition will continue to lead the child’s care, but the shared care with the local palliative care team will offer opportunities for additional, complementary, supportive care closer to home.

*If you are think that palliative care services may be able to help in some way, please contact the lead Palliative Care Paediatrician and or Palliative Care Nurse in your area. Referral form examples can be found in the Toolkit.*
Together for Short Lives has described the conditions that result in life limiting/life threatening conditions within four broad groups. However, categorisation is not easy and the examples used are not exclusive. Diagnosis is only part of the process, the spectrum of disease, severity of disease and subsequent complications and the impact on the child and family also need to be taken into account. They are useful to ensure that service provision encompasses all families who may require palliative care support. They outline which conditions might be included, and which therefore excluded from palliative care services. Those that are not encompassed by the categories may be better met through provision via other pathways.

The TFSL categories are as follows:

**Category 1**

This group includes life-threatening conditions for which curative treatment may be feasible but can fail. Here access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

Examples: Cancer, irreversible organ failures of heart, liver, kidney.

**Category 2**

This group includes conditions where premature death is inevitable, but where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

Examples: Cystic fibrosis, Duchenne muscular dystrophy.

**Category 3**

Here progressive conditions without curative treatment options are included, where treatment is exclusively palliative and may commonly extend over many years.

Examples: Batten disease, mucopolysaccharidoses.

**Category 4**

This group includes irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and the possibility of premature death.

Examples: Severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs with a high risk of an unpredictable life-threatening event or episode.
Integrated Multiagency
Paediatric Palliative Care Pathways

Together for Short Lives (previously ACT) has developed a Core Care Pathway for Children with Life-limiting and Life-threatening Conditions (http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/core_care_pathway), revised from ACT’s Integrated Multi-agency Care Pathways for Children with Life-limiting and Life-threatening Conditions.

The updated pathway sits alongside ACT’s neonatal and transitional pathways, to support integrated provision throughout the child’s palliative care journey.

Each pathway is divided into three stages supporting planning at:
- Stage 1, Diagnosis or Recognition of the condition or of need to move on
- Stage 2, Living with the condition, and
- Stage 3, End of life care phase

The pathways provide a framework from which to plan together with families and teams to provide care appropriate to the assessed needs of the child and family. Whereas the Together for Short Lives categories outline which conditions will be included and excluded from palliative care services, the Pathways outline what issues need to be addressed and which services may need to be provide at any given stage.

Each of the pathways are reproduced on the following pages in their three stages. These can then be applied both locally to a population and also and particularly, specifically to individual children and their families.

Together for Short Lives has also produced a Care Pathway to Support Extubation within a Children’s Palliative Care Framework, in 2011, available on their website: http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/extubation_care_pathway
Together for Short Lives Core Care Pathway

Figure 1: Pathway summary diagram: A Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions

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

2. Stage two – Ongoing care
   - Multi-disciplinary assessment of needs
   - A child and family care plan

3. Stage three – End of life
   - An end of life care plan
   - Bereavement support

The first standard
The second standard
The third standard
The fourth standard
The fifth standard
The sixth standard
Together for Short Lives Core Care Pathway - Stage 1

Figure 2: Core Care Pathway stage one: Diagnosis or recognition

Identification of concern
- Family: Parental concern
- Child: Critical event
  - Birth
- Professionals: Child health surveillance
  - Antenatal diagnostics

Clinical assessment of the child

Diagnosis or recognition of life-limiting or life-threatening condition

The prognosis - sharing significant news
- Family: Interpreter
  - Information
  - Emotional support
- Child: In-patient treatment
  - Community care and treatment
- Environment: Privacy
  - Information
  - One to one discussion

Transfer and liaison between hospital and community services
- Family: Information
  - Training
  - Contacts
- Child: Symptom management
  - Equipment
  - Medication
- Environment: Transport
  - Liaison between hospital team, GP, primary care team, community team and social services

Needs assessment

Home or community
Together for Short Lives
Core Care
Care Pathway – Stage 2

Figure 3: Core Care Pathway stage two: Ongoing care

Multi-disciplinary assessment of needs

Family
- Information needs
- Financial review
- Emotional needs
- Physical needs
- Sibling well-being
- Family functioning
- Short breaks
- Quality of life
- Interpreter
- Transition to adult services

Child
- Symptoms and pain
- Personal care needs
- Therapies
- Emotional support
- Information
- Short breaks
- Social and leisure activities
- Quality of life
- Transition plan
- Independent living needs

Environment
- Home assessment
- Equipment needs
- Transport needs
- Social and leisure activities
- Education

A child and family care plan

Clinical lead
- Multi-disciplinary team
- Family GP

Family
- Emotional and psychological support
- Training
- Access to benefits
- Parent support groups
- Short breaks
- Pharmaceutical and medical supplies
- Sibling groups

Child
- Symptom management
- Personal care
- Nursing support
- Education
- Social and leisure activities
- Spiritual support
- Short breaks
- Psychological support
- Independent living advice

Environment
- Home
- Aids and equipment
- Motability

Acute or planned admission

Review of needs

Discharge back to Community team

Review of prognosis

Recognition of end of life

West Midlands Children and Young People’s Palliative Care Toolkit 2015.
Section 1. 6
Together for Short Lives Core Care Pathway – Stage 3

www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/core_care_pathway
ACT’s Transitional Palliative Care Pathway – Stage 2
ACT’s Transitional Palliative Care Pathway – Stage 3
ACT's Neonatal Palliative Care Pathway – Stage 1

Diagram 1: Stage One: Entry to the pathway

Identification of concern

Clinical assessment of the baby

Diagnosis or recognition of life-threatening/life-limiting condition/prognosis

Advocacy

Breaking news

The First Standard

Family
- Information – choices
- Training in care of baby
- Transport
- Siblings
- Contact details for professionals
- Antenatal care of mother
- Bereavement support
- Interpreters
- Emotional support
- Religious and spiritual support

Baby
- Symptom control
- Emergency care plan
- Baby care needs
- Religious and spiritual care

Environment
- Place of care
- People involved in future care
- Outpatient and primary health team
- Midwifery team
- Hospital team: neonatal and paediatric services
- Social services
- Registration of birth

Planning for going home

The Second Standard

Family
- Information – choices
- Training in care of baby
- Transport
- Siblings
- Contact details for professionals
- Antenatal care of mother
- Bereavement support
- Interpreters

Baby
- Symptom control
- Equipment
- Follow-up (routine/emergency)
- Religious and spiritual care
- Baby care needs

Environment
- Place of care
- Outpatient and primary health team
- Midwifery team
- Hospital team: neonatal and paediatric services
- Social services

Stage Two: A multi-agency assessment of the family's needs

Discharge or transfer to family home or less technological care
**ACT’s Neonatal Palliative Care Pathway – Stage 2**

Diagram 2: Stage Two: Living with a life-threatening or life-limiting condition

**A multi-agency assessment of the family’s needs**

**Family**
- Information - care choices
- Support in care of baby
- Sibling well-being
- Contact details for professionals
- Post-natal care of mother
- Financial/benefits advice
- Emotional needs
- Family functioning
- Respite/short breaks
- Interpreter
- Genetic counselling

**Environment**
- Family
- GP and primary health team
- Midwifery team
- Hospital team: neonatal and paediatric services
- Social services

**Baby**
- Symptom control
- Equipment
- Follow-up (routine/emergency)
- Baby care needs
- Therapies

**The Third Standard**

**A multi-agency care plan**

**Family**
- Psychological support
- Training
- Access to benefits
- Parent support group
- Sibling support
- Respite/short breaks
- Pharmacy/equipment supplies

**Environment**
- Potential home adaptations
- Aids/equipment
- Mobility/Blue Badge Scheme

**Baby**
- Symptom management
- Baby care needs
- Nursing support
- Therapies

**The Fourth Standard**

**Recognition of end of life**

**Stage Three: End of life and bereavement**
ACT's Neonatal Palliative Care Pathway – Stage 3

Diagram 3: Stage Three: End of life and bereavement

An end of life plan

Family
- Information – choices
- Transport
- Sibling involvement
- Contact details for professionals
- Emotional support
- Spiritual issues
- Cultural/religious issues
- Funeral planning
- Heart valve donation
- Grandparents
- Post-natal care of mother
- Memory box

Baby
- Symptom control
- Equipment
- Follow-up (routine/emergency)
- Spiritual issues
- Cultural/religious issues
- Allowing a natural death care plan

Environment
- Place of death
- Place after death
- Ambience

The Fifth Standard

Continuing bereavement support

Family
- Information – choices
- Transport
- Sibling involvement
- Contact details for professionals
- Emotional support
- Spiritual issues
- Cultural/religious issues
- Funeral planning
- Grandparents
- Post-natal care of mother

Baby
- Funeral
- Burial/cremation

Environment
- Place of care
- Ceremony/ies following the death of baby
- Registration of death
- Ambience

The Sixth Standard
When to Use the Toolkit

The West Midlands Children and Young People’s Palliative Care Toolkit is designed to support palliative care planning and provision wherever and whenever a child requires palliative care. This applies to all stages from the time of diagnosis and or recognition of the condition.

Situations when it may be helpful include when:
- Initial planning is taking place at the time of diagnosis
- A reviewing of best practice approaches to sharing difficult news would help
- Families need written advice
- Referral to Palliative Care Services is required
- Symptom control issues arise
- Drug doses need to be confirmed
- Reviewing previously received best practice training re palliative care
- Plans around admission and discharge to HDU need to be formed
- End of life care plans need to be written and disseminated
- Informing Ambulance Control of resuscitation decisions
- Informing GP out of hours services of the clinical situation
- A Rapid Discharge from hospital is planned for terminal care at home
- Symptom control drug boxes are required
- Symptom support bags are to be provided
- Information re syringe driver use is required
- Documentation of drugs administered by nursing staff to support symptom control in palliative care, is required
- Spiritual care needs are to be assessed
- Help is needed to know who to contact for advice re symptom control
- Clarity is required re writing controlled drug prescriptions
- Information is required to take controlled drugs abroad
- Contact details are needed for advice about organ and tissue donation
- Information would support verification and certification of death
- Families need information on what happens when their child dies
- Staff need to notify Child Death Review Officers, Coroners, etc. along with many other situations throughout the child and families individual and unique palliative care journey.

It is intended to guide nurses, medical staff (including GPs) and pharmacy staff when a child/young person requires palliative care.

It acts as a resource toolkit which can be supplemented by the owner’s local information to enhance their access to local palliative care resources including:
- Local contact numbers of teams providing palliative care
- Local respite arrangements
- Local out of hours staff arrangements and accessibility
- Local out of hours pharmacy arrangements

to provide a robust source of locally relevant and regionally approved information for staff to access both in and out of hours.
The Palliative Care Team

An individual child’s palliative care team will consist of members from many different teams across different care settings from acute to community. These individuals need to work together as a virtual team for the child and family to enable care to appear seamless at the point of delivery. Access to 24/7 Children’s Community Nursing services forms the bedrock of children’s community palliative care service provision, providing families with choice to be able to receive their care at home where appropriate. It is also important that local medical support (usually a Paediatrician) is identified to support palliative care provision to an individual child and also to the local population of children and families with palliative care needs.

Community Based Medical Support to Children’s Palliative Care:
- Community based medical support, usually a Paediatrician, should be identified to take the lead for palliative care in each locality, whether that be in a geographical locality or a hospice based locality. They will work alongside the child’s specialist and local paediatricians, children’s nursing teams, GP, multidisciplinary teams and family to support safe and effective delivery of palliative care in an anticipatory manner.
- It is important that cover arrangements are clear when the lead medical support for palliative care is not available out of hours or during leave. This will involve both a local agreement for access to paediatric medical advice out of hours during leave and also specific plans for individual children within their terminal phase.
- The latter is likely to draw upon support from the child’s specialist teams, local paediatricians, General Practitioner, and at times, adult palliative care colleagues.
- It is important that Out of Hours information is logged with Out of Hours primary care services in the terminal phase.

The Responsibility for Agreeing Home Terminal care:
The responsibility for recognising the latter stages of the end of life phase and that a move towards the terminal phase of the condition has been reached lies with the lead consultant for the child. On occasion the lead consultant may not have seen the child recently. At these times the professional visiting the child at home should discuss the case fully with the lead consultant. It is essential that communication with the parents (and child if appropriate) regarding the terminal phase and its management in the home/community will already have been addressed at an earlier stage. Ideally, an Advanced Care Plan will have been completed. However a discussion between parents, child (if appropriate) and professional must occur to ensure that all parties remain in agreement.

The following guidelines within the Toolkit are provided therefore to support sound decision making, symptom and medicines management of the highest standard in the home/community. It is essential that users confirm guidelines are up to date and appropriate for the individual child’s situation.
Palliative Care Definitions and Terminology

Palliative Care:
Together for Short Lives defines palliative care for children and young people with life limiting conditions as an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Palliative care is underpinned by a philosophy of total, holistic approaches to care.

It is often best applied early in the course of illness in conjunction with other therapies to prolong life (such as chemotherapy and radiotherapy), including investigations to better understand and manage distressing clinical complications (NICE 2004)

End of Life Care:
This refers to the period when a child with advanced disease lives with the condition from which they will die. It includes those with any chronic, progressive, eventually fatal illness and could be a period of weeks, months or years.

Terminal Care:
This refers to care provided when a child is thought to be in the dying phase and usually refers to the last days or hours of life.
Respecting Equality, Dignity and Consent to Treatment

Equality:

- All public bodies have a statutory duty under the Race Relation (Amendment) Act 2000 to “set out arrangements to assess and consult on how their policies and functions impact on race equality.” This obligation has been increased to include equality and human rights with regard to disability, age and gender.

- Individual localities should endeavour to challenge discrimination, promote equality and respect human rights, and aim to design and implement services, guidelines and measures that meet the diverse needs of the service, population and workforce, ensuring that none are placed at a disadvantage over others.

- All staff are expected to deliver services and provide care in a manner which respects the individuality of each child/young person and their carers and treats them and members of the workforce fairly and respectfully, regardless of age, gender, race, ethnicity, religion / belief, disability and sexual orientation.

Dignity:

- All staff are expected to ensure that each child and their carers benefit from care that is focused upon respect for the individual. In order to achieve this, the seven factors of best practice from the Essence of Care* benchmark for privacy and dignity need to be taken into account.

  *The Essence of Care: Patient-focused benchmarking for health care practitioners, Department of Health, 2003

Consent to Examination, Care or Treatment:

- Before beginning an examination, providing care or treatment, staff must ensure that they obtain the consent of the person they are examining, caring for or treating. For consent to be valid, the person must:
  
  **Be competent to take the particular decision** – it is presumed that adults have capacity to consent unless it is shown otherwise. The Mental Capacity Act 2005 provides a test for assessing whether a person lacks capacity to take a particular decision at a particular time and the steps to be taken if the person lacks capacity. Young people aged 16 and 17 are presumed to have the competence to give consent for themselves. Younger children who understand fully what is involved in the proposed procedure can also give consent (although their parents will ideally be involved). In other cases, someone with parental responsibility must give consent on the child’s behalf.
- Have received sufficient information to make it – this will include information about the benefits and risks, including side effects, of the proposed course of action, the implications of not receiving the examination, care or treatment and alternatives.

- Not be acting under duress – there is a need to balance ensuring that all the child/young person’s concerns are fully identified and addressed whilst not persisting in discussions to such an extent that the person feels harassed. Staff must also be aware of the possibility of undue influence from family or friends.

If the child/young person does not have capacity to consent, decisions must be made in their best interests. The Mental Capacity Act 2005 provides structured and specific tests for capacity and a list of issues to be taken into account when determining what is in a person’s best interests.

For further information, see:
- Individual Trust’s policies, procedures and guidelines on consent and the Mental Capacity Act.
- Guidance within the Advanced Care Plan leaflet for professionals, within the Toolkit.
Record Keeping

- Record keeping must comply with individual Trust requirements for record keeping.
- Advance care planning discussions with the child and family and with other professionals must be recorded in the nursing records held in the family home and in a locked cabinet at base.
- All records must be recorded legibly, signed and dated with a print name next to an example signature.

The Palliative Care Toolkit supports best practice documentation. It provides tools to support the documentation at times when:

- Plans around admission to or discharge from HDU are being formulated
- End of life care wishes are discussed and recorded
  - Ambulance Services need informing of resuscitation decisions
- GP Out of hours services require up to date information
  - Rapid discharge plans and agreements are recorded
- Drugs for nursing administration are prescribed, instructed and reviewed, including as just in case medicines.
- Specific information around the completion of the documents accompanies the main tools, e.g. the Advanced Care Plan and are accessible within the Palliative Care Toolkit.