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.

Definition

“Palliative care for children and young people with life-limiting conditions is 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 the 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. (ACT 2009)

Many families find they need support in some aspects by palliative care services at times from the diagnosis onwards. Palliative care offers an active and total approach to the child and families care. The Community Children’s Nursing (CCN) Service are considered to provide a significant contribution for families with children with life limiting or life threatening conditions, from the time of diagnosis or recognition of the condition onwards.

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. It is helpful for the family if they have had the opportunity to form a relationship of trust with their specialist 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 they are listened to and respected and that the team around their child have their child’s best interest at the centre.

‘Where teams from different care settings work together well from the beginning, the family are more likely to feel supported by their ‘virtual team’.

(West Midlands toolkit 2011)

Many of these children will have complex health care needs and are supported by a range of speciality areas and staff. It is therefore important to identify a Lead Clinician at an early stage both at the Tertiary and Local hospital, to co-ordinate the clinical care and planning for the child. They will be someone known to the family with an establish relationship of trust and ensure that: all ‘interested parties’ are involved in discussions about the management for a particular child. They will raise the issue of the Children & Young Person Acute Deterioration Management form (CYPADM) with the family and document, disseminate and review those decisions with them as their condition progresses.

Referral to the CCN services can be made at any stage from the time of diagnosis or recognition of the potentially life limiting/life threatening condition. They will work closely with the child’s Lead Clinician (Paediatric Consultant) and local paediatrician. Joint working in early discussions with the family will help options to be explored that may benefit the family and identify clear Anticipatory Care Planning.

Many children benefit from attention to symptom control and assistance with practical and nursing care at a local level alongside the active treatment being progressed by their Specialist Team. The child’s Specialist in their condition will often be identified as their Lead Clinician but shared care with the local CCN team offers the additional, complementary, supportive care and planning closer to home.
The guiding principles for care provision are based soundly within the Association for Children with Life Limiting Conditions organisation (ACT), ‘Care pathway for children and young people with life limiting conditions and their families’ (2007) which states:

- Care should be child and family focused and should take account of children’s rights
- Care should encompass symptom management, emotional support, practical support, spiritual needs and bereavement for the whole family, and should respect cultural and religious differences
- Service delivery should be based on assessment of needs starting as soon as possible after diagnosis or recognition
- The delivery of care should be well coordinated, with an emphasis on the continuity of services
- Care plans should be flexible to accommodate changing needs and choices
- Regular review of needs, should be undertaken and care plans adjusted to take account of changes in circumstances

(ACT, 2007)

The CCN C&YP palliative and End of Life Care Pathway provides a practical implementation plan of the ‘ACT integrated multi-agency care pathway’ above and also reflects the Scottish Children & Young Peoples Palliative Care Network (SYPPCN) vision for children’s palliative care. This vision encompasses efficient coordinated services and well-informed families who are able to exercise real choice:

- Choice of place of care – home, hospital, or hospice
- Choice of place of death – home, hospice or hospital
- Choice in bereavement care and support

‘Every child or young person in Scotland with a life-limiting/life threatening condition, regardless of race, religion, age or where they live, should have access to the sustainable, holistic, family-centred and high quality palliative care and support that they need. To ensure that children and families receive good quality palliative care’.

(SCYPPN 2009)

**ACT’s 4 Categories of Life Limiting and Life Threatening Conditions**

ACT 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 ACT 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.

ACT Care Pathway Standards

ACT has developed three main pathways to support integrated provision throughout the child’s palliative care journey.

The 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
Stage 3 - End of life care phase

The pathway provides 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 ACT 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. Further information can be obtained at www.act.org.uk, where the full document can be obtained.

Pathway 1: DIAGNOSIS / RECOGNITION STAGE
The starting point for diagnosis / recognition is when there is concern that a child/young person may have a life limiting condition, whether that concern is raised through parental anxiety, professional concern or a critical event. The end point of this process is when when a child/young person who has been diagnosed with a life limiting condition moves from the immediate, intense activity around diagnosis/recognition to an on-going palliative care phase over days/weeks/months/years.

The Key goals in this stage are:
Breaking bad news (1st Standard)

Plenty of time should be made available for a face-to-face discussion, with sensitivity and honesty, including opportunities to ask questions at the time and subsequently. A place should be provided that ensures complete privacy where parents should be together to receive the news; if not possible, every effort should be made to ensure that another relative or a friend is present to support the parent hearing the news first. Helpful written material should be provided as a supplement to, but in no circumstances should this be thought of as a substitute for, direct communication. Information should be conveyed in readily understandable language, using an interpreter where necessary. The needs of the child or young person for information appropriate to their age and understanding should also be taken into account.

Planning transfer to home and community services (2nd Standard)

A lead Clinician (whom is usually the child’s Lead Paediatric Consultant) should be identified both at the discharging hospital and within the community district General Hospital if care is transferred back.

The CCN team should be notified as soon as practical to meet with the child and family and their clinical specialist team. Planning should begin as soon as possible and a clear plan for transfer should be agreed with child, family, hospital and community services. A lead community children’s nurse should be identified before transfer, the child’s GP should be invited to become involved and clear plans should be in place for shared medical care. Essential adaptations, equipment and supplies should be provided before transfer and other resources organized before discharge. Training should be provided for carers before transfer. Clear lines of communication should be agreed. 24 hour contact number should be provided to the family. Where possible a key worker should be identified.

Pathway 2: LIVING WITH A LIFE THREATENING OR LIFE LIMITING CONDITION
The starting point for this pathway is when a child/young person’s care moves from the immediate, intense activity around diagnosis/recognition to ongoing palliative care over weeks/months/years ending when there is recognition that the child/young person has reached the end stages of his/her life and moved into the ‘end of life’ care pathway.
The Key goals to achieve are:

**Assessment (3rd Standard)**
Children and families should have their needs assessed as soon as possible after diagnosis or recognition. Working with the child's clinical team and in partnership with the family, completion of an Anticipatory care Plan (ACP) should be implemented. This holistic and multi-agency approach should be used to avoid the need for multiple assessments.

The child or young person should be kept in focus and involved in the process and care should be taken to include the needs of fathers and siblings. Individuality and ethnicity should be respected.

The Information should be gathered and recorded systematically on the ACP to ensure consistency ensuring straightforward, non-jargon language being used. The issues of confidentiality and consent should be addressed with the family to sharing the information within the ACP with their child’s Multi-disciplinary team. Assessment information gathered should be available to the family.

There should be clarity in respect of the Lead Clinician role and the role of the Community Children’s Nurse allocated to the child and family. Those undertaking the ACP should have appropriate skills and local knowledge to complete this.

**Multi-agency Care Plan and Review (4th Standard)**

Every family should have a key worker to co-ordinate the plan and information should be available for the child and family. The plan should include the whole family and take account of:

- Provision for the child’s symptoms and personal care
- Psychological care for child, siblings and parents
- Access to benefits and financial assistance
- Access to flexible short breaks
- Access to social care and support
- Access to play and social activities
- Access to education
- Protection of carers’ health
- Access to aids and equipment
- Transition to adult services
- Individual spiritual needs, including where appropriate religious/or moral beliefs

The child and family’s needs should be regularly reviewed and a new care plan agreed to take account of the changes. The family should be able to request a review at any time. Services and professionals should regularly review their effectiveness in co-coordinating and delivering care plans. Families will need extra support at key times, particularly following hospital admission, a change in the child’s condition or in times of family crisis.

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**Pathway 3: RECOGNITION OF END OF LIFE PHASE / BEREAVEMENT**
Predicting the time when a child is likely to move into their end of life phase is not easy. For some, there may have been a series of peaks and troughs in the child’s condition before this over a number of years and it is not uncommon for children to return to greater stability following a period of serious decline. The realisation that death is imminent may be quite sudden, possibly only hours or days before death. The families of these children may have had little time to acknowledge this reality or plan for the death. For others, however, movement into the end of life phase may occur gradually over a period of months or be even clearer when there has been a decision to stop all life-prolonging
Professionals working with these children and families should be honest and open about the probability that the child’s life is nearing an end. Families should not be given false hope and should be allowed to plan for death. The term ‘good death’ is difficult to define, as it is personal to each individual. But the key is that the child and family should be able to exercise choice. It is therefore advisable for an Anticipatory Care Plan to be agreed in advance, based on the child/young person and family’s needs and wishes and resource availability.

The starting point for this phase of the pathway is when it is recognised that death for a child/young person is now inevitable, with progression preventing the return to previous health state and ending following the child’s’ death and the provision of bereavement support for the family.

The key goals to achieve are:

**Planning for End of Life Care (5th Standard)**
Professionals should be open and honest with families when the approach to end of life is recognised and completion of the Anticipatory Care plan with families and relevant professionals should take place as soon as possible.
The ACP should be reviewed and agreed with the family as early as possible (and child/young person where appropriate) to take account of changes.
Decisions about Children & Young Peoples Acute Deterioration Management (CYPADM) should be agreed with the family (and child/young person where appropriate) written up and communicated by the Lead Clinician to all relevant professionals within care settings and emergency services should be informed.

CCN will enable 24-hours access to pain and symptom control including access to medication.
Those managing the control of symptoms should be suitably qualified and experienced in this area.
Emotional and spiritual support should be available to the child and their parents/carers.
Children and families should be supported in their choices and goals for quality of life to the end within resource availability.

Clarity of who will verify and certify death should be identified.

**Care After Death (6th Standard)**

Following the child’s death the family should be allowed time and privacy with their child and parents should feel in control of events before during and after death and be able to make their own choices.
It is imperative that these choices are captured within the Anticipatory Care Plan at an earlier stage in preparation for this event.

The CCN will provide practical advice and written information should be given about removal and care of their child’s body, official procedures and entitlements. The needs of siblings and grandparents should be considered and included at the time of death and immediately afterwards. If identified fully informed consent should be given for post mortem if previously identified.

Bereavement support should be offered for as long as the family needs and the bereavement needs of siblings should be recognized and support provided. The needs of care staff should be considered.

Reflection upon the families care pathway journey, should consider whether throughout the journey, the following principles for children’s palliative care had been observed:
- Care had been child and family focused and taken account of children’s rights
- Care encompassed symptom management, emotional support, practical support, spiritual needs and bereavement for the whole family, and respected cultural and religious differences
- Service delivery was based on assessment of needs starting as soon as possible after diagnosis or recognition
- The delivery of care was well co-coordinated, with an emphasis on continuity of services
Care plans were flexible to accommodate changing needs and choices

Regular review of needs were undertaken and care plans adjusted to take account of changes in circumstances

Where standards have not been achieved, analysis should be undertaken as to why this occurred and what steps might need to be taken to improve provision in the future.

The NHS Fife Community Children's Nursing Paediatric Palliative / End of Life Care Pathway seeks to reflect the core Standards of the ACT Integrated Care Pathway and also the actions set out within Living and Dying Well – A national Action plan for Palliative care for Scotland

Professional Roles and Documentation Descriptions:

Lead Clinician – is identified as the Lead Clinician from the Tertiary/Secondary centre. The Lead Clinician will make the referral directly to the CCN’s, Local Lead Clinician and the General Practitioner.

Anticipatory Care Plan (ACP) – is a tool for discussing and communicating the wishes of the C&YP and their family. The completion of the ACP is led by the Lead Clinician and must be discussed and initiated at time of transition to palliative/end of life care and shared with their primary care team for inclusion to the e-PCS.

Children & Young People Acute Deterioration Management Plan (CYPADM) – status must have been discussed and planned with C&YP and their family and shared with the primary care team on recognition of a life limiting/life threatening diagnosis. Copies of CYPADM agreements must be shared at time of referral. If a child does not have a CYPADM plan then they should be made aware that full resuscitation will be implemented.

Local Lead Paediatric Consultant – is identified within the /Secondary centre and is responsible for sharing medical information and co-ordinating the care for the C&YP and their family within the primary care team.

General Practitioner (GP) – will be an active partner in planning and co-ordinating care within the primary care setting along with the Lead Paediatric Consultant and Community Children’s Nurse Service. The ‘electronic –palliative care summary’ (e-pcs) System within GP Systems can be used at any time for recording specific concerns/choices that the C&YP / family wishes, CYPADM agreements.

e-Palliative Care Summary (e-PCS) – The GP will record C&YP with a palliative/end of life care diagnosis on the e-PCS. The GP will liaise with the Lead Consultant /Named Health Professional and make any required amendments to the e-PCS summary.

Community Children’s Nursing Service – are the first point of contact for any referral for palliative / end of life care. A Community Children’s Nurse (CCN) will be allocated to the child and their family and act as the named health professional for the child and their family and co-ordinator for the completion of the ACP.
**IDENTIFICATION OF PALLIATIVE/End Of life phase of their illness: Antenatally/from birth**

Identification of palliative/end of life phase may in some cases be diagnosed antenatally or from birth eg: anencephaly, hypoplastic left heart syndrome. This diagnosis would be made by Lead clinician within Fife NHS (Acute), referral may or may not be required to CCN team.

**IDENTIFICATION OF PALLIATIVE/End Of life phase of their illness**

Child/Young Person diagnosed with incurable disease or change from curative to palliative / end of life phase of their illness by Lead Clinican at Tertiary Centre based within:
- RHSC Edinburgh
- Ninewells Hospital Children Services
- RHSC Yorkhill, Glasgow

(NB: Diagnosis may be from birth onwards)

**Children/Young People Acute Deterioration Management (CYPADM) form** – must have been discussed and planned with family and C&YP prior to discharge into primary care setting and shared with primary care team as part of discharge planning process. Copy of CYPADM agreements must be sent at time of referral.

**Anticipatory Care Planning** – initial discussions must have been initiated had with C&YP and their family around starting to plan and think ahead to share any wishes, thoughts concerns re palliative care. This will be followed up by local primary care team. Completion of the ACP is facilitated by the Childs Community Children's Nurse.

**Lead Professional / Lead Clinican / Local Clinican / e-PCS**

Lead Professional – The **community children’s nursing team will be** the first point of referral for any referral for palliative / end of life care for a C&YP within NHS Fife. The CCN allocated will act as lead professional and co-ordinate and activate members of the ‘virtual palliative care team’ as required pre / post discharge. The CCN team will keep an active list of clients with palliative care / end of life care needs. Lead professional will ensure checklist for referral locally completed.

**Lead Clinician** – is identified as the Lead Paediatric Consultant from the Tertiary/Secondary centre making referral. This individual will make referral directly to the CCN team but also liaise directly with the Local Lead Paediatric Consultant and C&YP’s General Practitioner.

**Local Lead Paediatric Consultant** – Local lead Paediatric consultant is responsible for sharing medical information and co-ordinating care for the C&YP with the primary care team in partnership with LEAD CLINICIAN from the tertiary centre. For C&YP services within NHS Fife this role will be filled by: Dr Aysel Crocket Consultant paediatrician

**General Practicioner (GP)** – the C&YP local CP and his team will be active partners in planning and co-ordinating care within the primary care setting.
Palliative Care Summary (e-PCS) – C&YP with a palliative diagnosis will be added onto the local GP palliative care register. C&YP registered on palliative care register within primary care will require the same assessment and follow up as any member of Fife’s population.

C&YP Referral Process:

- Referral and transfer of care co-ordination made to NHS Fife Community Children’s Nursing Team – CCN Lead Professional will be identified for C&YP and their family.
- CCN will co-ordinate with referrer date for local CCP with C&YP GP and family.
- Interagency assessment – utilise the NHS Fife Care Co-ordination Plan which includes child’s plan using shanari indicators – capture core assessment of need if time allows.
- CCN key worker will active referral and action from appropriate members within the NHS Fife Paediatric ‘Virtual Palliative Care Team’ as appropriate. E.g.: AHP’s, Dietician, District Nurse, GP, Health Visitor, School Nurse, Social Work, Education. Learning disability Nurse.
- CCN Team will provide information leaflet provided to family - dedicated phone number with hours of service. / Out Of Hours (OOH) contacts and resources for family following local CCP.
- CCN will complete Anticipatory Care Plan with family and medical team.
- Identify if referral made to Rachel House hospice – facilitate referral for service and support even if family chose not to utilise for respite provision.
- Liaison with Outreach service if a home care package is identified as a requirement.
- Young Adults with palliative care needs transferred to adult services at age 16yrs – utilise referral pathway to DN and Adult palliative care Service documents. (NB: young adults in full time education or with complex health care need and receiving a care package will continue to be supported by C&YP Services until their 19th birthday).

Monthly MDT at GP Practice:

CCN Lead professional for C&YP – attend monthly will therefore attend CCP meeting in Primary Care and take responsibility for updating GP / e-pcs data with any changes in clinical care for C&YP.

Anticipatory Care Planning:

- Completion of the ‘Anticipatory Care Plan’
- Handover form completed for out of hours service
- Special Notes form completed with GP uploaded onto NHS 24
- Local MDT with liaison with Rachel House with regard to out of hours support for choice of end of life care.
**EQUIPMENT**

- CCN to identify and access provision of equipment via Equipment Store (delivery within 1 day) – direct telephone referral before 12 midday / state required for palliative patient/ equipment will be provided by 12 following day (Monday to Friday only)

**PARTNERSHIP ROLE WITH DISTRICT NURSING OOH COLLEAGUES / SPIRITUAL SUPPORT**

- Community Children’s Nurse takes on care management / lead professional / key worker role for palliative / end of life care
- CCN will identify at initial GP MDT referral meeting role of DN for OOH Support for C&YP
- CCN will ensure referral to Chaplaincy service within NHS Fife for ongoing support to C&YP and their family and support for CCN Team

**SOCIAL WORK / BENEFITS ADVICE / PACKAGE OF CARE**

- CCN facilitates completion of DLA form under ‘special rules’ to ensure family gain benefit of any outstanding benefit support during this time.
- CCN referral to CAB office if appropriate for advice around benefits etc for family.
- CCN – ensure Referral to Social Work Children with Disability Team if not already known
- If CARE PACKAGE required CCN will liaise with Outreach team Manager and Senior community managers around application for funding as appropriate

**TEENAGERS / YOUNG ADULTS / TRANSITION & SUPPORT**

- For Young Adults with palliative care needs age 16 years and over – CCN can make referral to Marie Curie service as appropriate
- Referral for service is through the District Nursing Service.
- Marie Curie service will only see clients from age 16 yrs--18yrs and over.
- If child within age group or will be transferring into adult service ensure effective handover to DN and adult palliative care team, CCN responsible for holding information and sharing with District Nurse and Out-of-Hours Service (funding via package of care as above).

**ANTICIPATORY PRESCRIBING**

- At GP MDT handover meeting – drug kardex to be completed with all medication and anticipatory medications as identified for individual C&YP symptom management, utilising documentation currently in use within Outreach services.
- LEAD CLINICIAN/ LOCAL LEAD PAEDIATRIC CONSULTANT / GP - will agree prescription and dosages.
- CCN will provide copy of ‘Basic Symptom Control in Paediatric Palliative Care: The Rainbow Children’s Hospice Guidelines. 8th Edition 2011’ to GP and District Nurse
- CCN will provide individualised Anticipatory Care Plan and contacts list for family use for during and OOH support.
- CCN – utilise the standards set within the ACT Care pathway palliative and end of life care planning pathway

**LOCAL COUNSELLING ONGOING SUPPORT FOR C&YP AND THEIR FAMILY**

- Local Consultant Paediatrician and Community Children’s Nurse provide support to child and family in partnership with primary care
team and school and will liaise between secondary and tertiary care
- Maggies Centre – for Parents of C&YP with cancer Maggies centre will provide support for parents though provision of their services
- Onward referral to family GP for ongoing support

**BEREAVEMENT SUPPORT**

- Bereavement leaflet/resource – NNU/Acute service available
- Referral and early introduction of NHS Fife Chaplaincy Services
- Maggies Centre - Clinical Psychologist will provide counselling to parents whose child / young person has died from cancer related illness
- Rachel House – family and sibling support groups continue to support family

**RESOURCES AVAILABLE TO SUPPORT PATHWAY**

- Palliative Care Guidelines – SCAN website
- Basic Symptom Control in Paediatric Palliative Care Guidelines: The Rainbow Children's Hospice Guidelines. 8th Edition 2011
- Specialist Oncology, medical and pain teams, RHSC, Edinburgh
- Dedicated out of hours palliative care number – nursing service
- Out of hours access to children’s own specialist teams within Tertiary/Secondary centres
- NHS Fife equipment store – rapid access to equipment for patients with palliative care needs
- Community Children’s Nursing Team
- Community Children’s Outreach Team
- ACT Care Pathway guidelines (2007)
- NHS Fife C&YP – Virtual Palliative Care Team members
- AHP colleagues
- Adult palliative Specialist Services
- **Department of Spiritual Care**
- Rachel House Children’s Hospice
- Nurse Specialist - Paediatric Palliative Care Liaison Nurse (RHSC Edinburgh)
- 1 x Nurse Consultants C&YP Palliative Care