

Diana Children's Community Palliative Care Team Operational Policy

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1. Team Model and Structure

1.1 INTRODUCTION

The Diana Children's Community Palliative Care Team is a component of the Newham Children's Community Nursing Service within Community Health Newham and the Specialist Services Directorate of East London NHS Foundation Trust.

We provide multi-disciplinary care within family homes and other community settings for infants, children and young people (birth up to 19yrs) who have a palliative care condition (are not expected to live in to adulthood), including specialist nursing care, symptom control management, end of life care, health play specialist interventions and clinical psychology support and consultation.

The Diana Children's Community Team aims to work in partnership with infants, children, young people and their families facing life-limiting or life-threatening conditions and to co-ordinate with other services and agencies involved in their care to provide appropriate support that maximises their opportunities to live a full and enjoyable life and supports families to manage the challenges they face through their journey from recognition of prognosis, through changing health and care needs to end of life care, death and bereavement.

1.2 PURPOSE

This policy aims to provide clear information about the operating procedures of the Diana Children's Community Team for employees of East London NHS Foundation Trust.

This policy includes:

- Outline of the team's main aim and purpose of operation
- Explanation of how the team delivers care
- Clear information about roles within the team
- Description of the key principles involved in delivery care

1.3 AIMS OF SERVICE

The Diana Children's Community Team aims to:

- Offer nursing, play and psychology support for management of distressing symptoms and changing health needs throughout the course of the palliative care condition, including the end of life phase and after death care.
- Offer nursing and emotional support for infants, children and young people with complex care needs who have a palliative care diagnosis/prognosis (i.e. are not expected to live in to adulthood).
- Provide psychological assessment, support and interventions on a medium to long term basis to any member of and/or the whole family.
- Provide advice to schools about healthcare and psychological/emotional needs of children, young people and their families who have palliative care needs and/ or their siblings and the wider school community
- Provide advice, education and support to members of the multi-agency team when working with children and young people known to the team.
- Provide advice, education and support to family members and carers.

- Offer health play specialist interventions in the home and other community settings to prepare and support children and young people to cope with medical procedures, understand their health needs and enhance quality of life for the child.
- Act as lead professional/team for the infant/child/young person with palliative care needs, if appropriate, to co-ordinate a range of services and agencies, including transition from hospital to community services.
- Support families and professionals with the process of implementing the six standards of Together for Short Lives' "A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions (Third edition)":

The Together for Short Lives Core Care Pathway suggests a broad outline of the key events or processes that happen during the journey made by children with life-limiting and life-threatening conditions and their families.

The Core Pathway is divided into three stages:

- Stage one: Diagnosis or recognition
- Stage two: Ongoing care
- Stage three: End of life

Each of these stages begins with a key event that is significant to the family. Although this is shown as a linear process, children may move backwards and forwards between the different stages, or miss stages out in their care journey, depending on individual circumstances.

Within the stages of the pathway, there are six standards, which are described in detail in the core pathway. The standards identify the key points for many families in their patterns of care. These are the points at which there are sometimes difficulties achieving consistent best practice, leading to children and families experiencing confusing messages about what might happen next. The standards set down the level and quality of care that every family should expect during their journey.

The six standards are:

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

- Assist in transition of young people with palliative care needs to adult services
- Promote self-confidence, resilience and resources to enable children and young people to cope and live well with their condition
- Promote opportunities for learning and development at nursery, school and moving onto college or finding work and support referral for home tuition when appropriate.
- Offer emotional/ bereavement support and interventions for the family and arranging multi-agency commemorating and reflection sessions when a child known to the team dies
- Offer end of life support in coordination with other services, including referral for Continuing Care end of life care as appropriate (see CCNS Continuing Care Policy for further details)

1.4 Philosophy and model of care

The Children's Community Nursing Service Statement of Purpose states that *"The Diana Team provides clinical intervention, practical help and emotional support to infants, children and young people, aged 0 to 19 years, with a life-limiting condition and their families/carers, including management of palliative care needs and end of life care"*

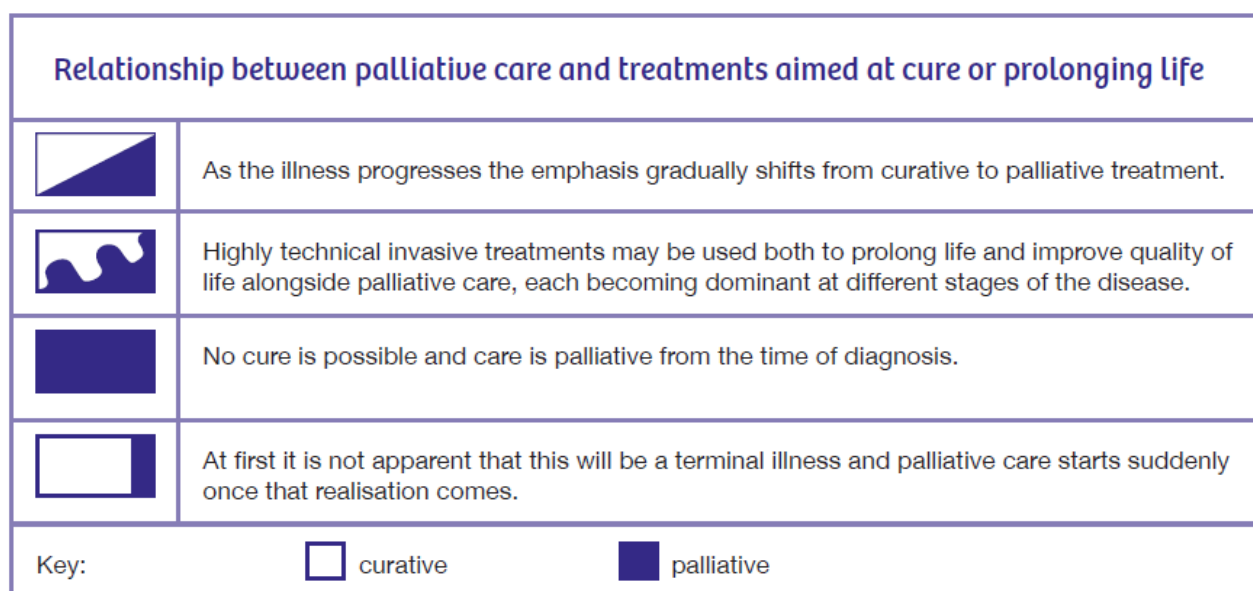
The Diana Team subscribes to the Together for Short Lives philosophy and model of Children's Palliative Care. Together for Short Lives (TfSL) is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. TfSL supports families, professionals and services, including children's hospices. NICE Guideline NG61 "End of life care for infants, children and young people with life-limiting conditions: planning and management. Full guideline. Methods, evidence and recommendations", published in December 2016 also promotes the TfSL definition and philosophy of Children's Palliative Care. The core principles of the TfSL approach are additionally coherent with the East London NHS Foundation Trust values *"We care, We respect and We are Inclusive"*.

The following is adapted from the Together for Short Lives document "A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions: Third edition" (TfSL, 2013):

Children's palliative care 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 or young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

The Together for Short Lives philosophy has always been to promote the best possible quality of life and care for every child with a life-limiting or life-threatening condition and their family. Giving families real choice has been key to this approach; a choice of place of care, a choice of place of death, a choice of emotional and bereavement support; and putting the child and family at the centre of decision making to produce a plan for care that is right for them.

Children's palliative care is an approach to care which can be used exclusively or in conjunction with curative treatments. The diagram below explores the relationships between palliative care and those treatments aimed at prolonging life.



1.5 Local Need

In a large scale epidemiological study, Fraser, et al (2011 and 2016) found that the prevalence of Life-limiting conditions in children and young people has been increasing throughout the last ten years in England and Scotland. This has been reflected in a 10 fold increase in the number of referrals to the Diana Team between 2006 and 2016. Fraser, et al (2001 and 2016) also found that the prevalence of life-limiting conditions in infants, children and young people was highest in the under 1 year-old age group and decreased with age. This is reflected in Diana Team referrals, with highest rates of referrals for infants, pre-school and primary school age children and a lower rate of referrals for teenagers.

Fraser, et al (2011) found the highest prevalence of children with life-limiting conditions in England to be in areas of highest deprivation and that prevalence was also significantly higher in Black and Ethnic Minority populations. Fraser, et al (2011) concluded that *“results clearly identify an escalating need for specialist paediatric palliative care services. When planning services for these increasing needs, the excess prevalence in ethnic minority groups especially in deprived areas needs to be considered.”* This conclusion supports the need for the Diana Team as a specialist palliative care service for infants, children and young people with life-limiting conditions in Newham, a London Borough which has a young, ethnically and culturally diverse population and, until 2015, was ranked as the second most deprived area in the UK.

Based on hospital admissions data from across England, Fraser, et al (2011) identified that in 2009/10 there were 356 infants, children and young people with a diagnosis of a life-limiting condition who were recorded as Newham residents.

Number of Cases of children with Life-limiting Conditions 2009/10

Local Authority	Number of cases	Population	Prevalence per 10000 population
Newham	356	82083	43.4

Data from: Fraser, L., Miller, M., Aldridge, J., McKinney, A. & Parslow, R. (2011) "Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity." Final Report for Children's Hospice UK. Leeds University.

Given the trend for increasing prevalence with infants and children living longer with these conditions, it is likely that there are now more than this number of children under the age of 19 years living in Newham who could be referred to the Diana Team if diagnosing clinicians made referrals to our service for all children with life-limiting conditions.

Between 2013 and 2016, between 45 and 55 infants, children and young people living with a life-limiting condition have been actively accessing the Diana Team service at any one time.

The Diana Team also supports bereaved families after the death of a child with a life-limiting condition. Numbers of deaths per year fluctuates, with an average of 8 (and a range between 5 and 14) deaths in each calendar year between 2006 and 2016.

In addition to providing immediate after-death care of the body and support for the family, the service also provides longer term psychological therapies for bereaved families members. On average, 8 bereaved families are actively accessing this longer term bereavement support at any one time.

1.6 Introduction to the team

Clinical setting: Community; appointments may take place in the child's home, school, children's centre or in a children's hospice or hospital if the child has been admitted.

Service context: Children's Community Palliative Care, within the Children's Community Nursing Service (CCNS)

Catchment area: Infant/child/young-person is resident within the London Borough of Newham

Age range: 0 – 19th birthday

Referrals are also encouraged to begin planning care and support for family during pregnancy when there is an antenatal diagnosis of a life-limiting condition

Diagnosis/Prognosis: Family have been informed that the infant/child/young person is not expected to live in to adulthood

1.7 Team composition

Multidisciplinary Team Composition

Band 7 Senior Paediatric Community Nurse (Diana Team Lead)
Band 5 Health Play Specialist
Band 6 Nurses working across Community Children's nursing service
Band 8 Lead Clinical Psychologist
Band 7 Specialist Clinical Psychologist

Additionally, the team offers placements for final year trainee clinical psychologists from the North Thames region Doctorate in Clinical Psychology Training Courses. When there is a trainee on placement with the team, they are employed by Camden and Islington NHS Trust at the Band 6 AfC level and have an honorary contract with East London Foundation Trust for a six month placement working 0.5 wte with the Diana Team.

Management structure

The Team Lead/Senior Paediatric Community Nurse is line managed by the Children's Community Matron.

The Team Lead/Senior Paediatric Community Nurse is responsible for line management of the Junior Paediatric Community Nurse(s).

The Lead Clinical Psychologist is line managed by the General Manager & Lead Nurse for Children and Young People's Services.

The Lead Clinical Psychologist is responsible for the line management and clinical supervision of the Specialist Clinical Psychologist and the Health Play Specialist.

When there is a Trainee Clinical Psychologist on placement with the team, their line management and clinical supervision is provided by either or both the Lead Clinical Psychologist and the Specialist Clinical Psychologist.

1.8 Team Roles and responsibilities

Diana Nurses Roles and Responsibilities

The Senior Paediatric Community Nurse is responsible for caseload management and line management of the Junior Paediatric Community Nurse and also holds a caseload themselves. Working in collaboration with the family and other healthcare teams involved in the team around the child and in accordance with the principles of children's palliative care and NICE guideline NG61 "*End of life care for infants, children and young people with life-limiting conditions: planning and management*", Diana Community Children's Nurses provide community nursing assessments and interventions, develop shared care plans with the family, coordinate provision of community equipment needs and provide advice and reassurance for family and other carers.

For children with complex symptom management needs and for children entering the end of life phase of their life-limiting condition, the Diana Nurses work in partnership with the Great Ormond Street Palliative Care Team Paediatricians and Clinical Nurse Specialists to provide palliative care, including joint visits to the family, and frequent telephone and email liaison to ensure coordination of care.

For children whose families have agreed to referral to Richard House Children's Hospice, the Diana Nurses work in partnership with Richard House Nurses to support transition from home or hospital to the hospice for short breaks, step down and end of life care and to coordinate around discharge from the hospice.

Diana Nurses have Specialist Palliative Care skills in:

- Communication and information provision for families about life-limiting conditions and possible medical interventions
- Participating in the development of and supporting implementation and review of Symptom Management Plans, Emergency Care Plans and Advance Care Plans, in partnership with families, paediatricians and the wider multidisciplinary team around the child,.
- Parallel Planning with families for Living with a Life-Limiting Condition and End of Life Care
- Recognising symptoms of reversible conditions that can be treated
- Assessment of deterioration and recognition that a child may be entering the end of life phase of their condition
- Supporting families to make decisions about preferred place of care and death
- Planning, coordinating and delivering End of Life Care
- Management of Syringe Drivers and use of controlled drugs for management of symptoms
- Supporting distressed families around child death and bereavement
- Managing care of the body after the death of the child
- Supporting family with processes and procedures around death (verification of death, child death overview panel processes, certification of death, registering the death, transporting the body, planning funerals)

Diana Psychologists Roles and Responsibilities

The Clinical Psychologists work across the whole caseload, as required, and lead on bereavement support for the family when a child dies. A psychology service is offered to all families referred to the Diana Service and can be accessed by any family member/carers (i.e. the child/young person, siblings, parent(s), extended family members and other involved in the care of the child with a life-limiting/threatening condition). Psychology sessions can be individual or involve several family members together and can be held in the family home or other locations in the community. Families can access this service at any point on their journey from the point of referral to the team through to end of life care and for post-bereavement support with frequency of contacts ranging

from weekly to one-off sessions, depending on the needs of the family. Psychology sessions are offered by either the Clinical Psychologists or, when available, the final-year Trainee Clinical Psychologist (on placement with the service three days per week for six months, under the supervision of the qualified psychologists in the service). Consultation and joint working is offered to all professionals involved in the care of the referred child. More details are given in the Diana Children's Community Child and Family Clinical Psychology Service Framework (January 2017) in the appendices of this Operational Policy.

Diana Health Play Specialist Roles and Responsibilities

The Health Play Specialist works with all children with an identified need for specialist play interventions. The aim of the Diana Team Therapeutic Play Service is to offer support to children and their families through therapeutic play session within the home environment. Pre-school age children and children who are unable to attend school for health reasons are offered a 3 month block of play sessions to parent /carer in playing with their child in the context of their complex health care needs. This may include baby message training sessions for family, with consent from the child's paediatrician (see baby massage policy document for further details). Children who have a continuing care package of 10 hours or more funded by health commissioners will be offered training for parents and carers around how to deliver play. School age children are offered an assessment of their play needs at the point of referral to the Diana Team. A block of targeted play sessions are offered for children who attend school when the need for specialist intervention (for example, preparation for medical procedures, understanding the body/condition, memory making work) is identified at the initial referral assessment or if the need arises later in the child's care pathway.

1.9 Hours of operation and service provision

Opening hours: Monday-Friday, 9am – 5pm

Home visiting times: Monday-Friday, 9am – 5pm

When a child is in the end-of-life phase of their condition and the family's preference is for care at home, nursing or health care support worker support may be provided within the home depending on the child's care needs and agreement for additional funding for agency staffing to provide end-of-life care at home.

When a child in the end-of-life phase of their condition with a preference for care at home requires administration of controlled drugs to manage their symptoms, CCNS generates an on-call rota of out-of-hours home visit support from CCNS nursing staff to deliver and check drug administration in accordance with community policies and procedures for management of controlled drugs and syringe drivers in the home. As need for out-of-hours provision of end-of-life care fluctuates across the calendar year, this rota is generated in response to need and is not in place throughout the year (with need fluctuating between several months in the year with no children requiring this support at home to months with multiple children facing end-of-life and needing access to controlled drugs at home simultaneously).

Out-of-hours contacts for service users:

Children with symptom management needs (e.g. pain, nausea, respiratory distress) will also be referred to the Great Ormond Street Palliative Care team who provide 24/7 telephone support.

CCNS has an answerphone service for families to leave messages out of hours which will be picked up when the office is open again.

Families of children receiving out-of-hours end-of-life care at home can contact the CCNS out-of-hours manager on-call via the Page One on-call pager system. Telephone numbers are given section 5.4 of the CCNS Operational Policy.

Contacting the team in and out of hours:

Newham Diana Children's Community Team
The Boleyn Medical Centre
Third Floor
152 Barking Road
East Ham
London E6 3BD

Telephone Numbers: 020 8475 8580

Fax Number: 020 8475 8591

1.10 Team meetings

- Diana Team members participate in the weekly CCNS service/business meeting
- Diana Team members participate in fortnightly multidisciplinary review of the whole caseload on alternate Tuesday mornings.
- The Lead Nurse and Lead Psychologist participate in monthly CCNS's Senior Health Care Professionals Meeting

1.11 Supervision

Management Supervision:

All team members take part in monthly management supervision with their line manager.

All team members have a management supervision contract with their line manager. This is stored on the shared drive.

In accordance with ELFT policy, signed records of management supervision are uploaded to staff files on the shared drive (only accessible to managers) and shared via email for storage on supervisee's personal folder.

The date of management supervision is recorded on the CCNS SAT excel spreadsheet on the shared drive to enable senior management to monitor whether monthly supervision is taking place for all team members.

Clinical/Professional Supervision:

All team members have access to peer support and psychology case consultation in monthly "Psychology case consultation sessions for CCNS", facilitated by one of the clinical psychologists in the service. Please see "Psychological Consultancy for Newham CCNS - Internal Agreement" document for further details.

All team members have access to debriefing/peer support when a child known to the service dies in the form of “Co-memorating Meetings” convened and facilitated by a psychologist in team. Please see “Co-memorating Meetings” document for details of the format for these meetings.

All team members attend Child Protection Supervision, facilitated by an ELFT safeguarding advisor on a 3 monthly basis.

Band 5/6 Nurse/s have monthly clinical supervision with the senior nurse who is also their line manager.

Band 7 Nurse has monthly clinical supervision with the Community Children’s Matron who is also their line manager.

Health Play Specialist has monthly clinical supervision with the lead clinical psychologist.

Health Play Specialist participates in play forum meetings for peer supervision and support from Health Play Specialists employed in other services in the region.

Band 7 clinical psychologist has a minimum of 1 hour supervision from a clinical psychologist per 10 days of work (minimum 1 hour every 4 weeks for 0.5 wte post). Clinical supervision is provided by the Band 8 clinical psychologist in the team. This is the minimum requirement to maintain professional registration at this grade with the health and care professions council (HCPC)

Band 8 clinical psychologist has a minimum of 1.5 hours supervision from a clinical psychologist per month worked. This is the minimum requirement to maintain professional registration at this grade with the health and care professions council (HCPC) as a practitioner psychologist. The current post holder is also a family therapist and is required to have 1.5 hours of systemic supervision from a systemic supervisor per month worked to maintain professional registration with the UK Council for Psychotherapy (UKCP) as a systemic psychotherapist. Hence, to maintain registration for both professions, the current post holder has 1.5 hours of external supervision per month from a supervisor who is dual qualified as a clinical psychologist and systemic supervisor, and also a recognised expert in children’s palliative care.

Trainee clinical psychologist has a minimum of 1.5 hours of clinical supervision from either the Band 8 or Band 7 clinical psychologist in the team. This is a minimum requirement for DClinPsy training course placements.

Psychologists in the team can access peer support from clinical psychologists working in end of life care in East London via “PELOPaC” meetings held every two months at Barts Hospital.
P.E.L.O.Pa.C. = Psychologists in East London in Oncology and Palliative Care

2. Clinical Processes

2.1 Referral

As detailed in the CCNS Operational Policy, the Community Children's Nursing Service has a generic referral form which is for the following parts of the service:

- Diana Palliative Care (play, nursing and psychology)
- Community Children's Nursing Team
- Continuing Care Team
- Epilepsy Nursing Service

Referrals are accepted by fax (0208 475 8591) or secure email elt-tr.CCNSNewham@nhs.net

Referrals can also be discussed verbally via 0208 475 8580 but must be followed up with a written referral. Only written referrals on CCNS referral form will be accepted and triaged.

Referrals will be triaged within 1 working day and for referrals allocated to the Diana Team, initial contact is made to the family/referrer within 2 working days.

Referrals from other agencies

Referrals are accepted from any agency that has documentation confirming the family have been informed by a paediatrician of either a diagnosis of a childhood life-limiting condition or prognosis that the child is not expected to survive in to adulthood.

Referrals are encouraged from diagnosing services, including antenatal screening services, from the point of recognition of life-limiting condition / shortened life to enable early access to support and planning. The infant/child/young person may not have an active nursing intervention need at the time of referral but advanced care planning and relationship building can begin with the nursing team and play and psychology interventions can be provided to enhance quality of life, coping and building resilience in anticipation of deteriorating health in the future.

Referring agencies are asked to complete the Children's Community Nursing Service referral form.

All referrals received by the Children's Community Nursing are screened/triaged to determine whether the infant/child/young person might meet criteria for the Diana Service. If the referrer has not explicitly requested the Diana Team on the form but the child appears to have a shortened life expectancy, the referring agency is contacted to discuss prognosis and whether family have been informed of prognosis before the family are contacted by the Diana Team to be offered a palliative care service (this is to ensure that families have been appropriately informed of the nature of the child's condition by the diagnosing clinician in advance of being contacted by the Diana Team).

A member of the Diana Team contacts families within 2 working days once all the minimum referral information is received to accept a referral.

Self-referrals

Self-referrals for bereavement support for family members and carers are also accepted for bereaved families who previously accessed the service during the child's life.

As there referring professionals are often uncertain about terminology of "children's palliative care", the Diana Team has developed the "Eligibility Criteria and Referral Guidelines for Newham Diana Children's Community Team" document, which can be found in the appendices of this document.

Inclusion and exclusion criteria:

We are able to offer support for the families (the child, parents, carers and siblings) of infants, children and young people who meet the following criteria:

- The infant, child or young person has a life limiting or life threatening condition in accordance with the Together for Short Lives definitions of 'life-limiting/shortening' and 'life-threatening' conditions (see below).
- The infant, child or young person is mainly cared for at home or discharge is being planned.
- The infant, child or young person is aged between 0 – 19 (this includes work with parent/s when a palliative care diagnosis is made during pregnancy)
- The infant/child/young person lives in the borough of Newham.

The following is adapted from the Together for Short Lives' document "A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions: Third edition"

Definitions of life-limiting/shortening and life-threatening conditions

Life-limiting/life-shortening conditions

Life-limiting /life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as cancers with high risk of treatment failure. Children in long-term remission or following successful curative treatment are not included.

Categories of life-limiting/shortening and life-threatening conditions

Together for Short Lives recognises that four broad groups of life-threatening and life-limiting conditions may be delineated. 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 as well as the needs of, and impact on the child and family need to be taken into account. These four categories outline the four types of illness trajectory which will require children's palliative care provision. The categorisation is important for the purpose of planning and needs assessment. The categories demonstrate the range of conditions children have and show how children may benefit from palliative care, or elements of palliative care during their journey. The need for palliative care should always be assessed on an individual basis.

Category 1	<p>Life-threatening conditions for which curative treatment may be feasible but can fail.</p> <p>Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
Category 2	<p>Conditions where premature death is inevitable.</p> <p>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: Leukodystrophy, Duchenne Muscular Dystrophy</i></p>
Category 3	<p>Progressive conditions without curative treatment options.</p> <p>Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses.</i></p>
Category 4	<p>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p><i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode.</i></p>

2.2 Nursing Allocation, Assessment, Care Planning and Intervention (All adapted from NICE NG61 Recommendations):

Allocation of “named nurse”

Named-nurse allocation is planned to avoid frequent changes to the healthcare professionals caring for the child and family.

Assessment

Initial assessment and review includes discussion with children and young people and their parents or carers about how they would like to discuss the life-limiting condition. This may include asking parents or carers what they think their child should be told about their condition and discussion with the child and their parents/carers about their right to confidentiality and how information about their condition will be shared.

Initial assessment and review includes sensitive, honest and realist discussion with the family about the condition, treatment and uncertainties about the future.

Initial assessment involves holistic assessment of the child and family’s care needs, including exploration of needs relating to:

- material support, for example housing or adaptations to their home, or equipment for home drug infusions
- practical support, such as access to respite care
- technical support, such as training and help with administering drug infusions at home
- education support, for example from hospital school services
- financial support.

Initial assessment and review also includes discussion of social, practical, psychological and spiritual support needs of parents, carers, siblings, other family members (for example grandparents) and people important to the child or young person (for example friends, boyfriends or girlfriends).

Initial assessment, care planning and review involve asking the child/young person with life-limiting conditions and their parents/carers if they want to discuss the beliefs and values (for example religious, spiritual or cultural) that are important to them, and how these influence their care. These conversations are carried out with sensitivity and awareness that some children and young people and their parents or carers find discussions about their beliefs and values difficult or upsetting while others find these discussions reassuring and helpful.

Care Planning

“Parallel planning” is a key principle of care planning in children’s palliative care. This involves planning to live as fulfilling a life as possible alongside planning for managing deterioration of health and end of life care. When developing plans for the care of the children with a life-limiting condition, it is important to take in to account and discuss with the family and professional network the possible unpredictability in the course of the condition.

Parallel planning includes providing children and young people and their parents and carers with the information they need on:

- their role and participation in Advance Care Planning (discussed in more detail below)
- the membership of their multidisciplinary team and the responsibilities of each professional
- the care options available to them, including specific treatments and their preferred place of care and place of death (discussed in more detail below)
- any relevant resources or support available to them.

Advance Care Planning involves developing and recording an Advance Care Plan at an appropriate time for the current and future care of each child or young person with a life-limiting condition. Advanced Care Plans are developed and reviewed regularly with relevant members of the multidisciplinary team and in discussion with the child or young person and their parents or carers.

The Advance Care Plan should include:

- demographic information about the child or young person and their family
- up-to-date contact information for:
 - the child or young person's parents or carers and
 - the key professionals involved in care
- a statement about who has responsibility for giving consent
- a summary of the life-limiting condition
- an agreed approach to communicating with and providing information to the child or young person and their parents or carers
- an outline of the child or young person's life ambitions and wishes, for example on:
 - family and other relationships
 - social activities and participation
 - education
- how to incorporate their religious, spiritual, and cultural beliefs and values into their care
- a record of significant discussions with the child or young person and their parents or carers
- agreed treatment plans and objectives
- education plans, if relevant
- a record of any discussions and decisions that have taken place on:
 - preferred place of care and place of death

- organ and tissue donation (in accordance with NICE guidelines NG61 and CG135)
- management of life-threatening events, including plans for resuscitation or life support
- specific wishes, for example on funeral arrangements and care of the body
- a distribution list for the Advance Care Plan.

Advance Care Planning begins with parents during the pregnancy if there is an antenatal diagnosis of a life-limiting condition. These discussions may need to involve some or all of the following:

- obstetricians
- midwives
- neonatologists
- specialists in the life-limiting condition
- a member of Great Ormond Street specialist paediatric palliative care team
- Richard House Children's Hospice

Care Planning discussions involve explaining to children/young people and their parents or carers that Advance Care Planning should:

- help them be involved in planning their care and give them time to think about their views carefully
- help them to understand the life-limiting condition and its management
- help to prepare for possible future difficulties or complications
- support continuity of care, for example if there are changes in the professionals involved or in the care setting (such as a hospital admission or discharge).

Developing an Advance Care Plan involves discussing with the child/young person and their parents/carers:

- the nature of the life-limiting condition, its likely consequences and its prognosis
- the expected benefits and possible harms of the management options.

Advance Care Plans are shared with the child/young person and their parents/carers (as appropriate), and, with consent to share, other professionals and services involved in the individual child or young person's care, which may include:

- GPs
- hospital consultants
- hospices
- respite centres
- nursing services (community or specialist)
- school and other education services
- ambulance services.

Advance Care Plans are updated when needed, for example if:

- new professionals become involved
- the care setting changes (for example hospital admission or discharge)
- the child or young person and their parents or carers move home.

Changes to the plan are discussed with the child/young person (if appropriate) and their parents/carers.

Diana Nurses explain to the family and other professionals involved in the child's care that all children and young people with life-limiting conditions should have an Advance Care Plan in their medical record, and that this should not be confused with a do-not-attempt-resuscitation order.

Advanced Care Planning discussions around organ and tissue donation (including donor identification and consent, and when and how to discuss the topic) are carried out in accordance with NICE recommendations and guidelines (NG61 and CG135).

Advanced Care Planning conversations relating to cultural, spirituality and religious practices are carried out with awareness that children and young people may feel differently to their parents, carers, or healthcare professionals about how their beliefs and values should influence their care. If there is disagreement, attempts are made to make a mutually acceptable care plan. If necessary, the chaplaincy service or another facilitator may be invited to support care planning in this situation.

Care of the child who is approaching the end of life

In the event of a life-threatening episode, resuscitation is attempted for children and young people with life-limiting conditions, unless there is a 'do not attempt resuscitation' order in place.

When a child or young person is approaching the end of life, discussions are held with them (where possible and appropriate) and their parents/carers about their specific support needs.

End of life care and support needs are reviewed regularly. These conversations are conducted with compassion, sensitivity and the awareness that discussing end of life care and the Advance Care Plan can be distressing for children and young people who are approaching the end of life and their parents/carers, and they may be reluctant to think about end of life care, have difficulties discussing end of life care with the professionals or with one another and have differences of opinion about the care plan.

When a child or young person is approaching the end of life, referral is made to the Great Ormond Street specialist paediatric palliative care team for joint work, consultation and access for 24/7 telephone support for the family and community professionals. If a referral has already been made to and accepted by the Great Ormond Street specialist palliative care team, then information is shared with them that the child's condition has deteriorated and they may be approaching end of life.

When making or reviewing the Advance Care Plan for a child or young person approaching the end of life, discussions are held with the parents/carers about the care and support they can expect when the child or young person dies.

Children and their parents/carers are asked whether they want and are able to talk about dying and whether they would like support in talking to each other about this from any member of the multidisciplinary team.

When thinking about the possibility of treatment withdrawal for a child or young person who is approaching the end of life, Diana Team Nurses work in collaboration with the Great Ormond Street Palliative Care Consultants and take into account the beliefs, values and wishes of the child and parents/carers.

When a child or young person is approaching the end of life, discussions are held with their parents/carers about what would help them, for example planning care to facilitate important rituals or providing support for preserving memories (e.g. with photographs, hair locks or hand prints), support for planning for funeral arrangements and for culturally appropriate care of the child's body after death.

When a child or young person is approaching the end of life, or as part of the Advanced Care Planning process, discussions are held with children with life-limiting conditions and their parents/carers about where they would prefer to be cared for and where they would prefer to die (often referred to as "preferred place of care and place of death").

NICE guidelines NG61 state, *“If possible, services should ensure that children and young people can be cared for at their preferred place of care and die at their preferred place of death.”* This recommendation is addressed in the following ways:

When discussing possible places of care or places of death, children and their parents/carers are provided with information about:

- the various care settings (for example home, hospice or hospital care)
- the care and support available in each setting
- practical and safety issues.

For a child to be cared for at home at end of life, an assessment is made of daytime and night-time practical and nursing care needs. Funding may need to be sought and agreed for nursing care outside of routine provision (e.g. for night care for a child who does not already have funding agreed for night care). Necessary practical and nursing care must be in place before a child who is hospital/hospice is transferred to the home.

If a child and their parents/carers would prefer to receive end of life care in a hospice, the hospice is contacted to determine whether they have a bed and nursing staff available to provide the hospice care. Advanced care planning review and transfer to the hospice is then developed in collaboration with the hospice and the family.

Preferred place of care and place of death are agreed with children and their parents/carers, taking into account:

- their wishes, which are personal and individual
- their religious, spiritual and cultural values
- the views of relevant and experienced healthcare professionals
- safety and practicality.

The child and parents/carers are informed that although every effort will be made to meet their wishes, the place of care or place of death may change, for example for clinical reasons, if the child dies suddenly or due to problems with service provision. The child and parents/carers are also informed that attempts will be made to change arrangements for place of care and place of death if the child or young person and their parents or carers change their minds.

If the child and their parents/carers prefer care at home, practical considerations are discussed with them, such as the possible need for:

- home adaptations
- changes to living arrangements
- equipment and support.

If it is suspected that a child may die soon and they are not in their preferred place of death, consideration is given to whether rapid transfer might be possible and in their best interest. This is discussed with them and their parents/carers.

Planning rapid transfer of a child or young person to their intended place of death involves consideration that the course of their condition may be unpredictable, and that they may die sooner or later than expected. Any uncertainties about the course of the condition and how this could affect care are discussed with the child and their parents/carers.

Rapid transfer processes may also be used to allow a child to be in their preferred place of death when withdrawing life-sustaining treatments, such as ventilation.

When rapid transfer is being planned to the preferred place of death, the Advance Care Plan is reviewed, and if necessary updated, in discussion with the child and their parents/carers and with the healthcare professionals who will be involved following the transfer. The updated Advance

Care Plan would include a record of any intended changes to care and when they should happen and care plans that cover:

- the final hours or days of life
- what will happen if the child or young person lives longer than expected
- support for the family after the child or young person dies
- care of the child's or young person's body after death
- the professionals who will be involved and their responsibilities
- the professionals who will help with the practical and administrative arrangements after the death.

Managing distressing symptoms

Referral is made to the Great Ormond Street specialist paediatric palliative care team for joint work and consultation if a child or young person has unresolved distressing symptoms as they approach the end of life.

Assessment and management of pain, agitation, respiratory distress and seizures is carried out in collaboration with the multiagency network supporting the child and in accordance with NICE guideline NG61 recommendations (see Appendix). Other common distressing symptoms at the end of life which the Diana Team Nurses assess and provide support around include nausea, vomiting, loose-stools/constipation and skin care/pressure areas.

The Diana Team is able to support parenteral drug administration in the home (for example continuous subcutaneous opioid or anticonvulsant infusions), as recommended in NICE Guidelines NG61. The Community Controlled Drugs Policy is currently in development and will provide further details of procedures relating to parenteral drug administration and management of controlled drugs in the community.

Managing hydration when a child is approaching the end of life

When a child with a life-limiting condition is approaching the end of life or is dying, discussions are held with them (if appropriate) and their parents/carers about how to manage their fluid needs.

If a child is dying, they are encouraged and supported to drink if they want to and are able.

If a child is dying, lip and mouth care is continued.

If a child is dying and cannot drink, discussions are held with them (as appropriate) and their parents/carers about whether starting or continuing enteral tube or intravenous fluids is in their best interests. Consideration is given as to whether enteral tube and intravenous fluids might have a significant effect on care, may be a burden for the child, and may mean the place of care and place of death need to be changed.

If a child who is dying is given enteral or intravenous fluids, this decision is reviewed regularly to make sure this intervention continues to be in their best interests.

Managing nutrition when a young person is approaching the end of life

When a child is approaching the end of life or is dying, discussions are held with them (if appropriate) and their parents/carers about how to manage their nutritional needs.

If a child with a life-limiting condition is dying, they are encouraged and supported to eat if they want to and are able.

If a child is dying and they are receiving enteral tube feeding or intravenous nutrition, discussions are held with them (as appropriate) and their parents/carers about whether continuing this is in their best interest. The decision is also reviewed regularly.

Recognising that a child or young person is likely to die within hours or days

NICE guidelines NG61 state,

“For children and young people with life-limiting conditions who are approaching the end of life:

- be aware that there is often uncertainty around when they are likely to die*
- be aware that there are various symptoms and signs (individually or in combination) that indicate they are likely to die within hours or days*
- take into account the wider clinical context.”*

Assessment to determine whether a child is likely to die within hours or days involves monitoring (non-invasively as far as possible) some or all of the following signs which are common in the last hours or days of life:

- a change of breathing pattern (for example noisy, laboured or irregular breathing)
- impaired peripheral perfusion (which can be indicated by a pale or grey appearance, or a prolonged capillary refill time), including temperature instability
- loss of interest in or ability to tolerate drinks or food
- a marked and unexplained fall in urine output
- an altered level of awareness (for example reduced consciousness, alertness or responsiveness, excessive sleeping, or confusion)
- intractable seizures that keep occurring even with optimal management
- new onset of profound weakness
- increasing pain and need for analgesia.

Assessing symptoms and signs to decide whether a child or young person is likely to die within hours or days, also involves taking account of the wider clinical context, including:

- their normal clinical baseline
- past clinical events (such as previous episodes of temporary deterioration)
- the overall progression of their condition.

If the child or their parents/carers feel that they are likely to die within hours or days, their concerns are taken seriously and discussed with them.

When a child is likely to die within hours or days, they and their parents/carers are provided with support through listening to any fears or anxieties they have and showing empathy and compassion.

When a child is likely to die within hours or days they and their parents are provided with opportunities to talk with a member/s of the Diana Team or another service if they prefer. Diana Team practitioners offer these opportunities in the awareness that the child or their parents/carers may not express their feelings openly, and may have intense and varied feelings such as fear, hopelessness or anger or become more accepting of the inevitability of death.

If a child is likely to die within hours or days, it is explained to them and their parents/carers:

- why this is thought to be likely, and any uncertainties
- what clinical changes can be expected
- whether there is a clinical opinion that the treatment plan should be changed.

When a child becomes seriously ill and is likely to die within hours or days, care is provided as specified in their Advance Care Plan (which can be reviewed if needed with family and professionals).

When a child is approaching the end of life, discussions are held with them and their parents/carers and with relevant healthcare professionals about

- any available invasive treatments that might be in their best interest
- any interventions they are currently receiving that may no longer be in their best interest.

If a treatment for a child who is dying is to be withdrawn, it is explained to them and to their parents/carers that it is often difficult to tell if or how this may affect them, or when they will die.

When a child is likely to die within hours or days, efforts are made to ensure that they can have private time with their parents or carers.

When a child is likely to die within hours or days, all members of the multi-agency network supporting the family are informed that the child is believed to be approaching the end of life to enable coordinated and compassionate support for the family. Additionally, if the child is being cared for at home, the Child Death Overview Panel are informed that they may receive notification of an expected death in the community and there are not thought to be safeguarding concerns that would require police investigation or a rapid response meeting if the child dies out of hours given that they are at the end of life.

Care and support for the family in relation to the death of a child or young person

The child and or their parents/carers are given opportunities to discuss practical arrangements that will be needed after the death if they wish to hold these conversations before the death. At this time, or after the death for families who did not wish to discuss practical arrangements earlier, the family are provided this information about:

- the care of the body
- relevant legal considerations
- the involvement of the child death overview panel
- the involvement of the coroner
- registration of the death
- funeral arrangements
- post-mortem examination (if this is to be performed).

When a child is approaching the end of life, family members are offered the opportunity to discuss the bereavement support available after the death of the child. This includes the offer of support from the Diana Team Psychologists and options to access local community and charitable bereavement services and helplines which are available at that time.

Bereavement support is offered by the Psychologists and Family Therapists in the Diana Team for all members of the family both before and after the death of a child or young person.

Planning bereavement support for the whole family/carers involves talking to them about the support that is available and exploring with them what they would find helpful and acceptable

Once a plan has been agreed with the family, the multidisciplinary team are informed about the support plan to co-ordinate this care across agencies.

Making a bereavement support plan with the family involves discussion of the possible options, such as opportunities to talk to the professionals caring for the child or young person, to:

- discuss memories and events
- answer any concerns or questions they may have
- home visits from the healthcare professionals caring for the child or young person
- bereavement support groups.

Following a death in the community of a child accessing the Diana Team, a death notification form (“Form A”) is completed and submitted by a member of the Diana Team. If the child died in hospital/hospice, this form is completed and submitted by the service caring for them at the time of their death. See Child Death Notification Policy for further details.

Following the death in any setting of a child accessing the Diana Team, a Child Death Overview Panel “Form B” is completed and submitted by the Diana Team.

Following a death of a child accessing the Diana Team, a Datix incident report is submitted for both expected and unexpected deaths. See section 15.4 of the CCNS Operational Policy for further details about management of incidents.

Following the death of a child in any setting, a member of the multidisciplinary team, in a timely manner, attempts to make contact with all members of the service and practitioners for all relevant organisations and other important people in the network to ensure that everyone in the network around the family who needs to be informed has received the information that the child has died. Professionals are also informed that they will be invited to a multi-agency “co-memorating meeting”, which provides a space for peer support, if they would find this supportive and useful.

Following the death of a child, relevant documents and databases are updated to avoid, for example, clinical appointments being offered or supplies being delivered by mistake.

2.3 Medication arrangements

The Diana Team and CCNS are currently working with Community Pharmacy services and the Sickle Cell and Thalassaemia Service to review policies relating to use of controlled drugs in the community and how this will be implemented in the Diana Team.

2.4 Discharge procedures

Discharge from hospital/hospice to home/community procedures

See sections 8.6 and 8.6.1. of the CCNS Operational Policy.

Discharge from the service / case closure procedures

Families who move out of Newham are discharged from the service once referrals are made to the children’s community nursing services and other key services that they will need to access in the area they move to. If the family inform the Diana Team that they will be moving in advance of the move, where possible, handover meetings and joint visits with services in the area they are moving to will be arranged.

If the child’s prognosis changes and they are no longer thought to be life-limited, then a number of sessions will be agreed to either end or transition their care to another service.

As the children and young people who access the Diana Team have palliative care needs and may not survive into adulthood, parallel planning with families takes place to plan for both transition to adulthood and the possibility of end-of-life care and death before the young person reaches 19 years of age. Planning for transition of nursing and psychology care to adult services at 19 years of age begins when a young person is 16 years of age and involves planning with the family and multi-agency team around the family. Transition pathways will differ depending on the young person's care needs and which adult services provide services for those needs (for example, a majority of young people accessing the Diana Team have learning disabilities and may meet criteria for adult community learning disability services, but this would not apply to young people who are cognitively able/high functioning).

As a palliative care service, the Diana Team is often involved in care of the body after an expected death and provides support to the family around after death care and bereavement support psychology sessions. As the RiO patient record system automatically discharges the deceased from the service and does not allow activity to be recorded in relation to a person who has died, contact with the family after the death of the child is recorded against RiO referrals and in the RiO records of surviving family members.

See section 8.1 of the CCNS policy for details of documentation completed when a child is discharged from the service.

2.5 Service-user and carers involvement in care planning

Parents/carers (and children who have the cognitive capacity to participate), are involved in the development of all nursing care planning for emergency care plans, symptom management plans and advanced care plans (e.g. making decisions about "ceilings of care" in end of life/life-threatening episodes). Copies of formal care plans are shared with families.

Family members accessing the psychology service are invited to agree therapy goals and review progress and experience of therapeutic interventions through collaborative conversations with the psychologist/s.

Parents/carers and children accessing the play service are invited to participate in co-creating a play-plan with the health play specialist. Copies of formal care plans are shared with families.

2.6 Team documentation

- Great Ormond Street Emergency Care Plan document (soon to be replaced with the Children and Young Person's Advanced Care Plan)
- Great Ormond Street Symptom Management Plan document (soon to be replaced with the Children and Young Person's Advanced Care Plan)
- Children's and Young Person's Advanced Care Plan (pending local clinical governance sign-off and pan-London agreement for cross-London use of the form on the CYPACP website <http://cypacp.nhs.uk/documentdownloads/careplan/generic>)

See CCNS Operational Policy for full list of other nursing documentation.

2.7 Liaison with other teams/agencies

Children with life-limiting conditions and their families often have multiple complex health, care, educational and social needs. They are often under the care of multiple specialist paediatric consultants (e.g. cardiac, respiratory, orthopaedic, metabolic, oncology, neuromuscular, renal, transplant, palliative, etc) and both national specialist and local hospitals as well as their GP and community paediatrician. In addition, they often have needs which require the involvement of several community therapies specialists (dietetics, speech and language therapy, occupational therapy, physiotherapy, wheelchair services, tissue viability, etc), social care services (disabled

children's social work team for coordination of social care hours and social care occupational therapy for home adaptation needs) and third sector organisations (Children's Hospices and other charities which support children with life-limiting conditions). When permission to share information is agreed with the family, the Diana Team works in collaboration with the whole multi-agency network around the child and family and, with agreement of the family, makes referrals to services as needed to meet the needs of the child.

3. Quality and Governance

3.1 RiO

Diana Team referrals are opened on RiO for the infant/children/young-person with the life-limiting conditions once it has been confirmed that all the necessary referral information has been received and the child meet criteria to access the service.

Diana Team referrals are also opened for all parents, siblings and other family members who choose to access psychology sessions from the Diana Team.

As the RiO patient record system automatically discharges the deceased from the service and does not allow activity to be recorded in relation to a person who has died, contact with the family after the death of the child is recorded against RiO referrals and in the RiO records of surviving family members.

All telephone conversations and face-to-face contacts with the child and/or family are recorded in both the RiO Diary and RiO progress notes.

When the content of the contact relates to the care of the child with the life-limiting condition, it is recorded in the child's RiO records.

When the content of the contact relates to the care of the family and does not need to be shared with professionals involved in the care of the child with the life-limiting condition, it is recorded in the RiO record for the relevant family members.

Non-face-to-face contacts with other professionals about the care of the child and family are recorded in the RiO records of the persons about whom information was shared. This includes discussions and plans from Child Protection Supervision meetings.

Care plans, letters and other documents about the child or family sent and received by the service are uploaded to the relevant person/s' RiO record/s.

All notes recorded by Diana Team members on RiO are visible to all members of the Diana Team, CCNS and other children's community health services on the ELFT RiO system. The RiO Team have not been able to set up a system for the psychologists to select specific entries to be hidden from non-psychology/mental health practitioners to protect client confidentiality if information which does not need to be shared and they do not want to be shared is disclosed. Hence, while the majority of psychology records are kept on the RiO system with consent from clients for this, very occasionally paper records are kept and stored in a locked filing cabinet only accessible to the Diana Team psychologists to protect client confidentiality.

3.2 Management of clinical case files

All nursing and play records are kept on the RiO records system.

As part of business continuity planning for the eventuality of a system failure/power cut that prevents access to RiO, paper copies of client contact details, emergency care plans, symptom management plans and child protection plans are kept in a locked filing cabinet.

While the majority of psychology records are kept on the RiO system, very occasionally paper records of sessions in which confidential information is shared are kept and stored in a locked filing cabinet only accessible to the Diana Team psychologists to protect client confidentiality. A note is then recorded on RiO that a contact took place and that details of the contact are recorded in the client's confidential paper psychology records.

3.3 Implementation and monitoring of the operational policy

Please see Children's Community Nursing Service operational policy.

Review date: April 2018

3.4 References

CCNS Operational Policy

CCNS Baby Massage Policy

CCNS Continuing Care Policy

Psychological Consultancy for Newham CCNS - Internal Agreement

Controlled Drugs Policy – in development

ELFT Datix Incident Reporting Policy.

NICE Guideline NG61: End of life care for infants, children and young people: planning and management. Full Guidance. (National Institute for Health and Care Excellence, December 2016).

NICE Clinical guideline CG135: Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. (National Institute for Health and Care Excellence, Published date: December 2011. Last updated: December 2016)

A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions: Third edition. (Together for Short Lives, 2013)

Fraser, L., Miller, M., Aldridge, J., McKinney, A. & Parslow, R. (2011) Life-limiting and life-threatening conditions in children and young people in the United Kingdom; national and regional prevalence in relation to socioeconomic status and ethnicity. Final Report for Children's Hospice UK. Published by Leeds University.

APPENDIX 1:

Eligibility Criteria and Referral Guidelines for Newham Diana Children's Community Team

1. Child is not expected to live in to adulthood (has a medical condition that is expected to cause their death in childhood or adolescence).
2. Child aged 0 – 19 years
(including unborn foetus if a clear diagnosis is made during pregnancy)
3. Family and child normally resident in Newham
4. Parents have been informed by diagnosing clinician that child is unlikely to live to adulthood

Although diagnosis can be a guide to life-expectancy, *prognosis is the key criteria for the Diana Team.*

Many children who have frequent Paediatric Intensive Care admissions do not have a clear diagnosis, but the frequency of life-threatening episodes or on-going deterioration of health and abilities may indicate a shorten life-expectancy.

Children should be referred to the Diana Team as soon as the family have been informed that the child is unlikely to survive in to adulthood. There is no need to wait for their health to begin to deteriorate. We work with families living with the knowledge that a child is likely to have a shortened life, regardless of current level of community nursing need. A child may be currently well – the opportunity to meet the nursing team, and access play and psychology before the child's health begins to deteriorate can make a difference to how well the family manage when abilities and/or health does begin to deteriorate.

In children's services, the word "palliative" is used in a different way from in adult services because the causes of child and adult deaths from illness can be very different. Because of this confusion, the Diana Team is now trying to use clear language to explain who we work with, i.e. 0 – 19 year olds who are not expected to live in to adulthood, and their bereaved families. We have previously described ourselves as a "palliative care" service for "life-limited" (in the sense of limited length of life, not limited quality of life or disability) and "life-threatened" children and young people, but professionals from other areas did not always understand how we were using these words. Hopefully the focus on shortened life-expectancy is less open to misunderstanding.

The following information is taken from the website for **Together for Short Lives** (the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. The website also gives more information about the different groups of conditions which children with shortened lives may be diagnosed with:

Children's palliative care is often confused with adult's palliative care. Many people think that only children at the end of their life can benefit from children's palliative care. This is not the case.

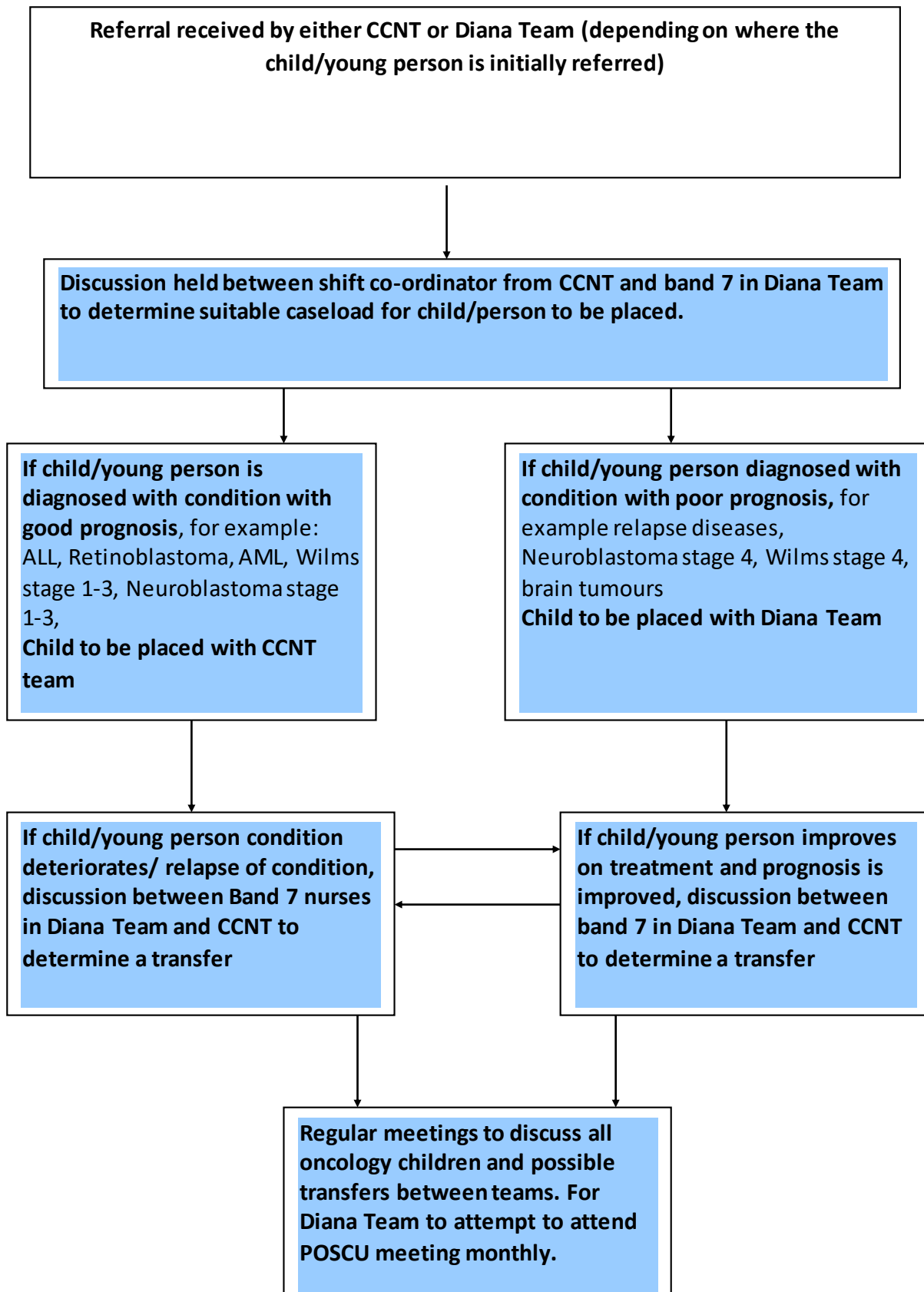
Palliative care for children and young people is an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person, and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support. Palliative care should be offered from diagnosis of a life-limiting condition or recognition that curative treatment for a life-threatening condition is not an option; however, each situation is different and care should be tailored to the child.

CCNS Internal Guidelines for allocation of new referrals to CCNT or Diana Team

(and for transition for existing patients from CCNT to Diana Team)

- Does the child have a confirmed diagnosis of a condition for which the prognosis is likely death before adulthood?
 - If “YES”, refer to Diana Team
- Has the child’s paediatrician told the family that the child is unlikely to live in to adulthood?
 - If “YES”, refer to Diana Team
- Would you be surprised if this child died prematurely due to their illness?
 - If “NO, I think there is a chance they may die”, discuss with the child’s paediatrician whether they think there is a risk of premature death and option of referral to Diana Team.
- Would you be surprised if this child died within a year, or during this episode of care?
 - If “NO, I think there is a chance they may die very soon”, there is need for urgent discussion with the child’s paediatrician whether they think this child may face end of life in the near future and make referral to Diana Team.
- Has this child had multiple life-threatening episodes in the last months/year (e.g. multiple PICU admission or recurrent chest infections)?
 - If “YES”, discuss with the child’s paediatrician whether they think there is a risk of premature death and option of referral to Diana Team.
- Does this child have a life threatening condition for which treatments may not be accessible (e.g. suitable transplant becoming available is very unlikely) or high probability of failure (e.g. >50% of children with this problem do not survive/respond to treatment)?
 - If “YES”, discuss referral to Diana Team with the team leading the child’s treatments.
- Does this child have an oncology diagnosis?
 - If “YES”, use the attached flow chart to guide decision about allocation and discuss final decision with both CCNT and Diana Service leads.
- Is the child waiting for organ transplant(s)?
 - If “YES”, inform leads for both CCNT and Diana Service and plan with them contacting the child’s transplant team to discuss their view of the likelihood of finding a donor and successful transplant and find out the transplant their view of the option of referral to the Diana Team.

ONCOLOGY REFERRAL ALLOCATION FLOWCHART:



Guidelines for discussing transition to the Diana Team with families:

To avoid disappointment/confusion/undue worry for families of children who may survive in to adulthood, if you are wondering whether a child currently on the CCNT caseload might meet criteria for the Diana Team, please **do not tell the family** that you are considering transition to the Diana Team **without first discussing with the Diana Team Senior Sister** the child's eligibility to access the Diana Team.

If the Diana Team Senior Sister confirms that the child does meet Diana Team access criteria as a child likely to have a "shortened life" and that transition is appropriate, **also discuss with the Diana Team Senior Sister how the reason for transition will be explained to (1) the family and (2) other services involved in their care.** It is likely that most appropriate way of explaining transition to the Diana Team to the child, family and other professionals will differ depending on:

- the child's condition and stage of illness
- family & child understanding/feelings/beliefs about prognosis
- family relationship with CCNT
- the views of the network around them about the appropriateness of "palliative care"

For some families it may be useful to make one or joint visits with CCNT and Diana Team nurses. It may also be useful to hold a multi-disciplinary / network meeting. The language that we use to talk about "shortened lives" will also vary depending on the family's way of talking about the illness and prognosis and it can be useful to talk about this with colleagues before talking to the family... "may not get better", "facing end of life", "may not survive", "very seriously unwell", "deteriorating health", "might not live in to adult hood", "shortened life expectancy" are just a selection of phrases which might be appropriate, depending on the child and family's understanding and use of language). It is important to remember that some parents choose not to tell their (patient and siblings) children about poor prognosis, or wait to tell them nearer the end of life - we must respect this choice in our conversations with the family and not disclose information to the children that the parents have not given us permission to share yet (also, some children also expressly say that they do not want to know themselves and we must also respect this).

APPENDIX 2:

Diana Children's Community Child and Family Clinical Psychology Service

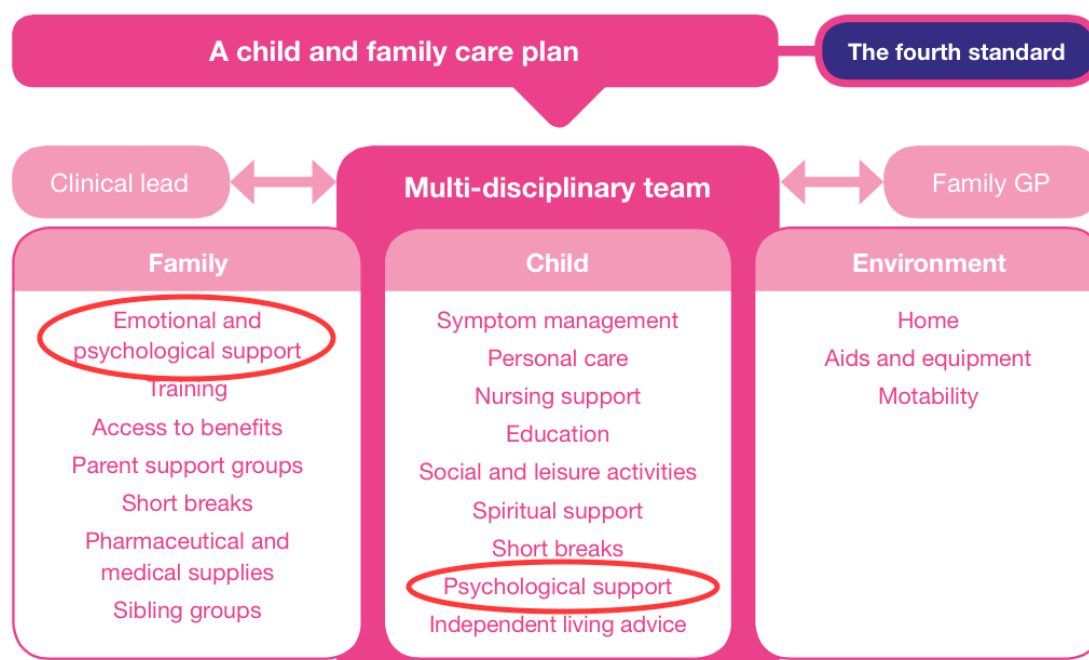
Service Framework: January 2017

Local Key Performance Indicator:

All families living in Newham in which there is a child (0 to 19 years) who is not expected to live into adulthood should be offered access to this psychology service. This includes families who have been bereaved through the death of a child from a life-limiting condition.

Key National Guidance:

- NICE Guideline NG61: End of life care for infants, children and young people: planning and management. Full Guidance. *Emotional and Psychological Support and Interventions - Recommendations* (National Institute for Health and Care Excellence, December 2016).
- NICE Guideline NG61: End of life care for infants, children and young people: planning and management. Full Guidance. *Care and Support for parents, carers and healthcare professionals in relation to the death of a child or young person - Recommendations* (National Institute for Health and Care Excellence, December 2016).
- National Core Care Pathway for Children with Life-Limiting and Life-Threatening Conditions: Third Edition (Together for Short Lives, 2013)



Newham Diana Clinical Psychology Child and Family Service Aims and Objectives:

To provide emotional support and psychological interventions for families of children with life-limiting conditions from a team of psychological practitioners with an appropriate level of expertise and clinical supervision for adapting psychotherapeutic approaches to working with families experiencing the journey from child palliative care to bereavement.

To reduce distress and enhance quality of life for children who are not expected to live in to adulthood.

To support the families of children with life limiting conditions to build resilience and cope with the psychological aspects of caring for their child and enable them create positive memories of their time with the child.

To provide early intervention to reduce risk of development of severe mental health problems.

To support the family and multiagency team around the child to develop collaborative working relationships towards minimizing the potential negative impacts of the child's health needs on all members of the family.

To enable families (parent/carers, siblings and significant others) to find ways to go on in their lives and remember their child after the death of the child.

To provide continuity of psychological support to the family after the child has died.

To increase acceptability of accessing bereavement support for families who might feel uncomfortable about being referred to mental health services to address bereavement.

Operational Definition:

Any member of the family (adults and children) can access psychology appointments (individually or together) for support, assessment and therapeutic intervention in relation to the impact of the child's life limiting condition, symptoms, medical interventions, dying and death on thoughts, feelings, behavior, day-to-day functioning/coping and relationships.

Psychological and Systemic Consultation is also offered to the wider multiagency team around the child and family (primary, secondary and tertiary health service, education, social care and third sector organisations involved in their care) to enable families and services to develop collaborative working relationships and work together to improve quality of life for the child and family.

Flexible, Accessible and Responsive:

- Information about service provided at first contact with any member of the wider multidisciplinary Diana Team (within 2 working days of referral)
- Psychology appointments are offered within 10 working days of request.
- Family members can self-refer to the service.
- Goals for appointments are negotiated with service users and reviewed regularly.
- The majority of appointments are offered as home visit. Visits can take place at hospital or hospice if the child has been admitted to either location. Attempts can also be made to arrange a room to meet at school or at a children's centre if this is more convenient for the family.
- Times of appointments are negotiated with the family.
- Frequency of appointments is negotiated and reviewed regularly.
- The option to continue or pausing/ending a series of appointments is negotiated and reviewed regularly.

- Spoken and sign language interpreters can be booked to support appointments. 5 days' notice is usually required to book an interpreter.
- Psychologists in the service employ creative approaches to working with children and people with communication difficulties.

Confidentiality

Consent is sought for records to be accessible to other health professionals on a need to know basis.

Separate records of confidential aspects of conversations may be kept if a family wishes aspects of their conversations to be kept confidential (provided that there are no safeguarding issues that need to be shared).

Access to Friday Family Therapy Clinics

Families experiencing relationship difficulties which impact on the wellbeing of the children in the family and for which a systemic psychotherapy team approach may be beneficial are offered the option of attending the Friday Clinic with the Diana Team Systemic Family Psychotherapist in which they can access consultation from a team of Family Therapists at the Child and Family Consultation Service.

Referral to mental health services:

If a child or adult has a severe or enduring mental health problem that requires assessment from a psychiatrist, consent is sought to make a referral to child or adult mental health services (as appropriate for the age and particular needs of the individual).

If a child or adult is at immediate risk of harming themselves or others, urgent referrals are made to emergency mental health services (urgent safeguarding referrals for protection may also be made if appropriate).

If a family member has mental health difficulties that do not relate to the child's life-limiting condition or bereavement, referrals are made to services specializing in their particular area of need.

When referrals are made for additional mental health services, the Diana Psychology Service will provide support in relation to the issue for which onward referral was made up to the point where the new service begins sessions with the referred individual. The family can also continue to access the Diana Psychology Service to address needs relating to the child's condition/death and consent will be sought for information sharing to coordinate care across services.

Discharge Protocol:

Families who move out of Newham are discharged from the service and attempts are made to signpost them or make referrals with consent to services in the area they move to.

If the child's prognosis changes and they are no longer thought to be life-limited, then a number of sessions will be agreed to either end or transition the therapeutic work to another service.

Staff Support and Consultation:

Diana Team Psychologists facilitate monthly “Psychology case consultation sessions for CCNS”, which can be accessed by all members of the children’s community nursing service. Please see “Psychological Consultancy for Newham CCNS - Internal Agreement” document for further details.

Diana Team Psychologists convene and facilitate debriefing/peer support for the multiagency team around the child and family when a child known to the service dies. These meetings take the form of “Co-memorating Meetings” (Fredman, 1997). Please see “Co-memorating Meetings” document for details of the format for these meetings and full references.

Diana Team Psychologists facilitate monthly “Staff Relaxation Session for CCNS”, which can be accessed by all members of the children’s community nursing service.

Diana Team Psychologists facilitate monthly “Reflective Practice Sessions for Health Care Support Workers”, using a “Reflecting Team” approach (Andersen, 1987). These sessions take place for 90 minutes as part of the team office day for CCNS employed health care support workers who deliver care in the home to children with continuing care needs.

Staff Teaching and Training

Diana Team Psychologists have developed “Talking about Death and Dying Workshops” for Children’s Services in Community Health Newham, which are currently delivered twice a year to professionals from across all teams within the children’s community health services in Newham.

Diana Team Psychologists have developed and deliver a series of induction training workshops for newly recruited CCNS employees on the following topics: Introduction to the Psychology Service; Impact of Childhood Illness on Families; Working in Families’ Homes; Working with Difference; Looking After Ourselves; Intensive Interaction as an Approach to Developing Social Communication in Children with Complex Needs; Working with Adolescents with Life-Limiting Conditions; Childhood Bereavement; Talking about Death and Dying.

Qualification, registration, clinical supervision and quality assurance.

Lead Clinical Psychologist (1.0 wte) holds a Doctorate in Clinical Psychology is a registered Psychologist Practitioner with the Health and Care Professions Council, a Chartered Clinical Psychologist and Associate Fellow of the British Psychological Society, a registered Systemic Family Psychotherapist with the UK Psychotherapist Council and has qualified as a Systemic Supervisor from the Tavistock and Portman. The post holder participates in 1.5 hours monthly of clinical supervision from a Clinical Psychologist and Family Therapist and has clinical practice observed at least once per month by an experienced Family Therapist and Systemic Supervisor in the Friday Family Therapy Clinic.

Clinical Psychologist (0.5 wte) holds a Doctorate in Clinical Psychology is a registered Psychologist Practitioner with the Health and Care Professions Council. The post holder attends monthly clinical supervision with the Lead Clinical Psychologist.

Trainee Clinical Psychologists (0.5 wte) are in their final year of training on a Doctorate in Clinical Psychology. They receive 1.5 hours per week of clinical supervision from either or both the Band 7 and Band 8 Clinical Psychologist who oversee/s all of their clinical work.

APPENDIX 3:

NICE Recommendations on Managing distressing symptoms

Extract from, “NICE Guideline NG61: End of life care for infants, children and young people: planning and management.” (National Institute for Health and Care Excellence, December 2016).

Managing pain

1.3.21 When assessing and managing pain, be aware that various factors can contribute to it, including:

- biological factors, for example musculoskeletal disorders or constipation
- environmental factors, such as an uncomfortable or noisy care setting
- psychological factors, such as anxiety and depression
- social, emotional, religious, spiritual or cultural considerations.

1.3.22 When assessing pain in children and young people:

- use an age-appropriate approach that takes account of their stage of development and ability to communicate
- try to identify what is causing or contributing to their pain, and be aware that this may not relate to the life-limiting condition
- take into account the following causes of pain and distress that might have been overlooked, particularly in children and young people who cannot communicate:
- neuropathic pain (for example associated with cancer)
- gastrointestinal pain (for example associated with diarrhoea or constipation)
- bladder pain (for example caused by urinary retention)
- bone pain (for example associated with metabolic diseases)
- pressure ulcers
- headache (for example caused by raised intracranial pressure)
- musculoskeletal pain (particularly if they have neurological disabilities)
- dental pain.

1.3.23 Be aware that pain, discomfort and distress may be caused by a combination of factors, which will need an individualised management approach.

1.3.24 For children and young people who have pain or have had it before, regularly reassess for its presence and severity even if they are not having treatment for it.

1.3.25 Think about non-pharmacological interventions for pain management, such as changes that may help them to relax, for example:

- environmental adjustments (for example reducing noise)
- music
- physical contact such as touch, holding or massage
- local hot or cold applications to the site of pain
- comfort measures, such as sucrose for neonates.

1.3.26 When tailoring pain treatment for an individual child or young person, take into account their views and those of their parents or carers on:

- the benefits of pain treatment
- the possible side effects of analgesia for moderate to severe pain (such as opioids), for example:
 - unwanted sedation
 - reduced mobility
 - constipation.

1.3.27 Consider using a stepwise approach to analgesia in children and young people, based on pain severity and persistence:

For mild pain, consider paracetamol[1] or ibuprofen[2] sequentially, and then in combination if needed

For moderate to severe pain, consider one of the following options:

- paracetamol[1] or ibuprofen[2] sequentially, and then in combination if needed or
- low-dose oral opioids (such as morphine[3], [4]) or
- transmucosal opioids or
- subcutaneous opioids or
- intravenously infused opioids (if a central venous catheter is in place).

1.3.28 If treatment with a specific opioid does not give adequate pain relief or if it causes unacceptable side effects, think about trying an alternative opioid preparation.

1.3.29 When using opioids, titrate treatment to find the minimal effective dose that will relieve and prevent pain.

1.3.30 Titrate treatment to provide continuous background analgesia, and prescribe additional doses for breakthrough pain if this occurs.

1.3.31 In addition to background analgesia, consider giving anticipatory doses of analgesia for children and young people who have pain at predictable times (for example when changing dressings, or when moving and handling). Do not include anticipatory doses when calculating the required daily background dose of analgesia.

1.3.32 Calculate opioid dosages for children and young people who are approaching the end of life using weight rather than age, because they may be underweight for their age.

1.3.33 If you suspect neuropathic pain and standard analgesia is not helping, consider a trial with other medicines, such as:

gabapentin[5]or

a low-dose tricyclic antidepressant (for example amitriptyline[6]) or

an anti-NMDA agent (for example ketamine[7] or methadone[8]), used under guidance from a specialist.

Managing agitation

1.3.34 Be aware that as children and young people with life-limiting conditions approach the end of life they may:

- become agitated, shown by restlessness, irritability, aggressive behaviour, crying or other distress
- show signs of delirium, such as confusion, disrupted attention, disordered speech and hallucinations.

1.3.35 If a child or young person who is approaching the end of life becomes agitated or delirious, make sure that they are safe from physical injury.

1.3.36 If a child or young person becomes agitated as they are approaching the end of life, look for causes and factors that may be contributing to this, including:

- medical disorders and conditions such as pain, hypoxia, anaemia, dehydration, urinary retention or constipation
- psychological factors such as fear, anxiety or depression
- adverse effects from medication.

1.3.37 For children and young people with a neurological disability who are approaching the end of life, be aware that the signs and symptoms of agitation or delirium can be mistaken for the signs and symptoms of seizures or dystonia.

1.3.38 If a child or young person who is approaching the end of life needs treatment for agitation:

identify and if possible treat any medical or psychological conditions that may be contributing to it
think about non-pharmacological interventions, such as:

- calm speaking, reassurance, distraction, and physical contact such as holding and touch
- changes to the environment to make it more comfortable, calm and reassuring, to reduce noise and lighting, to maintain a comfortable room temperature, and to provide familiar objects and people and relaxing music
- religious and spiritual support if this is wanted and helpful

think about pharmacological interventions (beginning with low doses and increasing if necessary).

Drugs to think about using include:

- benzodiazepines, such as midazolam[9], diazepam[10] or lorazepam[11]
- neuroleptics, such as haloperidol[12] or levomepromazine[13].

Managing seizures

1.3.39 If a child or young person is approaching the end of life and has a seizure, look for and if possible treat or remove any potential causes, triggers or contributing factors, for example:

- fever
- electrolyte disturbances
- drug reactions
- sleep deprivation
- pain
- excessive environmental stimulation.

1.3.40 If a child or young person is thought to be at increased risk of seizures (for example because they have had seizures before or because of an existing brain disorder), include seizure

management in their Advance Care Plan. Think about the benefits and drawbacks of specific seizure treatments and:

take into account how any decisions could affect the choices available for place of care and place of death and

discuss this with the child or young person and their parents or carers.

1.3.41 For children and young people who are approaching the end of life, be aware that abnormal movements (such as dystonic spasms) might be mistaken for seizures. If in doubt seek specialist advice.

1.3.42 If a child or young person is approaching the end of life and is thought to be at increased risk of seizures, explain to them and their parents or carers:

- how likely it is that they may have a seizure
- what they might notice if a seizure happens
- that seizures can be frightening or upsetting
- what parents or carers should do if a seizure happens at home (for example placing the child or young person in a safe position).

1.3.43 Ensure that parents or carers who have been provided with anticonvulsive therapy (such as buccal midazolam) know how and when to use it if the child or young person has a seizure at home.

Managing respiratory distress

1.3.44 If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing, think about and if possible treat the likely contributing factors or causes. If these are likely to be caused by:

Anxiety:

- discuss why they are anxious
- reassure them and manage the anxiety accordingly
- consider breathing techniques and guided imagery
- consider anxiolytic agents.

Physical discomfort – think about what could be causing the discomfort (for example their position) and help them with it if possible.

Environmental factors – think about environmental changes such as changing the temperature.

Accumulated airway secretions – think about repositioning, airway suctioning, physiotherapy or anti-secretory drugs.

Medical disorders (for example pneumonia, heart failure, sepsis or acidosis) – use appropriate interventions such as:

- bronchodilators
- nebulised saline
- opioids
- oxygen supplementation.

1.3.45 For children and young people who are approaching the end of life and have respiratory distress, breathlessness or noisy breathing that needs further assessment, consider referral to an appropriate specialist (for example a respiratory or cardiac specialist).

1.3.46 If a child or young person is approaching the end of life and has respiratory distress, breathlessness or noisy breathing:

- explain to them and to their parents or carers that these symptoms are common
- discuss the likely causes or contributing factors
- discuss any treatments that may help.