

**Luton Children and Young People
Palliative Care Strategy**

2016 – 2019

Edition 2



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1. Executive Summary

In February 2008, the national Children's Palliative Care strategy 'Better Care, Better Lives' was published, setting out both the government's vision for palliative and end of life care for children and young people and also a clear directive as to how services should be transformed.

In January 2015, 'Ambitions for Better Lives, Better Care for children and young people in the East of England' (T. Rennie, Director of Care, EACH) was published. Developed by the East of England Children and Young People's Palliative Care Forum as an update to the 2011 regional response, it sets out the aspirations for children's palliative care services in the East of England.

Luton's palliative care strategy for children and young people has been developed collaboratively with a working group which comprised members from Luton Clinical Commissioning Group; Luton Borough Council, Luton & Dunstable University Hospital, Keech Hospice and a local children's charity. This group is responsible for the strategy's implementation. There is a need for cross boundary arrangements; Keech children's hospice, as the regional provider serves Bedfordshire, Buckingham and Hertfordshire; Luton and Dunstable University Hospitals' Neonatal unit is the lead for Hertfordshire and Bedfordshire network and part of the wider regional East of England network. Developing partnership working with neighbouring authorities and clinical commissioning groups to share good practice and produce a joint strategy will benefit all children and young people in the locality and thereby avoid a 'postcode' palliative care service.

Set against a background of significant change, both nationally and locally, in health and social care and, particularly, in Children's Services, this document

describes the current need for children's palliative care services in Luton and attempts to predict future need, describing how services are configured and functioning currently and sets out the vision for how they should look and function in three years' time, and the strategic goal for each area of development.

The key points in this document are summarised below and are discussed in greater detail in the main body of the document.

Overall Aim

We intend to develop timely, flexible and responsive, child and family centred, palliative care services, by strengthening universal services so that generalists can support children and families appropriately and build upon strengthening and further developing the current multidisciplinary model of specialist palliative care

The National and Local Context

- The national strategies: 'Better Care Better Lives' and 'Aiming High for Disabled Children' are the main drivers for change
- Strong local commitment and investment will be available to support the service transformation
- A strong history of partnership working in Luton, together with a clear overarching children's plan and effective organisational development, will support the future development of children's palliative care services

Children's Palliative Care

- Palliative care aims to alleviate symptoms and improve quality of life rather than cure

- The time span of many children's illnesses means that palliative care may span over many years and that those children will continue to develop and change throughout the period of care
- Palliative care for children should, therefore, be a 'continuum' of care
- Every child and young person with a life limiting or life-threatening condition will have equitable access to high quality, family centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes. (Better Care, Better Lives', DoH, 2008)

Current and Future Need for Children's Palliative Care Services in Luton

- The number of children, needing palliative care in Luton, is likely to increase steadily over the next five years
- A significant proportion of those children and families will be from the South Asian community
- In order to understand the need and plan services effectively, we will establish and maintain an accurate database of children with disabilities and life-limiting conditions

Future Development of Services

- This strategy has been developed through an inclusive, methodical process and using a range of data sources
- Through this process, the group has identified the key areas for future development
- The Children's Palliative Care strategy group, comprising the key local stakeholders, has led the development of this strategy and will be responsible for its implementation

2. Introduction

This document sets out Luton's response to the recently launched national strategy for children's Palliative Care Services, 'Better Care; Better Lives'.

It has been developed by the Luton's Child Health Steering Group and led by a Children's Palliative Care Strategy Group, comprising a partnership of key local stakeholders:

- **Luton Clinical Commissioning Group**
- **Cambridgeshire Community Services (Luton)**
- **Luton Borough Council**
- **Keech Hospice**
- **Luton and Dunstable University Hospital**

and describes how Luton proposes to build on the recent developments in children's palliative care services and to raise the bar even further so that children and young people, who are living and dying with life limiting conditions, are assured of the highest quality, child and family centred, personalised and responsive services as and when they need them.

3. Background

3.1 National context and drivers

This strategy is set in the context of a number of recent national initiatives which focus on raising the quality of health and social care overall, and the care of children and young people, and their families, in particular:

'Ambitions for Better Care Better Lives' 2015

'Ambitions for the palliative care of children and young people in the East of England' is an update to the previous 2011 regional response to the national document 'Better Care Better Lives (2008) and sets out the aspirations for children's palliative care services in the East of England.

'Better Care Better Lives' 2008

The national strategy for children's Palliative Care Services, 'Better Care, Better Lives', was launched in February 2008 and developed in direct response to the Independent Review of Children's Palliative Care Services (2007). The strategy sets out the government's vision for children's palliative care services, challenging commissioners to radically improve services for children and young people with life threatening and life limiting conditions and their families.

Key Messages:

- An emphasis on cost effectiveness and multi-disciplinary, community based, teams
- An increased focus on disability (which is a Government priority) as well as cancer
- A renewed focus on Children's Palliative Care networks
- An emphasis on partnership working and strong steer towards real partnership working with Voluntary organisations
- Responsive, flexible services able to respond to complex, changing situations driven by child/parent choice
- A focus on transition

3.2 The Local Context

Luton is a vibrant, multicultural town with a population of approximately 205,843 people, approximately 52,876 of whom are children. (Source: 2012 Mid-Year Population estimate - ONS)

Luton Children's Trust

Local statutory agencies formed the Children's Services Partnership in 2005 in order to work together to plan, develop and provide high quality services for children and young people in Luton and, in October 2008, the Partnership became **Luton Children's Trust**.

Within the Trust, local agencies work cooperatively - steering developments, monitoring progress and reviewing (and refreshing) the plan. The **Children's Trust Management Group and the Children's Trust Board** are the organisational structures which drive, support and monitor developments in local services and which will ensure the implementation of this strategy.

Luton Children and Young People's Plan

The Luton Children and Young People's Plan 2014-19 'Safe, Healthy and Successful in Luton' outlined Luton's comprehensive, whole system, approach to developing and improving children's services and identified key areas that the Partnership wanted to make a real difference for children

- **improving outcomes for vulnerable children and young people**
- **improving outcomes for children with a disability**
- **increase the uptake of immunisations and vaccinations**
- **preventing and managing obesity**
- **improving educational achievement**
- **helping children feel safe and tackling bullying**
- **decreasing the numbers of children and young people not in education, employment or training**
- **reducing infant mortality**

This strategy directly addresses three of Luton's Children and Young People's Plan's key targets.

4. The Vision for Children's Palliative and End of Life Care

'Every child and young person with a life limiting or life-threatening condition will have equitable access to high quality, family centred, sustainable care and support, with services provided in a setting of choice, according to the child and family's wishes'

(Better Care, Better Lives', DoH, 2008)

What Is Palliative Care?

Palliative care refers specifically to the care of the child and family when a child has a life limiting condition and includes end of life which continues through bereavement. Palliative care involves care of the child and family from the time when therapy is no longer given with curative intent. It is 'an active and total approach to care which embraces physical, emotional, social and spiritual elements and focuses on enhancing quality of life for the child and support for the family'. It includes symptom management, short breaks, end of life care and bereavement support.

Care aims to:

- diminish or eliminate adverse symptoms
- improve physical function
- enhance the child and family's quality of life and
- enable a child or young person to achieve their full potential as a human being in the time that they have
- care for the child and their family prior to death and through bereavement

Children may continue to develop physically, emotionally and cognitively throughout the course of their condition. Therefore, palliative care is seen as a 'continuum' of care – from the provision of universal services for children (e.g. education, social care, transport, home help, short breaks etc) through acute care and the management of the individual child and family, to very specialist

support such as those provided by tertiary centres and specialist bereavement services. (Better Care, Better Lives', DoH, 2008)

There are significant differences in childrens palliative care from palliative care for adults:

- The number of children who die is small compared with the number of adults.
- Many of the conditions are extremely rare with diagnoses specific to childhood, although the child may survive into early adulthood.
- The timescale of childhood illness is generally different from adults; palliative care may last only a few days, weeks or months, or may be delivered on and off for a number of years.
- Many of the conditions are genetic, and therefore more than one child in the family may be affected.
- Children's palliative care embraces the whole family. Family members, especially parents and siblings, will be vulnerable as they face the changes in life that the child's diagnosis creates, and as they anticipate bereavement.
- Children's palliative care providers need to be aware of the continuing physical, emotional and cognitive development throughout childhood and respond to each child's changing levels of communication and their ability to understand.
- Provision of education and play when a child is seriously ill is essential. This introduces an additional dimension which adds to the complexity of care provision.

http://www.togetherforshortlives.org.uk/professionals/childrens_palliative_care_essentials/approach

5. Current Service Provision

5.1 Care Model

The model of care in Luton has the child at the centre of a multi-agency pathway. It is a flexible and responsive model - tailored, as far as possible, to the choices of the child and their family, using a family centred approach to care.

The model functions with ***the children's community palliative care specialist nurse as the child's key worker***. It has been established through, and is reliant on, the close working relationships that clinicians and managers have established with each other - individuals, teams and service providers. Paediatric Passports for children and young people with complex health care and palliative care needs enable access to mainstream primary care services and the health support they need at any time. Children with Paediatric Passports should be offered same day appointments either face to face or via telephone.

Practises should ensure children and young people with palliative care needs are included in monthly MDT meetings and that the palliative care nurses are invited to be part of that discussion.

This model reflects current 'best practice' as described in 'Better Care Better Lives' and, therefore, a key objective of this strategy will be to embed this model so that it is less reliant on the individuals in post and is more 'standard practice' see Diagram A below.

DIAGRAM A - LUTON MODEL OF PALLIATIVE CARE

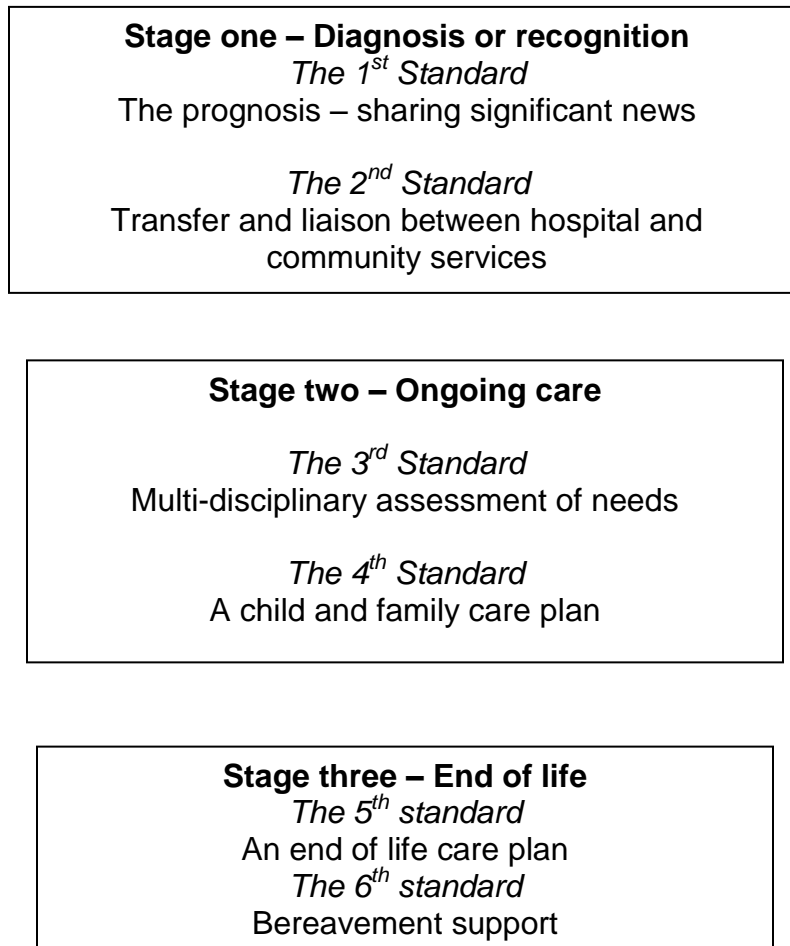


5.2 Pathways of Care

There are currently three pathways of care in Luton:

1. Neonatal and Stillbirth Pathway
2. Palliative Care Core Pathway
3. Transition Pathway (awaiting ratification, see section 8.10)

The Palliative Care Core Care Pathway has been summarised in the diagram below:



Source: Together for Short Lives Core Care Pathway 3rd edition, 2013

5.3 Provision of Children's Palliative Care

There are four main providers of a wide range of Palliative and End of Life care services to children, young people and their families in Luton

- **Cambridgeshire Community Services (Luton)**
- **Keech Children's Hospice**
- **Luton and Dunstable University Hospital**
- **Luton Borough Council.**

In addition, children are registered with one of the **35 GP practices** in Luton; can be seen at other major acute centres - such as:

- **UCLH**
- **Great Ormond Street Hospital**
- **Addenbrookes Hospital Trust**

which are also supported by a wide variety of voluntary agencies, special interest and pressure groups.

The **Children's Community nursing team** offer palliative care support 7 days a week. **Keech Children's Hospice Community Nursing Team** extends this through an 'on call' system which operates from 5pm to 9am. At the moment, the 'on call' service is solely for children at the end of their lives and where there is a risk of 'carer breakdown'. These teams work closely with all **GP practices** in Luton.

Inpatient facilities, both for contracted overnight care and 'emergency' placements (for example: symptom control, carer breakdown, end of life or to facilitate early discharge) is provided by **Keech Children's Hospice**.

In addition, there are a wide range of support services provided by statutory and voluntary providers:

- **Therapy Services e.g. music, art, recreation**
- **Occupational Therapy**

- **Physiotherapy**
- **Continence service**
- **Infant Feeding Service**
- **Epilepsy Nurse Specialist**
- **Wheelchair Service**
- **Social Services, Specialist Disability Team**
- **Community Care provided by Keech Hospice**
- **Child and Adolescent Mental Health Service (CAMHS)**
- **Young Carers support service**

5.4 Bereavement Services

There are a range of specialist bereavement services available and supported by various voluntary agencies:

- An Oncology Nurse to support the families of children with Cancer.
- CHUMS child bereavement service provides support for children whose siblings or parents are dying or who have died.
- Parents, children and young people can also access support through Keech Hospice
- Following a child's death, families can use the Meadow Suite at Keech Hospice (even if they have not, previously, used the hospice's facilities).

6. Needs – current and future

One of the key strategic goals of 'Better Care Better Lives' highlights the need for better data about the needs of children who require palliative care to enable evidence based decision making and commissioning at a local level.

In this strategy, we have attempted both to establish the current need and also to predict the future need for children's palliative and end of life care services.

6.1 What We Know

We know that the numbers of children in Luton living with life limiting or life-threatening conditions are steadily increasing.

- Luton has higher than national and regional rates of infant mortality and morbidity, perinatal mortality and morbidity, stillbirths, and babies born with a low birth weight.
- Of the live births, the proportion of children with disabilities is also significantly higher than national and regional rates.

Therefore, overall, the number of children with conditions likely to require palliative and end of life care is currently, and will continue to be, significantly greater than elsewhere.

Population Distribution within Luton

1. Age and Gender

The population of Luton was estimated to be 205,843 in 2012. Lutons population is younger than the East of England and England as a whole – 23.1% of Lutons population are aged 15 years or under compared with 19% in the East of England and 18.9% in England as a whole. (Source: 2012 Mid-Year Population Estimate 2012 ONS)

2. Population Projections

The population of Luton is projected to rise by 18.9% from 2011 to 2041 (Source: Luton Borough Council using POPGROUP). Figure 2 shows the projected year on year growth for different age groups. These ONS projections look at birth, death and local migration rates but do not take into account local policies such as new housing developments. Therefore, Luton Borough Council publishes its' own local population estimates and forecasts, which also include assumptions based on housing completions and recommended house builds.

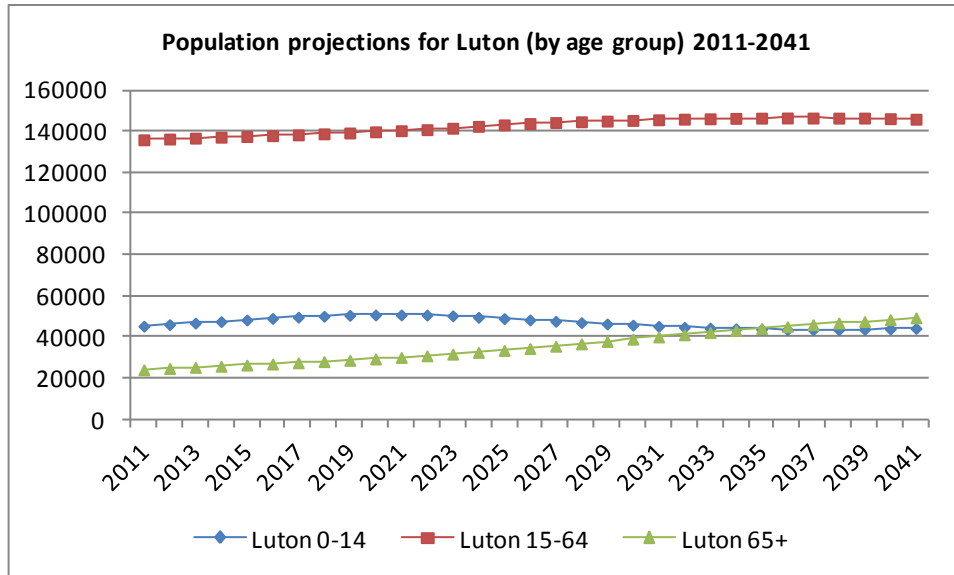


Figure 2: Population projections for Luton (by age group) 2006-2031

Source: ONS 2006-based Sub national Population Projections/Luton Borough Council using POPGROUP

Luton's population is predicted to increase every year up to 2041. The data also indicates that the recent trends in increases in very young children (under 5) are set to reverse from 2018. The 5-15 year old age group is projected to rise 23.2% from 2011 to 2024. The 16-19 year olds are projected to decrease up to 2021 but then increase by 24.61% to 2028 as shown in Figure 3.

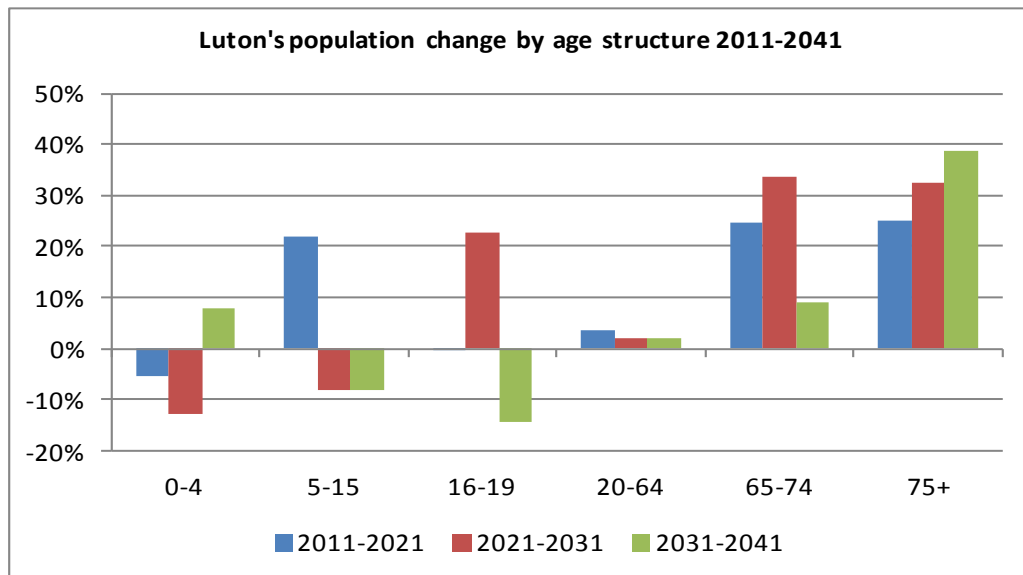


Figure 3 – Population change by age 2011 -2041. Source: Luton Borough Council using POPGROUP

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3. Ethnic group information

Ethnic group estimates from ONS for 2011 show Lutons younger population (0-15) to be very different from national and east of England estimates. In England as a whole, 73.9% of children aged 0-15 are White British but, in Luton, only 31% of children are estimated to be White British. The largest proportion of children in Luton, other than White British, is the Pakistani group followed by Bangladeshi and Black African groups (see Figure 4 below)

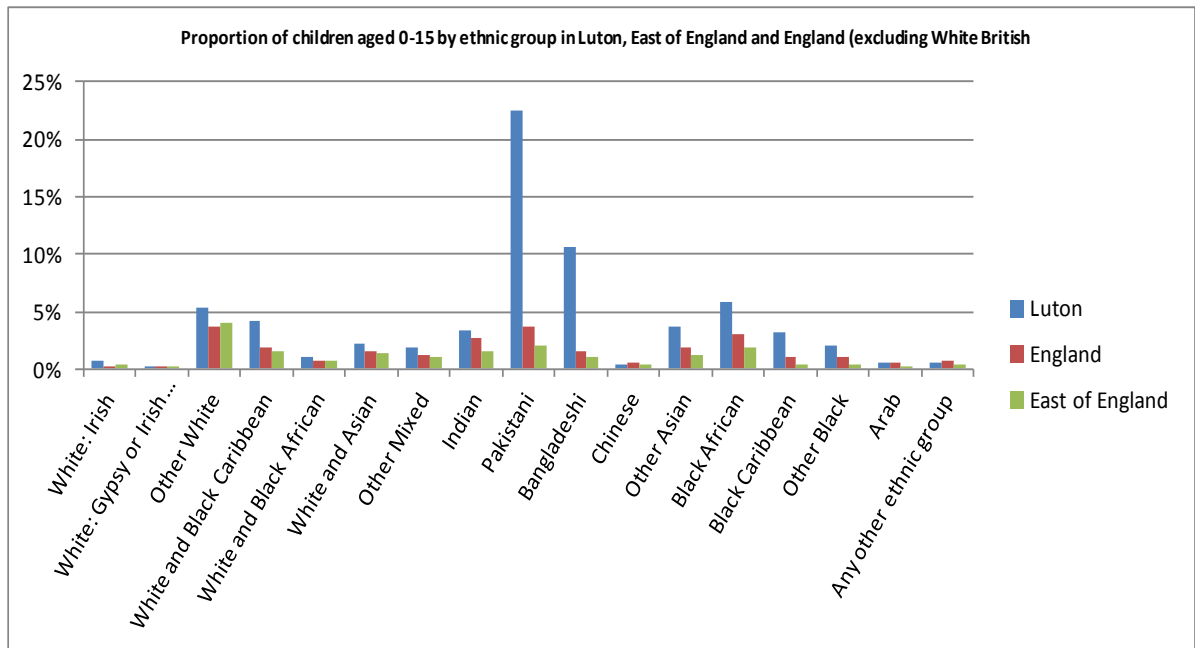


Figure 4 – Population by ethnicity
Source: ONS 2011 Census

6.2 The Luton Caseload

It is generally accepted across the Luton palliative care system that the caseload held by Luton's children's community palliative nursing team is the current known and shared children's palliative care caseload. Each young person is assessed and given a rating category based on the Gold Standard Framework (GSF) according to their individual need; blue - stable, red - terminal, yellow – deteriorating, green – unstable. Navy is for bereavement after care. Data captured in **January 2016** show there are approximately **69** children and young people known to Palliative care services: 52 blue (stable), 7 green (unstable), 8 yellow (deteriorating) and 1 red (terminal).

A team of multi-agency professionals meet monthly to review all young people on the caseload and may amend the rating dependent on the needs of the young person.

The Association for Children with life-threatening or terminal conditions (ACT) and the Royal College of Paediatrics and Child Health (RCPCH) identified four broad groups of conditions that may lead to children requiring palliative care. Together for Short Lives Core Care Pathway recognises the importance of categorisation as an important part of the planning and needs assessment process. Children from all four of these categories would benefit from some, if not all, elements of this pathway.

Category 1	<p>Life threatening conditions for which curative treatment may be feasible but can fail.</p> <p><i>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.</i></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><i>There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</i></p> <p><i>Examples: cystic fibrosis, Duchene muscular dystrophy</i></p>
Category 3	<p>Progressive conditions without curative treatment options.</p> <p><i>Treatment is exclusively palliative and may commonly extend over many years.</i></p> <p>Examples: Batten disease, mucopolysaccharidosis</p>
Category 4	<p>Irreversible but not progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.</p> <p>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</p>

Source: Together for Short Lives Core Care Pathway, 3rd edition, 2013

There are a number of children living with conditions likely to require palliative care, who are not currently known to palliative care services. These include:

- a) Children with a serious cardiac condition
- b) Children who are under the care of acute units other than the Luton and Dunstable Hospital Trust (such as Addenbrookes)

The introduction of the Child Death registration process is likely to give more accurate data relating to child deaths – particularly in cases where there has been late diagnosis (of a palliative care condition) or late referral to palliative care services.

6.3 Predicting the Need

We can assume from recent trends that the need in Luton for Children's Palliative and End of Life Care is likely to increase steadily – the difficulty is in predicting the level of increasing need, and the care that might be required, accurately.

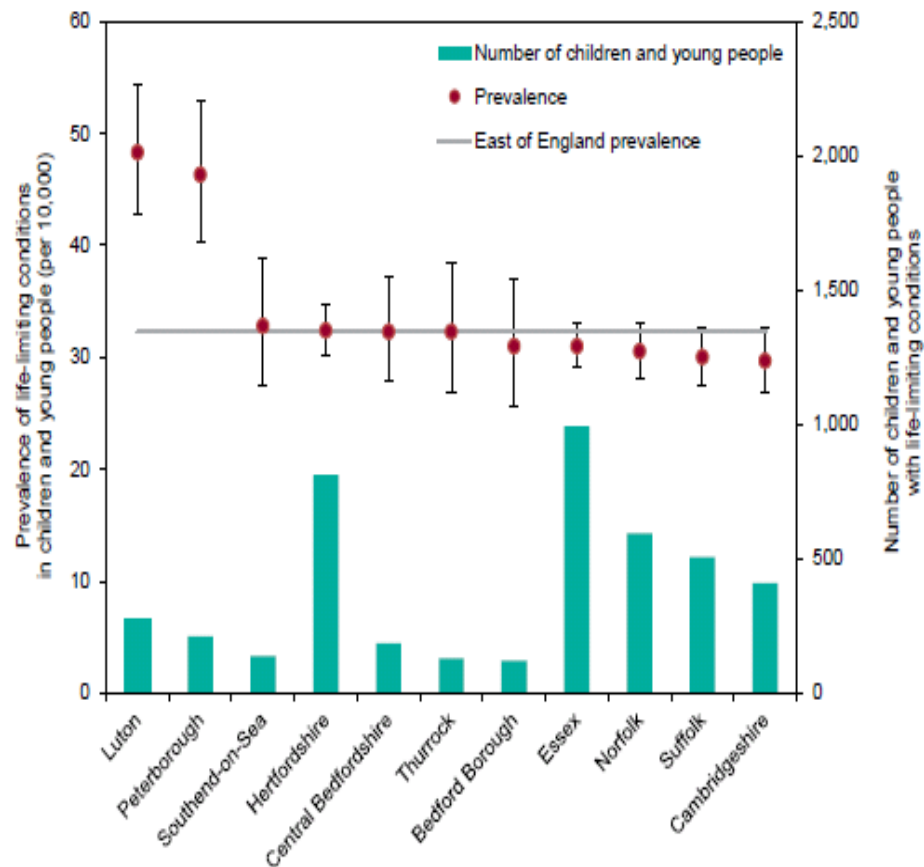
It is widely acknowledged that there is currently no direct measure to successfully capture use of palliative care services. Using the Fraser Method (Fraser et al, 2011, 2013) recent data from Public Health England updated the prevalence of palliative care in the East of England and estimated how the need for services may change in the future. This data was used to make projections up to 2024/25 and describes the prevalence by several characteristics including gender, ethnicity and diagnoses.

The diagram below shows the prevalence of life limiting conditions by Local Authority; note Luton's cases are predicted to rise substantially compared to others in the East of England. The second diagram shows prevalence of long term conditions by diagnoses.

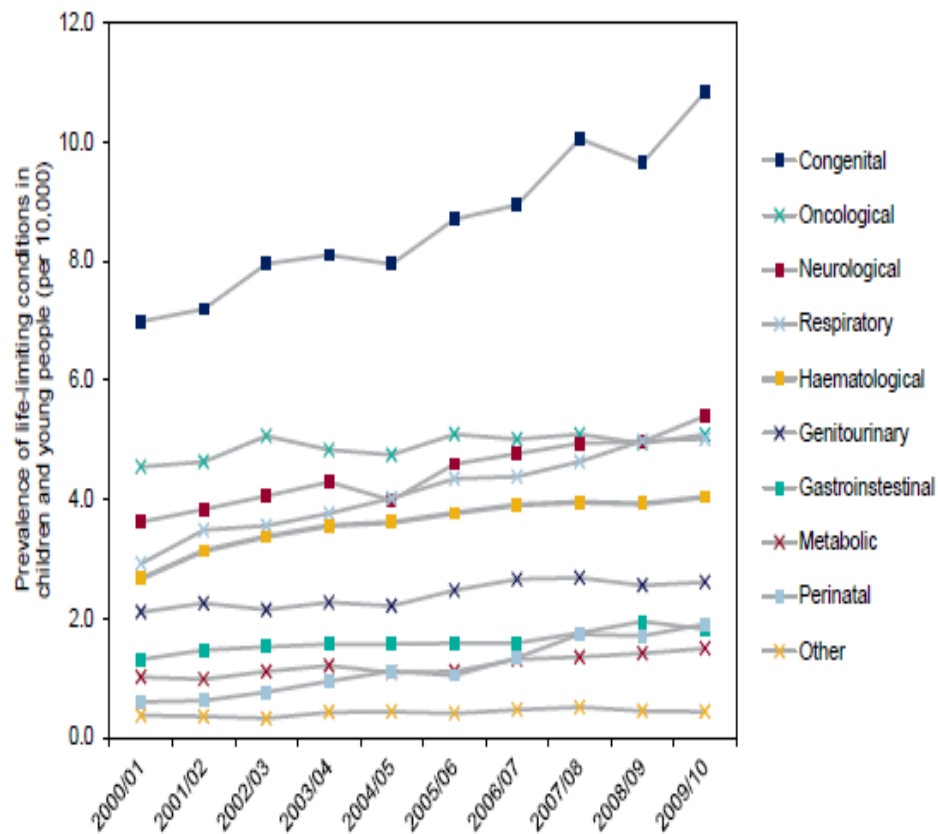


Public Health
England

Local authority



Estimated prevalence of and number with life-limiting conditions by county and unitary local authority, children and young people 0 to 19 years old* in the East of England, 2009/10.



Estimated prevalence of and number with life-limiting conditions by diagnosis*, children and young people 0 to 25 years old in the East of England, 2000/01 to 2009/10.

The discrepancy is probably due to a number of factors:

- The ethnic profile of Luton (for example: the South Asian population suffers a higher than average incidence of complex and/or degenerative conditions)
- Luton has a significantly above average incidence of complex disabilities - again with a higher concentration in the South Asian (Pakistani and Bangladeshi) population

In addition, the following factors will have to be taken into consideration in estimating the future need for children's palliative care services in Luton:

- It is forecasted that the population of children and young people in Luton will increase year on year until 2023. It will then fall year on year until 2039. (Source: Luton Borough Council using POPGROUP)
- Continuing improvements in obstetric, neo-natal and paediatric care will influence the survival rates of children and young people in Luton (particularly of those children not expected to survive beyond days, weeks or months) and this will be difficult to predict or to quantify
- Improved survival rates amongst children with genetic disorders and chronic diseases will mean a growth in the numbers of young people in transition between child and adult palliative care services.

Using the data available to date, we can estimate that there are approximately 94 children and young people (not including those with Cystic Fibrosis or cancer) with Palliative Care needs currently living in Luton. A number of data sources indicate that number of children needing Palliative Care will increase steadily. A significant proportion of children needing palliative care in the future will be from the South Asian community.

A key strategic goal for Luton is gain a clear, accurate, understanding of the demand for children's palliative care in the future and, therefore, we plan to develop an accurate, comprehensive and easily updated database on children in Luton with disabilities, life-limiting and life threatening conditions.

7. Areas for Future Development

Using an inclusive, open approach to strategy development and a range of data sources (including local and national data, local and national strategies, previous service reviews, local children and families, local research a) on the needs of South Asian children and their families and the views and experiences of b) parents of children with disabilities, and 'best practice' from neighbouring areas and elsewhere) we have identified our key areas for future development:

- Increase the breadth and choice of palliative and end of life care – particularly for hard to reach families
- Improve the links between health, education and social care services
- Develop 24 hour care for all children with palliative care needs (24 hour care is, currently, only for end of life care)
- Improve the transition from children's services to adult services
- Improve timeliness generally - of response and of provision of services and/or equipment
- Increase the range and availability of transport provision
- Develop 'Step Up' services (to prevent admission to hospital) and 'Step Down' services (after discharge from acute care)
- Increase access to psychological support for whole family
- Ensure services are accessible, flexible and sustainable
- Deliver reciprocal training between hospice and community staff
- Better partnership working
- Strengthen links between community nurses and GP's Gold Standard
- Introduce End of Life Plans
- Improve data capture

8. Strategic Goals

8.1 The Vision

There is a model of care to ensure that all children have responsive, flexible care tailored to their needs - including access to 24 hour care, a choice on the location of care and, when needed, specialist palliative care advice and services.

We will achieve this by:

- Developing monthly multi-agency meetings which will ensure that children are referred in a timely manner to appropriate palliative care support services

- Strengthening the community-based palliative care teams and developing a multi-disciplinary children's community team
- Removing any barriers to services (i.e. if some services can only be accessed through the Hospice)
- Developing a 24 hour service for all children with palliative care needs (currently end of life only)
- Increasing the number of hard to reach families' access to all children's palliative care services
- Radically improving 'timeliness' - of response, provision of services and/or equipment)
- Reviewing and addressing gaps in services (listed above)
- Strengthening the links between health, education and social care
- Equipping and training all school staff to care for children with Palliative Care needs
- Developing and strengthening relationships with wider base of voluntary agencies
- Developing flexible, specialist, age appropriate services for teenagers / young adults (which also supports transition between children's and adult's services and between health and social care services)
- Working better with adult services to ensure a smooth transition from paediatric to adult care

8.2 End of Life Care

We will ensure that all children and young people who are at the end of their lives have an advanced care plan including a clear end of life plan, and that they and their families are able to make decisions and have access to specialist end of life care, 24 hours a day

We will achieve this by:

- Ensuring all children and young people have an Advanced Care Plans which includes a clear end of life plan
- Strengthening community-based, multi-disciplinary, palliative care services
- Maintaining the 24 hour service for all children with end of life care needs
- Radically improving 'timeliness' - of response, provision of services and/or equipment)
- Strengthening the links between health, education and social care
- Using the 'best practice' tools
- Ensuring there is a wide range of appropriate and responsive bereavement support for all families in Luton
- Establishing links to, and working in more ways with, a wider number and range of local and national voluntary agencies
- Working in partnership with local providers so that children and families can exert choice (for example: preferred place of death)
- Establishing and implementing care pathways

8.3 Equality of Access and Provision

We will ensure that all children and young people have equal access to universal and generic services, regardless of their condition and regardless of their ethnic background

We will achieve this by:

- Using commissioning based model to strengthen local children's commissioning arrangements so that it remains a proactive rather than reactive process
- Working together in partnership across the health, education and social care and voluntary and community service organisations

- Removing any existing, artificial barriers to services
- Where appropriate, joint funding (or aligned budgets) and agreed decision-making formulae
- Auditing the local database to ensure representation of children from ethnic minority backgrounds across areas of children palliative care services
- Ensuring appropriate uptake, of suitable services, by hard to reach families
- Ensuring that information methods are appropriate for and support all families' needs
- Ensuring that, where families are in need, adequate financial support is provided

8.4 Data

We will have clear and current data about all children and young people with or likely to have palliative care and end of life care needs, so that we can more effectively plan, commission and provide services

We will achieve this by:

- Developing a multi-agency approach
- Identifying and adding other children needing palliative care ie 'Cardiac children' to the database
- Keeping the database up to date
- Implementing the mapping programme and/or the NSF Standard 8 Audit tool
- Cross referencing with other sources of data (for example: the Children in Need census and children and young people on the local Disability Register, children and young people on the social care database.)

- Auditing the database to ensure representation of children from ethnic minority backgrounds across areas of children palliative care services
- Ensuring the involvement of GPs

8.5 Patient Information

We will radically improve the quality and range of information available for children, young people and their families.

We will achieve this by:

- Working closely with parents and children and young people in designing materials and methods of information
- Ensuring that there is a wide range of methods of informing people about current services
- Responding to the outcomes of the parent consultations and feedback

8.6 Network

We will establish effective, accountable, local and regional structures to lead and manage the implementation of this strategy.

We will achieve this by:

- Establishing a locally based Strategy Implementation Group (comprising parents, clinicians, managers, commissioners)
- Establishing clear links between the local groups
- Establishing a locally based working group (comprising managers, clinicians, parents) which will provide regular feed back to the strategic group
- Establishing links with other, relevant, networks (such as the local neonatal network)
- Ensuring progress is reported to relevant strategic partnerships

- Establishing links with adult services through the children's transition team
- Establishing links with general practitioners

8.7 Short breaks

We will ensure that there is choice and flexibility in the provision of short breaks for children, young people and their families which contribute to positive outcomes for the child and their family

We will achieve this by:

- Ensuring that there is a wide variety of flexible, responsive provision
- Ensuring that short breaks can be provided both *at home* and *close to home*
- Stimulating the market and encouraging innovation in this area so that there are a variety of providers and styles of provision
- Work in partnership with adults social care to develop and establish appropriate short breaks following transition
- Underpinning this objective through a separate strategy

8.8 Parent / child involvement

We will ensure that parents, children and young people are directly involved in improving Children's Palliative Care Services in Luton.

We will achieve this by:

- Involving children, young people and their families in commenting on / developing early drafts of this strategy and in determining priorities
- Continuing to involve children, young people and their families in current and future service design
- Including children, young people and their families as members of the local implementation group

- Asking children, young people and their families to lead on key elements (such as information for parents, children and siblings)
- Asking for feedback on the outcomes from implementing the strategy
- Using the children's and parents' stories in service development
- Using the outcomes to influence service design and provision

8.9 Workforce Development

We will ensure that children and young people with life limiting conditions are cared for across the system, by an expert workforce, based on their specific individual needs

We will achieve this by:

- Ensuring that services have both an understanding of the care of children and young people with palliative care needs and their families, and know how to access (and how to help families to access) appropriate palliative care services
- Influencing / contributing to the workforce development across generalist services
- Reviewing specialist palliative care expertise across the system
- Ensuring workforce is trained, experienced and competent in meeting the varying needs of children and young people
- Developing and implementing a planned approach to achieve a workforce of the required capacity and expertise
- Auditing the level of cultural competence within the current workforce and developing / implementing a training programme to address gaps in knowledge (particularly in 'End of life' beliefs)
- Ensuring and enabling an agreed transition pathway into Adults social care services

8.10 Transition

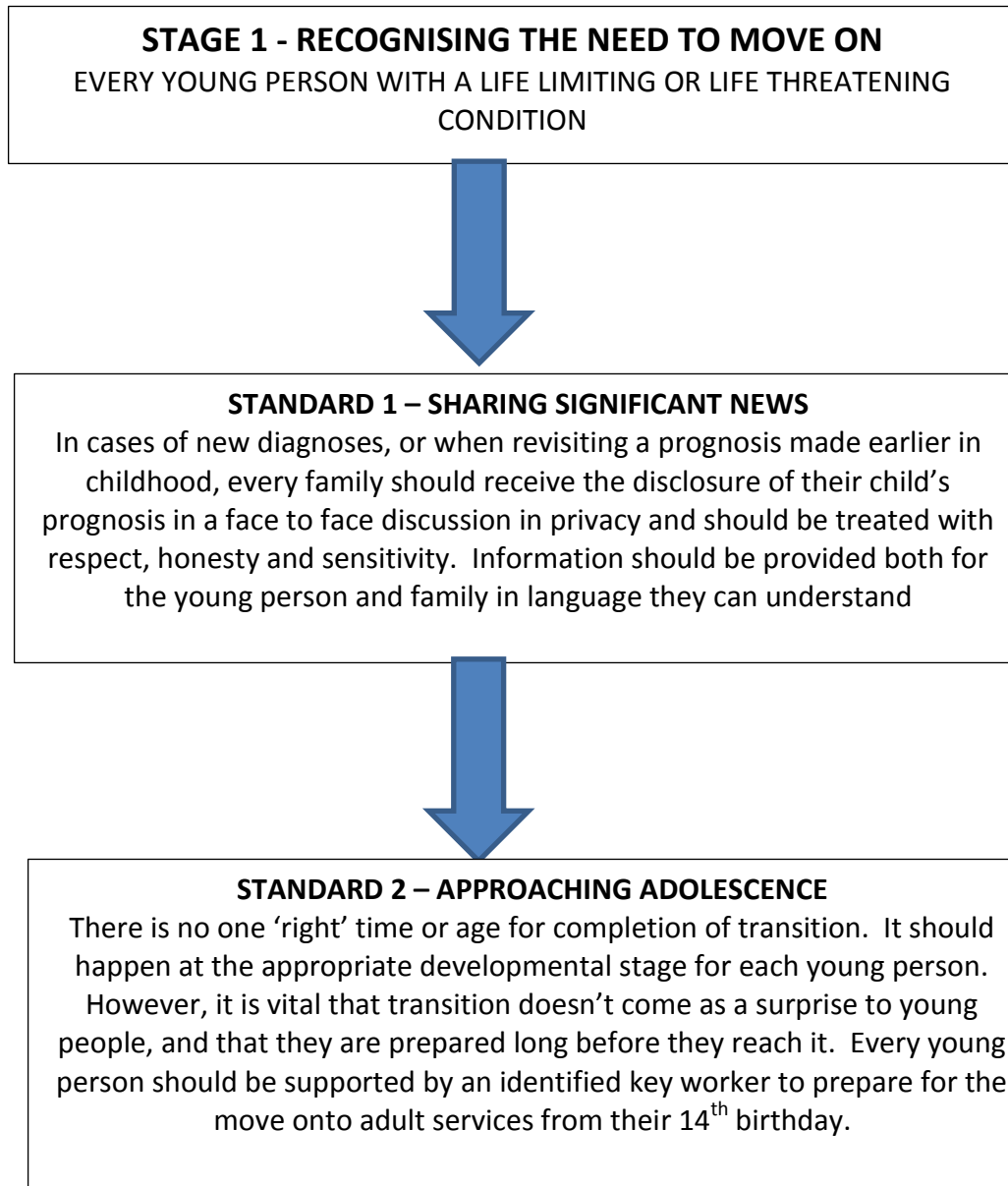
We will ensure that teenagers and young adults are cared for in the place and by the people of choice, and that transition to adult services is a planned and purposeful process

We will achieve this by:

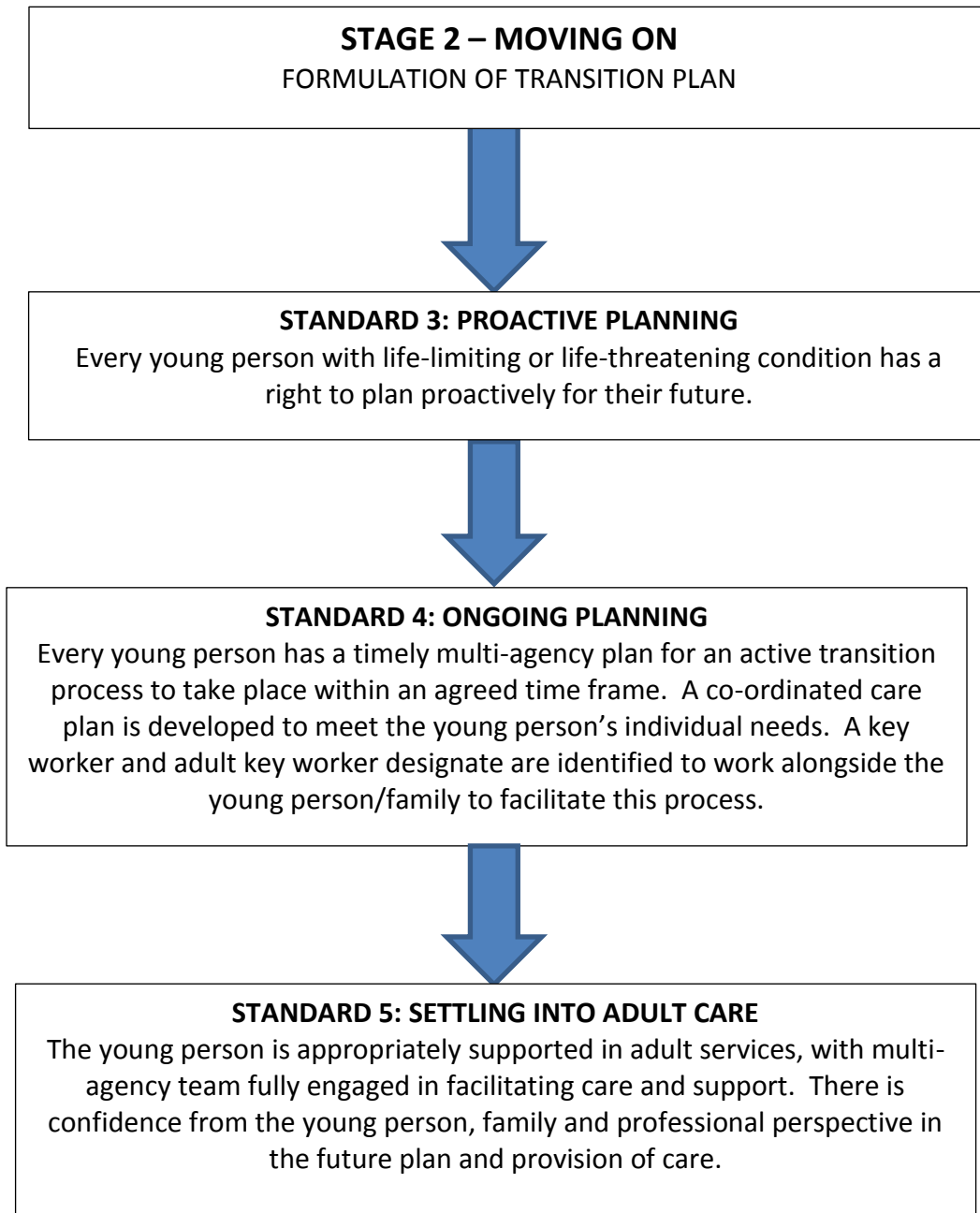
- Establishing and implementing a Transition pathway for palliative care young adults
- Developing flexible, specialist, age appropriate services for teenagers / young adults (which also supports transition between children's and adult's services and between health and social care services)
- Working in partnership with the Transition service to support Transition plans for palliative care
- Supporting transition between children and adults social care
- Early identification of individual needs including equipment
- Alerting and supporting Adult social care services to training needs
- Having a dedicated Transition Nurse
- Linking this strategy to the Adult Palliative Care strategy
- Securing the timely engagement of adult health care

The framework for the Transition Pathway has been summarised on the following three pages:

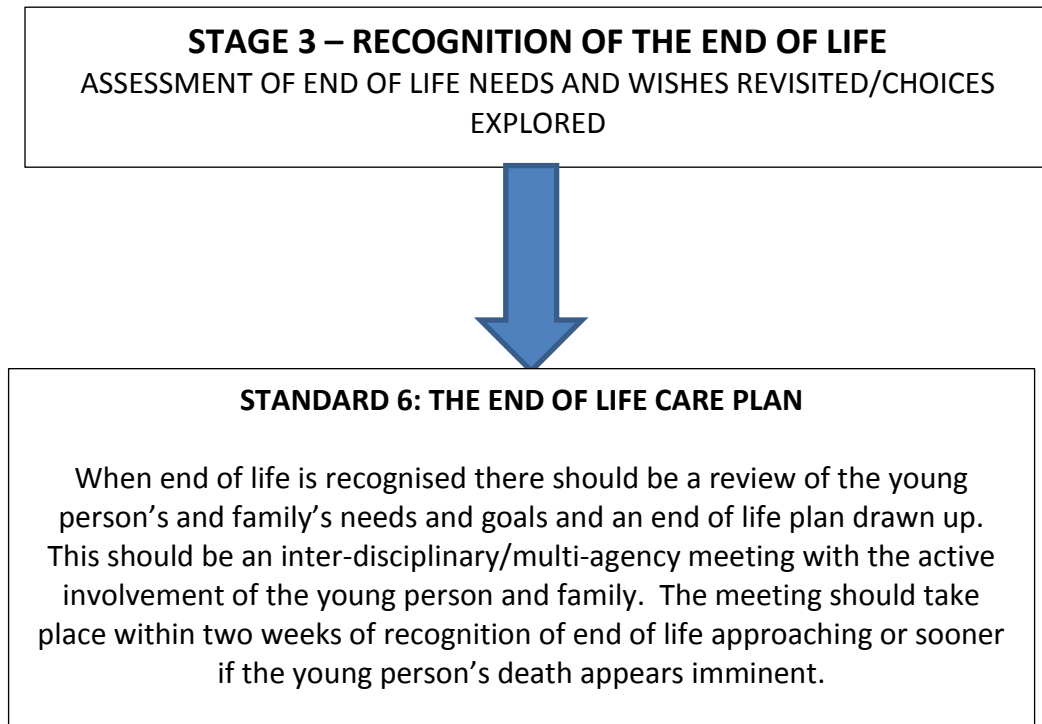
Palliative Care Transition Pathway Framework



Palliative Care Transition Pathway Framework (continued)



Palliative Care Transition Pathway Framework (continued)



Source: ACT Young Life Matters (2007)

8.11 Transport

We will ensure that all children and families are able to take up the services that are offered to them and are not denied access to services by the lack of appropriate transport

We will achieve this by:

- Ensuring that local transport provision available to families is well publicised, known and used by children and families
- Reviewing what else is needed and where the gaps are
- Looking for and generating opportunities to develop further provision, through partnerships with individuals, local agencies (both voluntary and statutory) and private providers

9. Taking the Strategy Forward

9.1 Implementation

The local joint strategy group will be responsible for implementing this strategy. This is a proven and effective structure in improving Children's Palliative Care Services. The implementation group will be responsible for developing an implementation action plan and will report directly to Local Clinical Commissioning Groups and relevant boards.

9.2 Monitoring and Reviewing Arrangements

In accordance with the 'Better Care, Better Lives' guidance, the local strategy group will be supported by and connected to a local Children's Palliative Care network. Following Strategic Clinical Network reprioritisation the continuation of the regional network group is currently under review.

9.3 Data Improvements

We will achieve this through development of an improved information sharing agreement among professionals, however, current systems and processes are not suitable for this purpose, a situation recognised nationally. To address this

issue, NHS England will be publishing a Child Health Digital Strategy (due summer 2016) this document will look at the options for transforming the way in which information is gathered and used, and set out the strategic direction for child information for the next 4 years up to 2020.

9.4 Outcome Measures

Success is measured when:

- There is an increase in the amount, quality and range of locally based, culturally appropriate service provision;
- Palliative care provision as a whole is evaluated by users and professionals as meeting the requirements of children and young people; supporting families to continue to care for their children; families have choice; services are reliable, easily accessible, responsive and flexible;
- The palliative care service is delivered more cost effectively;
- Legislative requirements are met.

Successful outcomes for children, young people and their families will be measured in terms of the following criteria:

- a) Child/young person experiences a peaceful death
- b) Child/ young person does not die in pain
- c) Child/young person dies in the place of their or their parents' choice
- d) Child/young person has an end of life or advanced care plan
- e) Parents are included in multi-disciplinary meetings regarding their child's care
- f) Parents report they feel supported in planning their child's care
- g) The recommendations in the end of life care plan are adhered to where possible

Successful outcomes for professionals will be measured in terms of:

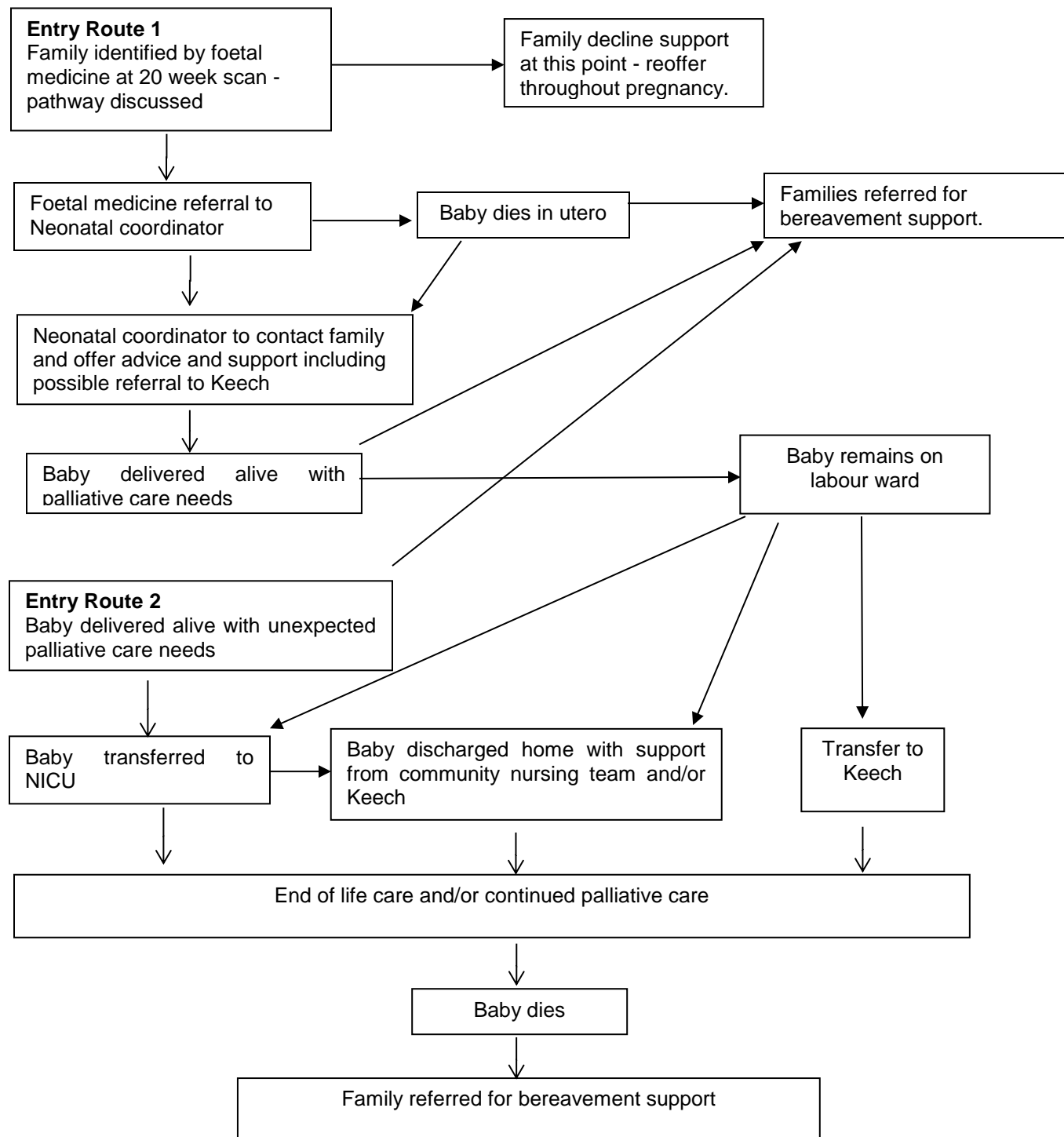
- a) Professionals are able to provide appropriate support in a co-ordinated, managed way
- b) Professionals are able to take parents' wishes and feelings into consideration when planning end of life care
- c) Professionals are afforded the opportunity to have protected clinical time within an MDT prior to the involvement of parent
- d) Professionals report they are satisfied with the co-ordination of end of life care
- e) The recommendations in the end of life care plan are adhered to where possible
- f) There is accurate data available on the numbers of children and young people with palliative care needs in Luton.
- g) Information is shared and made available to relevant professionals
- h) Professionals work in partnership to deliver high quality palliative care services

10. Luton Palliative Care Case Study

Title
Multi-disciplinary approach to providing support for palliative and end of life care.
Content
<p>Background:</p> <p>Child A was diagnosed in early 2013 with an inherited, genetic, progressive neurological condition, experiencing progressive neurological deterioration and gut failure resulting in multiple admissions to local hospitals, her last admission to Addenbrookes being for feed intolerance.</p> <p>As she moved into the final stages of her illness, she was admitted to Luton and Dunstable Hospital with a complete intolerance of enteral feeds. She experienced massive aspirates and became dehydrated and was ultimately discharged home for ongoing management of her gut failure and dehydration.</p> <p>A's home life was complex, with several generations and extended family living under one roof. After consideration, parents decided that their daughter should be admitted acutely to Keech Hospice for crisis management. While at the hospice, and in spite of IV fluids, end of life was diagnosed.</p> <p>A's mother had always taken a 'hands-on' approach throughout her daughters' care, and professionals found it challenging that she wanted to continue to provide all of A's care herself, even when she herself was ill. This was complicated by A's intolerance of food and drink and the added cultural and emotional meaning that this carries.</p> <p>During her last 24 hours A underwent a rapid but very peaceful deterioration. She died peacefully in the early morning in March 2014, and her funeral took place the same day.</p>
Outcomes
<p>What improvement in outcomes took place for children, young people and/or families, in terms of:</p> <ul style="list-style-type: none"> a) the perspectives of children, young people and their families <p>Throughout A's illness, her parents were keen to be involved in all decision making. They were invited to their daughters' MDT meeting and were able to consider the health professional's advice as part of the team.</p> <p>Though the involvement of so many professionals and different clinical opinions was initially confusing, A's parents reported that they were glad to be part of the MDT and were reassured to see all the professionals working together.</p> <p>Parents said they had appreciated the opportunity to try to give A fluids until they realised it was not having an effect, and took comfort in the knowledge they knew their daughter had been given every chance. Parents expressed relief that her suffering had ended and, because of their strong faith, they believed she had gone to a better place. Parents said that they had felt very supported by the professionals and appreciated being allowed to be actively involved in all decisions relating to their daughter.</p> b) the perspectives of managers, practitioners and services providers <p>Professionals reported that the MDTs involving the parents were valuable, but have stressed the importance of having protected time at a clinical MDT to address key issues such as clarifying what stage of life A was at, before having the opportunity to discuss this with the parent.</p>

<p>Professionals stated that although managing the child's care was challenging due to the unpredictable nature of her disease, with slow deterioration and acute crisis, they felt they did manage to give co-ordinated care, take parents' wishes into consideration and support them in their decision-making. Professionals were reassured that the child experienced a peaceful death.</p>
<p>Why it works?</p> <ul style="list-style-type: none"> i) Parents feel empowered when involved in the decision making and planning of care for their child. j) Professionals are able to take parents' wishes and feelings into consideration when planning end of life care. k) Professionals are able to provide appropriate support in a co-ordinated, managed way
<p>Success criteria</p> <ul style="list-style-type: none"> h) Child/young person experiences a peaceful death i) Child/young person dies in the place of their or their parents' choice j) Child/young person has an end of life care plan k) The recommendations in the end of life care plan are adhered to where possible l) Parents are included in multi-disciplinary meetings regarding their child's care m) Parents report they feel supported in planning their child's care n) Professionals are afforded the opportunity to have protected clinical time within an MDT prior to the involvement of parents o) Professionals report they are satisfied with the co-ordination of end of life care
<p>Contact Details</p> <p>Lindsey Barron, Childrens' Commissioner, Luton Clinical Commissioning Group/Luton Borough Council Lindsey.barron@luton.gcsx.gov.uk Tel: 0782 448 33 40</p>

Appendix A - Neonatal End of Life Professionals Pathway



Appendix B - Neonatal Service Pre Pathway Protocol

STEP ONE

MDT at Early Intervention Meeting agrees prognosis and suitability for pathway.
Prognosis is shared with family. Parents are engaged in Care Introduction Meeting.
Family request supported discharge for end of life care in the community.
Pathway Commenced

STEP TWO

Pathway Documentation is prepared and agreed to plan and facilitate discharge to the community destination of the family's choice.

STEP THREE

Arrangements are made for the most appropriate manner of transfer to the community destination, including clinical handover and covering the necessary arrangements for the certification of death should it occur in transit or soon after.

STEP FOUR

The Team around the family continues to deliver support throughout the end of life process including pre-funeral and funeral arrangements, registration of death, spiritual ceremonies, post-natal care of Mother and continuing bereavement support.

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