



Thames Valley Children's Palliative Care Network

The Thames Valley Children's Palliative Care Pathway

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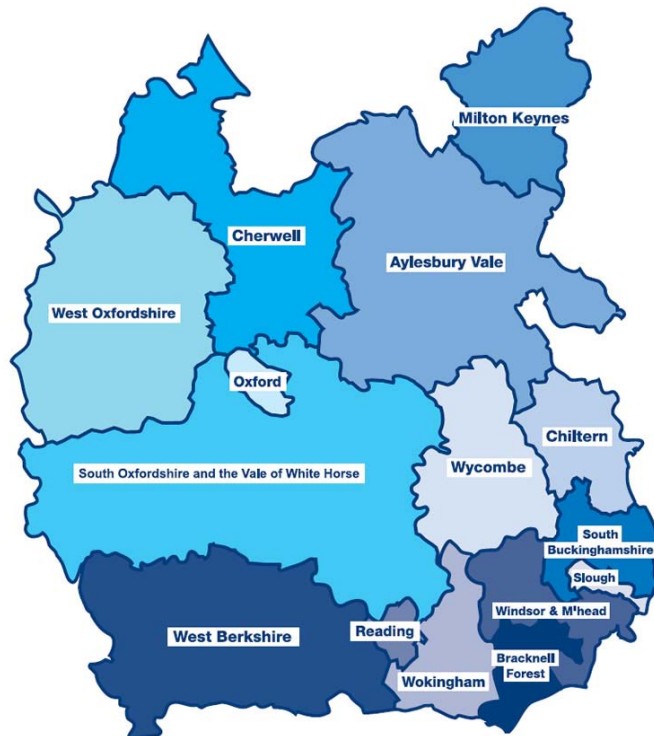


The Thames Valley Children's Palliative Care Network Pathway

1. Introduction

The Thames Valley Children's Palliative Care Network (TVPCN) was established in 2009. The network includes a group of health and social care professionals and parent representatives who actively support the strategic and operational development of children's palliative care across the Thames Valley. The network supports all children with life limiting conditions (LLC) where there is no hope of cure and to which we believe palliative care services should be available. A recent study estimates the prevalence of LLC to be 32 per 10 000 population suggesting over 1700 children requiring palliative care in the Thames Valley. The development of a children's palliative care pathway is fundamental to ensuring that all children and their families within the Thames Valley receive high quality, appropriate care throughout their illness and that all care is appropriately commissioned and funded. The 2015/16 development currency for palliative care will provide a framework for providers and commissioners to support the commissioning of palliative care services. Local authorities, CCGs and NHS England will need to work together to commission all care on the pathway and have a duty for joint commissioning set out in the Children and Families Act.

Fig 1 The Thames Valley covers the geographical counties of Buckinghamshire, Oxfordshire and Berkshire.



2. Purpose and Aims

The Thames Valley Children's Palliative Care Pathway (TVCCPCP) has been produced to support professionals, services and commissioners to identify children and young people who have a life limiting or life threatening condition and their families' children and the services required to meet their changing needs. The pathway has been guided by the key principles and recommendations outlined in Core Care Pathway (TFSL 2013) and NHS England Service Specification for paediatric palliative care (2013) both of which promote an integrated multiagency service delivery model of support.

The aim of the pathway is to facilitate a seamless, coordinated and timely service appropriate to the child/ young person's needs. The focus is on enabling choice whether there is a need for ongoing care or end of life care.

The pathway should be used to support:

- children / young people requiring ongoing complex and palliative care within the home, hospice, or hospital setting to access appropriate services and support
- children and young people at the end of life to receive timely appropriate care.

3. Data and Costs

The network recognises that robust and detailed data to demonstrate the number of children requiring all levels of service within the pathway is essential for service delivery and commissioning. However, although we are able to identify children and young people requiring palliative care there is limited data that identifies those children who access different levels of care and support across organisations and services in the region. The network is currently developing a tool for data collection that will provide this information. Until this data is available the TVCCPCN proposes an overview to support this pathway.

It is estimated that there are 49 000 children under 19 years across the UK living with a LTC or LLC who may require palliative care services (Fraser et al 2011). The largest percentage increase is identified within the age groups of 16 – 19 years and under 1 year (neonates). There is an urgent need to understand the patterns and direction from this data to ensure we target resources where it is most needed and that we are able to shape services to meet the needs of children and families.

The most comprehensive data to date that informs the cost of service delivery was outlined in the Palliative care statistics for children and young adults (DH 2007), highlighting a third of total NHS expenditure for paediatrics was spent on children's palliative care with 99% in NHS trusts. A quarter of children's palliative care costs was on neonates. Although these costs were calculated in 2004/5 increasing numbers of children with LT and LLC, in particular within neonates would indicate a greater cost across NHS, CCG and non-statutory services.

The Palliative Care Funding Pilots (2014) and analysis of the data collected will contribute to a more comprehensive understanding of activity and differences in complexity of care and associated costs. However it will be crucial for the Thames Valley to engage in robust and consistent data collection processes and agree a single minimum dataset for the region to gain data that is meaningful for the region that will support commissioning of local and regional services.

Furthermore accurate data reflecting levels of care will inform a potential funding system for commissioners within the region. NHS England is aiming through its Palliative Care Funding Pilot (PCFP) to develop a currency for palliative care. This will provide an evidence based funding system to inform discussions about costs and funding for commissioners and providers.

Planning quality, safe and cost effective pathways of care would mean costs are appropriately distributed, reducing the cost to NHS trusts.

4. Definition of Terms

Life limiting conditions is sometimes referred to as life shortening and are those conditions for which there is no reasonable hope of cure and from which children or young people will die.

Life threatening means that the child has a health condition for which curative treatment is possible but may fail, if the treatment does not work then the child will die.

Complex care needs have been identified as children with disabilities or continuing health care needs who require a range of services in the community. They require an individualised package of care beyond which is available through standard health services.

There are no universally agreed definitions for **specialist and specialised services** and different levels of care and service input are guided by practice guidance and policy.

5. Principles of Care Pathways

The use of the pathway should be considered as soon as it is clear that the child has a life limiting or life threatening condition or is moving towards end of life care. The pathway should support care in the most appropriate setting.

The key aims of the pathway will be to:

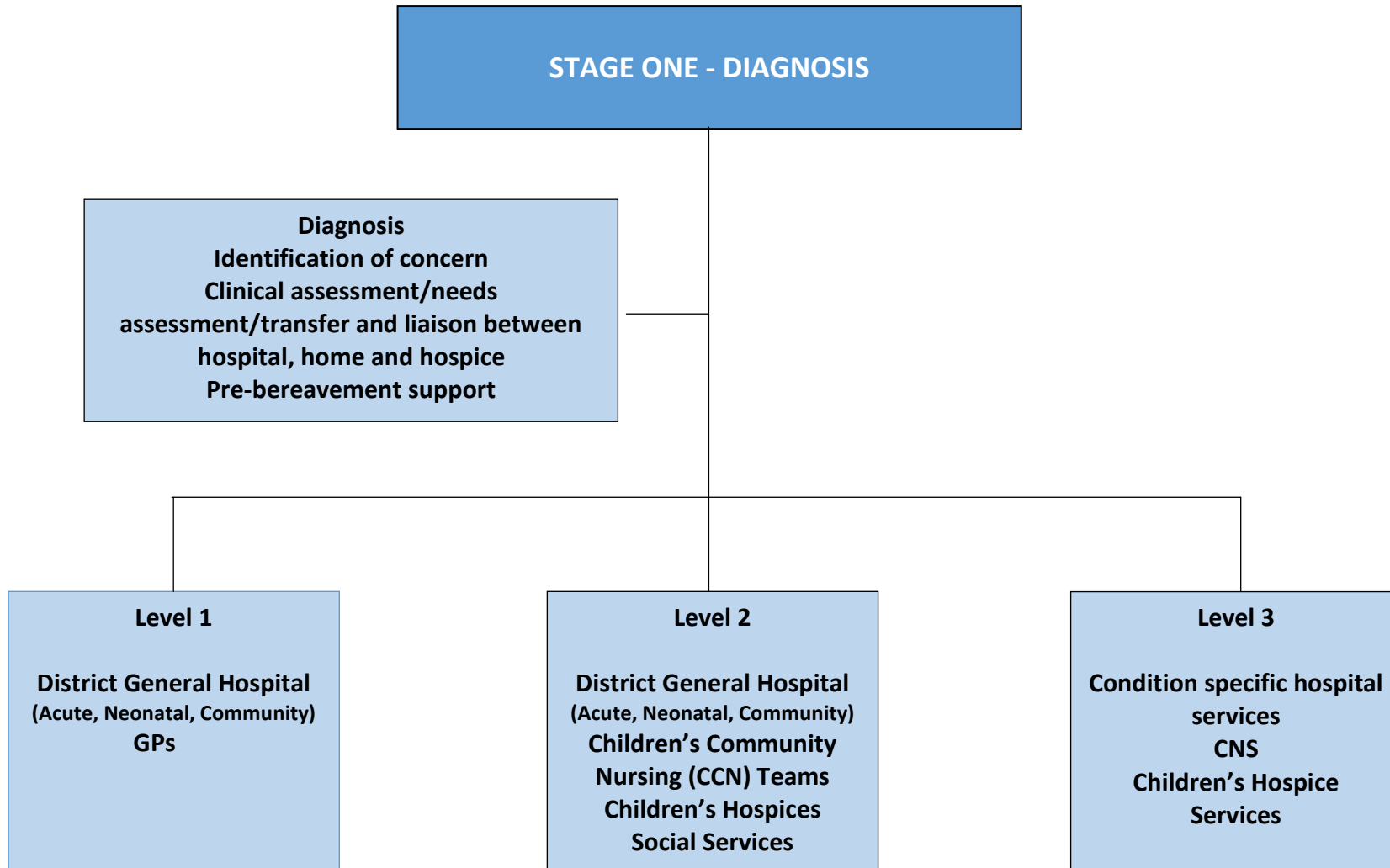
- ensure palliative care is child and family centred
- ensure families have choice in care delivery
- deliver consistent high quality care
- reduce variance of practice
- provide evidenced-based practice
- be used for audit and outcome measurement
- enhance communication and sharing of information between professionals and services and commissioners
- ensure the team around the child is drawn from local and regional teams
- provide clearly defined professional roles which apply wherever the child is cared for

6. The Thames Valley Children's Palliative Care Network Pathway

The Thames Valley Children's Palliative Care Network Pathway (TVPCNP) is a multiagency pathway that identifies different levels of service delivery that children and families may access dependent on choice and need. Level 1 indicates all children requiring core palliative care services through to Level 4 for those children who may need a specialist palliative care team. The pathway should be used alongside organisational end of life pathways to ensure seamless service delivery at the time of death and after death.

Although the focus of the pathway is specific to health care delivery it recognises a holistic and multi-professional approach inclusive of social care and education. The case studies (section 7) demonstrate a multiagency pathway approach.

THAMES VALLEY CHILDREN'S PALLIATIVE CARE PATHWAY



STAGE TWO – ON-GOING CARE

MDT assessment
Supporting family and child environmental needs
Symptom management
Consideration of Advance Care Planning
Therapeutic care/psycho-spiritual support and pre-bereavement support

Level 1

GPs
Education
Social/leisure
Pharmaceutical

Level 2

District General Hospital (Acute, Neonatal, Community)
CCN teams
Continuing care
Short breaks
Therapies
Children’s Hospice Services
Social Services

Level 3

District General Hospital (Acute, Neonatal, Community)
CCN teams
Condition specific hospitals
Specialist nursing services (CNS)
Children’s Hospice Services

Level 4

Consultant led multi-professional specialist palliative care team

STAGE THREE – END OF LIFE

Assessment of end of life
End of life plan/symptom management plan
Advance Care Plan/Do not Resuscitate
Support at time of death and after death
including funeral and immediate bereavement
support

Level 1

GPs
Education
Social/leisure
Pharmacy services

Level 2

District General Hospital
(Acute, neonatal, Community)
CCN Teams
Continuing care
Short breaks
Therapies
Children's Hospice Services
Condition specific Clinical
Nurse Specialist

Level 3

District General Hospital
(Acute, neonatal, Community)
CCN Teams
CNS
Children's Hospice Services

Level 4

Consultant led multi-
professional specialist
palliative care team

STAGE FOUR - BEREAVEMENT

Bereavement services are offered/provided by palliative care services and individual organisations across the Thames Valley

7. Case studies - Names have been changed for reasons of confidentiality

Case Study 1 – Emma

Emma was born with a life-limiting condition which meant she was unable to walk, talk, eat orally and she had complex health needs. She was the second of four children and her siblings were unaffected by the condition. Her parents separated when she was six years old which added to the stresses on the family.

For the majority of her life Emma had been receiving care at home from a local hospice children's community service and accessing support from an inpatient children's hospice. Both services provided a range of support to Emma and her family including planned respite and emergency care at times of illness and deterioration in her condition. The family also needed significant social and psychological support as a consequence of the demands and pressures of having a child with such complex needs. This was provided jointly by both services – weekly visits from the community service and regular admissions to the hospice ensured a consistent level of support. This support continued with Emma's family being her main carers and Emma receiving specialist palliative care and treatment when necessary alongside support in the community.

Over the course of a couple of years it had been observed that Emma's condition was gradually deteriorating. As a child prone to chest infections, these were increasing in frequency and her recovery from these episodes was slower. She often needed oxygen during times of illness but there were periods when she was generally well but showed signs of respiratory compromise. Gradually her need for oxygen therapy increased and she needed it most of the time. Emma's family were aware of her prognosis but her parents were often at different stages of acceptance and had difficulty in recognising the general deterioration in her condition and the potential impact that each bout of ill health presented.

One Thursday Emma was sent home from school unwell and Mum contacted the hospice community service for advice and support. One of the nurses visited and arranged for the GP to visit and oral antibiotics were prescribed. The nurse also contacted the Children's Community Nurses who were able to support with equipment supplies and referral to a community physiotherapist who visited Emma and carried out chest physio to help relieve some of her discomfort. The advice and support of the physiotherapist enabled the nurses caring for Emma to continue a level of therapy over the coming days. Over the course of the weekend one of the hospice community team visited each day, staying for several hours at a time to care for Emma. Her condition deteriorated with a persistent fever, increasing oxygen needs and difficulties tolerating feeds. The nurse made contact with the Hospice on Saturday and although at this time the family did not wish to go into the hospice, medical advice was obtained and the lines of communication sustained over the weekend. By Monday morning Emma had deteriorated further and did not appear to be responding to the antibiotics or chest physiotherapy. The hospice community nurse maintained contact with the Doctors from the hospice over the weekend, keeping them informed of Emma's condition and how the family were coping. The nurse requested another GP visit and expressed her concern both to the family and the GP regarding Emma's condition and ability to recover from this episode. The GP spoke with medical staff at the hospice and they agreed that based on his assessment she was very sick and may not recover.

Emma was transferred to the hospice. She did not respond to antibiotics and gradually deteriorated. She had occasional morphine to keep her comfortable. Her family were around her when she died peacefully. Emma and her mother stayed at the hospice for 3 days following her death. The other members of the family returned home.

Case Study 2 - Freddy

Freddy was born at term, delivered at home, and appeared a healthy baby boy. Shortly before he was 2 years old following months of concerns about his development, he was diagnosed with a progressive degenerative disorder. Freddy's parents cared for him and managed his care needs at home, accessing essential services around his development and specific needs. He was able to start school and continued to access a range of therapies including support with feeding.

The Children's Community Nursing Team (CCNT) became involved as nutritional achievement became harder to manage and Freddy required nasogastric and then gastrostomy feeding. As Freddy's condition deteriorated, the CCNT increased their support; by attending hospital appointments, increasing the frequency of home visits to offer support and clinical skill with dressings and feeding management. In addition they provided support and training to school staff involved in Freddy's care.

Freddy was referred to the local Childrens Hospice and he and his family received support and guidance around symptom management, with some in house respite. The liaison between the hospice and the CCNT allowed greater support for the family in addition to more seamless care. The local Childrens Hospice, CCNT and Paediatrician supported the family to achieve an Advanced Care Plan (ACP) and decide on appropriate symptom management.

As Freddy's ability to access school decreased and his condition deteriorated the CCNT provided increased respite at home. This developed from fortnightly teatime sessions to daytime weekly visits on a regular basis. The CCNT also provided liaison with the sibling's school, with consent from the family. Support was offered at night however this was declined. Visits became more frequent with early morning and afternoon visits. These visits involved liaison with the local Hospice and the GP to ensure support around symptom management. The family needed ongoing support around changes in feeding management, review and support of the wound site, and liaison re care and access to dressings/ and the medications required following review and assessment of pain management. At this time support at nights were again offered in respect of the family wishing for Freddy to remain at home for his 'end of life care', however night care at home was declined again by the family.

The local Hospice outreach provided regular symptom management review in the home during the last few months, often as shared visits with the CCNT. This liaison allowed communication to be achieved between the family and multidisciplinary teams with ease and ensured support around the introduction of new medication and changes in care.

During the final week of Freddy's life, the community team offered 7 day support, with telephone contact, supportive visits, and respite. This support was achieved early morning with a telephone call or visit to allow liaison, and then be followed up with an afternoon visit. This was tailored to meet the family's needs. Over Freddy's final few days these visits supported the evening time as the family prepared for the night, ensuring that the family were equipped with a plan of management for the night if required. The family's wishes were respected and regularly reviewed during this phase. The family still declined night care. During Freddy's last few days his medication needs changed. Symptom management was managed via a syringe driver with medication directed by the local Hospice medical team. The community nursing team managed safe routine medication changes of this and cover for possible overnight support with two nurses.

Freddy died peacefully at home with his parents as the family had wished.

8. Services represented across the Thames Valley

Alexander Devine Children's Hospice Service
Buckinghamshire PCT
Children & Young People Joint Commissioning Directorate, NHS Berkshire
Children and Maternity Strategic Clinical Network, South Central
Children's Commissioning, Buckinghamshire PCT
Children's Community Nursing Team Berkshire HealthCare Foundation Trust
Children's Community Nursing Team, Buckinghamshire
Children's Community Nursing Team, Wexham Park Hospital Frimley Health NHS Trust
Children's Community Nursing Team, Milton Keynes
Children's Community Nursing Team, Oxford Health NHS Foundation Trust
Children's Community Nursing Team, Royal Berkshire NHS Foundation Trust
CLIC Sargent
Community Children's Respite Team, Oxford Health NHS Foundation Trust
Complex Care Community Nursing Team, Swindon
Florence Nightingale Hospice, Bucks
Health Commissioner, Children & Young People's Joint Commissioning Team, Bucks
Helen & Douglas House
Rennie Grove
Joint Children's Commissioner for Oxford
Keech Hospice Care
Milton Keynes Complex Care Team
Naomi House & Jack's Place
NHS Aylesbury Vale CCG
NHS England Southern Central Commissioning Support Unit
Nurse Assessor for Children & Young People, NHS Buckinghamshire & Oxfordshire Cluster
Paediatric Oncology Outreach Nursing Team, Children's Hospital, Oxford University Hospitals Trust
Rainbow Trust
ROSY (Respite Nursing for Oxfordshire's Sick Youngsters)
Sebastian's Action Trust
Thames Valley Strategic Clinical Network
Together for Short Lives

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