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# **Palliative and End of Life Care Strategy for Children and Young People 2021-2024**

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## Executive Summary

The following document is a strategy focused on End of Life Care for Children and Young People. Produced by Shropshire Community Health Trust (SCHT) it reflects plans for 2021-2024. This strategy has been established to support the care of the child at the end of life, at the time of death and beyond. It reflects 'what we are good at' and identifies areas for improvement in line with NICE guidance and other key documents. The identified action plan is aimed at enhancing current practice to provide a sustainable, high quality and consistent approach to care that will be reviewed for impact and progress.

The document recognises that in Shropshire, Telford and the Wrekin children and young people's (C&YP) palliative and end of life care is being delivered well. Services have responded to advancements in technology and the increasing numbers of children and young people with life limiting illnesses that go on to access palliative and end of life care. However, this review process has allowed us to look at how we can add strength to current services and reflects an approach to delivery that aligns to our Trust values.

SCHT offers a multi-agency, person-centred approach to end of life care for C&YP (0-19 years) that is flexible and responsive at different stages of life limiting illnesses. SCHT recognises that child and families must be central to the care provided and given choice.

When a child is diagnosed to have a life limiting or life-threatening condition, the Children's Community Nursing (CCN) team are instrumental in coordinating careful planning and facilitating complex decision-making with children and their families. SCHT promotes a care pathway approach to children's palliative care and with its partner's aims to reduce inconsistencies surrounding end of life care for children and young people.

The Children's Community Nursing signpost's families to comprehensive bereavement care and recognises the heavy emotional weight paediatric palliative care has by supporting staff with various mechanisms of supervision.

Areas have been identified for further development such as Transition to adult services, increased service user feedback, staff training and earlier identification of children who may need an Advanced Care Plan. We recognise that Transition planning needs to start earlier in the child's life and collaboration with adult services must be more robust. Increased staff training is an area previously identified for future development and the availability has been increased to support staff to work with this very complex client group, enhancing quality of care thus helping to reduce inconsistencies in service provision. We know that numbers of children with life limiting illness are increasing and workforce planning needs to align with these projections to ensure we have adequate capacity in the future. It is also acknowledged that a central local database of children requiring palliative care would greatly assist earlier identification and improve analysis of current figures and this is now in development.

This document includes an action plan of measurable outcomes that addresses the gaps locally as well as NICE (2017) standards to be monitored to ensure continued high quality service delivery.

## Introduction / Background

*“There can be few greater tragedies for a family than the death of their child. The circumstances surrounding their child’s death can have a huge impact on family members and imprint memories which may last a lifetime.”*

*Sister Frances Dominica, OBE DL, FRCN FRCPCH Vice President, Together for Shorter Lives, 2012*

This document is written for all practitioners working with Children and Young People (C&YP) 0-19 years, living with life limiting illness. The information aims to support professionals working in Shropshire Community Health Trust (SCHT) in making sense of the complexities surrounding end of life care for children and promoting consistency. It is important that our services in SCHT have agreed processes within our current clinical networks that are collaborative on care planning and service delivery.

The CQC inspection of 2016 for End of Life (EoL) care in SCHT was one of the catalysts for change, there were areas the needed addressing and improvements are always beneficial. This led to the development and agreement of the End of Life Strategy which was separated into Adults and Children and young People. An overarching statement made connections between the two strategies by the need to develop a Transitional process for those children with Life Limiting illnesses now surviving into adulthood. The rationale for the two strategies being that Children and Young Peoples Services were already in part working in an upstream way and needed a different set of actions to deliver from those in Adult Services

CQC undertook a repeat visit in January 2019 of the adult End of Life care delivery and made comments for the Adult service but did not focus on this service delivery in children’s services

## National Context

Research figures from ‘Together for Short Lives’ (2020) show that numbers of children living with life limiting illness in the UK has continued to rise over the last 17 years. The number of children with life-limiting or life-threatening conditions increased to 86,625 in 2017/2018 compared to 32,975 in 2001/2002. It is likely that these figures will increase by a further 11% by 2030. It is acknowledged nationally that local data collection is often patchy for children receiving palliative care, this flags up potential issues for CCGs in underestimating the level of provision that is needed, leaving existing resources overstretched.

Due to the gap in good evidence-based literature or direction surrounding the care of the child at the end of life and after death, much of our current evidence is drawn from a consensus of professional practice and from wider literature published on death and bereavement. In 2016, NICE published their key document on End of Life Care for Children, in response to the Health and Parliamentary Ombudsman report published in May 2015 (HPO 2015), which identified poor communication as a major contributing factor to people receiving poor palliative care in England. Poor pain management, a delay in referrals and a failure to recognise when the person was in their final days are all highlighted in the report, which calls for people to be able to die with dignity (NICE 2019).

It is envisaged that the new NICE guidelines will identify, promote, and extend best practice, enhancing the quality of care for children and young people with life limiting conditions and their families. It is imperative that this local strategy is read in conjunction with the documents listed in Appendix one.

## Local Context

Local commissioning data tells us that there are approximately 70,000 children and young people (0-18) living in Shropshire, Telford, and Wrekin. A study from 2013 conducted by Together for Short Lives reported that there approximately 7 children per 10,000 in our local area living with Life Limiting Illness (taken from 'The Big Study' -TFSL 2013). This suggests that approximately 49 Children and Young People in Shropshire, Telford and Wrekin are in this client group. The Disease Categories included in the above study are displayed in Appendix 1.

We know that from our caseload data extracted from SCHAT's Children's Community Nursing Team there are 102 children (out of caseload of 237 0-19 years) with one or more of the above conditions. Local archived data shows us that this number has risen considerably over the last ten years. Wider data from commissioners has been requested for these groups of patients but this has been unable to obtain. Data collection is a gap that is addressed later in this document.

Current caseload figures from Hope House Hospice (voluntary charity sector) reflect that 55 children with life limiting illness from Shropshire and 34 children from Telford and Wrekin are accessing their services at present. These figures suggest that since *The Big Study* in 2013 the numbers are rising of Children and Young People living in Shropshire, Telford and Wrekin with Life Limiting Illness.

Together for Short Lives informs us that the number of children living with Life limiting Illness in England is growing year on year particularly in the 16-19 age group. This suggests that the growing need for support associated with these conditions is being driven by longer survival times rather than a rise in the incidence of the disease.

This raises the important issue of Transition to adult services for the 16-19 year age group. Transition needs to be a key element of local service planning as we embrace that this client group are living longer, requiring services for longer.

It is important to mention that this strategy does not cover care for sudden deaths not known to the Community Children's Nursing Team although there is provision for these families to access after care and bereavement services from Hope House Hospice.

## Definitions

### What is Paediatric Palliative Care (PPC)?

Palliative care aims to optimise quality of life in the face of an ultimately terminal condition. Paediatric palliative care is an active and total multi-disciplinary approach to the care of children and young people with life-limiting conditions that embraces physical, emotional, social, and spiritual elements through death and beyond. Palliative care is not a single intervention; it is a philosophy of care. It can be seen as a thread that weaves through the lives of all children with a life limiting illness, often alongside active interventions, and treatment. PPC services in SCHAT incorporate the following: Children's Community Nursing, Paediatric Palliative Care Consultant, Paediatric Psychology and Hospice Services.

### **What is End of Life Care?**

End of life care is the care a child and family receive in the last few days or weeks leading up to the child's death. Medication and interventions are reviewed in relation to their appropriateness throughout this time.

The end-of-life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the child/young person or family who first recognises its beginning.

### **When should PPC be introduced?**

Evidence has shown that families with a child with a life-limiting or life-threatening condition value the on-going support from palliative care professionals, including psychological and spiritual support along with symptom management, from the point of diagnosis. However, palliative care is often only considered right at the end of the child's life. There are often times during the child's illness that families need to be supported to make difficult and highly distressing decisions, for example about reassignment of treatment goals. Palliative care professionals may be better able to support this process if they have already had the opportunity to build a relationship with the child and family. A referral to palliative care services can be made at any point from the diagnosis of a life-limiting or life-threatening illness.

## **Our Vision**

**That every child in Shropshire, Telford and Wrekin should have access to excellent palliative care when and where they need it. We will support children and young people with Life limiting Illness and their families to lead fulfilling lives, offering the best end of life care and support to the family in bereavement.**

## **Aims of this Strategy**

- To address the national and local context of Paediatric End of Life and Palliative Care
- To demonstrate how we will deliver our vision statement
- To highlight 'what we do well' and identify areas for improvement
- To develop an action plan to that adheres to trust values and offers assurance on delivery
- To deliver knowledge and identify the skills required for the care of the child at the end of life; before death, at the time death and after death for the child/young person and family
- To enable sharing of practice across SCHAT and wider care sector
- To enable our organisation to improve and inform current policy and procedures

## **What we have done well to date**

- In Shropshire, Telford and Wrekin we offer comprehensive, multi-agency and expert Paediatric Palliative Care services to children and young people who are living with life limiting illness or are at the end of their life. The Community Children's Nursing Team offer a 24/7 on call service for end of life care to include home visits, individual symptom-control management and support to the child and family. This has been adapted to be delivered on an individual assessed needs basis rather than maintaining an on-call system all year round.
- Care is accessible to C&YP in Shropshire, Telford and Wrekin of all faiths, culture, and locations



- Working closely with the acute trust and tertiary centres, SCHT can provide child specific discharge planning, offering rapid transfer home or to another location for end of life if this is the choice of the family. Other services aim to provide continued access to family where possible (see appendix 2)
- Paediatric palliative care in Shropshire, Telford and Wrekin has a multi-professional approach, those involved include hospital and hospice staff (secondary and tertiary centres), community nurses, doctors-GP, Paediatricians, paediatric clinical psychologists, pharmacy, family support, ambulance services, education, care staff and others. We recognise good communication and coordination is vital between all relevant professionals and the revitalisation of the local Paediatric Palliative Care Steering Group which now has county wide representation by a multi-agency membership and is very well supported.
- It is vital that staff caring for C&YP have the expertise, knowledge, and experience to recognise when the child or young person is likely to be in the last few days (and hours) of life. Families are informed that there can often be uncertainty around this and that this is not unusual. We ensure end of life care protocols are put in place if death is thought to be expected within three days (see appendix 3 - Care at the time of death), although this is difficult to assess the decision making is supported by the MDT planning process
- Anticipatory prescribing and availability of medications for End of Life (EoL) care has continued to improve with more paediatricians gaining experience of developing Anticipatory care plans across the community and SATH teams and them having the support of both community and acute trust medical consultants
- SCHT palliative care services access governance from The West Midlands Paediatric Palliative Care Forum as well as our own SCHT Paediatric Palliative Care Steering Group. We take part in national and local audits to ensure our services are benchmarked against national standards and this information is reported through the divisional Quality and Safety committee.
- Respite Services are offered to local families who have children with life limiting illness. The CCN service provide their own respite team of highly skilled support workers that offer care in the home, allowing family members to take break. Hope House Hospice provides respite/Short Breaks in the Hospice (see appendix 7) where the whole family can stay whilst staff provide comfort, support and specialist care for their child and family. This includes sibling support and counselling services for the whole family. Hope House also provide an outreach home respite service. Short breaks can also be accessed through social care for children with complex health needs although there are no specialist palliative services in social care settings.
- Neonatal palliative care is generally initiated from the Neonatal Unit within the Acute Trust or in specialist units in tertiary centres The Children's Community Nursing Team in SCHT work with the acute medical team and Community Palliative Care consultant to provide outreach nursing care depending on what is required/decided by the family. Hope House Neonatal outreach worker and the CCN Team collaborate with the specialist midwife and neonatal nurse in the Acute Trust, SCHT can provide child -specific discharge



planning and offer rapid transfer home or to another location for end of life if this is the choice of the family. Hope House Hospice offer expertise from their Neonatal Specialist Nurse for this client group and our Palliative Care services liaise with this organisation to coordinate care whether this will be at home or transferring to the hospice environment.

- Prescription management and drug review are a key priority for Paediatric end of life care and within SCHT we have access to community pharmacists however this may not be an individual with paediatric palliative care experience. The pharmacological management is covered in the 'Association for Paediatric Palliative Medicine' Master Formulary (APPM, 2020). Individualised risk assessments are carried out in the home in liaison with Community Pharmacy and decisions are made whether Controlled Drugs can be stored in the home. For Oncology patients, specialist locked drug boxes are supplied for the home from the tertiary centre. All palliative care drugs include anticipatory medicines and prescription charts are written to reflect this. Recent improved paper trails have led to better stock management and selected Pharmacies in Shropshire, Telford and Wrekin have agreed to stock commonly used medications during End of life.
- When planning to transition young people into adult services, we work towards the criteria in the Together for short lives (2016) Transition Pathway which gives a comprehensive template to follow. We recognise there are challenges to Transition due to the complex nature of these conditions, this is addressed in our action plan further in the strategy. Due to life expectancy rates increasing for this client group we plan for adult services to be in place from 18 years
- We recognise a timely and collaboratively written Advanced Care Plan is key to person-centred end of life care. We recognise that this a joint process with child, family and senior clinician who know the child well. NICE (2019) recommends Advanced Care Planning should be reviewed at regular intervals and be contributed to by child and family and all relevant professionals as appropriate, adhering to confidentiality agreements. SCHT use the Collaborative Child & Young person's Advance Care Plan (West Midlands Paediatric Palliative Care Network, WMPPCN) with the ReSPECT document embedded, in line with the Adult Pathway.
- Care pathways include emotional and specialist paediatric clinical psychology support for families that they can access from onset of referral to the CCN Team. This psychology provision is patient led, delivered across acute and community services and families can dip in and out of input to suit their changing needs and wishes Support is available for the family following the death of their child and through their bereavement. The Paediatric Psychology team works with families both before and following death. The psychology service is well integrated with the CCN service and joint appointments can be offered to families, as required. CCNs and Paediatric Psychology can provide bereavement home visits if required and will continue to visit the family for up to two years afterwards if felt necessary. The bereavement needs of siblings and extended family members are also be recognised and supported. SCHT staff also work closely with Hope House Hospice who offer comprehensive 'after care' for families of place of death.
- We recognise the emotional weight for staff working in this field and offer support in the following ways: Informal support within the team as required, formal individual or group supervision to support practice, reflection, access to psychological consultation, advice and

supervision for the multi-disciplinary team, bereavement debrief session following the death of a child or young person and NOSS—Staff Counselling (see appendix 6) is available through Occupational Health.

- We understand that choice and flexibility for families is needed when planning preferred place of death. We recognise that preferences may change due to the changing needs of the child and family, and this is reviewed regularly in line with the ACP. We offer responsive rapid transfer in End of Life and after death meet the needs of the child and family wherever possible. Key professionals from the MDT (such as consultant, CCN, Hospice staff) can help support families with these decisions and families are given appropriate information, resources, and advice (see appendix 2,3,4).

### **Developments and improvements for 2021/2024**

We have identified the following areas that we can improve on to ensure we continue to deliver high quality, responsive and compassionate care to C&YP with life limiting illness who require palliative and End of Life Care.

- There is an absence of central and local data collection on Palliative and End of Life Care, and an agreed data set is needed with a centralised system for storage. This would provide us with an effective mechanism in which to identify children and young people with life-limiting or life-threatening conditions at any point from the time of diagnosis or recognition right through to the approach of their end of life phase.
- SCHT have undertaken a local audit on the prevalence of children with ACPs who have life threatening illness (Buch 2020). Initial findings show 64% of this client group have an ACP in place, this highlights a need for improvement in identifying when the ACP process should commence
- Although SCHT has a Community Paediatrician with a specialist interest in palliative care who is available Monday to Friday, there is no access to specialist advice from this professional overnight or weekends. Families have access to out of hours medical cover in the Acute Trust however this is not a children's palliative care specialist (as recommended by NICE 2016) we have access to.
- Pharmacy is a key part of the PPC, and NICE (2019) recommend that pharmacists should be paediatric trained with palliative care drug experience. In SCHT there are no pharmacists with a speciality in Paediatrics or End of Life Care. There is however a part time pharmacist that covers children's services. The team have good links with the SCHT medicines management team as well as with the acute hospital and hospice pharmacies
- NICE (2019) recommends that the core workforce for PPC should consist of Paediatric Nurses with expert skills in palliative care, a specialist palliative care consultant, a pharmacist with experience of paediatric palliative care drugs and bereavement services. In SCHT our Medical and Nursing Workforce includes this level of expertise however for sustainability we need to develop training for new staff and wider MDT staff to broaden this expertise.

- Competencies related to end of life care must be identified, recognised and access to multidisciplinary training explored (see appendix 6) The CCN Team have access to monthly teaching sessions from the Community Paediatrician with Special interest in Palliative Care
- As numbers of children with life limiting illness grow, workforce planning needs to be considered that aligns with this increase. Up until now capacity of staff has been sufficient but different models of service delivery may need to be considered to create a robust future paediatric care workforce
- Historically there is a lack of family/service-user feedback in end of life cases. Having this information would assist us in measuring quality of care and inform service development. Naturally this is sensitive and not easy to obtain from bereaved families. Creative and sensitive methods of collecting this data with families need to be explored such as patient stories, questionnaire feedback and carefully planned conversations.
- The geographical patch of Shropshire, Telford and Wrekin and location of families within the county in more remote areas can challenge whether we are as responsive as we could be too out of hours care. Agreements with neighbouring NHS Trusts or shared care options should be explored
- Transitioning children with life limiting illness into adult services remains a challenge due to the complex nature of their conditions. This process is complicated, time consuming and resources need to be available to ensure our approach is truly person-centred. We know that we need to start planning for Transition earlier to ensure this process has the best outcome for young people and their families. We must engage with our adult colleagues and provide opportunity for skilled dialogue between all agencies to ensure a robust Transition plan is in place. As a Service Delivery Group, we are committed via our Quality Improvement Project to ensure all CYP and their families have access to transition planning discussions and plans from when the young person is 14 years of age and reviewed at least annually.
- Communication could be improved by consistently identifying a lead professional from the C&YP palliative care team to coordinate care and communication between agencies

## How we will deliver this agenda

Our approach to how we deliver our action plan will be in line with our Trust Values:

- Improving Lives
- Everyone Counts
- Commitment to Quality
- Working Together for Patients (for us this includes families)
- Compassionate Care
- Respect and Dignity

Our action plan is underpinned by the recommendations from NICE (2019) and the standards set by Together For Short Lives (2015)

SCHT continues to promote a care pathway approach to children's palliative care and with its partner's aims to reduce inconsistencies surrounding end of life care for children and young people. 'Together for Short Lives' has produced three care pathways which relate to different age groups and a further one specifically focused on making choices surrounding the withdrawal of life-sustaining treatment. All of these contribute to the framework of our care delivery.

They are as follows:

- Neonatal Care Pathway for Babies with Palliative Care Needs (for babies)
- Core Care Pathway for Children with Life-threatening and Life-limiting Conditions
- Transition Care Pathway (for young people)
- Care Pathway to Support Extubation within a Children's Palliative Care Framework

We believe giving families' choice is central to a successful care pathway approach: a choice in place of care, place of death, in accessing emotional and bereavement support, putting the child and family at the centre of decision -making to produce a care plan that is right for them all.

It is nationally recommended that services commissioned to deliver care for children with life limiting and life-threatening conditions follow these recommended care pathways. They have also been adopted by the West Midlands Paediatric Palliative Care Network (WMPPCN) and are apparent within the West Midlands Toolkit (WMPPCN, 2018) which is consistently used by the CCN Palliative Care Service and details every aspect of end-of-life care.

To evidence how we will achieve this agenda, we have produced a detailed action plan that addresses the gaps but also includes areas we currently do well and want to continue to monitor in line with NICE recommendations (2019)

## Action Plan

This is an action plan of measurable outcomes that address the gaps locally as well as the NICE recommendations which are to be monitored to ensure continued high quality service delivery.

What we will achieve (Outcome)	What we need to do to achieve this (Process)	How will we evidence this (Structure)	When will we do this?
Families will have access to information on organ and tissue donation before death if appropriate.	Assess the knowledge-gap of staff Follow NICE guidance on Tissue and Organ donation Set up local training for staff Obtain current, relevant information on organ donation to give to families	Case notes Audit projects Service evaluation/feedback from families Self-assessments of children's services in SCHT against NICE guidance 2016 Development of a staff training programme	Sep 2023
All C&YP will be offered an Individual approach to symptom management, person-centred approach	Ensure anticipatory Care Planning for symptom control for all CYP at EoL Develop clear symptom management plan with medical lead and family	Audit notes to measure response times to changing needs, professional involved and outcomes for patient  Multi-agency palliative -pathway to be created for end-of-life care.	Sep 2023

All C&YP will have 24-hour access to anticipatory prescribing and just in case medications for EoL symptom management.	Liaise with paediatric pharmacy to ensure access to just in case medications – mirroring those provided in adult services Development of symptom management training and resources for community children's nursing team	Audit notes to measure response times to changing needs, professional involved and outcomes for patient  Multi-agency palliative -pathway to be created for end-of-life care.	Jan 2023
The Shropcom Multidisciplinary team will react quickly to changing needs of child and family	Access to medical cover 24 hours a day Access to urgent therapy assessments when needed e.g., OT obtaining equipment Access to Hospice Services 24 hours a day  Access to 24-hour CCN cover	Audit notes to measure response times to changing needs, professional involved and outcomes for patient  Multi-agency palliative -pathway to be created for end-of-life care.	Jan 2023
Verification of death is completed in a timely manner for all C&YP	Access to staff training updates for the community children's nursing team Access to hospice out of hour services for those situations where verification is not appropriate for the CCN Team	Audit notes to measure response. Development of a SCHAT CYP verification of death policy and competence-based training.	Sep 2022
Families will have access to Paediatric Palliative Care Consultant out of hours and at weekends	SCHAT need to keep this gap on the agenda and address increasing numbers of client group Ensure communication with acute and tertiary centres is maintained for out of hours medical cover	Audit from multi agency case notes Feedback from families Audit from hospice feedback Identify response times from CCN case notes.	

	<p>Robust anticipatory care planning in place for all children at end of life stage to ensure changes to condition are addressed ahead of time.</p> <p>Identify community pharmacy that can supply palliative care drugs if stock runs low</p> <p>Access to 24 hour CCN on call service</p> <p>Availability of a 24/7 on call rota for medical advice</p>	<p>Identify any gaps in care at weekends/out of hours report through quality and safety committee.</p> <p>Discussion and presentation at the palliative care steering group followed by leasing with commissioners regarding options for out of hours medical cover</p>	Jan 2023
There will be timely, person-centred Transition planning for young people with life threatening illness moving into adult services	<p>Discussions on Transition with CYP&amp;F to start from 14 years old where possible in line with NICE guidance. Follow current care pathway</p> <p>More joined up thinking between Paediatric and adult services</p> <p>Mapping of services to start earlier and lead professional identified in both Paediatric and Adult discipline to coordinate process</p> <p>Parallel planning to take place in adult services when EoL may be unpredictable</p> <p>Transition occurs at 18 years, planning through to 25years for EoL care</p>	<p>Self-assessments of children's services in SCHAT against NICE guidance 2016</p> <p>Audit on Transition within Trust ACPs are circulated to acute medical team to ensure most up to date information on child held in acute setting.</p> <p>Audit of notes – did care meet with family preferences and expectations ,is there evidence of this documented?</p>	March 2022



Ensure psychologically informed end of life care for all CYP and their families/ensure the social, psychological, and spiritual needs of CYP receiving EoL care are assessed, addressed, and regularly reviewed.	Integrated working between the CCN and Paediatric Psychology team and other relevant services. Comprehensive MDT assessment. Joint visits with nursing and psychology as required. Provide information about paediatric psychology provision to all CYP receiving EoL care and their families.	Case notes Audit projects Service evaluation/feedback from families	By July 2023
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## Consultation

The following people have been involved in the development of this Strategy:

Nikki Davies – Team Lead, Community Children's Nursing Team

Dr Camilla Johns – Professional Lead Consultant Clinical Psychologist, Paediatric Psychology Service

Dr Shachi Buch – Consultant Paediatric with special interest in Palliative Care

Kate Medhurst – Community Children's Nursing Service Manager

## Monitoring

The measurement and reporting the outcome of this strategy will be measured against NICE guidance and local Key Performance Indicators (KPIs) as identified by local Clinical Commissioning Groups (CCGs) and Clinical Reference Groups (CRGs).

Any identified appropriate national and local audits of End of life care will be included in the organisation's annual audit programme.

Monitoring of the action plan will take place yearly by community children's nursing team leads. The action plan will be cascaded to relevant clinical teams to ensure implementation of the framework has occurred.

NICE Guidelines (2016) will be used as the basis for audit 3 yearly to inform the next strategy.

Ongoing monitoring will occur through local service Clinical Governance Frameworks and Divisional Quality and Safety Group.

The risk register will also be reviewed and monitored through the Quality and Safety Group.

The Children and Young People's End of Life strategy group will develop from the action plan a high-level outcome that can be reported at board level to give assurance on progress.

## Summary

Children and young people's Palliative and End of Life care has been delivered well over time in Shropshire. This review has provided an opportunity to allow us to look at how we add strength to current services. We have identified an action plan which we commit to deliver against whilst continuing to enhance quality and responding to changing situations of technology, medical treatments and age and size of population.

We recognise that some constraints will need to be addressed on a commissioner level to ensure we can continue to deliver these services well. This document however gives us a vehicle to do this, address the gaps and monitor improvements to enable us to deliver the excellence in care that our local children and young people at the end of their lives so rightly deserve.

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Together for short lives (2020) Bringing colour to families' lives Our value and impact 2019-2020 <https://www.togetherforshortlives.org.uk/app/uploads/2020/11/Together-for-Short-Lives-Impact-Report-2019-2020.pdf> (accessed 3<sup>rd</sup> May 2022)

University Hospitals Bristol (2014) Clinical Guideline Planning end of life care in BRCH and for children who may have a change in care location at the end of life <http://www.icpcn.org/wp-content/uploads/2014/06/Childrens-End-of-Life-Guidance-2014-University-Hospitals-Bristol.pdf> (accessed 20<sup>th</sup> April 2022)

WMPPCN (2018) Palliative Care Toolkit <https://www.togetherforshortlives.org.uk/resource/west-midlands-toolkit/> (accessed 20<sup>th</sup> April 2022)

## Further Reading

Children's Palliative Care Education and Training (2020) Education Standard Framework and Self Audit Tool <https://www.icpcn.org/wp-content/uploads/2020/10/CPCET-Education-Standard-Framework-and-SelfAudit-Tool.pdf> (accessed 20<sup>th</sup> April 2022)

Larcher V, Craig F et al (2015). Making decisions to limit treatment in life-limiting and life threatening conditions in children: a framework for practice. Arch Dis Child 2015, 100 (suppl 2):s1-s26 [https://adc.bmj.com/content/archdischild/100/Suppl\\_2/s1.full.pdf](https://adc.bmj.com/content/archdischild/100/Suppl_2/s1.full.pdf) (accessed 20<sup>th</sup> April 2022)

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## Appendices

- Appendix 1: Grouping of Life limiting Conditions
- Appendix 2: Care Planning for life limiting illness
- Appendix 3: Care at the time of death
- Appendix 4: Care after death
- Appendix 5: Bereavement Support
- Appendix 6: Staff support and Supervision
- Appendix 7: Local services in Shropshire

## Appendix 1 Grouping of Life-Limiting Conditions of Children included in The Big Study

Children's conditions were categorised by ICD10 and then further into disease groups that would be meaningful for practitioners.

Disease Group	Description of conditions included in the disease group	ICD10 Codes
<b>Congenital and chromosomal</b>	Includes children with chromosomal conditions such as Downs, Patau, Edwards Syndromes and other less common abnormalities. Also children with congenital abnormalities of the central nervous system such as lissencephaly, hydrocephalus, microcephaly. Also children with congenital heart disease, short bowel, biliary atresia.	Mainly Q codes. (Congenital malformations, deformations and chromosomal abnormalities) Some K codes (Diseases of the digestive system).
<b>CNS Static encephalopathy</b>	Non-progressive CNS disease including cerebral palsy, developmental delay and epilepsy. Brain injury, Birth asphyxia, Hypoxic ischaemic encephalopathy	Mainly G codes (Diseases of the nervous system). Some P codes (Certain conditions originating in the perinatal period) e.g. 'Brain injury'/'birth injury', 'hypoxic ischaemic encephalopathy
<b>CNS progressive</b>	Disease often categorised as 'Progressive Intellectual and Neurological Deterioration (PIND)' characterised by loss of skills. Includes children with mucopolysaccharidoses (Hurlers, Hunters, Sanfilippo), lipofuscinosis (Juvenile, Late infantile and Infantile Battens), leucodystrophies (Adrenoleucodystrophy, metachromatic leucodystrophy, Krabbes), Retts, Juvenile Huntington's. Most conditions in this group are inherited as single gene and/or mitochondrial disorders.	Mainly E codes (Endocrine, nutritional and metabolic diseases). Some G codes (Diseases of the nervous system).
<b>Neuromuscular</b>	Duchenne muscular dystrophy, Spinal muscular atrophy, Congenital muscular dystrophy, Ataxia telangiectasia. Friedreich's ataxia. These are also inherited as single gene recessive or x-linked conditions or as mitochondrial disorders	Mainly G codes (Disease of the nervous system).
<b>Cancer</b>	Solid tumours, Brain tumours, Cancer of blood and lymphatic systems	C codes (Neoplasms).
<b>Pulmonary and respiratory</b>	Cystic Fibrosis (single recessive gene disorder), Chronic lung disease (sometimes resulting from prematurity	Cystic fibrosis E 84.9. Chronic lung disease J98.4.
<b>Other</b>	Endocrine and renal disorders. Immunodeficiency. Trauma (for instance due to road traffic accident).	B & D (Immunodeficiency), E (endocrine), K (digestive), M (musculoskeletal), N (genitourinary), S & T (Injury and trauma).

## Appendix 2 Care Planning for life limiting illness

### The 'surprise questions'

The framework of 'surprise questions' has been designed to help health professionals think about the potential need for palliative care in a timely manner thus avoiding complex and important decisions being made out of hours by professionals who do not know the child and family well. Some clinicians find it helpful to ask themselves "Would you be surprised if this patient were still alive in 6-12 months?" If you **would not be surprised** it is important to establish what measures might be taken to improve the child's quality of life and what advance preparations will be.

The following tool has been developed specifically for Paediatric Palliative care:

#### Surprise questions.

#### Diagnosis or recognition

- ❖ Would you be surprised if this baby / child died as a result of this condition or problem?

#### Death before adulthood

Would you be surprised if this baby/ child died before adulthood (18<sup>th</sup> birthday)?

#### Increasing instability

- ❖ Would you be surprised if this baby / child died in the next few months to years?
- ❖ Would you be surprised if this child died in the next five years?

#### Critical illness or end of life

- ❖ Would you be surprised if this baby / child dies in the next few days / weeks?

**If your answer is 'NO I would not be surprised' to any of these questions you should be thinking about palliative care for this child or young person.**

University Hospital of Bristol 2014

When a child or young person is diagnosed to have a life limiting or life threatening condition, there needs to be careful planning and complex decisions made in the following areas:

- Advance Care Planning
- Preferred place of care

- Symptom management planning
- Emotional, psychological and spiritual well-being
- Organ and tissue donation

Professionals involved in the care include hospital and hospice staff (secondary and tertiary centres) community nurses, doctors-GP, Paediatricians, psychologists, family support, ambulance services, education, care staff and others. It is of vital importance to have good communication and coordination between all relevant professionals and local services to facilitate this care with excellent record keeping and correspondence.

### **Communication and the Foundations of Planning Care**

Once it has been identified that a CYP requires palliative care (or is approaching EoL) it is important that communication with them is open, honest, transparent and regular, and that discussions fully involve the child, young person and their family as much as possible. For CYP this is not just verbal conversation, but might include play, art, music, non-verbal communication, stories and narrative approaches, and digital media.

Communication will need to be age-appropriate and take into account developmental needs. It should be understood that children frequently regress to earlier developmental stages when in distress and that everyone concerned will deploy psychological defences such as denial, avoidance and displacement at times.

Staff will always aim to communicate openly with both CYP and their families, although there will be times when the families' views and those of the professional team may differ. In these circumstances the team will always attempt to discuss, review and revisit the issues whilst respecting parents' wishes. Similarly, there will be some CYP who opt not to participate in discussion regarding their condition, its prognosis, and/or their care plan. Where there are conflicting views, the team will aim to negotiate with everyone involved and to reach an agreed plan, which is subject to regular review.

It is important to remember that communication is an ongoing, two-way process and that its meaning, impact and timing may need to be different for different people.

### **Advance Care Planning**

For children with life threatening and terminal illness, a decision will be made in collaboration with their families when the right time is for an Advanced Care Plan to be written. This should be a joint process with child, family and senior clinician who knows the child well. SCHAT use the Collaborative Child & Young person's Advance Care Plan (West Midlands Paediatric Palliative Care Network, WMPPCN).

An Advance Care Plan (ACP) includes decisions and preferences about the child's care during life and also at the end of life, their preferred place of care and death and management of any acute and inter current illness. Important decisions regarding resuscitation are recorded after sensitive discussion with the child and family. Specific wishes from the child or young person are included. The religious and cultural beliefs of the



family need to be acknowledged at all times. Decisions regarding organ and tissue donation are also recorded. (NICE 2016).

A copy of the ACP is circulated to all relevant professionals or organisations involved in the care of the child. They need to be updated annually or earlier if necessary.

Ethical principles are based on:

#### - **Parallel Planning**

The concept of 'Parallel Planning' is useful in situations when the child has been diagnosed with a life limiting condition, but remains well at that point in their illness trajectory. This is the concept of planning for life whilst also planning for deterioration or death which allows a child's full potential to be achieved and initiates the mobilisation of services and professionals where necessary.

#### - **Symptom Management**

Effective symptom management for the child or young person is essential not only to ensure comfort but also to enhance their quality of life, and involves anticipatory planning for the end of life. The following symptoms are most commonly encountered:

- Pain
- Seizures
- Agitation
- Breathing difficulties
- Managing hydration and nutrition
- Anxiety and fear

The pharmacological management is covered in the 'Association for Paediatric Palliative Medicine' Master Formulary 2015.

Professionals need to be able to recognize that the child or young person is likely to die within hours or days.

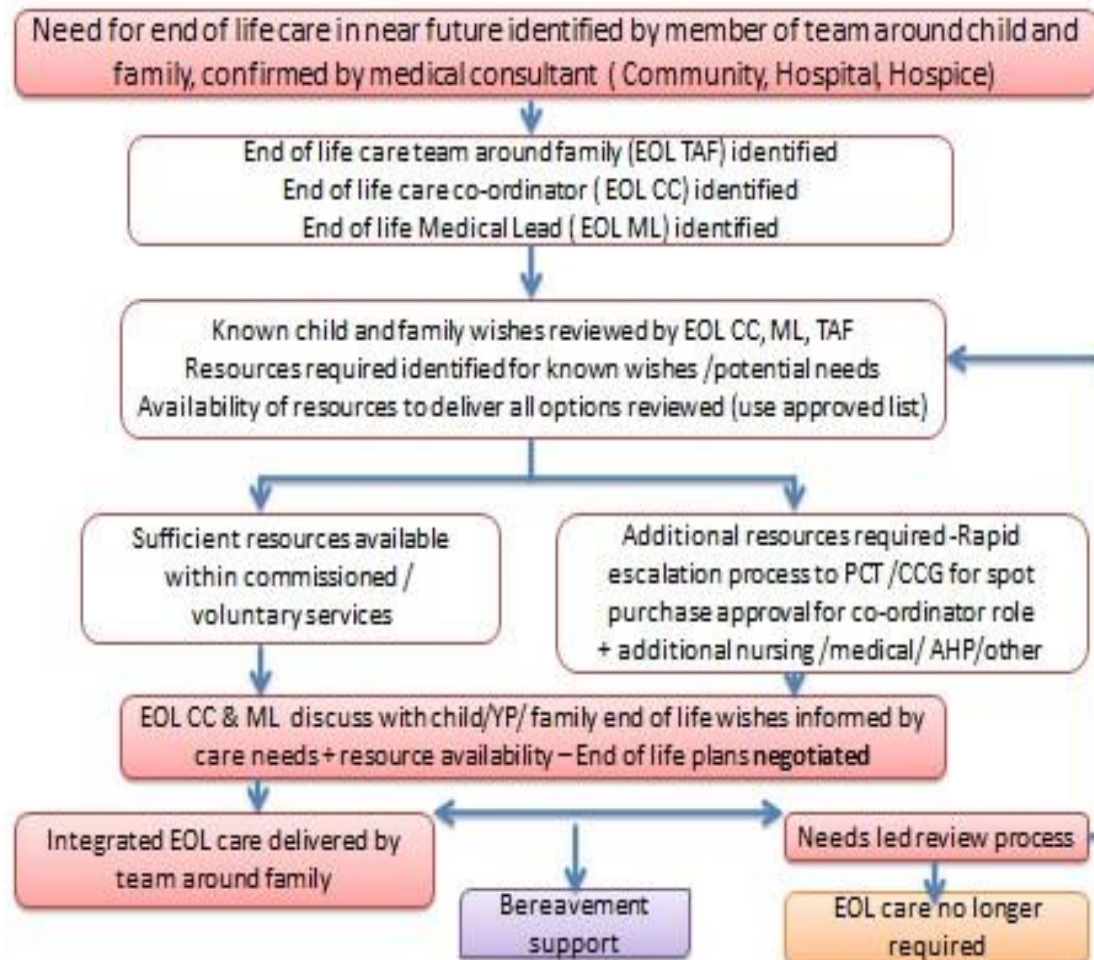
The child or young person and their families also need

- Emotional and specialist psychological support and interventions
- Social and practical support
- Religious spiritual and cultural support.

#### - **End of Life Care Pathway**

To aid the planning process locally this process map can be utilised when starting to think about and plan a child's end of life care. It sets out the steps that should be taken from the point of recognition of 'need' by the professionals. It is important that these steps are taken *before* approaching the family and asking them where their preferred place of care would be at the end of life.

## High level end of life care delivery pathway



*From: Bristol University Hospital End of life Guidance (2014)*

## Appendix 3 Care at the time of death

It is vital that staff caring for C&YP have the expertise, knowledge and experience to recognise when the child or young person is likely to be in the last few days (and hours) of life. Families should be informed that there can often be uncertainty around this and that this is not unusual. This judgement can be difficult to make. End of life care protocols will be put in place if death is thought to be expected within three days.

Clear communication from knowledgeable staff will minimise mixed messages that raise false hope or uncertainty about the likely outcome; this can enable the family to achieve their preferences for care around the time of death.

Plans for ongoing care will include a review of symptoms the child may experience and how these can be/will be managed. Medications and doses will be clearly documented in anticipation. A multi-agency approach will be used to ensure appropriate care can be delivered over a longer period if death does not occur as expected. If death does not occur then there will be an urgent Multi-Disciplinary Team (MDT) meeting to plan the best options for ongoing care including management of symptoms and place of care.

Families and carers will be informed of likely changes as the child approaches death in a sensitive and compassionate manner. Key professionals should be aware of and try to meet any wishes that the child and their family have expressed in advance.

Professionals will ensure that the child (where appropriate) and family have had the opportunity to consider care outside hospital, at home, in a hospice or in a hospital closer to home. Arrangements for rapid discharge, should the family wish, will be supported by a collaborative approach from the acute setting, hospice, community, primary care, ambulance service.

Plans should be in place for practical and legal considerations. Staff will be aware of all the relevant legal and regulatory issues around death when a child in their care dies. This should be clear for whatever care setting is chosen. Families will be informed who will verify and certify the death. Support discussions will be considered regarding organ and tissue donation and if this is likely to be an option staff will provide families with appropriate written information if required.

Families choosing for their child to die at home will be given written information on what to do to which includes emotional and practical advice as well as outlining the legal requirements of what to do and what options they have.

Staff will offer the family an opportunity to discuss care of their child after death, whilst being aware that some families will not want to consider this at this stage. Families' wishes for the moments before and after death should be respected, and staff will try to facilitate the presence of the people they want around them at these times.

Community Children's Nursing team will offer 24/7 on call service for end-of-life care to include home visits when needed for symptom management and support to the child and family. Other services will aim to provide continued access to family where possible.

## Appendix 4 Care after death

Good end of life care does not stop at the point of death. When a child or young person dies all staff need to be familiar with good practice - for the care and viewing of the body as well as being responsive to family wishes. The support and care provided to carers and relatives will help them cope with their loss and are essential to 'a good death'.

In an expected death, when a child dies, support after death should already have been discussed through the development of the ACP and staff will know where the child should be cared for. Prior to death the child may have participated in the development of their own ACP and contributed to this decision. If this is not the case, sensitive and thoughtful communication is essential at all times to plan this phase with the family by trained, experienced staff.

The child may be cared for on the ward, in the hospital mortuary, at the funeral director, or in a cool room at a children's hospice or in their own home. Care can also be provided by a combination of these options. Key professionals from the Palliative Care Team (such as consultant, CCN, Hospice staff) can help support families with these decisions and families should be given appropriate information, resources and advice (see Appendix Two).

Parents should be informed that (within reason) whatever choice they make is an acceptable choice and that there are no right or wrong ways to care for their child. It is also acceptable for them to change their minds. In all cases professionals will endeavour where reasonably possible, within available resources, to support the wishes of the family in whatever they choose.

After death, professionals will allow the family as much time as possible to remain with their child. Families may require guidance and information around registration of their child's death and professionals should check that families have appropriate support with funeral planning.

All staff caring for C&YP requiring palliative or during end of life care should be aware of the policy and procedures within SHCT and verification of death should be timely to prevent delay of further care. If a referral to the coroner is necessary, the reasons for this will be clearly explained to the family including what this means in practical terms. If a post mortem is required, the family will be given relevant advice.

Sensitive and thoughtful communication is essential at all times when supporting families after their child has died and the families' cultural, psychological and spiritual needs should be considered and addressed. If appropriate siblings will be included and involved, grandparents will also be cared for and supported along with other family members and friends that are important to the child and family. The bereavement needs of the whole family should be assessed and supported.

It is essential for parents to retain control and choice in the care of their child. Siblings may also wish to be involved in caring for their brother or sister. Families will need to be informed of any expected changes to their child's body and staff should make them aware of these.

Good care coordination will continue after death, including ensuring that all relevant services are informed, and this is recorded and documented clearly. A death discharge summary will be completed and sent to all relevant services within the time frame stipulated in the Trust policy. A copy must be sent to the Lead Nurse for the Child Death Overview Panel (CDOP) so that they can complete the necessary paperwork. If the family have specific post bereavement needs that have been identified, these will be included in the summary and appropriate arrangements made for on-going support/follow up.

## **Appendix 5 Bereavement Support**

At such a significant time, it is essential to provide sensitive and meaningful support that meets the needs of each individual family. Staff will be trained to support bereaved families and will have excellent communication skills.

Assessment and review of families' needs is vital to deciding what type of support is needed. This will lead to signposting towards relevant services; this could be spiritual, emotional, psychological, practical and/or financial support.

Staff will know what local support is available for the family following the death of their child and through their bereavement. The Paediatric Psychology team works with families both before and following death and we also work closely with Hope House Hospice who offer comprehensive 'after care' for families. CCNs and Paediatric Psychology also provide bereavement home visits if required and they will continue to visit the family for up to two years afterwards if felt necessary. The bereavement needs of siblings and extended family members should also be recognised and supported which is a service also offered by Hope House. The Guidance for Bereavement Needs in Palliative Care Assessment (Hospice UK, 2010) is a useful resource for staff.



## Appendix 6 Staff support and supervision

One of the biggest challenges for health professionals working in palliative care is to achieve a balance between compassionate care and self-care. Self-care includes preserving health and well-being, exploring beliefs and feelings about death and grief and knowing when to seek support.

Caring for terminally ill children and young people and working closely with their families is emotionally challenging and supporting our staff is very important to us.

### The emotional health and wellbeing of our staff is supported in the following ways:

- Informal support within the team as required
- Formal individual or group supervision to support practice reflection and support staff to deal with their own feelings of grief and loss.
- Access to psychological consultation, advice and supervision for the multi-disciplinary team including working with professionals and the family before, during and after the death.
- Bereavement debrief session following the death of a child or young person
- NOSS Staff Counselling

New staff working within teams who care for children and young people at the end of their life are given the opportunity to shadow experienced colleagues as he/she supports a child and family through end of life care and death.

## Staff training and professional development

All staff should receive regular training and have frequent opportunities to develop their skills and competencies in practice. To ensure a standard of competence staff need to be able deliver high quality care from a robust professional knowledge base and reflect on the care given to support improved practice.

### Competencies for all staff supporting end of life care in children and young people

- Communicates effectively with children and young people requiring palliative care, and their families
- Provides holistic nursing, therapeutic and clinical care for children and families and contributes effectively to multidisciplinary working
- Assesses, plans and provides a range of supportive and practical evidenced-based interventions for a child or young person at the end of life, and their families
- Participates and facilitates effective discussion as a member of the team with primary carers to identify a range of symptoms

RCN 2018

To enable all staff to develop their competencies in practice a mix of face to face and e-learning training is offered. This formal offer is complemented by self-development through reflective practice and clinical supervision.

The West Midlands Children and Young People's Paediatric Palliative Care Network supports Shropshire Community Health practitioners to work together with regional colleagues to share best practice and plan services effectively. In addition, the Together for Short Lives Digital Care Forum (<https://www.togetherforshortlives.org.uk/changing-lives/sharing-learning-networking/digital-care-forum/>) is a place for practitioners to seek expert advice from international children's palliative care practitioners and join in discussions about innovative approaches to caring for children and young people with life-shortening conditions.

## **Appendix 7 Local Services in Shropshire available to Children and Young People and their families with life limiting illness and during End of Life Care**

### **Princes Royal Hospital**

Apley Castle  
Apley  
Telford  
TF1 6FT  
01952 641222

### **Paediatric Palliative Care Consultant**

Stepping Stones Child Development Centre  
Brunel Road  
Malinslee  
Telford  
Shropshire  
TF3 2BF  
01952 567300

### **Paediatric Psychology Services**

Monkmoor Campus  
Woodcote Way  
Shrewsbury  
SY2 5SH  
01743 282374

### **Children's Community Nursing Team**

Coral House  
Longbow Close  
Harlescott  
Shrewsbury  
SY1 3GZ  
01743 450855

### **Hope House Hospice**

Nant Lane  
Morda  
Nr Oswestry  
Shropshire  
SY10 9BX  
01691 671671

Hope House offers the following:

Snow Flake Suite – Offered to families of any child that dies in Shropshire. This is a cooled 'bedroom' in a homely environment that allows the family to spend time with their child after death. This gives time to say goodbye and come to terms with their loss in those initial stages after death. This can be decided as part of the child's ACP and planned or discussed at time of death.

Bereavement Care for siblings and other family members – This service can be offered to all families that experience loss of a child in Shropshire. This 'after care' can continue for years after death and can be offered as group or individual support sessions.

### **Education**

Pastoral Support in school is offered for children who have experienced death of a sibling.