

Children’s palliative care network audit 2020

Response form: Thames Valley

For the standards we refer to in each of the following questions, please describe the geographical areas within your network region where they are being met. Please do this in a way which will make it as easy as possible for Together for Short Lives to draw these areas on our digital maps; for example, please reference ICS areas, STP areas, CCG areas (all England), health and social care trust areas (Northern Ireland), NHS boards (Scotland), local health boards (Wales) or local authority areas (UK-wide). For each question, please also describe how those services are funded, which organisations provide them – and if they are only available to children with certain conditions (for example, children accessing oncology services). Please add in any further details if you would like to, for example how many whole time equivalent (WTE) staff involved in meeting these standards. There is no word limit on your answer – please use all the space you need. Please do add further lines to each table if needed.

1. Infants, children and young people with a life-limiting condition can access palliative care at home provided by a multidisciplinary team that includes members of the specialist paediatric palliative care team^[1].

Together for Short Lives analysis of network response received:

This is available in:

- Oxfordshire
- Buckinghamshire
- Berkshire
- Northamptonshire
- Part of Wiltshire

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Children with Complex Needs Team Central and North West London (CNWL) NHS Foundation Trust	Borough of Milton Keynes providing the patient is registered with a General Practitioner within the borough	NHS Currently a team of 2 WTE plus 2 Part time staff of 22.5 hours per week
Keech Hospice Care	Milton Keynes, Bedfordshire and Hertfordshire	NHS/Charity
Helen and Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	NHS/Charity
Forever Colours Children’s Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity
Alexander Devine Children’s Hospice Service	Berkshire East, Berkshire West, and surrounding	Full MDT team providing nursing

^[1] This is defined in NICE guideline [NG61] ‘End of life care for infants, children and young people with life-limiting conditions: planning and management’:
<https://www.nice.org.uk/guidance/ng61/chapter/recommendations#multidisciplinary-team>

	boundaries including South Buckinghamshire and North Hampshire	care, symptom management, end of life care, play specialist, music therapy and psychological support. Medical cover from paediatricians with special interest and training in children's palliative care, pharmacist - NHS/Charity		
<p>Community Children's Nursing (CCN) Service, Oxford Health NHS Foundation Trust (OHFT) provide palliative care for children (0-18y) with a nursing need.</p> <p>-Designated 1WTE Paediatric Palliative and End of Life Care Practitioner -7 day a week service to include weekends and Bank Holidays. -Hours; 08:00-20:00h accessed via CCN Single Point of Access (SPA).</p> <p>CCN support includes palliative and end of life care with additional access to;</p> <ul style="list-style-type: none"> -Acute, Chronic, Complex Nursing Care. -Case Management. -Respite care in the home. -Special School Nursing support. - Play Specialist; +skills in palliative care/ psychology. -Training & support to empower family/ formal carers to support the child's health care needs. <table border="1" data-bbox="209 1301 699 1928"> <tr> <td data-bbox="209 1301 699 1335">Team members have additional training;</td> </tr> <tr> <td data-bbox="209 1335 699 1928"> <ul style="list-style-type: none"> • Paediatric Palliative foundation Course. • HCA study days • Paediatric palliative care module. • Paediatric palliative care symptom management. • Critical care skills. • Bereavement skills. • Advanced history taking/assessment. • Non-medical prescribing. • Community Children's Nurse qualification. • In house education to includes; • Symptom management /end of life care • Advanced care planning • Difficult Conversations • Medication Administration to include sub cut continuous infusion </td> </tr> </table> <p>Additional MDT partners; -Health visiting & specialist teams (OHFT).</p>	Team members have additional training;	<ul style="list-style-type: none"> • Paediatric Palliative foundation Course. • HCA study days • Paediatric palliative care module. • Paediatric palliative care symptom management. • Critical care skills. • Bereavement skills. • Advanced history taking/assessment. • Non-medical prescribing. • Community Children's Nurse qualification. • In house education to includes; • Symptom management /end of life care • Advanced care planning • Difficult Conversations • Medication Administration to include sub cut continuous infusion 	<p>GP; Oxfordshire CCG Anywhere in Oxfordshire + Oxfordshire GP.</p> <p>CCN Team provides care using integrated locality approach <i>(ref Ambitions for palliative and end of life care (eolc) / NHS Long term plan; care closer to home)</i></p>	<p>Oxford Health NHS Foundation Trust (OHFT) -NHS funding.</p> <p>Respite for Oxfordshire Sick Youngsters (ROSY); Charitable funding: CCN commissioned by ROSY.</p> <p>Fast Track EOL Care- CCHC funded Agency or CCN Commissioned</p>
Team members have additional training;				
<ul style="list-style-type: none"> • Paediatric Palliative foundation Course. • HCA study days • Paediatric palliative care module. • Paediatric palliative care symptom management. • Critical care skills. • Bereavement skills. • Advanced history taking/assessment. • Non-medical prescribing. • Community Children's Nurse qualification. • In house education to includes; • Symptom management /end of life care • Advanced care planning • Difficult Conversations • Medication Administration to include sub cut continuous infusion 				

<p>-OHFT Children's therapy support for children with life limiting conditions; Includes specialist support if indicated i.e. wheelchair/SALT.</p> <p>-Community Children's Dietitian support for children with life limiting conditions</p> <p>-Transition phase for Child to adult; Includes support or transfer to Community Nursing Service and Locality Matron for End of Life and Supportive Care as indicated to provide ongoing care within their role. Young person may remain supported by CCNT if death is anticipated within a short period. To include access to Community respiratory physio</p> <p>-CCN participation in formal forums Children's Continuing Care (CCHC) Liaison to include access to a fast track provision of care at end of life.</p> <p>-Out of Hours/ Urgent Care Support; Liaison for children at end of life with OHFT Urgent care teams to provide additional wrap around support for nursing interventions</p>		
External Partner Working		
<p>Helen House; Specialist Palliative care. Outreach/ inhouse medical team to include consultant Family and sibling support</p>	Regional	Charitable funding
<p><u>Oxford University Hospitals NHS Foundation Trust (OUH FT) Specialist Paediatric Teams</u> <u>Examples include</u> -Paediatric Oncology Outreach Nurses (POONS) for Oncology advice/support and shared community home visiting. -Paediatric Respiratory Team for access to Clinical advice -Neuro Muscular Teams</p>	Regional	NHS
<p>Zoe's Place Baby Hospice. Specialist Palliative care respite</p>	Regional (based S, Warwickshire)	Charitable funding
Alexander Divine	South Oxfordshire/ Berks	Charitable
<p>Sebastian's Action Trust; Family and sibling support</p>	Regional	Charitable funding
<p>GP; Liaison/ joint visit with CCN to review symptom management and use of medication. Liaison re family support if required.</p>	Oxfordshire CCG	NHS
<p>Social care; NB. CCN advisory/ health information and training for social care and education with children at end of life.</p>	Anywhere in Oxfordshire + Oxfordshire GP	NHS funding
<p>Education; NB. CCN provides advisory support/ health information to family, formal carers and local health professionals, to include training for education setting to enable child to continue to access education during end of life.</p>	Anywhere in Oxfordshire + Oxfordshire GP	NHS funding

Oxfordshire CCN Team, OHFT for children with nursing need or/ and at end of life.	Anywhere in Oxfordshire where child has an Oxfordshire GP	NHS funding.
Children's Community Nursing East (BHFT)	East Berkshire and a few Bucks GP practices	NHS funding with support from hospice charities.

- Parents or carers of infants, children and young people approaching the end of life can access support for grief and loss at home when their child is nearing the end of their life and after their death.

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This is available in:

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- Berkshire
- Northamptonshire
- Part of Wiltshire

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Children with Complex Needs Team . Central and North West London NHS Foundation Trust	Milton Keynes	NHS
Keech Hospice Care	Milton Keynes Bedfordshire and Hertfordshire	NHS/Charity
Helen and Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	NHS/Charity
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity
Alexander Devine Children's Hospice Service ,	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire ,	Charity
CCNT offer initial support for grief and loss, with additional information to signpost family for ongoing specialist support.	Anywhere in Oxfordshire + Oxfordshire GP	NHS.
ROSY -CCN able to request counselling for parents during life and death of child.	Oxfordshire	ROSY- Charitable
		NHS- for eol and identified period after death.

3. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care^[2] and advice from a consultant in paediatric palliative care^[3] during normal working hours.

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Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Helen and Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	NHS/Charity - Community Nursing Team core business hours 09.00-17.00 Mon-Fri Telephone symptom management helpline support 24/7
Keech Hospice Care	Milton Keynes, Bedfordshire and Hertfordshire	NHS/Charity - Community Nursing Team core business hours 09.00-1700 plus 24/7 senior nurse on call with availability for visits for EOLC Telephone symptom management helpline 24/7 Access to medical support 24/7 - not always a

^[2] We would like to capture those areas where registered nurses can provide both core and specialist children's palliative care in the community, to children with a range of medical complexity. We acknowledge that, where this is provided, it is done so by nurses with different roles, employed by the NHS and/or the voluntary sector. This will include specialist children's palliative care nurses providing care directly, or providing advice to other nurses providing direct care.

^[3] NHS England and NHS Improvement state that specialist children's palliative care teams should be led by specialist medical consultants. These specialist consultants are vital because they:

- have specialist expertise in managing life-threatening illness and life-limiting conditions across the paediatric spectrum
- the ability to manage the full range of symptoms experienced as disease and illness progresses
- lead and develop services within their region
- enable, support, teach and train other health care professionals.

		paediatric doctor from Keech but in Bed's & Herts this may come from a tertiary centre in addition to the Keech medical team. Potential to work with HDH in MK
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity Funded - Nursing Team 24/7. Senior Nurse on-call with availability for visits for EOLC 24/7. Would use referred baby/child/young person own Medical Team e.g. provided during core business hours by a community Paediatrician or Specialist Palliative Care Team (If available).
Alexander Devine Children's Hospice Service ,	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire ,	Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity Paediatricians with Special Interest and training in CPC– NHS/Charity (Specialist Consultant – not funded / Good will)
Paediatric Outreach Team – Buckinghamshire Healthcare NHS Trust	Buckinghamshire	NHS
CCNT offer initial support for grief and loss, with additional information to signpost family for ongoing specialist support.	Anywhere in Oxfordshire + Oxfordshire GP	NHS.
ROSY -CCN able to request counselling for parents during life and death of child.	Oxfordshire	ROSY- Charitable
		NHS Children's nursing care 7/7 8-8h (routine hours
Children's Community Nursing East (BHFT)	East Berkshire and a few Bucks GP practices	NHS funding for nursing care only. No consultant care currently.

4. Children and young people approaching the end of life and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care 24 hours a day, seven days a week.

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- Berkshire
- Northamptonshire
- Part of Wiltshire

Not Berkshire

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Children with Complex Needs Team CNWL	Milton Keynes	On call provision 24/7 for clinical support CCN- responsive 24/7 for 7/7 for chil with EofL needs via on-call mechanism . Support provided by experienced CCN with experience in SMP. ACP, difficult conversations
Helen and Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	NHS/Charity - Home visiting for EofL during core business hours for registered Helen House patients Telephone support 24/7 outside of these hours for
Keech Hospice Care	Milton Keynes, Bedfordshire, Hertfordshire	NHS/Charity Home visiting for EofL 24/7 if is a registered Keech patient Telephone support 24/7 for symptom management advice Medical support as above
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity Funded - Nursing Team 24/7. Senior Nurse on-call with availability for visits for EOLC 24/7. Would use referred baby/child/young person own Medical Team e.g. provided during core business hours by a community Paediatrician or Specialist Palliative Care Team (If available).
Alexander Devine Children's Hospice Service ,	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire ,	Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity

		Paediatrician with Special Interest in palliative care - Charity (Specialist Consultant – not funded / Good will)
Paediatric Outreach Team – Buckinghamshire Healthcare NHS Trust	Buckinghamshire	Paediatric Outreach Team can provide 24/7 on call support service for children on a syringe driver with support from local hospice service in conjunction with Helen House Palliative Care Team. Children have to be accepted by Helen House and Rennie Grove service to qualify. NHS funded
CCN offer 24-hour tel contact with home visit if indicated 7 days a week or child approaching end of life). N.B. Advice accessed via hospice or medical speciality team.	Anywhere in Oxfordshire + Oxfordshire GP	NHS
		CCN- responsive 24/7 for 7/7 for child at eol via SPA. Support provided by experienced CCN with experience in SMP. ACP, difficult communications.
Children's Community Nursing East (BHFT)	East Berkshire and a few Bucks GP practices	NHS funding CCN support but only with hospice charity support.

5. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care) during normal working hours.

This is available in:

- Oxfordshire
- Buckinghamshire
- Berkshire
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Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
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Children with Complex Needs Team – CNWL	Borough of Milton Keynes	NHS CHC Funding for children qualifying care for packages Support also provided during core business hours by a community Paediatrician Alternate monthly Palliative care MDT's attended by all local care providers
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity Funded - Nursing Team 24/7. Senior Nurse on-call with availability for visits for EOLC 24/7. Would use referred baby/child/young person own Medical Team e.g. provided during core business hours by a community Paediatrician or Specialist Palliative Care Team (If available).
Alexander Devine Children's Hospice Service	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire ,	Clinical Nurse Specialist service - NHS/Charity Nursing Team-Charity Paediatricians with Special Interest in palliative care – NHS/Charity (Specialist Consultant – not funded / Good will)
Helen & Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	NHS/ Charity
Paediatric Outreach Team Buckinghamshire Healthcare NHS Trust	Buckinghamshire	Paediatric Outreach Team can provide 24/7 on call support service for children on a syringe driver with support from local hospice service in conjunction with Helen House Palliative Care Team. Children have to be accepted by Helen House and Rennie Grove service to qualify. NHS funded

Keetch Hospice Care	Milton Keynes, Bedfordshire & Hertfordshire	2 dedicated paediatric doctors who will provide support and advice around symptom management and will do reviews at home or in the hospice Senior nurses working in house and community who will assess and advise. CNS carries out assessments and advises regarding symptoms
CCN team offers a 7 day a week service for children known to the team. Hours; 08:00-20:00h accessed via SPA (see above). Specialist Paediatric Palliative and EOL care Practitioner. On call team have additional knowledge on symptom management. Access to children's therapists to include specialist therapist if required to support non-pharmacological symptom management.	Anywhere in Oxfordshire + Oxfordshire GP	NHS funded.
<u>Partner working with Helen House Hospice;</u> Specialist Paediatric Palliative Care + medical advice	Regional	Charitable funding
		NHS funded. Access to nursing care 8-8 7/7 routine hours
Children's Community Nursing East (BHFT)	East Berkshire and a few Bucks GP practices	NHS funding CCN support but only with hospice charity support.

6. Children and young people with a life-limiting condition and being cared for at home have access to both children's nursing care and advice from a consultant in paediatric palliative care to manage their symptoms (not including end of life care), 24 hours a day, seven days a week.

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- Buckinghamshire
- Berkshire
- Northamptonshire
- Part of Wiltshire

Not Berkshire

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
		Currently for eol only. From ? Aprilincrease in service to 24/7
Keech Hospice Care	Milton Keynes, Hertfordshire, Bedfordshire	Specialist Children's Nurses providing care and support in community and in-patient setting. 24/7 advice line manned by nurses, with senior nurse back up. Medical support for non EOLC during office hours and occasional on call
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity Funded - Nursing Team 24/7. Senior Nurse on-call with availability for visits for EOLC 24/7. Would use referred baby/child/young person own Medical Team e.g. provided during core business hours by a community Paediatrician or Specialist Palliative Care Team (If available).
Alexander Devine Children's Hospice Service ,	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire ,	Clinical Nurse Specialist service - NHS/Charity Nursing Team – Charity Paediatrician with Special Interest in Palliative Care – Charity (Specialist Consultant – not funded / Good will)
Helen and Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	NHS Charity
CCN team offers a 7 day a week service for children known to the team. Hours; 08:00-20:00h accessed via SPA (see above). Service includes support for children with life limiting conditions	Anywhere in Oxfordshire + Oxfordshire GP	NHS
<u>Helen House;</u> Specialist Paediatric Palliative Care + medical advice	Regional	Charitable
		Currently for eol only. From ? Aprilincrease in service to 24/7

7. Infants, children and young people with a life-limiting condition and their parents or carers can access emotional and psychological support at home.

This is available in:

- Oxfordshire
- Buckinghamshire
- Berkshire
- Northamptonshire
- Part of Wiltshire

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Children with Complex Needs CNWL	Milton Keynes	NHS. Clinical Psychologist 2 days per week Charitable support from hospice providers Keech Hospice /Helen and Douglas House
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity Funded - Therapist Trained Nurses, Carers 24/7. Senior Nurse on-call. Complimentary Therapist support – Flexible hours available around family need.
Alexander Devine Children's Hospice Service	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire	Charity
Helen& Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes, Northamptonshire, Swindon and Wiltshire	Charity/ NHS
Keech Hospice Care	Milton Keynes, Bedfordshire, Hertfordshire	NHS/charity
Infant, child and YP support through Play specialist and respite nursing team. CCN; Parent and child emotional and psychological support	Anywhere in Oxfordshire + Oxfordshire GP	NHS-CCN Rosy respite- commissioned via charitable funds
Referral to identified NHS services i.e. psychological medicine, talking space, charity support (OHFT/ OUH FT)	Anywhere in Oxfordshire + Oxfordshire GP	NHS
CCN able to facilitate swift access to counselling for parents through ROSY charity,	Anywhere in Oxfordshire + Oxfordshire GP	Charitable funding.
Helen House Outreach & family support	Regional	Charitable

		Access to counselling through ROSY charity, Referral to identified NHS services ie psychological medicine, talking space, charity support.
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8. Infants, children and young people with a life-limiting condition and their families can access regular short breaks for respite at home should they wish^[8].

This is available in:

- Oxfordshire
- Buckinghamshire
- Berkshire
- Northamptonshire
- Part of Wiltshire

Name of individual professional, team or provider organisation	Geographical areas where this standard is being met	How this work is being funded (NHS, local authority or charitable)
Children with Complex Needs CNWL	Milton Keynes	Referral to CHC for additional funding and gain access to care or increase existing care package Current Covid pandemic means local Hospice providers are only able to offer symptom management stays for max of 1-2 nights/days
Forever Colours Children's Hospice (Charity No. 1191073)	Buckinghamshire (Pending CQC Registration)	Charity Funded - Trained Nurses, Carers, Holistic Team Members and Volunteers available flexibly covering a 24/7 period. Senior Nurse on-call. Flexible hours available around family need.
Alexander Devine Children's Hospice Service ,	Berkshire East, Berkshire West, and surrounding boundaries including South Buckinghamshire and North Hampshire ,	Charity
Helen & Douglas House	Oxfordshire, Buckinghamshire, Milton Keynes,	Charity / NHS Currently short breaks are limited to 2 night stays

^[8] Short breaks may take place in the child's home or in a setting outside of the home such as a long-term care facility or hospice. It may include overnight breaks, or breaks lasting only a few hours.

	Northamptonshire, Swindon and Wiltshire	
Sebastian's Action Trust	Hampshire, Berkshire, Surrey, Oxfordshire and Buckinghamshire	Charity
Rosy- Respite team offer short periods of respite as per identified dependency.	Anywhere in Oxfordshire + Oxfordshire GP	(ROSY commission CCN team)
Helen House/Zoe's Place/Alexander Divine	See Q1	Charitable funding
Referral to social care for access to additional social support i.e. direct payments.	Oxfordshire county council	
Referral to social respite centre	Oxfordshire county council	Oxfordshire County Council (OCC)/ Barnardo's
Referral to additional resources-flexicare	Oxfordshire (central/ south)	Charity/ supported by OCC funding
		Access to Respite via Rosy through charitable funding. Referral to CCHC for additional funding and access to care

Please return your completed form to james.cooper@togetherforshortlives.org.uk and dan.steer@togetherforshortlives.org.uk