

Response form

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].

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)
KCHFT Childrens community Nursing Team	East Kent covering Thanet, Dover, Deal, Shepway, Ashford and canterbury Districts	NHS funded
MCH / MFT and specialist input from Tertiary centres	Medway and Swale	CCG and NHSE specialised commissioning

^[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

2. 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.

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)
KCHFT Childrens community Nursing	East Kent	NHS funding
	DGS	
	WK	
Demelza house hospice	East Kent	Charity funding
Pilgrims hospice	East Kent	Charity funding
GP	East Kent	NHS funding
Charitable organisations	Medway and Swale	Charity funding
GP	Medway and Swale	NHS funding

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^{1[3]} during normal working hours.

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)
Childrens Community Nursing Team	East Kent	NHS funding
East Kent Hospital Trust	East kent	NHS funding
Royal Marsden Symptom Care Team	East Kent	NHS Funding
GOS Symptom Care Team	East Kent	NHS funding

^[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.

Evelina Childrens Symptom Care Team	East Kent	NHS Funding
Children's Community Nursing Teams (MFT and MCH)	Medway and Swale	CCG

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.

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)
Childrens Community Nursing Team (KCHFT)	East Kent	NHS funding
East Kent Hospital Trust (EKUFT)	East Kent	NHS funding
Royal Marsden Symptom Care Team	East Kent	NHS Funding
GOS Symptom Care Team	East Kent	NHS funding
Evelina Childrens Symptom Care Team	East Kent	NHS Funding
MFT - COaST	Medway	CC packages funded by CCG
MFT - COaST	Medway and Swale	Oncology EoL nursing, funded by CCG
MFT - COaST	Swale	EoL care – non-oncology
MCH CCN	Medway	EoL care – non-oncology

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.

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)
Childrens Community Nursing Team (KCHFT)	East Kent	NHS funding
East Kent Hospital Trust(EKUFT)	East Kent	NHS funding
Royal Marsden Symptom Care Team	East Kent	NHS Funding
GOS Symptom Care Team	East Kent	NHS funding

Evelina Childrens Symptom Care Team	East Kent	NHS Funding
MFT - COaST	Medway	CC packages funded by CCG
MFT - COaST	Medway and Swale	Oncology EoL nursing, funded by CCG
MFT - COaST	Swale	EoL care – non-oncology
MCH CCN	Medway	EoL care – non-oncology

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.

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)
Childrens Community Nursing Team (KCHFT)	East Kent	NHS funding
East Kent Hospital Trust (EKUFT)	East Kent	NHS funding
Royal Marsden Symptom Care Team	East Kent, Medway and Swale	NHS Funding
GOS Symptom Care Team	East Kent, Medway and Swale	NHS funding
Evelina Childrens Symptom Care Team	East Kent, Medway and Swale	NHS Funding

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

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)
KCHFT Childrens community nursing	EK, NK	We would signpost to other services/charities
MCH CCNS	Medway	We would signpost to other services/charities
MFT CCNS / COaST	Medway and Swale	We would signpost to other services/charities

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].

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)
Childrens Community Short breaks service (KCHFT)	East Kent	NHS funding
Demelza House hospice short breaks service	East Kent	Charitable funding

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

^[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.