

TfSL Mapping Exercise 2021 – re Community- Based Children's Palliative Care

Group Discussion at SW PPC Network Meeting 13 May 2021

Mapping exercise re community-based children's palliative care - Rationale

- Together for Short Lives is keen to create a comprehensive map which shows the extent to which different standards are being met for children and families across the UK
- Information being requested from all geographical regions
- Standards lifted from NICE Guidance
- Information will be used to populate a google map
 - With eight separate layers, one for each standard
- TfSL want results asap:
 - To discuss with All-Party Parliamentary Group for Children Who Need Palliative Care in June
 - Will work with them to develop recommendations to government

Why?

- To highlight to key audiences the extent to which established children's palliative care standards are being met (or not)
 - UK Government, MPs and peers, NHS England and NHS Improvement (NHSE/I), Integrated care systems
- To articulate where the gaps are – and to use this information to influence those who plan, fund and provide children's palliative care

The ask of us.....

To map the geographical areas in which 8 standards are being met for children and families in the community:

- By statutory, voluntary, private sector services, or a combination, free at the point of use.....
- NB – NOT those provided on good will basis

Questions answered by SW PPC Steering Group

As a region with just one Level 4 trained Pall Care Consultant (whose remit is only for a small part of the region currently), our answers to Questions 1, 3, 4, 5 and 6 are straightforward.....

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 - **Nowhere**
3. 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 during normal working hours - **Nowhere except Bristol, North Somerset, South Glos 3 days a week 9-5**
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 - **Nowhere**
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 - **Nowhere except Bristol, North Somerset, South Glos 3 days a week 9-5**
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 - **Nowhere**

Standards addressed at 13.05.21 network meeting

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

Question 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.”

As long as the support is provided in the home, whether in person, by telephone or by video call, we would regard that as the standard being met. We use the same definition as in the NICE quality standard and guideline - “Therapies aimed at supporting a person anticipating or experiencing the loss of a loved one.”

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, charitable etc...)
Bristol Children’s Hospital Paediatric Palliative Care and Bereavement Support Team	Families whose children have died at BCH or been brought to BCH after death, regardless of their home address which could be anywhere in the region	NHS
Children’s Hospice South West - Charlton Farm - Little Bridge House - Little Harbour	Bristol, North Somerset, South Glos, Somerset, Devon and Cornwall and anyone on CHSW caseload (includes Bath and North East Somerset, Wiltshire, some of Swindon and Dorset)	Charitable

Question 2 (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, charitable etc...)
Lifetime, Sirona care and health NHS Services – Community Nurses	Bristol, North Somerset, South Glos	NHS
Jessie May Trust	Bristol, North Somerset, South Glos, Bath and North East Somerset, Swindon, Wiltshire	Charitable
Children’s Complex and Palliative Care Team, Taunton, Yeovil and Somerset	Taunton, Yeovil, Somerset and East Mendip	NHS
Virgin Care Bath and North East Somerset	Bath and North East Somerset	NHS
Bath Oncology Team	Bath and North East Somerset	NHS

Question 2 (3)

“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, charitable etc...)
Devon Children’s Palliative Care Team, Torbay and South Devon Health Care Trust	North, East, South Devon	NHS
Plymouth Hospital Trust – Community Nursing Team	Plymouth, North Cornwall, West Devon	NHS
Balloons (Support for Bereaved children)	Exeter	Charitable
FIG (Support for Families in Grief)	North Devon	Charitable
Cornwall CCN Team	Cornwall	NHS
Oncology Teams and ‘CLIC’ Services – Nursing and Social Work	BNSSG, Somerset, Devon and Cornwall	NHS/Charitable

Question 2 (4)

“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, charitable etc...)
Julia’s House Hospice	Dorset and Wiltshire	Charitable
Rainbow Trust	Bristol and Gloucester	Charitable
Penhaligon’s Friends	Cornwall	Charitable
Acorns Childrens Hospice	Gloucestershire (but also covers other areas)	Joint local commissioned and charitable funding. Only available to children known to the service before death.
Childrens Community Nurse team (GHC)	Gloucestershire	NHS
Childrens Oncology nurse team	Gloucestershire	NHS

Question 7

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

- As long as the support is provided in the home, whether in person, by telephone or by video call, we would regard that as the standard being met.
- Have clarified and this only includes services provided by a psychologist.

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, charitable etc...)
Bristol Children’s Hospital Paediatric Oncology Team – Psychologists	Bristol, North Somerset, South Glos	NHS
Children’s Hospice South West - Psychology provision - Little Harbour only at present - Ongoing work to establish provision for all families from all 3 hospice sites	Anyone on Little Harbour Caseload (could be Devon, Cornwall, Plymouth)	Charitable
Lifetime, Sirona care and health NHS Services – Psychologists	Bristol, North Somerset, South Glos	NHS

Question 7 (2)

“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, charitable etc...)
Oncology Teams across South West – Psychology provision	BNSSG (as above), Bath and North East Somerset, Taunton, Devon, Cornwall, Plymouth	NHS
Children’s Complex and Palliative Care Team, Taunton, Yeovil and Somerset – Psychology provision	Taunton, Yeovil, Somerset and East Mendip	NHS
Virgin Care Bath and North East Somerset – Psychology provision	Bath and North East Somerset	NHS – but post currently vacant
Acorns Childrens Hospice	Gloucestershire (but also covers other areas)	Joint local commissioned and charitable funding

Question 7 (3)

“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, charitable etc...)
Childrens Community Nurse team (GHC)	Gloucestershire	NHS
Cornwall CCN team – Psychology	Cornwall	NHS (0.8 WTE post but currently vacant)

Question 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”

Short breaks definition - to provide the child or young person with an opportunity to enjoy social interaction and leisure facilities, to support the family to take a break from caring for their child at home or an alternative community environment such as a children's hospice, to provide opportunities for siblings to have fun and receive support in their own right.

- May offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.
- Includes those at home arranged by local authorities or provided through continuing care packages.
- They do not need to be of a specific length, but the family should be able to take a complete break from caring during that period.
- Specialist short break care e.g. for symptom control is included also

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, charitable etc...)
Children’s Hospice South West - Charlton Farm - Little Bridge House - Little Harbour	Bristol, North Somerset, South Glos, Somerset, Devon and Cornwall and anyone on CHSW caseload (includes Bath and North East Somerset, Wiltshire, some of Swindon and Dorset)	Charitable

Question 8 (2)

“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”

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, charitable etc...)
Jessie May Trust	Bristol, North Somerset, South Glos, Bath and North East Somerset, Swindon, Wiltshire	Charitable
Health and Social Care provision - e.g. care packages, other social care respite, direct payments, health payments via CCG etc...	<p>Available across SW Exact details vary by area, CHC/direct payments everywhere plus...</p> <p>BNSSG – Respite provision (e.g. Belbrook, Bush) Somerset – Providers include Somerset Children’s Homecare Team, Newcross, Prestige, Synergy Complex Care, Thornbury Devon and Plymouth – access to LA funding for short breaks assessment (either as placement in own home or elsewhere), Action for Children (foster placements for short breaks) Cornwall – 3 residential short break homes for children with a learning disability and complex health care need (Cornwall Partnership NHS Foundation Trust) and 3 homes for children with a learning disability (Cornwall council) Glos - Complex Health/Respite Packages (Gloucestershire Health Care complex care team)</p>	Huge range of care providers, statutory, private, charitable

Question 8 (3)

“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”

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, charitable etc...)
Acorns Childrens Hospice	Gloucestershire (but also covers other areas)	Joint local commissioned and charitable funding.
James Hopkins Trust	Gloucestershire	Charitable - for children <6 years old
Julia’s House Hospice	Dorset and Wiltshire	Charitable

Information to feedback (1):

- Challenge of unclear network boundaries so risk that some provision will be missed
- Re geographical areas:
 - We have done our best to answer to Bristol, North Somerset, South Glos, Somerset, Devon and Cornwall
 - Some of our attendees had relevant info re other areas which we have included but I'm afraid we are not in a position to answer to the whole of those areas (incl BANES, Wiltshire, Dorset, Glos etc....)
- NB Definition of Consultant in PPC is key
 - Level 4 definition means standard rarely met – we do have high level PPC delivery by other consultants in the South West, but there is unfortunately currently no route by which those consultants can get their knowledge and experience formally recognised (e.g. a Level 3 consultant who has Level 4 competencies but on paper remains Level 3)
- We don't have social care or education representation in our Network so we may not have included everything they offer I'm afraid

Information to feedback (2):

- If being published to families we would ask please that:
 - A clear message is included that what is actually available may look different to what is on the map (as lots of 'over and above' and good will provision exists but the purpose of this map was only to evidence provision that is funded)
 - To include clear recommendation to families that they check with local providers re what is available currently as may vary from what is on the map and will be constantly evolving
- Relying on network leads to update re any changes in real time is likely to be unrealistic (as network leads won't necessarily know when things change) –esp for the networks that are voluntarily run – our group feel this exercise would need to be formally repeated at intervals if updated version/s required please
- Re Question 7 – based on the clarification we sought, we have included psychology provision only but it looks like the Thames version includes a range of emotional as well as psychological support – so responses to this question may need moderating at TfSL level