

Reference: FOI.ICB-2324/104

Subject: Children's Palliative Care

I can confirm that the ICB does hold the information requested; please see responses below:

QUESTION	RESPONSE
<p>a) Do you have a children's palliative care service specification? (Yes/No). If so, please attach a copy to your response to this request.</p> <p>b) Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should have opportunities to be involved in developing an advance care plan? (Yes/No)</p> <p>c) Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should have a named medical specialist who leads and coordinates their care? (Yes/No)</p> <p>d) Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their parents or carers should be given information about emotional and psychological support, including how to access it? (Yes/No)</p> <p>e) Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition should be cared for by a</p>	<p>a) Please find attached the service specification for children's care held with a local hospice.</p> <p>b) Yes – see service specification above for further detail.</p> <p>c) Yes – <i>“A named member of the team (key worker) should be responsible for maintaining contact with a family in order that support continues when a child is at home between visits”.</i></p> <p>d) Yes</p> <p>e) The service specification states <i>“The provider will deliver children's palliative care in accordance with the “ACT Integrated Multiagency Care Pathway for Palliative Care for Children (2004)”.</i> <i>This pathway has been agreed as the most appropriate model for NHS palliative care delivery.”</i></p> <p>f) Yes - <i>“After death, bereavement care will be available to the family with support being an integral part of that care, respectful of cultural and religious needs”.</i></p> <p>g) No</p> <p>h) The service specification is for a specific hospice which provides short respite breaks for infants, children and young people with a life-limiting condition and their families. In addition to this, we jointly fund with our relevant local</p>

<p>multidisciplinary team that includes members of the specialist paediatric palliative care team? (Yes/No)</p> <p>f) Do you have a children's palliative care service specification which states that parents or carers of infants, children and young people approaching the end of life should be offered support for grief and loss when their child is nearing the end of their life and after their death? (Yes/No)</p> <p>g) Do you have a children's palliative care service specification which states that infants, children and young people approaching the end of life and being cared for at home should have 24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care? (Yes/No)</p> <p>h) Do you have a children's palliative care service specification which states that infants, children and young people with a life-limiting condition and their families should have access regular short breaks for respite? (Yes/No)</p>	<p>Authorities short breaks for children with life limiting conditions which are separate to any service specification outlined above.</p>
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The information provided in this response is accurate as of 11th July 2023 and has been approved for release by Sarah Truelove, Deputy Chief Executive and Chief Finance Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.

SCHEDULE 2 – THE SERVICES

A. Service Specifications

1. Population Needs

1.1 National/local context and evidence base

Children’s palliative care is concerned with the treatment of children with life-limiting or life-threatening conditions by maintaining quality of life, not just in the dying stages, but also in the weeks, months and years before death. It is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement (ACT 2008).

Better Care Better Lives (Department of Health, 2008) recognises the specialist skills and expertise of the voluntary sector, particularly children’s hospices, in palliative care and end-of-life care. The document also recognises the needs of families to access specialist short breaks, whether at home, in a children’s hospice or other voluntary sector provider, or in the community. This service model is based on the guidelines for best practice by Children’s Hospice UK 2008.

National Policy

- Children Act (2004)
- Standards for Better Health (2004)
- Our Choice, Our Care, Our Say (2006)
- Better Care Better Lives (DH 2008)
- Healthy Lives, Brighter Futures (DCSF, DH 2009)
- Working together to safeguard children (HM Government 2010)
- National Framework for Children and Young People’s Continuing Care (DH 2010)
- NHS at home: children’s community nursing services (DH, 2011)
- Getting it right for Children and Young People: Overcoming cultural barriers in the NHS so as to meet their needs (DH, 2010)
- Achieving Equity and Excellence for Children (DH, 2010)
- NHS Five Year Forward View (2014)
- Children and Families Act (2014)

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people from dying prematurely	
Domain 2	Enhancing quality of life for people with long-term conditions	
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care	
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm	

2.2 Local defined outcomes

- Children and young people with palliative care needs and their families will have their emotional and physical challenges mitigated by the care and support they receive by the services delivered by the hospice.
- Families and children report that their social, cultural, spiritual, physical and emotional needs are met.
- It can be demonstrated that the child/young person is pain free or pain is minimised as far as possible.
- The child and family are supported to improve the quality of their lives through access to specialist clinical and psychological expertise, either for regular interventions, in an emergency or for respite care.
- Parents and children report that they are well informed about their conditions and the support/services available to them both within the hospice and within their own local area.
- Parents and siblings have a positive experience in the last days/hours of their child's (sister or brother's) life through the provision of timely interventions and support.
- The child and family will expect clear links and regular information exchange to be made with the named professional (key worker) in the child's local community.
- Close family involvement around choice of place of death, including use of the Wishes document

3. Scope

3.1.1 Aims of the service

Children's Hospice South West (the Provider) will offer high quality care and support to children and young people with life limited or life threatening illnesses, who are registered with a GP within the catchment area for NHS B&NES.

The Provider will provide a range of services, which should include short breaks, emergency and end of life care, which will include various leisure and therapeutic activities and facilities to help children to be comfortable.

The Provider will work in the context of the wider network of services and support commissioned and provided by the NHS and other partners for these children and families.

Care definitions (ACT and RCPCH, 1997)

- Group 1 – Life-threatening conditions for which curative treatment may be feasible but can fail (cancer, irreversible organ failures)
- Group 2 – Conditions with long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death possible. (cystic fibrosis, muscular dystrophy)
- Group 3 – Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Batten's disease, mucopolysaccharidosis)
- Group 4 – Conditions with severe neurological disability which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive.

(severe multiple disabilities, such as following brain or spinal cord injuries)

3.1.2 Objectives of the service

To enter and build a collaborative relationship with NHS Commissioners which will enable care to be available to local children with palliative care needs. This will include children and who are eligible for care in line with the local eligibility criteria for Continuing Care for Children and Young People.

The Provider will offer eligible children and young people high quality services, including but not restricted to:

- End of life care and support
- Short breaks care and support
- Emergency/crisis support
- Associated care such as bereavement and sibling support, symptom control, the provision of therapies including play and social activities, and advisory support to families.

These services may be agreed with NHS commissioners as part of a care package.

3.2 Service description/care pathway

The provider will deliver children's palliative care in accordance with the "ACT Integrated Multiagency Care Pathway for Palliative Care for Children (2004)". This pathway has been agreed as the most appropriate model for NHS palliative care delivery.

The service will provide holistic, family centred care. It is anticipated that the model of delivery will be as non-medicalised as possible within the parameters of the child's medical and nursing needs.

The hospice service may be delivered in different ways through a menu of services designed to deliver specialised individual packages of care, tailored to an individual child. Hospices have always aspired to the highest standards for this group of children and this specification is supportive of that trend continuing, with clear and transparent requirements that enable demonstration of their high quality work.

3.2.1 Environment

The hospice will provide a safe, homely and appropriate environment which facilitates privacy, relaxation and enjoyment but with the provision of specialist equipment such as hoists, soft play, sensory equipment and communication aids to support the care offered, where required.

An appropriately furnished area for young people/older service users, facilities for siblings and other family members and a range of leisure activities may also be made available.

3.2.2 Care

The care offered will aim to meet the social, cultural, spiritual, physical and emotional needs of the child/young person and their family. The team will endeavour to meet the needs of families from all cultural and ethnic backgrounds taking into account the customs, values and spiritual beliefs of the child and his/her family. The confidentiality, privacy and choice of the child/young person will be respected. The team will promote welfare and protection for children/young people (Children Act 1989) and may provide advocacy where needed. (Children Act 2004 and National Service Framework for Children, Young People and Maternity Services 2004). The care given will

be guided by the wishes of the individual child/young person and their family, whether in the children's hospice or in the community. Care will be provided in partnership with the child and family in a spirit which acknowledges their right to confidentiality and choice and recognises the child's individual needs, whilst preserving dignity.

3.2.3 Support

Appropriate support will be made available to meet the needs of the family members and those closely involved with the child/young person and family. The provider should aim to develop facilities and services which are flexible enough to meet the support needs of all family members. Particular and appropriate facilities and care should be provided for the child/young person's siblings staying in the hospice. A named member of the team (key worker) should be responsible for maintaining contact with a family in order that support continues when a child is at home between visits. The frequency of this contact will depend upon the needs of individual families.

3.2.4 Symptom Control

Symptom control will aim to promote comfort and enhance quality of life. Collaboration with paediatricians, paediatric palliative care consultants, GPs, specialist nurses and other professionals will ensure that every effort is made to control distressing symptoms and provide choices of management. The child/young person should be involved in all decisions relating to care, and consent for any invasive procedures should be obtained. Symptom control requires frequent evaluation in order for it to be effective. Forward planning which anticipates a change in need is often required to facilitate effective medicines management within the hospice and community settings. Advanced Care Plans should be discussed and documented. All care, whether conventional or complementary, will be given by staff with appropriate knowledge and experience, aimed at enhancing quality of life for the child and his or her family.

3.2.5 End of life care

Care will be continued during the terminal phase of a child's illness and following death if it is the choice of the child/young person or family. The spiritual care offered to the child and family at this stage will be appropriate to their individual wishes.

When death occurs within the children's hospice there should be facilities for the child's body to remain there until the funeral if this is the family's wish. The family can then spend as much time with their child after death as is helpful. Unless the service offered is "hospice care at home", accommodation should be available for the family to remain at the children's hospice during this time. A team member must be available to give support and information to the family as well as practical help if desired with organising the funeral and any other issues relating to the death. Sensitive, emotional support is essential for all close members of the family and the other children and families in the children's hospice at the time.

3.2.6 Bereavement

After death, bereavement care will be available to the family with support being an integral part of that care, respectful of cultural and religious needs.

Staff working with bereaved families must have access to supervision/support.

Staff will have appropriate skills and experience and work closely with other agencies who may offer support in the family's own locality.

3.2.8 Transition and Discharge processes

It is recognised that packages of support may vary to that predicted and as a result, plans may need to be reviewed more regularly than quarterly. Similarly children/families may wish to be discharged at their choice and it will be the responsibility of the lead NHS professional and commissioners to find alternative provision if this is needed.

A number of children previously not expected to survive until adulthood are now living longer and reaching adulthood. Where this occurs, the service will support the smooth transition to adult services. Given the small number of young people, this may require conversations with commissioners of both adult and children's services. This requires early co-operative planning and delivery across health, social care and education services which is supportive without compromising the need for the young person's increasing independence.

The provider should ensure that they have a clear policy identifying transition arrangements to adult services.

3.2.9 Response time and prioritisation

The provider should respond to urgent referrals within 48 hours. If capacity prevents this then they will liaise with the referrer/lead professional and commissioner to prioritise while alternative provision (if appropriate) is sought elsewhere.

3.2.10 Self-care and patient carer information

The provider will be involved in the review and evaluation of care packages for children on their case load with other professionals, at each contact throughout the illness and at the request of the patient or carer.

When larger multiagency meetings are needed the provider is expected to be involved. These meetings will be to review packages of care. The date of the next review will be set and recorded.

Multiagency review of the care plan will include:

- The relevance and appropriateness of current care package
- The effectiveness of care plans
- Any newly identified needs
- Patient satisfaction with the care
- Modality and frequency of all therapies and support
- Activities of daily living/social care support
- Medication – how monitored/reviewed
- Pain plans
- Risk assessment procedures and crisis/urgent response

3.2.11 Workforce

An appropriate skill mix will be maintained and reviewed regularly, for both inpatient and outreach activity in order to deliver a service which meets the population needs.

- All trained staff are registered with the appropriate Professional body with membership and registration audited regularly to ensure compliance

- Non-professional staff must undertake training to ensure they have a minimum set of competencies to undertake their role.
- Staff should have access to a process which enables them to raise, in confidence, concerns over any aspect of service delivery that could affect the quality of patient care.
- Staff should have undertaken training for Lone Working, if applicable
- Mandatory training including CPR, manual handling, infection control, child protection must be undertaken and delivered in accordance with the Provider's policies.
- Support and train students to ensure future workforce and capacity.
- All staff should be skilled in adult and paediatric resuscitation.
- Also see requirements for safeguarding.

3.2.12 Record Keeping

The following must be delivered as a minimum:

- Record management policy, which ensures as a minimum adherence to Data protection Act, confidentiality and regular audit of records.
- Work towards a system to allow client information to be kept electronically
- Care plan completed with risk assessment where appropriate
- All visits/activity must be recorded in a legible, timely and accurate manner
- Clear process for moving and tracking records to be in place
- Clear process of working towards the development of joint records
- The provider will have policies and procedures in place to reduce risk of errors resulting from poor information recording and sharing. This will include timely sharing of information between family hand-held records and the clinical records

3.3 Population covered

The funding agreement for this service specification covers all children who reside in the BNSSG or B&NES area and are registered with a Bristol/North Somerset, South Gloucestershire or B&NES GP.

	GP registered Population 0-17 January 2017	Number of children using CHSW 1 April 2017
NHS Bristol CCG	103,134	72
NHS North Somerset CCG	42,995	29
NHS South Glos CCG	55,588	31
Bath &NES CCG	39,973	19
Total		

3.4 Any acceptance and exclusion criteria

This service is commissioned for children and young people with life-limiting and life threatening conditions up to the age of 19. .

Children and young people will not be removed from the caseload if their prognosis changes, unless they become ineligible for the service against the agreed criteria.

3.4.1 Referral criteria

A consultant paediatrician or children's community nursing team manager will need to make a referral (or endorse a referral) in order for a child to be included within the activity for this contract.

Any new referral to the Hospice for which funding from the NHS is being requested will be approved by the Commissioning Manager or Children's Continuing Care Nurse Manager. It is expected that an holistic assessment, including health, social care and any specialist assessment will have been completed by the provider, jointly with other services if appropriate

The provider will develop a package of support with the child / family, and sharing this and its costing with the Commissioning Manager. Once agreed this will then be included in the agreed contract activity for the relevant commissioner. Any admissions or accepted cases for services of children that fall outside the agreed package of support will require authorisation by a commissioning manager in advance, unless as a result of urgent/end-of-life/crisis support.

If the referral to the hospice is not deemed to be meeting a need as described above, the services provided by the hospice will not be included in the agreed contract activity. The provider may choose to provide a package of care funded through other income..

It will be the responsibility of the Provider to undertake regular reviews of the need of the child or young person to ensure that the service is meeting the outcomes identified and that they meet the criteria for provision of support under this Contract

3.4.2 Out of hours / End of Life

In a crisis/immediate-end-of-life/emergency situations new referrals may be made directly to the provider. However the commissioning manager / Children's Continuing Care Nurse Manager will be informed of this action at the earliest opportunity by both the provider and the referring clinician.

In exceptional circumstances where a commissioner cannot be contacted (such as out of normal business hours or bank holidays) the referrer (consultant paediatrician or children's community nursing team manager) may at their clinical discretion arrange appropriate hospice admission. However, a notification in writing discussion with a commissioner **must** take place as soon as possible thereafter (i.e. no later than 72 hours). It is anticipated that this scenario would only apply to immediate end of life care or a health/social crisis situation where the only alternative to this hospice placement is a hospital admission over a weekend/bank holiday.

3.4.3 Acceptance criteria

The service will be available to children and young people with life-limiting or life-threatening conditions and their families.

3.4.4 Exclusion criteria

- Young people over the age of 18 will not normally be accepted and should be discussed with the local commissioner in advance of their 18th birthday
- Children or young people not registered with a GP in NHS Bristol, North Somerset, South Gloucestershire or Bath and North East Somerset areas.
- Children or young people not meeting the referral criteria specified in Section 3.4.1
- Children or young people referred and admitted to any of the provider's services without being subjected to the agreed referral pathway and panel process. These patients will not have funding agreed by NHS commissioners.

It is acknowledged that the hospice may choose to provide services to a child or young person and their family who do not meet the NHS criteria and requirements in Section 3.4.1. This arrangement is separate to any NHS agreement and may be funded charitably at the discretion of the hospice.

3.5 Interdependencies with other services and providers

The provider will make available specialist expertise and advice to children's community nursing teams and paediatric teams within the child's local area.

The provider will link with all relevant NHS, social care and independent providers in and out of the Local Authority as required ensuring continuity of care for children and their families.

Sub-contractors

The Provider must notify the NHS Commissioners if it intends to use subcontractors when delivery of care cannot be met through the organisation's own service capacity.

If nursing agencies are used to augment capacity then the Provider must supply NHS Commissioners with details of these agencies, and the contractual arrangements.

Whole system relationships

The Provider will work collaboratively with NHS commissioners and other providers to ensure that referrals of locally eligible children go through the agreed referral pathway as outlined in section 3.4.1.

Safeguarding Children and Young People and Vulnerable Adults

The Provider must ensure that they meet the quality standards of all the required policies and procedures relating to safeguarding.

- All staff must be in receipt of child protection training and updating, on a minimum 3 yearly basis, at an appropriate level to their role
- All staff are compliant with Care Quality Commission Standards.
- All staff working with children and young people will have undertaken an enhanced or appropriate Criminal Records Bureau check, checked on a three yearly basis
- The provider should have an identified Named lead professional for safeguarding children within the organisation.

- All staff to have regular checking of their registration on annual basis
- All staff with patient contact will access CP supervision on a regular basis (minimum 3 monthly)
- All staff must adhere to National legislation with regards to safeguarding and local LSCB policies, including that pertaining to safer recruitment
- Mechanisms for ensuring that allegations towards staff pertaining to safeguarding issues are fully investigated must be in place and adhered to, including informing the relevant commissioner.
- Processes should be in place for managing allegations against staff and any incidents or complaints relating to any aspect of safeguarding children, including informing the relevant commissioner
- A clear process to ensure all children who do not attend for whom there are safeguarding concerns are flagged with the safeguarding team.
- The Hospice must have child protection policies and procedures in place that comply with the South West or South Central Child Protection procedures. : <http://www.proceduresonline.com/swcpp/>

4. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

The services provided will be subject to inspection by the Care Quality Commission.

All services will be required to meet the following:

- Care Quality Commission Essential Standards of Quality and Safety
- NSF Standards for disabled and ill children
- Relevant NICE guidelines
- Children Act (2004) section 11 and other safeguarding legislation
- PEAT (patient environment assessment tool)
- All service provision should be delivered in an appropriate, safe, child/young people centred environment, which promotes effective care and optimises health outcomes
- Essence of Care –Privacy and dignity
- “You’re Welcome”
- Adherence to all hospice policies including Serious Untoward Incident reporting, management of emergencies, Risk Management, Complaints. Diversity, safety notices/alerts, CQC. *(For a list of policies refer to the main body of the contract)*

3.2 Applicable local standards

for the area in which the hospice provides services

- Local Safeguarding procedures
- Local Area Agreement
- Locally applicable NHS or multi-agency policies and procedures
- Children and Young People’s Plan

5. Applicable quality requirements and CQUIN goals

Not applicable

6. Location of Provider Premises

CHSW Head Office
Little Bridge House
Redlands Road
Fremington
Barnstaple
EX31 2PZ

01271 325270