

SCHEDULE 2 – THE SERVICES

A. Service Specifications (Full Length Contract)

Service Specification No.	11J/0238
Service	Palliative Care Services for Children and Young People Julia’s House
Commissioner Lead	Service Improvement Manager for Children & Young People – NHS Dorset
Provider Lead	Director of Finance – Julia’s House Children’s Hospice Trust
Period	01 April 2018 – 30 March 2023
Date of Review	01 April 2019

1. Population Needs

1.1 National/local context and evidence base

The government paper *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. Local partners should work with hospices to identify the most appropriate ways to provide and deliver this support for children and their families. The document also recognises the needs of families in being able to access the specialist short breaks they need, whether at home, in a children’s hospice or other voluntary sector provider, or in the community. This service specification is based on a funding agreement that has been reached between this Clinical Commissioning Group (CCG) and this Provider (as identified within this contract) who will have available a menu of services for children with palliative care needs who are eligible, based on the threshold criteria.

The provider is expected to provide holistic, family centred care in either a residential establishment or within a child’s own home. 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 provider will also make available specialist expertise and advice to children’s community nursing teams and paediatric teams within the child’s local area.

Please note: Throughout this specification the term “Children’s Hospice” includes both those services provided in a residential setting specifically for that purpose as well as palliative care services provided in the child’s own home/community.

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 of the child/young person and their family are met.
- It can be demonstrated that child/young person is pain free or pain is minimised as far as possible
- Child and family can demonstrate that they 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 they are well informed about their conditions and the support/services available both within the hospice and within their own local area
- Parents and siblings experience 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 child's local community
- Choice of place of death

3. Scope

3.1 Aims and objectives of service

The children's hospice will aim to 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 the Clinical Commissioning Group (CCG). The hospice will provide a range of services which should include short breaks, emergency and end of life care, either within the hospice premises or within the child's home which will include various leisure and therapeutic activities and facilities to help children be comfortable. The provider will work in the context of the wider network of services and support commissioned and provided by the CCG and other partners for these children and families.

Care definitions

- 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) (ACT and RCPCH (1997))

Objectives

To enter and build a collaborative relationship with this/these Clinical Commissioning Group(s) which will enable care to be available to local children with palliative care needs who are eligible for care in line with the local eligibility criteria and the identified level of need set out in the Decision Support Tool from the National Framework for Continuing Care for Children and Young People (DH 2010).

The service will provide for these patients high quality:

- Respite care (domiciliary or residential)
- End of life care and support
- Short breaks care and support
- Emergency/crisis support

This would be agreed with Clinical Commissioning Group commissioners as part of a care package for each patient.

3.2 Service description/care pathway

The provision of services for children and young people with palliative care needs provided by the

hospice may be delivered in different ways through the provision of a menu of services designed to enable the delivery of 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 enables demonstration of their high-quality work.

Service Model

The services offered by the Provider will be available to children and young people with life-limiting or life-threatening conditions and their families. This service model is based on the guidelines for best practice by Children's Hospice UK 2008.

Environment

Where residential accommodation is available the provider will provide a safe homely appropriate environment which enables 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.

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. (New 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, recognises the child's individual needs, whilst preserving dignity, within available resources.

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.

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. Julia's House will work with the paediatric team to support symptom control.

3.1.5. End of life care

Where a child is considered by the referring clinician to have a prognosis of less than 6 weeks, the appropriate service specification (01-MRFH -0025) shall apply. In the event that the prognosis is incorrect and the child survives beyond 6 weeks, an application for CHC funding should be sought. If a child already in receipt of CHC Funding is considered to have reached End of Life, a CHC Fast Track assessment is also required. In such cases an End of Life Care Plan should be developed as early as possible with the child and family, in line with the ACT Care Pathway. CHC funding will cease on the date of death. If the hospice does not anticipate being able to provide the resource to support End of Life care within the Hospice, this needs to be discussed with the commissioners at the earliest opportunity, to enable alternative arrangements to be made in a timely manner, minimising distress and disruption to the child/family and enabling relationships with trusted professionals to be maintained. Care will be continued during the terminal phase of a child's illness and following death if it is the choice of the child/ 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. Julia's

House aim to support each child and young person with end of life support.

Care Pathway (as per Appendix 1)

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.

3.3 Population Covered

The funding agreement for this service specification covers all children who reside in Bournemouth, Dorset and Poole and who are registered with a Bournemouth, Dorset or Poole GP.

3.4 Any acceptance and exclusion criteria.

The services offered by the provider will be available to children and young people with life-limiting or life-threatening conditions and their families as outlined in Section 3.

The service can be accessed by children from the age of 0-18 years registered with a local GP. Referrals to the provider will be subject to approval by the Clinical Commissioning Group commissioners. See section 3.3.

3.5 Interdependence with other services/providers

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.

The Provider will work collaboratively with NHS commissioners and providers to ensure that referrals of locally eligible children go through the agreed referral pathway as outlined in section 3 and 6.

All providers will continue to be invited and encouraged to attend the South West Children's Palliative Care Commissioner forums.

4. Applicable Service Standards

4.1 Applicable national standards (eg NICE)

National Policy

- The National Service Framework for Children Young People & Maternity services (2004)
- Children Act (2004)
- *Every Child Matters* - Change for Children programme 2004
- Standards for Better Health (2004)
- Our Choice, Our Care, Our Say (2006)
- Aiming High for Disabled Children (2007 DCSF.DH)
- The Children's Plan (Department of Children, Schools and Families, 2007)
- Darzi review (October 2007)
- Better Care Better Lives (DH 2008)
- World Class Commissioning. (DH 2008)
- Healthy Lives, Brighter Futures (DCSF, DH 2009)
- Transforming Community Services (DH 2009)
- The Operating Framework for the NHS 2010-11
- Working together to safeguard children (HM Government 2010)
- National Framework for Children and Young People's Continuing Care (DH 2010)

1.2.2. National Standards

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 Core Standards and performance indicators
- NSF Standards for disabled and ill children
- Relevant NICE guidelines
- Children Act (2004) Section 1 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"

4.2 Applicable standards set out in Guidance and/or issued by a competent body (eg Royal Colleges)

None

4.3 Applicable local standards

for the area in which the hospice provides services

- Local Safeguarding procedures
- Local Area Agreement
- Local applicable Clinical Commissioning Group or multi-agency policies and procedures
- CYPP

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

6. Location of Provider Premises

The Provider's Premises are located at:

Julia's House
135 Springdale Road
Broadstone
Dorset. BH18 9BP
Tel 01202 389837

- a) Residential - 24 hours variable on demand – refer to Statement of Purpose
- b) Community – variable 0800 – 2400, Monday – Sunday

7. Individual Service User Placement

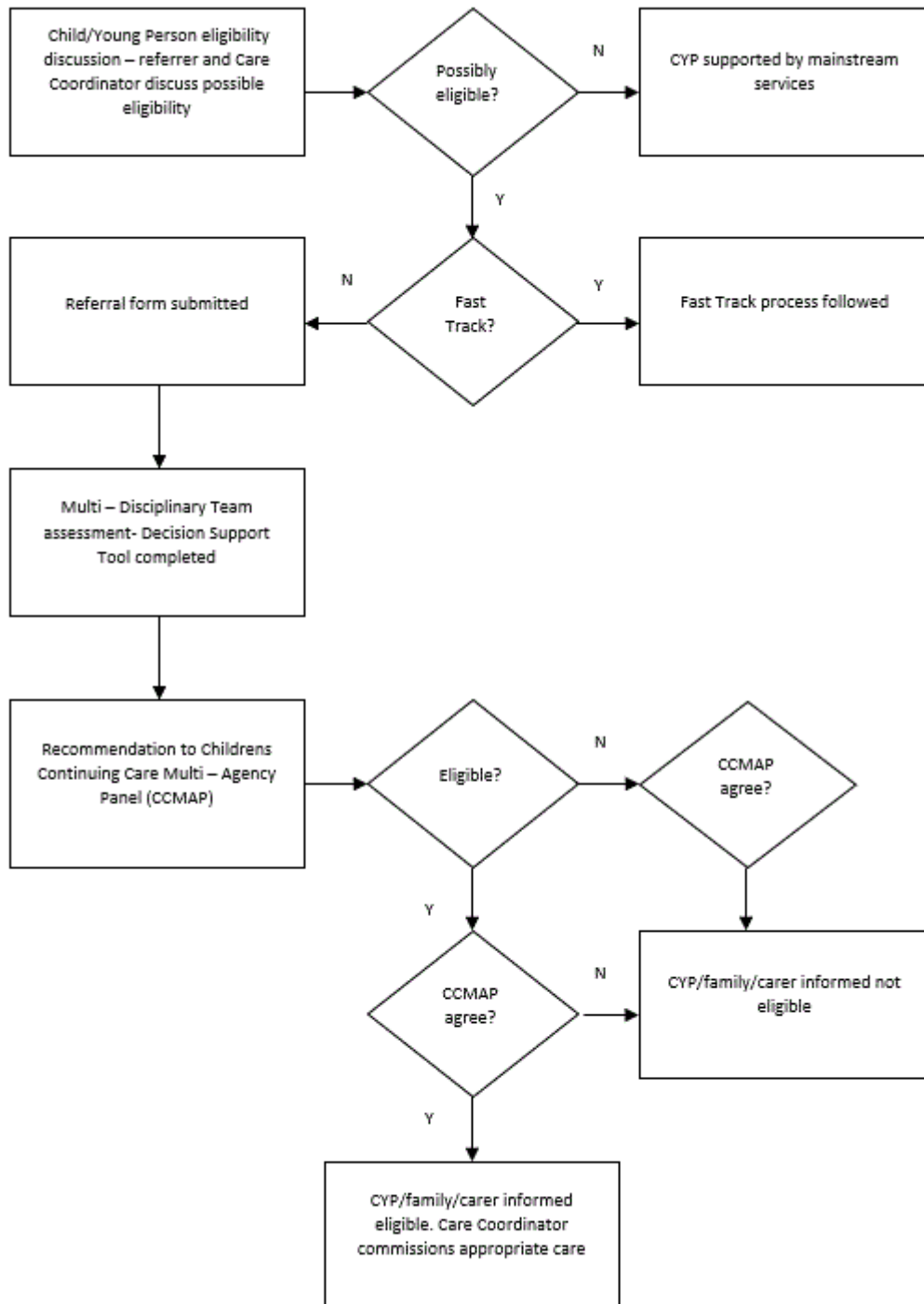
Julia's House will provide respite support to each CHC eligible child for a maximum of 200 hours per year. Additional support may be provided in event of an emergency (e.g. in the event of the breakdown of an existing care package, family crisis, or similar event where the safety and wellbeing of the child might otherwise be compromised). In such cases, CHC will consider funding of additional hours upon receipt of a request from the provider.

The hourly fee for services provided by Julia's House to CHC eligible children shall be agreed between the parties to this contract, and shall be reviewed annually.

Appendix 1

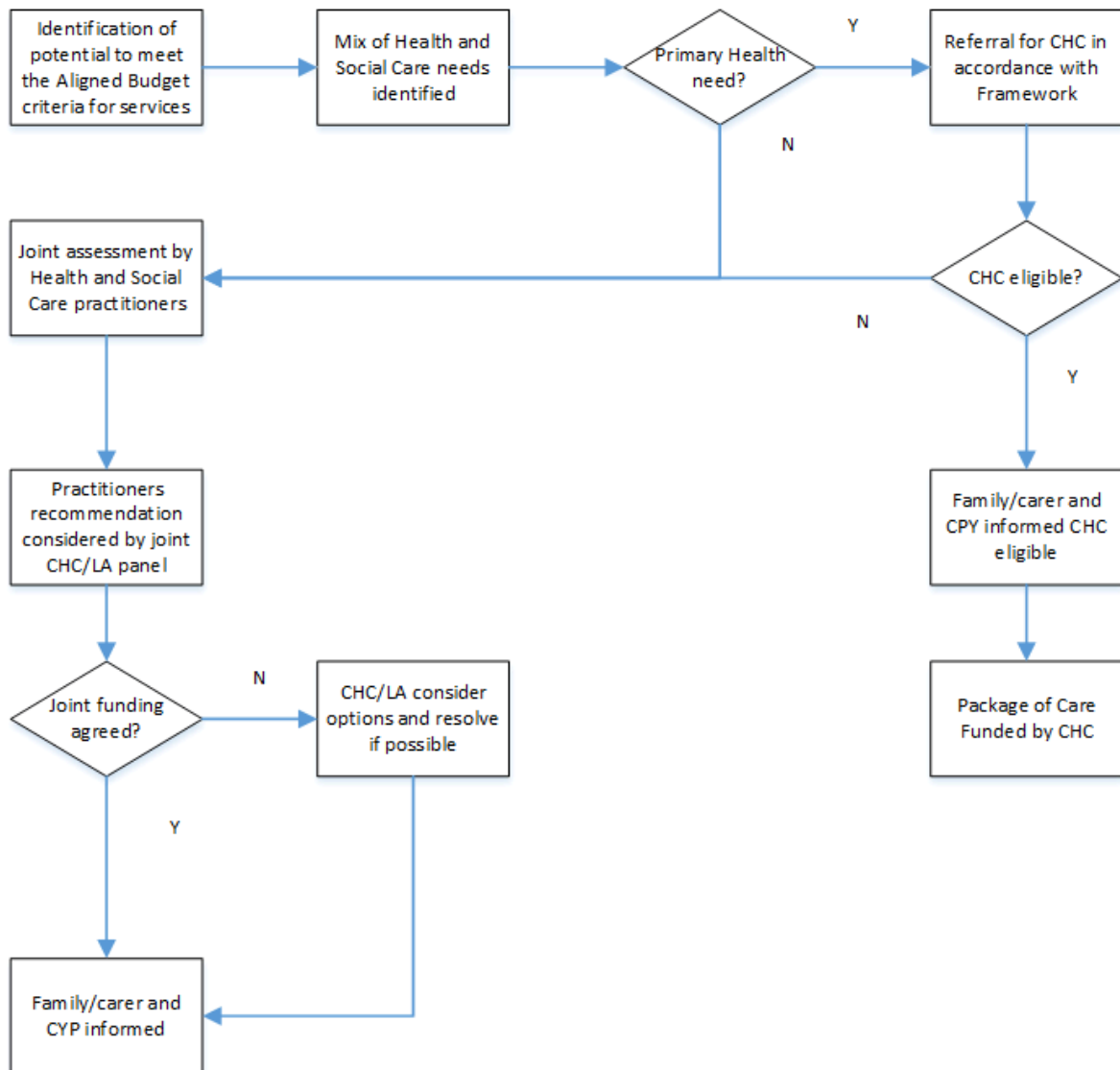
Referral pathway (route)

CHILDREN AND YOUNG PEOPLES CONTINUING CARE NATIONAL PATHWAY 2016



ALIGNED BUDGETS CARE PATHWAY (Locally implemented March 2010)

ALIGNED BUDGETS CARE
PATHWAY (Locally
implemented March 2010)



Exclusion Criteria

Children who do not meet the care group definitions and children referred and admitted to any of the providers services without being subjected to the agreed referral pathway and panel process will not have funding agreed by the Clinical Commissioning Group.

Response time and prioritisation

The provider will aim to respond to urgent referrals within two working days. 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.

Discharge criteria and planning

The provider will develop a package of support with the child and family, and share this and its costing with the Commissioning Manager. Once agreed this will then be funded based on the funding agreement with the hospice. Any admissions 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.

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.

Self care and patient and 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

Service Delivery Information

See Schedule 4 & 6 of this Contract