

SCHEDULE 2 – THE SERVICES

A. Service Specifications (B1)

Mandatory headings 1-4. Mandatory but detail for local determination and agreement

Optional heading 5-7. Optional to use, detail for local determination and agreement.

All subheadings for local determination and agreement

Service Specification No.	01-MRFH-0025
Service	Children and Young People's Palliative and End Of Life Service
Commissioner Lead	Maternity, Reproductive and Family Health Clinical Commissioning Programme
Provider Lead	Dorset County Hospital and Poole Hospital Paediatric Directorate
Period	1 Oct 2013 to 31 March 2014
Date of Review	Date to be inserted by Commissioners

1. Population Needs

1.1 National/local context and evidence base

1.2 There are a number of National policy documents and guidance that set out a requirement for the NHS to develop a Strategy for Children's Palliative Care. These include:

- National Service Framework for Children, Young People and Maternity Services (2004)
- Every Child Matters: Change for Children (2004)
- Commissioning Children and Young People's Palliative Care Services: A practical guide for NHS commissioners (2005)
- Aiming High for Disabled Children: better support for families (2007)
- Palliative care services for children and young people in England: an independent review for the Secretary of State for Health (Craft & Killen, 2007)
- Better Care: Better Lives: Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions (2008)
- Healthy lives, brighter futures: The strategy for children and young people's health (2009)
- ACT guidance, including 'Integrated multi-agency pathways for children with life-limiting and life-threatening conditions' (2004); 'A guide to the development of children's palliative care services' (2009);
- 'A neonatal pathway for babies with palliative care needs' (2009)
- National framework for children and young people's continuing care (2010)
- The Coalition: our programme for government (May, 2010)

- NHS at home: children's community nursing services (DoH, 2011)
- Local safeguarding Children documentation
- Working Together to Safeguard Children (2010)

1.3 This Service model will embrace the Department of Health model of best practice and principles

1.4 For the purposes of this specification, “children and young people” will refer to children until their 18th birthday. However, it is acknowledged that some young people may remain in children’s services if their life expectancy is such that the transition to adult services would not be beneficial.

1.5 This service aligns with the strategic aims of NHS Dorset CCG, the Department of Health guidance ‘The NHS National Framework for Children and Young People’s Continuing Care. 2010’.

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

2.2.1 The service will deliver high quality end of life care and/or palliative care for children, young people and their families, who have life-limiting or life-threatening conditions in line with best practice principals.

2.2.2 The service will provide nursing, care support, medical support and highly specialist interventions and treatments which generally provided on an inpatient basis, at home and with the Children’s Community Nursing Team to enable 24/7 high quality, choice based service, aligning with any other service children and families are seeking at critical periods in these children’s lives. The service will provide a period of care and support not exceeding 6 weeks only going beyond this in exceptional circumstances.

2.2.3 If the period of care exceeds or is expected to exceed 6 weeks the service will make an application to Children’s Continuing Healthcare.

2.2.4 The service will be co-ordinated and every child/family will have a named key worker.

- 2.2.5 No child will have an unnecessary admission to hospital.
- 2.2.6 For those children who do need to be admitted to an acute service provider the length of stay will be kept to a minimum
- 2.2.7 There will be equity of care for all sick children requiring clinical intervention in the community.
- 2.2.8 More children and young people will be cared for at home.
- 2.2.9 For any young person coming of age for transfer to adult service there will be planned and coordinated transition to adult services.
- 2.2.10 The service will ensure that children with palliative health needs are not discriminated against.
- 2.2.11 Access to services and activities within mainstream and community settings will be maintained.
- 2.2.12 The service will support a reduced absence from education due to better co-ordinated appointments and better support at home.
- 2.2.13 Children and their families will be supported in defining choice of place of death in the end of life phase.
- 2.2.14 The service will ensure that Information is available and in a language and format that is appropriate to the family needs (written and verbal)
- 2.2.15 Data recording of all aspects of care co-ordination will be logged according to best practice guidelines for recording, giving a full audit trail for the provider and the Commissioner.

3. Scope

3.1 Aims and objectives of service

The Children's community nursing teams will work with children until their 18th birthday. The service will be needs-led and provide a flexible and continuing care approach with reviewable personalised care plans that support the coordination of services over the span of childhood/adolescence

The service will:

- Work with families in supporting and enabling children with palliative and/or end of life care needs, optimising the quality of life of children and their families by providing appropriate care and support in the home or location of family choice, providing time responsive services where child wishes at home, school, hospital or hospice
- Provide high-quality assessment, clinical care and support to children and

their families who have end of life, or palliative care needs.

- Develop care plans to meet the identified needs of children within their home/school/ community and/or other appropriate setting such as Hospices
- Reduce inequalities and improve the right to access educational and vocational settings, leisure services and activities, for children and young people with end of life and/or palliative care needs, and carrying out competency based training to support carers and staff around medical conditions.
- Integrate partnership working in the community with other children's agencies to ensure access to the right services at the right time and improved co-ordination of services

3.2 Service description/care pathway

3.2.1 The service acts within a wider multidisciplinary team to provide a holistic approach in caring for children with palliative or end of life care needs. This involves working in partnership with parents and other professionals in drawing up health care plans to support the child within the education setting, as well as facilitating and carrying out competency based training to staff and carers around specific tasks.

3.2.2 CARE PATHWAYS:

- The Provider will ensure effective mechanisms are in place to identify individuals with palliative and/or end of life care needs
- Professionals identify children and young people in a timely fashion
- Professionals initiate discussion with the family
- At discharge from hospital, all children have a key worker/lead professional coordinating the discharge process
- All children have on-going care co-ordination across organisational boundaries.
- Children have a full assessment of their needs and written care plan which is shared with all agencies involved in their care.
- All services use an advanced care plan document for the planning and documentation process for end-of-life care preferences, at the point where this is appropriate, and staff are trained and confident in its use.
- Ensure pathways are in place for transition to adult services.
- Ensure systems are in place for sharing information between agencies

3.2.3 The child, young person and their parents will be supported in the setting of their choosing, by a team of staff who are committed to supporting them on their final journey.

3.2.4 The service will address the community-based medical and nursing interventions and care support requirements of the children with palliative care/end of life needs to improve outcomes for them and their families.

- 3.2.5 Collaborative working as virtual “ward team” between the two Community nursing teams will meet the need of this small number of children appropriately
- 3.2.6 The service will provide choice of place for palliative and end of life care for the children requiring support from the Children’s Palliative Care Services across Dorset
- 3.2.7 The service will provide a safe, knowledgeable, timely service delivery which works in partnership with the child, young person, family, carers and professionals to listen and identify and meet needs in an individualised and flexible way; to professionally deliver care in the appropriate setting, while ensuring the child or young person’s healthcare needs are met.
- 3.2.8 Staff will be trained in the provision of care for rapidly deteriorating clinical condition, including palliative care and end of life provision.
- 3.2.9 The service will facilitate and participate in multi-professional and multi-agency team and partnerships working.
- 3.2.10 The service will provide psychological and social support including formal counselling and therapy, including play therapy.
- 3.2.11 The service will be sensitive to and make provision for cultural, spiritual and practical needs.
- 3.2.12 The service will provide support (back office) mechanisms and co-ordinate care delivery to support patients and their carers within the pathway.
- 3.2.13 The service will work collaboratively with multi-disciplinary team, to meet the end of life care needs of both child/young person and the family throughout the last phase of life and into bereavement including management of pain.
- 3.2.14 The service will be needs led, responsive and flexible with the ability to offer help and advice 24 hours a day, 7 days a week, to ensure that, where appropriate, the patient dies in their preferred place of death.
- 3.2.15 The service will ensure end of life prescribing is in line with national and local guidelines.
- 3.2.16 Care will be delivered according to national best practice guidelines for end of life.

3.3 Any acceptance and exclusion criteria and thresholds

- 3.3.1 The service will be required to undertake care delivery for any patient who

is registered with an NHS Dorset CCG GP, and therefore may be required to deliver the service across County boundaries.

3.3.2 Referrals to the service will include patients who are in the end of life phase of their condition. Patients receiving the Children's and Young People's Palliative and End of Life Service. The referrals will be received from a number of sources including, (but not limiting):

- Children's Community Nurses
- Paediatricians
- Children's social workers
- District nurses
- Acute hospitals- e.g. GOSH, Southampton, Dorchester, Bournemouth, Poole, Salisbury, Yeovil or other acute hospitals
- GPs
- GPSIs in End of Life
- Hospices

This list is not exhaustive

3.4 Exclusion Criteria

3.4.1 Children who are not in the end of life phase of their life limiting or life threatening condition.

3.4.2 Patients who are not in the end of life phase of their illness will be signposted to other services by the provider.

3.4.3 Children in receipt of universal health services where other services can already offer the appropriate help, support and advice.

3.4.4 Children who are being cared for by secondary or tertiary care services where input from the Palliative Care service would be duplicative and deemed inappropriate

3.4.5 No alternative medicine therapies will be funded unless provided directly through NHS commissioned services and must be recognised as clinically beneficial

3.5 Interdependence with other services/providers

3.5.1 A system where universal, targeted and specialist provision work together in a coordinated way that enables both local accessibility for support and management of everyday problems, and access to first class specialist services for the management of and care of more complex symptoms. The service may have interdependences and contact with health and social care professionals including (but not limiting):

- Patients and their parents/or their carers/ family
- NHS Dorset CCG Continuing Healthcare staff
- Commissioners (NHS Dorset CCG and Local Authority)
- Pain Control teams
- Health visiting teams and school nurse
- Pharmacy
- Midwifery services
- Leisure and play services
- Sure Start
- Early years programmes
- Education services
- Housing
- General Practice (including GP's and Practice Nurses)
- GPwSI in end of Life
- Community Children's Nurses and District Nurses
- Paediatricians (acute and community)
- POON and Specialist services (i.e. specialist palliative/ respiratory nurses and care teams)
- Occupational Therapists, Physiotherapists
- Social Services, Children's Services
- Residential Schools and Residential Short breaks providers
- Special Schools, Schools and educational services
- Hospices and specialist palliative care teams.
- Acute sector staff
- Ambulance staff
- Looked After Children's Services
- Transition and Continuing Care Team and all other adult services for transition
- Hospital based paediatric care (Neonatal Intensive Care, Paediatric ICU and HDU Units Children's Wards, outpatient departments)
- Health Visiting and School Nurse teams
- Early Years / Pre-school settings and Children's Centres
- Safeguarding
- Generalist palliative care team in Bournemouth and Poole (Transition)

3.5.2 The services will link to relevant local clinical networks and support programmes including the palliative care

4. Applicable Service Standards

4.1 Applicable national standards (eg NICE)

- Children and Young People with Cancer (CSGCYP) August 2005
New NICE guidance in progress Due March 2014. Under development and intended to design, drive and measure quality improvements within this

particular area of care

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

- RCN 2011 Healthcare Standards in caring for neonates, children and young people.

4.3 Applicable local standards

- Children's and Young People's Palliative and End of Life Care Strategy.
- Local Children Safeguarding Policies and standards

5. Applicable quality requirements and CQUIN goals

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

- Log/ record on-going feedback from family

6. Location of Provider Premises

6.1 The Provider's Premises are located at:

6.1.1 This provision will be delivered in the most appropriate setting; including children's own home environment, school and/or community facility, within short break settings including hospital and/or hospice care

6.1.2 Provision of a responsive 24 hour, 7 days a week service to meet the patient needs and nursing input when required

7. Individual Service User Placement

7.1 End of an episode of care from the palliative needs service can occur if:-

- The child's prognosis improves and/or another services provides the required support
- Family no longer require the service
- The death of a child and post bereavement support ends

7.1.1 On the confirmation of the death of a patient: the service provider will ensure that they;

- Make arrangements for the issue of death certificate / cremation form.
- Introduce Child Death review and provide associated information if appropriate.
- Remove all remaining drugs, especially controlled drugs, from the home by medical and nursing staff. Return to hospital pharmacy or account for, document and store securely until pharmacy open

- Notify all relevant social and health care professionals of the death and accurate records are maintained and updated.
- Signposting to bereavement counseling should be available for the patient's friends/family/next of kin.

7.1.2 The provider will ensure that all necessary paperwork is clearly completed and notifications provided to all key professionals. All multi-disciplinary team members will be informed of outcomes.