# SCHEDULE 2 – THE SERVICES

## A. Service Specifications

| | |
|---|---|
| **Service** | Support Services for Children and Young People with Life-Limiting Conditions |
| **Commissioner Lead** | NHS Nottingham and Nottinghamshire ICB |
| **Provider Lead** | |
| **Period** | 01/10/2021-30/09/2024 |

## 1. Population Needs

### 1.1 National/local context and evidence base

Having a child with life-limiting conditions and palliative care needs places an enormous strain on the whole family and it is therefore essential that a broad range of good quality, holistic support is provided over the long-term to alleviate the variety of pressures that could impact upon family life.

Unfortunately data relating to the number of children and young people who will have a need for this service is hard to establish, given the challenges around defining what 'disability' means. In addition, more children with a severe disability and complex needs are living longer (Healthy Lives, Brighter Futures 2009), owing to new interventions and technology.

Approximately 4,000 children and young people aged 0 - 24 years living in Nottingham City are disabled and 900 are considered to have a severe disability. Estimated numbers of children and young people experiencing some form of disability in the county of Nottinghamshire can be seen in the table below.

| | |
|---|---|
| Thomas Coram Research Unit (2010) Based on 2014 population and a prevalence of 3-5.4% | 6,598-11,882 (0-24 year olds) |
| Child and Maternal Health Observatory (2000) | 7,615 (0-19 year olds) |
| Census (2011) CYP with life limiting long term health problems | 7,891 (0-15 year olds) |
| Disability Living Allowance (2011) | 9,198 (16-24 year olds) |
| School SEN (Statements & School Action Plus) (2011) | 6,095 (3-19 year olds) |

*(Source: Nottinghamshire JSNA 2014)*

This service will provide practical support for children and young people with life-limiting conditions living registered with GPs in the Mid Nottinghamshire, Nottingham City, and South Nottinghamshire areas of the Integrated Care Partnership (ICP) i.e. the historic Nottinghamshire ICB areas of:

- Mansfield and Ashfield
- Newark and Sherwood
- Nottingham North and East
- Nottingham West
- Rushcliffe
- Nottingham City.

## 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

- Parents, children and siblings can make sense of what is happening and begin to make positive choices and decisions.
- Parents are confident and competent in parenting.
- Parents are able to talk about what is happening with children and wider family.
- Children and young people are able to make smooth transitions.
- Children and young people are able to make informed decisions about their care.
- Children and young people can make choices about living lives to full potential.
- Families are able to support their child in exercising choice about plans for death.
- Prevent the need for inappropriate ambulance call outs, hospital admissions and intensive care, enabling earlier discharge if/when admitted and reducing the incidence of family breakdown and need for mental health services.

## 3. Scope

### 3.1 Aims and objectives of service

To provide a service designed to support the needs of a child or young person with a life limiting condition and complex health needs. Support will be provided from birth to 18 years of age with the aim of enriching the lives of families and children.

Provision of a holistic family based support service will promote family resilience to impact positively on the child's well-being. This support should improve quality of life for the child/young person and support their care being maintained within the family for as long as possible.

The support team will work closely with the wider palliative care team and provide sensitive, skilled and practical support on an individual basis (home or hospital/hospice based), or through groups (eg. parents and sibling groups) and one off activities, events and outings.

The service will also support the wider family members by providing emotional support to parents and siblings. Support will be provided to the family unit throughout the journey from when a child is first diagnosed with a condition to the bereavement stages.

### 3.2 Service description/care pathway

To provide a sensitive, skilled and practical support service to children and young people with life-limiting conditions registered with GPs in the Mid Nottinghamshire, Nottingham City, and South Nottinghamshire areas of the Integrated Care Partnership (ICP) and to their parents, carers and siblings.

Services provided will be responsive to the needs of the child and family at any point along the palliative care pathway. The service will work closely with hospital and community medical teams and will develop links with Integrated Community Children and Young People's Healthcare Programme (ICCYPH) to ensure children are able to access facilities and services when and where they want them.

This service will offer a holistic approach to meeting the needs of a life-limited child or young person and ensure all needs are considered (for example, to have fun, achieve at school, make friends) and

not just focus on medical needs and care. The needs and well-being of the family are also important as this will impact on the child, so the aim is to support and promote resilience within the whole family.

The team will provide a key worker, specialised service to children, young people and their families:

- to ensure planned services and a high level support at an early stage and at stages of transition or periods of crisis
- to enable families to make choices, to be signposted to/access appropriate mainstream services and be able to cope with challenges and changes as the child progresses along the palliative care pathway.

The service outcomes for families are outlined in 2.2 above, but it is envisaged that the service will prove cost effective by preventing the need for inappropriate ambulance call outs, hospital admissions and intensive care, enabling earlier discharge if/when admitted and reducing the incidence of family breakdown and need for mental health services.

The support provided will be planned and managed by the service through a co-ordinated multi-disciplinary approach, involving parents/carers and children, as appropriate, in identifying need and agreeing services and objectives. Families referred to the service will have an initial assessment to identify needs, discuss what the service could offer and agree a work plan to achieve the desired goals and outcomes.

The service will meet regularly with the multi-disciplinary Palliative Care Team to plan and allocate workloads, share information and progress. This will ensure that families receive the most appropriate support, utilising the skills of different members of the team in the most effective way, including utilising (properly trained) volunteers where appropriate. Work plans agreed with a family will be reviewed at least twice a year and outcomes monitored.

Services offered:

1. **Individual work**

Individual support sessions will be provided with:

- Children and young people with life-limiting conditions
- Parents/carers
- Siblings
- Whole family

The focus of the work can include: emotional support, dealing with loss and bereavement, parenting support, behaviour and stress management, confidence building, life skills work, health and relationships advice, practical help (benefits, housing, transport etc.) signposting to other services or agencies, advocacy, linking to community activities, opportunities for play and leisure or 'time-out' from the family, supporting families to communicate their feelings, or to plan for death.

2. **Group support**

Group support will be provided via family activities as described below.

3. **Programme of activities**

The service will provide two events for families and children per year. This will create opportunities for families to have fun together and increase confidence in accessing community facilities.

4. **Work with other agencies**

The service will provide training and support for other professionals working with children and young people with life-limiting conditions. Links will also be made with other specialist and

targeted/universal agencies (including through attendance at relevant meetings) in order to promote multi-agency co-ordination and the inclusion of children in community activities. The service will foster partnership working and the sharing of resources, where appropriate.

**Palliative care pathway and support to be provided by the service**

| Services | Pathway | Services |
|---|---|---|
| -Help to access services, including advocacy<br>-Information about condition or disability<br>-Welfare Rights support<br>-Emotional support<br>-Advising on Education, Health and Care plans<br>-Access to continuing care services | **Breaking the News** | |
| | **Ongoing** | -Peer support<br>-Parents groups<br>-Links to volunteers |
| -Practical support<br>-Advocacy<br>-Link to other agencies<br>-Co-ordinated services | **Transition to school** | |
| | **Ongoing** | -Children's groups<br>-Holiday activities<br>-Sibling support<br>-Therapeutic play |
| -Inclusion support<br>-Links to community and leisure activities | **Transition to secondary school** | |
| | **Ongoing** | -Self-esteem and confidence building |
| -Life skills and independence work<br>-Links to agencies, further education and training | **Transition to adulthood** | |
| | **Preparation for death** | -Pre-bereavement work<br>-Planning for death |
| -Practical support<br>-Bereavement and grief work | **Death and bereavement** | |

### 3.3 Population covered

Children and young people up to the age of 18 with life-limiting conditions registered with GPs in the Mid Nottinghamshire, Nottingham City, and South Nottinghamshire areas of the Integrated Care Partnership (ICP).

### 3.4 Any acceptance and exclusion criteria and thresholds

The service will accept referrals for children up to the age of 18 who have been diagnosed with a life limiting condition and complex health needs who:

- Are registered with a GP practice located in the Integrated Care Partnership (ICP) – Mid Nottinghamshire, Nottingham City, and South Nottinghamshire areas
- Are considered by their medical team to be likely to pass away before reaching adulthood
- Do not have a diagnosis for which there are other specialised services which can provide similar support (for example children with a diagnosis of cancer or Muscular Dystrophy).

Service users can be referred by any health or children's services agency or can refer themselves. On receipt of a referral, the family will be contacted and a discussion about services and access to them would be part of the initial contact. Most services will be delivered in the family home.

**Caseload management**

The service will continue to work with the current caseload (when referrals were accepted from home address rather than address of their registered GP). Barnardo's will actively manage caseloads, reviewing family needs at each staff supervision session in relation to the level of support needed, and, in discussion with families, and children where appropriate, will assess the level of support provided.

For families not engaging with the service a discussion will take place with them and the multi-disciplinary team, regarding whether they need to remain on the Butterfly case-load. If it support is stopped by the Butterfly Service, this will be on the understanding that, if this changes in the future, they can be re-referred.

For bereaved families, support will be offered for a period of up to 2 years, and this will be reviewed on an on-going basis within that period, to close, with agreement, at a time appropriate to the needs of the family.

If the service receive more referrals than can be allocated at any one time they will prioritise referrals in the following way:

- Those children likely to pass away more immediately
- Those children in families with additional complexities or needs not being met by other agencies
- Consideration of the level of existing support in place and/or other services available to address needs.

If there is a need to hold a waiting list, this will be actively managed. The Butterfly Team Manager will inform the referrer if they are unable to allocate a case which is appropriate for the Service but which they are unable to allocate immediately, and will keep in contact with the referrer on a 6-8 weekly basis to check whether there are any changes, discuss the likelihood of allocation, and/or whether there might be other sources of support for the family. Referrers will be encouraged to inform the Butterfly Service if the support needs change/increase during this time. The service will review the measures to manage caseloads/prioritisation of referrals if it transpires that a long waiting list develops, and/or referrals are on the waiting list for more than 3 months.

Barnardo's and commissioners will meet on a quarterly basis to review performance against all aspects of the contract.

### 3.5 Interdependence with other services/providers

The provider will have interdependencies with:

- Integrated Children and Young People's Healthcare Programme
- Children's Centres
- Schools (including Special Schools)
- Social Work Teams
- Voluntary Agencies (including Rainbows Hospice)
- Nottingham University Hospitals Staff

- Clinical Commissioning Groups
- GPs/Practice Nurses
- School Nurses/Health Visitors
- Community Therapy Staff

## 4. Applicable Service Standards

### 4.1 Applicable national standards (eg NICE)

- Together for Short Lives Transition Care Pathway http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/transition_care_pathway
- Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children http://media.education.gov.uk/assets/files/pdf/w/working%20together.pdf
- Equality Act 2010 http://www.legislation.gov.uk/ukpga/2010/15/contents
- 'You're Welcome': quality criteria for young people friendly health services http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813

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

### 4.3 Applicable local standards

- Nottinghamshire County Joint Strategic Needs Assessment for Children and Young People http://jsna.nottinghamcity.gov.uk/insight/Strategic-Framework/Nottinghamshire-JSNA.aspx
- Nottingham City Joint Strategic Needs Assessment for Children and Young People with Learning Difficulty and Disabilities http://www.nottinghaminsight.org.uk/insight/jsna/jsna-home.aspx
- Nottinghamshire County Pathway to Provision http://www.nottinghamshire.gov.uk/caring/childrenstrust/pathway-to-provision
- Nottingham City Council - Nottingham City Early Intervention Programme http://www.nottinghamcity.gov.uk/index.aspx?articleid=520
- Nottinghamshire and Nottingham City Safeguarding Children Boards' Safeguarding Children Procedures http://www.nottinghamcity.gov.uk/article/23729/Safeguarding-Children-Procedures-and-Practice-Guidance-Documents
- Families statement of expectations (ICCYPH) – Appendix One

ICCYPH Families' statement of expecta

## 6. Location of Provider Premises

**The Provider's Premises are located at:**

Barnado's Services Ltd, Regional Office - 9 Mundy Street, Heanor, Derbyshire, DE75 7EB