

SCHEDULE 1 - THE PROJECT

Service	Douglas Macmillan Hospice – Children & Young People
Commissioner Lead	Nikki Ravenscroft, Commissioning Manager, North Locality
Provider Lead	David Webster, CEO / Jannette McCartney, Director of Care
Period	1 April 2022 - 31 March 2023
Date of Review	30 September 2022

Population Needs

A new research study shows that the number of children in England with life-limiting or life-threatening conditions has continued to rise over the last 17 years. The Make Every Child Count study, conducted by the University of York, has revealed that the number of children in England with life-limiting or life-threatening conditions increased to 86,625 in 2017/2018 compared to 32,975 in 2001/2002.

The prevalence of children with life-limiting conditions has increased from 26.7 per 10,000 in 2001 to 66.4 per 10,000 in 2017/18.

The number of young people with life-limiting conditions living to age 19 is increasing, from 921 in 2001/02 to 3,075 in 2017/18, and there is a large number of deaths among young people in their early 20s.

This study identified the following local prevalence:

Local Authority area	Number of cases	Total population	Prevalence per 10,000
Stoke on Trent	502	62,831	79.9
East Staffordshire – Including Burton upon Trent	175	27,954	62.6
Lichfield	102	22,204	45.9
Newcastle- under -Lyme	215	27,554	78.0
South Staffordshire	120	21,963	54.6
Stafford	167	28,050	59.5
Staffordshire Moorlands	154	19,851	77.6
Tamworth	121	18,684	64.8
TOTAL NUMBER OF CASES	1,556		

Specialised palliative care for children is provided to children with life-threatening or life-shortening conditions representing an extremely wide range of diagnoses (in excess of 300) and there is an overlap with those with severe disabilities and complex needs. However, a significant proportion of children with palliative care needs (up to 15%) do not have a definitive underlying diagnosis. Children with life-threatening or life-shortening conditions often have multiple complex healthcare needs, including needs related to their underlying condition, as well as palliative care needs. Palliative care services will potentially be needed for all of these children at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement. But a significant portion of these children will be cured and not all children will have active palliative care needs at any one time. It is therefore not possible to identify provision of Specialised Paediatric Palliative Care for children by diagnosis alone.

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	✓

Local defined outcomes

- Improving the experience of care for Children and Young People at the end of their lives.
- Improving Children and Young People's experience of healthcare.
- Improving people's experience of integrated care.
- Safe and effective provision of healthcare for Children and Young People with complex needs (physical disability).
- Early risk identification and effective management.
- Early identification and robust management of any safeguarding issues.
- Care of Children and Young people using 'case management approach' whilst within the care setting.

Aims and objectives of service

The service shall provide children's palliative care and end of life care services to life-limited or life-threatened children, young people and families in Staffordshire aged 0-25 years; this is the primary purpose and aim of the service.

- Children and Young People shall be treated with respect and their right to privacy upheld.
- Children and Young People and their families shall have a service which matches their expectations and preferences, as far as possible, and satisfies their social, cultural and religious and recreational needs.
- Children and Young People shall be supported to exercise choice and control over their lives.
- Where appropriate, the service shall support Children and Young People to maximise their independence.
- Appropriately trained and competent staff shall be used to ensure the Child and Young Person's healthcare needs are met; ensuring all training needs are up to date and 'current' to provide such care provision.
- The service shall be available according to the needs of the children, young people and their families and where care needs can be safely provided.

Service description/care pathway

The service shall be available according to the needs of the Children and Young people and their families.

The service offered to families will include any combination of the following based on the child and families assessed needs and identified outcomes:

- In house short breaks in the hospice Home based short breaks.
- Day care in the hospice.
- Counselling and emotional support, including specialist play, music and art interventions. Social care and support via the in hospice social worker.
- Care co-ordination and navigation via the dedicated Care Co-ordination service.
- End of life care and support either at the hospice or at home (in partnership with local Children's Community Nursing teams).
- Post bereavement care in our dedicated "Garden suite".
- Symptom Management via the Children's Palliative Care consultant, 24/7 telephone support and

advice.

The Provider is required to embrace and implement the values and behaviours of the 6Cs. Information on 6C can be found at:

<https://www.england.nhs.uk/6cs/wp-content/uploads/sites/25/2015/03/introducing-the-6cs.pdf>

The service shall review EHC draft plans for which they have provided information to quality assure the accuracy of the information included in line with the specified timeframes.

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The Provider shall:

- Provide qualified nursing cover.
- Ensure medical cover is available.
- Ensure all Service Users have a key case worker and have an individual care plan.
- Ensure individual care packages/plans are developed by and are subject to ongoing review and evaluation by a Registered Nurse.
- Ensure individual care plans, risk plans and contingency plans are up to date.
- Include all meals and additional supplementary food or drinks if appropriate.

The service shall contribute to Education Health and Care needs (EHC) assessments for Children and Young People known to the service, this will include providing reports/ information regarding identified health needs and provision required in line with the specified timeframes.

The service shall engage and work in conjunction with the Designated Clinical Officer (DCO) for Special Educational Needs and Disabilities (SEND) to ensure compliance with statutory requirements.

Activity Supporting the Child and Young Person to Admission into Hospital

When an admission to hospital is required whilst the Child or Young Person is within the care of the Provider, the Provider shall ensure that the hospital receives all the relevant information regarding the Child and Young Person. Clinical documentation, e.g. medication charts, should be transferred with the Child or Young Person.

Population covered

Children, Young People, and their families accessing the service shall meet the current eligibility criteria for Donna Louise Trust services.

The service shall provide children's palliative care services, respite and end of life care to life-limited or life-threatened children, young people, aged 0-25 years, and their families; registered with a Staffordshire GP; this is the primary purpose and aim of the service.

Any acceptance and exclusion criteria and thresholds

Children, Young People and their families accessing the service shall meet the current eligibility criteria for Donna Louise Trust services.

Interdependence with other services/providers

Contact with relevant services will vary according to the needs identified in each Service User's specific case. The Provider shall proactively communicate with and co-ordinate all relevant services such as medical, specialist nursing, social services, primary care services, Commissioners, other NHS health providers and ensure relevant and accurate communication is maintained.

Applicable Quality Requirements

Douglas Macmillan Children's Service will provide the commissioner with an Activity Report on a quarterly basis.

Location of Provider Premises

The Provider's Premises are located at:

The Service will be provided from Douglas Macmillan Children's Service, Main Building at 1 Grace Rd, Trentham, Stoke-on-Trent, ST4 8FN.

Individual Service User Placement

In response to sudden changes in Child and Family circumstances. Occasional additional support packages may be agreed between the Provider and the Commissioner. In these cases, both additional support needs and the associated costs of these additional needs will be agreed by both Provider and Commissioner in advance.