

Service Specification No.	2022/2023
Service	Acoms Children's Hospice
Commissioner Lead	Annette Alexander – South East Locality Commissioner
Provider Lead	Sue Jordan - Statutory Partnerships and Contracts Lead
Period	1 April 2022 - 31 March 2023
Date of Review	Biannually

<p>1. Population Needs</p> <p>1.1 National/local context and evidence base</p> <p>Make Every Child Count – (Lorna Fraser et al Feb 2020)</p> <p>This study looks at the number of children with life-limiting conditions in England, showing a significant rise in number over 17 years. The research shows 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</p> <p>Palliative care for children is provided to children and young people with life-limiting or life-threatening 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 and young people with palliative care needs (up to 15%) do not have a definitive underlying diagnosis. Children and young people with life-limiting or life-threatening conditions often have multiple complex healthcare needs, including needs related to their underlying condition, as well as palliative care needs. Services that embrace the philosophy of paediatric palliative care, and have the competencies to do so, will offer support and care for children and young people at any point from diagnosis or recognition, through active treatment, including that aimed at cure, to end of life care and bereavement. Palliative care is not dependent on diagnosis or prognosis and can be provided at any stage of a child or young person's illness. As some of these children and young people will be cured and not all children and young people will have active palliative care needs at any one time. It is therefore not always possible to identify provision of paediatric palliative care for children and young people by diagnosis alone.</p> <ul style="list-style-type: none"> • Nice Guidelines 2017 End of Life Care for infants, children and young people • TFSL A Guide to children's Palliative care 4th Edition 2018 • Palliative and End of life care report for children and Young people in the West Midlands; NHS Eng. 2017 • End of Life Care; Strengthening choice; The All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care End of life care: strengthening choice October 2018 • Working Together to Safeguard Children DoH 2018 <p>General Overview</p> <p>Acoms provide a holistic service that meets the needs of both the children and young people, their families and carers. This includes symptom management, emergency and end of life care, short breaks and respite care in the hospice or at home, outreach home support services, therapeutic and psychosocial support, sibling support and a range of support groups for all members of the family which includes pre and post bereavement support.</p> <p>Acoms forms partnerships and works collaboratively with a range of NHS professionals and other agencies to ensure that individual care plans are responsive to the needs of the children, young people and families in its care.</p>
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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

- Improved quality of life for the whole family (including both emotional and physical health).
- The service will be flexible and responsive, providing co-ordinated assessment and care plans tailored to the individual needs of children, young people and their families Managed care pathways and strong relationships with other care providers and their use of [ReSPECT](#).
- Work in partnership with families and carers to deliver the service to ensure they feel supported, and their needs are assessed and addressed where applicable.
- Improvements will be realised in wellbeing and quality of life for the child or young person with a life-limiting or life-threatening condition.
- Work in partnership with the young person and their family in signposting and guiding families in their choices and decisions about transitioning into adult services.



Policy Transition at
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- 24/7 access to emergency palliative short breaks and psychosocial support.
- Work with families to provide planned palliative short breaks for children and young people to support and promote the emotional and physical health of carers and siblings.
- Provide psychosocial support pre and post bespoke bereavement support for parents/carers.
- Provide psychosocial support pre and post bespoke bereavement support for wider family members, siblings and Grandparents.
- Provide culturally sensitive service for the diverse community groups it serves.
- Children, young people, their families and the professionals that care for them will have access to specialist advice and support.
- Provide a rolling programme of digital palliative care for an acutely unwell child training programme, consisting of 6 sessions. To be accessible to all community children nurses (CCNs) within Staffordshire.
- Provide an opportunity for Staffordshire CCNs to go to Acorns to do an assessment and see families there.

3. Scope

3.1 Aims and objectives of service

Aims

- Provides palliative care to children 0-18 who have a life-limiting or life-threatening condition and provides support for their families.
- Work with families in a direct response to their expressed needs in palliative care and bereavement support, being committed to a family led service where clients and families are viewed as partners in the care offered.

- Acorns Hospice offers planned palliative short breaks, day care, emergency short breaks, end of life care, symptom management support, hospice outreach care, community psychosocial support, and access to hydrotherapy and physiotherapy and, where appropriate, interpreters.
- Team members also strive to work collaboratively with professionals from other care agencies who may already be involved with a family at the time their child is referred to Acorns.

Objectives

- Support children and young people to enjoy life.
- Strengthen whole family health and well-being.
- Support families to access treatment for pain and symptom control for specialist complex health conditions.
- Provide emergency / crisis support both for medical and social emergencies.
- Reduce hospital admissions via planned short-breaks, provision of step-down beds and emergency admissions to the hospice.
- Reduce family isolation and increase support networks.
- Reduce family breakdowns by offering consistent and comprehensive support.
- Provide psychosocial support pre and post bereavement to families.
- Provide a rolling programme of digital palliative care for an acutely unwell child training programme, consisting of 6 sessions. To be accessible to all community children nurses (CCNs) within Staffordshire.
- Provide an opportunity for Staffordshire CCNs to go to Acorns to do an assessment and see families there.
- Work in partnership with the young person and their family in signposting and guiding families in their choices and decisions about transitioning into adult services.



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- Where possible supporting the reduction in avoidable high intensity care or in-patient stays by working in partnership with CCN teams supporting children, young people and their families to manage the child or young person's conditions safely in their own homes.

Four groups of life-limiting and life-threatening conditions

- Category 1 – Life-threatening conditions for which curative treatment may be feasible but can fail. (Examples: cancer, organ failures of heart, liver, kidney, transplant and children on long-term ventilation).
- Category 2 – Conditions where premature death is inevitable. These may involve long periods of intensive disease-directed treatment aimed at prolonging life and allowing participation in normal activities. Children and young people in this category may be significantly disabled but have long periods of relatively good health. (Examples: cystic fibrosis, Duchenne muscular dystrophy and SMA Type 1).
- Category 3 – Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. (Examples: Batten's disease, mucopolysaccharidoses and other severe metabolic conditions)
- Category 4 – Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death. (Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex health care needs, high risk of an unpredictable life-threatening event or episode).

Together for Short Lives (2018) A Guide to Children's Palliative Care. 4th Edition

- To support the further development a community-based provision for patients within the Staffordshire and Stoke on Trent CCGs/ICB's footprint, which includes:
 - Working with the Commissioner on its journey to achieve an ambitious and transformative

approach to palliative and end of life care, to ensure sustainable, responsiveness, and personalised palliative and end of life care for all conditions.

- o Support the Commissioner to achieve the Ambitions Framework's 6 ambitions - <https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf>

3.2 Service description/care pathway

Acorns operates its core services on a 24/7, 365-day basis where actual access to services is determined by the needs of the individual child, young person and their family.

Once a child or young person is accepted at Acorns, the Family Team worker visits the family in their home to undertake a holistic needs assessment to identify current need and establish what existing support is in place. An agreed package of support is then offered to the family.

Prior to their child accessing palliative short-break care in any of the hospices a care plan is drawn up in partnership with the family by a paediatric nurse. This is regularly reviewed and updated to ensure it accurately reflects the current need. In addition, all care plans are reviewed at every palliative short break visit.

The holistic needs assessment identifies the child's and family's overall requirements for Acorns care support services. The care plans focus on the individual needs of each child with detailed descriptions of daily routine, cultural and dietary needs, symptom control and pain management.

Palliative short break provision is based on individual need, with families/carers able to request day care, or stays of varying length to meet their own and their child's needs.

In addition to these services, Acorns will also provide:

- Activities – sibling workers organise bespoke activities to ensure they experience age-appropriate opportunities to support social development.
- The Care Team can provide advice and signpost to advocacy services for children, young people and their families.
- Access to complementary therapies.
- Our family team workers can sign-post families to access transition advice for young people transferring into adult care services.
- Community Support services including psychosocial support.
- Bereavement support services.
- Interpreters.

The service will ensure that children, young people and families will have their care and support reviewed at regular intervals in partnership with Acorns.

There are two reviews undertaken each year:

- Criteria reviews which establish if a child continues to meet Acorns criteria of having a life limiting and life-threatening condition <https://www.acorns.org.uk/our-care/professionals/refer-a-child/>
- Family Support Plan reviews which are undertaken with each family to inform the Holistic Needs Assessment (HNA) and identifying any change in need.

This review will include:

- Consideration of the relevance of the care plan to the families current and future needs including planned respite (short breaks).
- Measurement of the progress and effectiveness of previous plans/outcomes from both the parent/carer and Acorns perspective.
- Identification of any unmet needs.
- The parent/carer/child's views of the service(s) received.
- The date of the next review.

Accessibility/Acceptability

Acorns will work in partnership with families and carers to deliver the service

- The service will be equitable, flexible and responsive; assessing need and developing care plans tailored to the individual needs of children, young people and their families in terms of their circumstances.
- Acorns will provide 24/7 access to emergency respite care and psychosocial support.
- Acorns will work with families to provide planned respite (short breaks) in accordance with its core offer and policy.

3.3 Population covered

Services will be provided for children and young people registered with a GP contracted to NHS East Staffordshire Clinical Commissioning Group, NHS South East Staffordshire & Seisdon Peninsula Clinical Commissioning Group, NHS Cannock Chase Clinical Commissioning Group and NHS Stafford & Surrounds Clinical Commissioning Group.

A full list of GP Practices can be found on the following websites:

- <https://sesandspccg.nhs.uk/about/our-members/gp-practices>
- <https://eaststaffscg.nhs.uk/about-us/our-gp-member-practices>
- <https://www.cannockchaseccg.nhs.uk/about-us/our-members/gp-practices>
- <https://www.staffordsurroundscg.nhs.uk/about-us/our-members/gp-practices>

3.4 Any Acceptance and Exclusion Criteria and Thresholds

The service is available to all children and young people who have a life-limiting or life-threatening condition and have not yet reached their 18th birthday who are registered with GP contracted to NHS East Staffordshire CCG, South East Staffordshire & Seisdon Peninsula CCG, Cannock Chase CCG and Stafford and Surrounds CCG and meet the Acorns acceptance criteria.

Referral Criteria and Sources

- Referrals may be made by GPs, community and hospital Paediatrician's, or community children's nurses.
- Referrals must meet Acorns acceptance criteria as detailed on the web page www.acorns.org.uk.

Referral Route

In non-emergency situations there is a referral process which includes the completion of a referral form which needs to be presented to the multi-disciplinary panel within Acorns. In cases of End of Life referrals, can be accepted outside of the normal panel process. In both these scenarios the parents and or carers with parental responsibility must provide their consent to the referrals.



CRP Process for
referrals flowchart CD

Discharge processes

Discharge from the service occurs if a child or a young person no longer meets Acorns' criteria or if a family decides it no longer wishes to access the service. In either circumstance, Acorns will collaborate with other agencies to ensure continuity of appropriate care.

3.5 Interdependencies with other services/providers

Acorns cannot operate in isolation and must work with partners who will include:

- Paediatric Consultants
- GPs
- Allied Health Professionals
- Hospital Clinicians and staff
- Social Care
- Mental Health Services
- Representatives of religious groups
- Education Services
- Community Nursing Teams and Palliative Care Nurses
- Safeguarding – local and city-wide teams / arrangements
- Other Third Sector and Voluntary Organisations

This will involve both Children and Adult sectors of partnerships as required.

4. Applicable Service Standards

4.1 Applicable national standards

Please refer to section 1.1.

4.2 Applicable standards set out in Guidance and/or issued by a competent body

Please refer to section 1.1.

4.3 Applicable local standards

Short Breaks are offered to all children meeting Acorns criteria and informed by their individual HNA. The maximum number of Short Breaks provided for is either the number agreed in the child's HNA or up to a maximum of 12 Short breaks in any calendar year.

Additional Short Breaks above this level can be commissioned and are charged at Acorns applicable Paid for Bed rates.

Outreach –The Outreach service, led by an outreach nurse lead at each hospice, provides a tailored package of clinical care is delivered by a multi-disciplinary team comprising registered children's nurses, healthcare assistants, physiotherapists, family team workers and trained volunteers. The service is provided through planned sessions Monday – Friday.

Individual Outreach care packages may be commissioned subject to a full assessment of the child's needs and available resources to deliver them. Charges will vary according to the agreed package of care.

End of Life (EOL). Acorns cares for children at the EOL. We support the child with compassion and care with full clinical intervention guided where necessary by a Paediatric Palliative Care Consultant. Families can often be accommodated in family suites during this time to be with their child.

The child can remain following death in one of Acorns Special Bedrooms where post death care of the child continues until funeral arrangements are made.

Acorns care includes full pre and post bereavement support for family and siblings.

Our EOL care and support is not chargeable for the first fourteen days following the child being accepted into the hospice. Where a child survives beyond this period Acorns will implement is chargeable paid for bed rate.

Response Time & Prioritisation

All families will be contacted within 7 working days of being accepted by Acorns, or 48 hours for urgent referrals.

For families where the referral is not accepted the referrer will be notified within 7 days by the service.

Training /education / workforce/ research activities

- All trained staff must be 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 the minimum set of competencies to undertake their role.
- All staff must have enhanced DBS checks.
- Staff must be provided with adequate support and supervision, specifically for Child Protection/Safeguarding.
- Staff must 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 must undertake training for Lone Working, if applicable.
- Mandatory training including CPR, manual handling, infection control, child protection is to be undertaken and delivered in accordance with hospice policies.
- Student training and support should be available to ensure future workforce and capacity.
- All staff should be skilled in adult and paediatric resuscitation.

Safeguarding

The Provider will ensure that policies and procedures relating to safeguarding of children are in place, up to date, and that these are understood by, and accessible to, all staff.

The provider will ensure that all staff undertake training commensurate with their role and responsibilities (and in accordance with relevant national and local guidance).

All staff working with children and young people will have undertaken an enhanced DBS check (which is updated appropriately).

The provider will ensure that all staff are aware of Safeguarding Children policies and procedures, (all relevant staff will have training in relation to Safeguarding Vulnerable Adults Policies) as well as ensuring that staff know what to do in the case of suspected abuse or neglect of children or adults.

The Provider will ensure staff in all areas respond sensitively to the needs of individuals, children and young people, and provide appropriate environments for their care/treatment; ensuring risks are minimised to those using the service.

West Midlands Palliative Care Network

Acorns will continue to participate in the work of the West Midlands Paediatric Palliative Care Network and other appropriate groups and networks related to paediatric palliative care.

Whilst Acorns does not organise or run any screening programmes the service will support health partners in delivery of any national or local screening programmes for children, young people and their families through advertising and encouraging attendance where appropriate.

5. Applicable quality requirements

5.1 Applicable Quality Requirements

The provider will report to the lead commissioner any incidents, serious incidents or patient/carer complaints to:

qualityadmin@staffsstoke.icb.nhs.uk and MLCSU.CMT@nhs.net

6. Location of Provider Premises

6.1 The Provider's Premises are located at:

The service will be provided from Acorns Hospice sites, other suitable premises within the locality and through home visits.

Acorns Children's Hospice 103 Oak Tree Lane Selly Oak Birmingham B29 6HZ Tel 0121 248 4850	Acorns Children's Hospice 350 Bath Road Worcester WR5 3EZ Tel: 01905 767676	Acorns Children's Hospice Walstead Road Walsall WS5 4LZ Tel: 01922 422500
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7. Individual Service User Placement

Individual Service User Agreements (IPAs) with Acorns SLAs will be used where the commissioning of services specific to an individual child are required that fall outside of, or are in addition to, the providers core offer to all children accepted under the referral criteria.