

Statement of Purpose

July 2024

(Original document written in 2004 and updated annually as per requirements of the Care Quality Commission)



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Registered provider:

Cope Children's Trust

Registered location:

Rainbows Hospice for Children and Young People Lark Rise, Loughborough, Leicestershire. LE11 2HS Tel: 01509 638 000

Email:

administration@rainbows.co.uk

Website:

rainbows.co.uk

Registration Company in England and Wales Number:

2743297

Registered Charity Number:

1014051

Care Quality Commission Provider ID:

1-101728495



Introduction

Cope Children's Trust is a registered company limited by Guarantee and is a charity registered in England that operates in a facility known as Rainbows Hospice for Children and Young People.

The building is a purpose built, 14 bedded unit in Loughborough, Leicestershire serving life threatened and life limited babies, children and young people (from birth to 25 years) and their families in the East Midlands.

The hospice is registered with, and regulated by the Care Quality Commission (CQC). The CQC are the independent regulator of health and adult social care services in England. They make sure health and social care services provide people with safe, effective, compassionate and high-quality care.

As part of our CQC registration, we nominate a member of staff to act as our Registered Manager. It is a requirement of Schedule 3 of the CQC (Registration) Regulations 2010 that the Registered Manager provides a Statement of Purpose for the hospice. The information that must be included in this statement is listed in the Regulations and is incorporated in this document. The Statement of Purpose should be available for all families/carers.

We regularly review this document and update it to reflect ongoing changes in services. We would be very pleased to receive comments from anyone regarding the content of this statement or ideas about information for inclusion.

Our Philosophy of Care

We work with babies, children, young people, their families and other agencies involved in their care, to provide accessible, flexible and friendly home from home services. We offer support, relaxation and rest enriching quality of life. We also ensure the provision of individualised holistic assessment and care which meets identified physical, emotional, psychological, spiritual and cultural needs.

As a nurse led hospice, we support the Chief Nursing Officer for England's 3 priorities (2019):

- A workforce fit for the future
- Renew the reputation of the Nursing Profession
- A collective voice, that is powerful and heard



Ensuring we have the right staff, with the right skills, in the right place, by continuously developing our staff, embracing change and upholding our signature behaviours at all times.

Our Vision

The Rainbows experience wherever you are.

Rainbows Mission

Across the East Midlands we will:

- Transform care for those babies, children and young people who have a life-limiting or life-threatening condition
- Relieve the pain and symptoms associated with life-limiting or life threatening conditions
- Support every baby, child and young person to achieve their full potential
- Create memories for families to treasure
- Provide comfort and compassion at the time of and following the death of a baby, child or young person

Rainbows Values

One Team- Working together, Working respectfully, Working fairly

People Centred- Champion well-being, Champion clarity, Champion inclusivity

Aim High- Always learning, Always adapting, Always sharing

Own It- Be committed, Be accountable, Be focused



Purpose

Our purpose is to provide end of life, palliative and short break care to babies, children and young people, aged 0 to 25 years, with life limiting conditions from across the East Midlands. Holistic support is also available for the baby, child, young person and their families.

Rainbows works to ensure that all families have equity of access to the full range of services we provide which are then tailored to their needs. We aim to give the most effective treatment and care to our babies, children and young people to assist in the relief of their physical and emotional symptoms. We work closely with other agencies and services, across the NHS, voluntary and independent sector to offer a well-co-ordinated, multi-professional and 'seamless' specialist palliative care service. We consider it equally important to give support to those who care for the babies, children and young people, whether they are professional carers, members of the family, friends or volunteers.

We treat babies, children, young people and their families as individuals with compassion, humility, honesty and respect. We listen to them and, whenever possible, involve them in decisions about care. We respect their preferences, beliefs and customs and ensure their privacy and dignity. We ensure that all staff have an awareness and understanding of equality, diversity and inclusion and privacy and dignity. We always take account of the needs of babies, children and young people at different stages of their illness.

Babies, children and young people in our care are respected as individuals and as members of their wider family and community. We always refer to them by name. Our population is diverse and multi-cultural, Rainbows approach is non-judgmental and non-discriminatory. We recognise and respect diversity and we promote equality of access to our services.

Ongoing support is available including access to telephone advice and support 24 hours a day/365 day a year. Thanks to the support we receive from our donors and funders, there is no charge to babies, children, young people or their families for the use of our services.



Aims and Objectives

Families of children with life limiting /life threatening conditions are often overwhelmed by the challenge of caring for their children. Challenges such as the complexities of working with many professionals, services and appointments; the difficulties of maintaining family life and employment; and isolation in the community. Accessing hospice care from Rainbows helps by providing them with relief from the day-to-day responsibility of care. We provide expert care for their sick child and support for the whole family. This means that families feel supported and enabled to continue to care for their life limited baby, child or young person at home. Their needs are assessed and reviewed by a multi-disciplinary team who specialise in palliative care.

- To provide care from point of diagnosis of a life-limiting or life-threatening condition and offer palliative care for the duration of the family's journey.
- To offer flexible palliative care and end of life care and support at the hospice, in the hospital and in the community.
- To provide short breaks for babies, children and young people with life-limiting or life-threatening conditions in a homely, warm and welcoming environment
- To ensure we recruit and retain a workforce of dedicated and skilled multi-disciplinary staff, with expert knowledge and skills through a comprehensive induction and on-going training and development plans, including regular training and supervision sessions and personal development reviews.
- To provide creative flexible support for the whole family through individual and group work including support from dedicated sibling workers, play specialists, social workers, youth workers, transition co-ordinator, cultural link workers and spiritual support worker.
- To offer bereavement (including anticipatory) support to all members of the family, which is appropriate to their individual needs and for as long as they may need it. Including helping with the practical matters that follow a death, as well as offering emotional support. Bereavement support includes one to one support, support groups and remembrance events.
- To listen to children, young people and their families and involve them in as much of the decision-making regarding their life, personal care and treatment. Providing choice and information as required.
- To assess the baby, child or young person's needs, to care and support them in a way that is sensitively tailored to their needs and wishes.



- To work as part of a wider network of services providing care and support to babies, children, young people and families. To maximise the support that can be offered and to create a seamless service that minimises disruption to the family.
- To support the development of knowledge and skills in children's palliative and end of life care in the wider community through the provision of education and training events and participation in regional and national networks and forums.
- To provide care and support to babies, children, young people and their families in their home should it be their choice or necessary to do so.



Nominated Individual and Registered Manager Details

Care Quality Commission Registration

Rainbows Hospice for Children and Young People is registered with, and inspected by, the Care Quality Commission under the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

We are registered in respect of the regulated activity "Treatment of Disease, Disorder or Injury". The hospice's Provider ID is 1-101728495 and the certificate of registration is displayed in the hospice reception.

The Nominated Individual is:

Anne-Marie Rosak
Head of Hospice and Community Services – Deputy Executive Nurse
Rainbows Hospice for Children and Young People
Lark Rise, Loughborough
Leicestershire LE11 2HS
E-mail: anne-marie.rosak@rainbows.co.uk
Telephone: 1509 638068

The Registered Manager is:

Julie Taylor
Executive Nurse & Director of Clinical Operations
Rainbows Hospice for Children and Young People
Lark Rise, Loughborough,
Leicestershire LE11 2HS
E-mail: julie.taylor@rainbows.co.uk
Telephone: 01509 638038

Staff Skills and Competencies

We have on record the details of the qualifications and skills of all clinical staff. The Nominated Individual and Registered Manager are both registered nurses and hold other relevant professional qualifications. Rainbows has a team of Palliative Care Specialist Nurses and Advanced Clinical Practitioners and two Physiotherapists. Our team of senior nurses have dedicated roles which include Quality and Governance.

Our multi-disciplinary clinical team is appropriately skilled and qualified to deliver children/young people's palliative care in a hospice setting and a dedicated education team deliver both an induction programme on appointment and an ongoing education programme to maintain and develop these



skills. Our Care Team is supported by a team medical staff from across the region including GP's and specialist doctors.

We also have a Multidisciplinary Family Support and Outreach team.

Services, Facilities and Range of Needs to be Met

Our hospice building is purpose built and babies, children and young people are admitted in order to receive hospice care. We have designed the hospice to provide a warm and welcoming environment; to have a range of opportunities and facilities to enrich each baby, child and young person's day; fully accessible facilities; and the clinical equipment and facilities to meet the needs of babies, children and young people with complex needs, including technology dependent babies, children/young people.

There are extensive gardens including an eco- garden, a mini garden, a remembrance garden and outdoor play areas. Inside there are 14 bedrooms with intercoms and call bells; there is accommodation for families including 4 double bedrooms with en-suite facilities and a separate lounge. A gym, multi-sensory room, soft play and a children's lounge, teenage den, an over 18's activity room. The provision of complementary therapies ensure that all babies, children and young people and their family members are catered for.

We have made provision and space for peace, prayer and spiritual reflection in a multi faith 'reflection' room, and a suite of rooms are available where families, and their friends and relatives can be supported in the immediate period following their baby, child or young person's death. Comprehensive provision is available to meet the health and care needs of the sick baby, child or young people including therapy rooms.

There is resuscitation equipment to fully meet the basic life support needs of babies, children, young people and adults in an emergency and a wide range of moving and handling equipment, including built in hoists, assisted bathrooms and a wide range of bathing aids. There are separate medicine cabinets in bedrooms, a range of electric beds, cots and specialist mattresses. A range of essential clinical equipment is available.

We provide hydrotherapy for babies, children and young people in our care who can enjoy their swim sessions with their families in the pool which is complete with hoists. We have two physiotherapists and a team of trained staff to enable safe use of the hydrotherapy facilities.



User Involvement

We are committed to user involvement in all of our plans. Our service users and staff have developed the Participation Policy for the hospice which outlines our commitment to user involvement. We uphold the values of the 2010 Together for Short Lives 'Participation Toolkit', ensuring where possible, children, young people and their families are involved in hospice service development and review. We regularly consult users for their opinions and suggestions through an audit of services, questionnaires, comment forms and provider visits.

Summary of our Complaints Procedure

We deal with all complaints sensitively. They may be made verbally to any member of staff or in writing by the family or their representative. They may be formal or informal.

We welcome comments and suggestions from those who use our services or donate to fund our work.

We take a positive and constructive approach to feedback and complaints. We deal with complaints in a timely and responsive manner and learn lessons from them, taking remedial action as required in order to improve our services. Feedback forms are located in several locations around the hospice.

A complaints procedure is in place for use across the organisation and can be obtained from the administration team at the hospice or on our website <https://www.rainbows.co.uk/about-rainbows/charity-information/service-satisfaction-rainbows>

For clinical complaints, if you are not satisfied with the outcome of your complaint, you can raise your concerns with the Parliamentary and Health Ombudsman. You can contact the Ombudsman via www.ombudsman.org.uk or 0345 015 4033 or write to Parliamentary and Health Service Ombudsman, Millbank Tower, Millbank, London E1 6EP.

For fundraising complaints, if you are not satisfied with the outcome of your complaint you can raise your concerns with the Fundraising Regulator via www.fundraisingregulator.org.uk

For data protection complaints, if you are not satisfied with the outcome of your complaint you can raise your concerns with the Information Commissioner's Office via <https://ico.org.uk/make-a-complaint>

Rainbows Hospice for Children and Young People is registered with, and regulated by, the Care Quality Commission. The Care Quality Commission cannot get involved in individual complaints about providers, but is happy to receive information about our service at any time, their contact details are:



Care Quality Commission National Correspondence
Citygate,
Gallowgate,
Newcastle upon Tyne
NE1 4PA

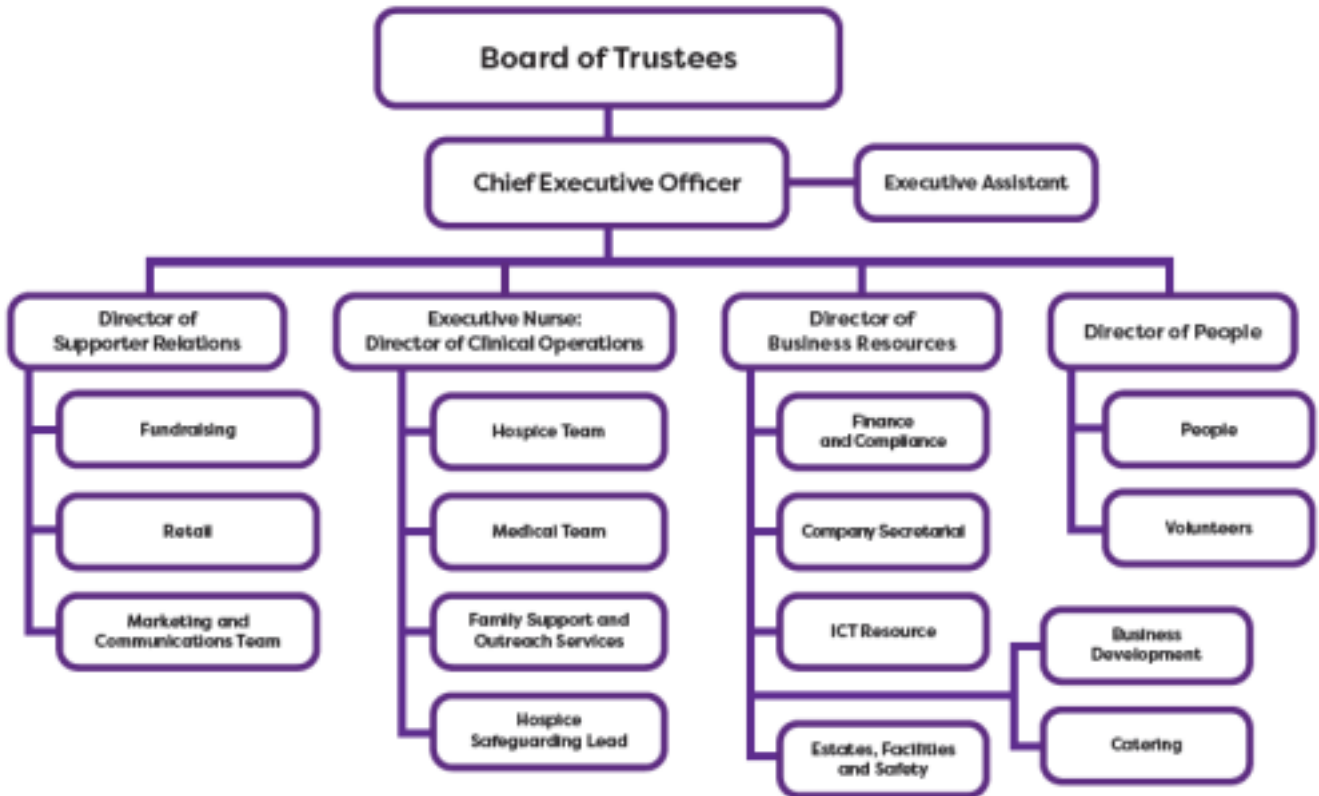
T: 03000 616 161

W: www.cqc.org.uk/contactus.cfm



Appendix 1: Organisational Structure

1. Overall Structure



Appendix 2: Safeguarding

