

Statement of Purpose

April
2025

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



Contents

Organisational Details	2
Introduction.....	3
Our Vision.....	3
Our Mission	4
Our Purpose	4
Our Values	4
Overview.....	5
Aims and Objectives.....	6
Staff Skills and Competencies	7
Services and Facilities.....	7
User Involvement.....	8
Complaints Procedure	8
Registered Manager and Nominated Individual Details	9
Appendix 1.....	10
Appendix 2	11

Organisational Details

Registered provider: Cope Children's Trust

Registered location: Rainbows Hospice for Children and Young People, Lark Rise, Loughborough, Leicestershire, LE11 2HS

Telephone: 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 as Rainbows Hospice for Children and Young People. The Hospice has a purpose built, 14 bedded unit in Loughborough, Leicestershire, as well as teams working in East Midlands major hospitals and the community, 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 ensure 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 Vision

THE RAINBOWS EXPERIENCE WHEREVER YOU ARE

We believe every baby, child, young person and their family should have the "Rainbows Experience" throughout their palliative or end-of-life care. We provide the best possible care where choice, quality and expertise is prioritised, ensuring families can make informed decisions that are right for them. As a child nears the end of their life, we help and support them to make treasured memories while surrounded by comfort, dignity and love. After death, we continue to provide support and compassion as families go through bereavement and grief.

Our support and care reaches beyond walls and locations, and we believe the Rainbows Experience should be wherever families need it to be, whether that's at the Hospice, at home or in hospital.

Our Mission

We provide compassionate, expert palliative and end-of-life care to babies, children, and young people across the East Midlands.

The unique needs of each baby, child, young person and family are at the centre of everything we do, and our mission is to support them in their most comfortable and preferred setting. Working collaboratively with other professionals and volunteers, we provide care, support and opportunities to make meaningful memories, through illness, death and bereavement.

Our Purpose

Rainbows exists to support babies, children, young people and their families in life and in death. We create lasting, precious memories and provide care and support wherever a family needs us – in the Hospice, at home or in hospital. For families facing the unimaginable, we provide compassionate and dignified support during dying and bereavement. Helping families to navigate their grief while honouring the memory of their child.

Our 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

Overview

Rainbows provides essential end-of-life, palliative and short break care to babies, children and young people, aged 0 to 25 years, with life-limiting and life-threatening 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 collaboratively with other organisations 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 diversity and inclusion. We always take account of the medical, spiritual and cultural 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 and the 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 days 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 unable to cope, and 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 baby, child or young person at home. Their needs are assessed and reviewed by a multi-disciplinary team who specialise in children's palliative care. To achieve this we aim to:

- provide essential 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.
- offer flexible palliative care and end-of-life care and support at the Hospice, in the hospital and in the community.
- provide short breaks for babies, children and young people with life-limiting or life-threatening conditions and their families in a homely, warm and welcoming environment.
- ensure we recruit and retain a workforce of dedicated, highly skilled multi-disciplinary staff, with expert knowledge and a range of skills. A comprehensive induction and on-going training and development programme is in place, including regular training and supervision sessions and personal development reviews.
- provide creative, innovative and 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-ordinators, a Cultural Link Worker and a Spiritual Support Worker.
- 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 and spiritual support. Bereavement support includes one to one support, support groups and remembrance events.
- 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.
- assess the baby, child or young person's needs holistically, to care and support them in a way that is sensitively tailored to their individual needs and wishes.
- 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.
- 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.
- provide care and support to babies, children, young people and their families in their place of choice, whether that be Hospice, Hospital or Home.

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 Advanced Clinical Practitioners and Palliative Care Specialist Nurses and two Physiotherapists. Our team of senior nurses have dedicated roles which include Quality, Governance and Compliance.

Our multi-disciplinary clinical team is appropriately skilled and qualified to deliver baby, children and young people's palliative care in the Hospice, in hospital or in a community setting. We also have a dedicated education team deliver both an induction programme on appointment and an ongoing education programme to maintain and develop these skills. Our services are supported by medical staff from across the region, including GP's and specialist doctors.

Services and Facilities

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 to meet the needs of babies, children and young people with complex needs, including those who are technology dependent.

There are extensive gardens including an Eco-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. Our facilities include a Gym, Multi-sensory Room, Soft Play, Children's Lounge and a Young People's Lounge for our over 18s. We offer a range of therapeutic interventions including complementary therapy, music therapy and hydrotherapy.

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.

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.

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.

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 at rainbows.co.uk

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 ombudsman.org.uk or 0345 015 4033 or write to Parliamentary and Health Service Ombudsman, Milbank Tower, Milbank, 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 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 by visiting 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: cqg.org.uk/contact-us/contact-us-online-form

Registered Manager and Nominated Individual 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:

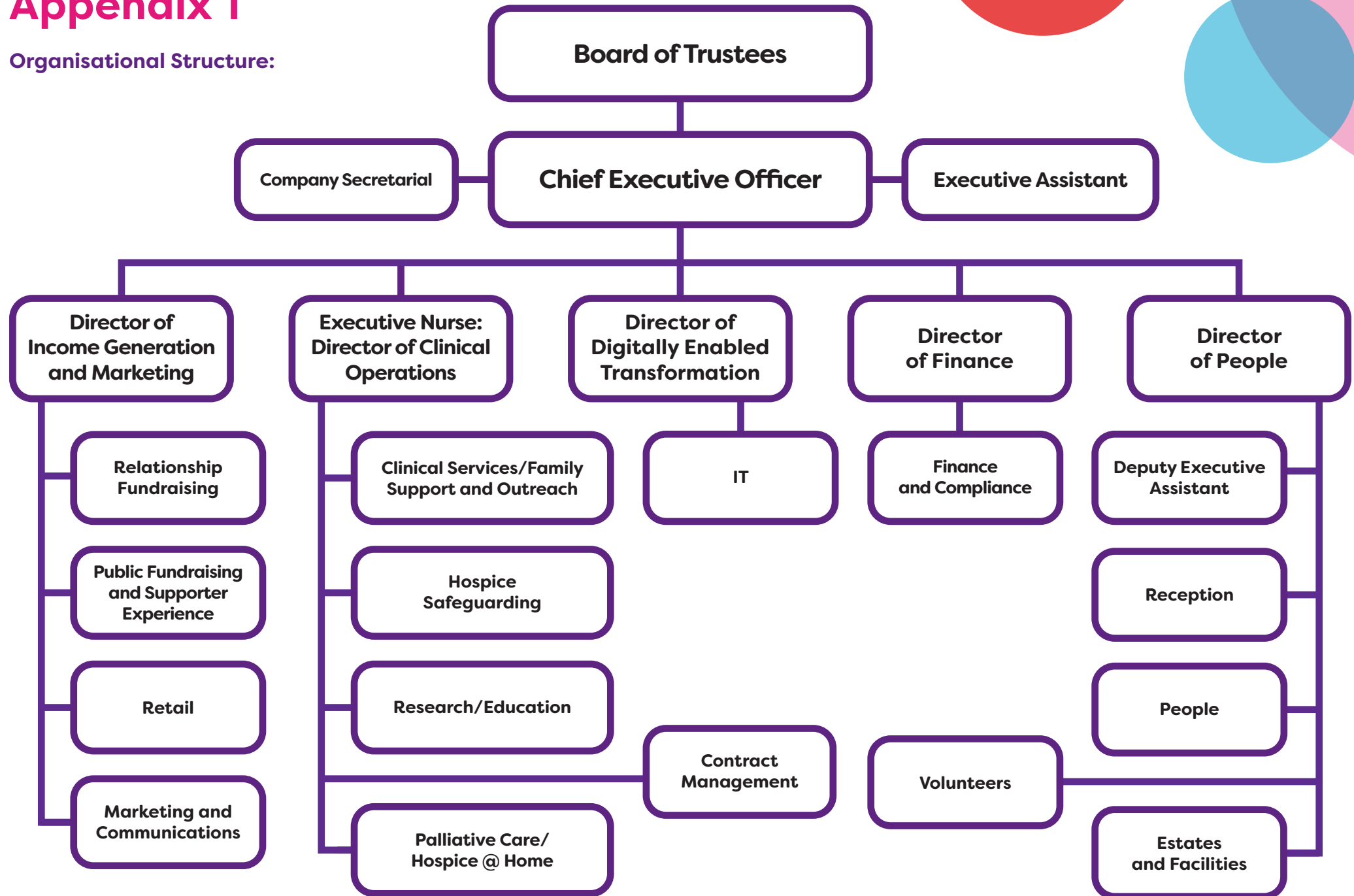
Anne-Marie Rosak, Head of Hospice and Community Service Deputy Executive Nurse
Rainbows Hospice for Children and Young People
Lark Rise, Loughborough, Leicestershire, LE11 2HS
anne-marie.rosak@rainbows.co.uk

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
julie.taylor@rainbows.co.uk

Appendix 1

Organisational Structure:



Appendix 2

Safeguarding Structure:

