



# Chestnut Tree House **Care Strategy** **2023 – 2028**

Adding Life to Shortened Years





# Contents

## 1. Introduction

- A message from the CEO
- A message from the Director of Children's Services
- About Chestnut Tree House
- Our Vision, Mission, Strategic Objectives and Values

## 2. Developing our new Care Strategy

- Our service users' views
- Our partners' views
- Staff views
- Responding to a changing landscape
- Our catchment population and patient referrals

## 3. Palliative and end of life care needs of children and young people in East Sussex, West Sussex and South East Hampshire

## 4. A new Chestnut Tree House Model of Care

- Introducing our new Model of Care
- LEAF Branch
- Child and Family Support Branch
- Community Care Branch
- In-House Care Branch

## 5. Delivering our Care Strategy 2023/24

# 1. Introduction



## A message from the CEO

At Chestnut Tree House, our goal is to provide the best quality of life for children, young people and their families. For the past 20 years, we have looked after children and young people with life-limiting conditions, ensuring that they and their families get all the care and support they need. Most importantly, helping them to make as many precious memories as possible.

As we all emerge from the COVID-19 pandemic, I believe it's important to take learnings from it. As an organisation, we are at a pivotal point for developing our new care strategy and ensuring our model of care helps to support as many children, young people and families as possible. The healthcare system is adjusting to a 'new normal' following the pandemic, and we have the opportunity as experts in our field to work with our partners and shape the future for children and young people.

Looking ahead, we will strive to give children and young people new opportunities, support them closer to home in their own communities, and give them the best experiences using our expert knowledge and skills. We recognise that we cannot achieve this alone and going forward, we will work much more closely in collaboration with our partners in the wider healthcare system. Partnership-working will be key to our success in extending our reach to as many children and families as possible.

In this document, we set out our ambitions for palliative and end of life care for children, young people and their families across East Sussex, West Sussex and South East Hampshire. It outlines the organisation's ambitions for its services, its standards, and its people. We are pledging our resources to pursuing excellence in paediatric palliative and end of life care over the next five years and I hope that by reading this strategy, you are assured of our commitment to this cause.

With best wishes,

**Amanda Fadero**

Chief Executive

Chestnut Tree House



## A message from the Director of Children's Services

Children and families living with a life-limiting condition can face significant challenges. As a team, we are committed to supporting children and families to navigate the trajectory of a child's condition and manage the many challenges they face throughout their life. Our services are designed to help children and families to live well, enabling them to participate in activities and to have fun – 'adding life to shortened years'.

The courage and ambition of our children and families inspires me on a daily basis and drives the team to provide the special care that they do. I regularly hear from our children and young people how important it is to them to be able to participate in activities, and the team have worked hard to ensure the inclusivity and accessibility of our services. Furthermore, we have invested in our grounds at the hospice, installing an incredible inclusive adventure playground and sensory garden.

We recognise the increased challenge and impact brought about by the COVID-19 pandemic and our new model of care addresses the needs of our children and families. We are proud of the development of a comprehensive outreach programme for children, young people, siblings, parents and carers. We will work over the coming years to ensure equity of provision across the three counties and will continue to provide opportunities for our children and families to provide feedback and help co-design future services.

I am proud of our diverse team of professionals who work so hard to make a difference to the lives of children and families. We are in a privileged position to currently be fully staffed and the skills of the team are exemplary, ensuring we can provide safe care to children and young people with a high level of clinical complexity. The recent investment in a lead nurse for learning disabilities will ensure we give children and young people the best opportunity to achieve and reach their full potential.

Looking to the future with positivity and excitement, we want to ensure that our service transformation and design meets the needs of our children and families, both now and in the future. We have pledged to ensure effective communication with our families, providing opportunities for engagement as well as updates about service delivery and developments.

We are committed to working collaboratively with our partners to achieve sustainable, equitable and excellent palliative care across our counties. We also hope to work with professionals across health, social care and education to achieve our vision in reaching all children and young people who would benefit from palliative care amongst the communities we serve. We need the support of other partners and other voluntary organisations to help raise awareness of paediatric palliative care and the support that Chestnut Tree House can provide.

Due to the current challenging and uncertain financial climate, we need to be conservative with our plans for expansion and development. Yet I am confident that our ambitions will be achieved over the next five years. I always remain so grateful for the generosity of our communities who support us financially to provide the special care that we do, and also the relentless work of our fundraising team to ensure that we can continue with our important work.

I look forward to the future of Chestnut Tree House which will be full of ambition, confidence and courage in developing and transforming our service to provide palliative care for our wonderful children and families.

With warm wishes,

**Anna Jones**

Director of Children's Services  
Chestnut Tree House



# About Chestnut Tree House

## Our team and services

Chestnut Tree House is the children's hospice for East Sussex, West Sussex and South East Hampshire. We provide hospice care services and community support for children and young people with life-limiting and life-threatening conditions across the region. There are many challenges in caring for a child with a life-limiting or life-threatening condition, and our team offers support for the whole family, including parents, siblings, and grandparents.

We offer a complete package of care and social and spiritual support throughout each child's life. From specially-trained nurses to activity coordinators, counsellors and health care assistants – our dedicated team works closely together to help children and families enjoy time as a family, have fun, and make as many precious memories as possible.

- **Community Care:** Clinical staff provide short respite visits in the family's own home or take the child on fun trips out in their local community.
- **In-House Care:** Children and young people have the opportunity to use the hospice for short breaks, either on their own or as a family. The clinical team provide specialist care whilst the activities team organise fun activities for children and their families using our specialist facilities such as the hydrotherapy pool, multisensory room, and music room.
- **Therapeutic Services:** The Child and Family Support Team provide specialist emotional, social and spiritual support. The team includes counsellors, a psychotherapist, chaplain, and social workers. Children and families are able to use these services in whatever way feels right to them, and we aim to be inclusive by offering telephone, video link and face to face meetings, as well as offering language interpreters. The chaplain can also facilitate the involvement and support of local faith leaders and communities if needed.
- **Activities:** Our creative Activities Team organise fun and inclusive events for children and their families: from treasure hunts to karaoke performances, summer parties and more. There are daily activities set up at the hospice for children involving sensory play, all of which are inclusive for all children to be able to enjoy.

## Our history

We were first established as Chestnut Tree Trust in 1997, with the aim of looking after children with life-shortening conditions and their families. A community team was launched in 2001 to start caring for families in their own homes before the hospice was officially opened in November 2003. At that time, we were caring for around 30 children and their families.

Today, we care for around 300 children and young people every year, both at the hospice and in families' own homes. Since we opened in 2003, due to advances in medical technology and the introduction of pioneering treatments, children with certain conditions are living longer than ever expected, with increasingly complex needs.

To ensure that children and young people continue to get the best possible care and support, in an environment which can address all medical needs and complexities, we have undertaken a few renovations, such as increasing the ceiling height in the Teenage Wing and pool area and installing piped oxygen and suction, as well as improved mechanical hoisting. A new wet and dry changing area has also been added to allow more children and young people to use the pool with greater privacy.



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**Chestnut Tree House is a children's hospice, but it definitely isn't a place of sadness. This is where children like my daughter Maisy-Leigh come to spend happy days laughing and playing and whizzing up and down the corridors – and to make every moment count.”**

Hayleigh, Maisy-Leigh's mum



## Our Vision

Anyone facing life-limiting illness should receive the care and support they deserve

## Our Mission

St Barnabas and Chestnut Tree House hospices seek to achieve dignity, comfort and choice for adults and children facing life-limiting illnesses through specialised supportive care

## Our Strategic Objectives



We will provide excellence in Palliative and End of Life Care for all we serve, through continuous improvement, utilising research and education.



We will support all in our communities affected by life-limiting conditions to live and die with choice and dignity.



We will build a sustainable model of care in collaboration with our partners.



We will create a culture that enables staff and volunteers to reach their full potential through support and investment.

## Our Values



### We are Caring

- We place children and adults, their families and carers, at the heart of all we do.
- We care passionately about the difference we make.
- We are inclusive and treat everybody with compassion, care, dignity and respect.



### We are Courageous

- We have the courage to aspire to deliver excellence in all we do.
- We are ambitious, brave, and innovative and continually strive to improve our knowledge and skills.



### We are Connected

- We listen, connect with and understand the needs of the people we support and work with and ensure we respect their choices.
- We work as a team to motivate, encourage and support each other.
- We are connected and work collaboratively with others through strong partnerships.



Here are the views of their parents and carers:



Across our services, **95%** of parents and carers would recommend Chestnut Tree House to friends and family if they needed similar care. When asked how they would like us to develop our services in the future, the overwhelming majority said they would like to see **more of what we currently offer**: from activities across the region and community visits, to in-house respite stays at Chestnut Tree House.

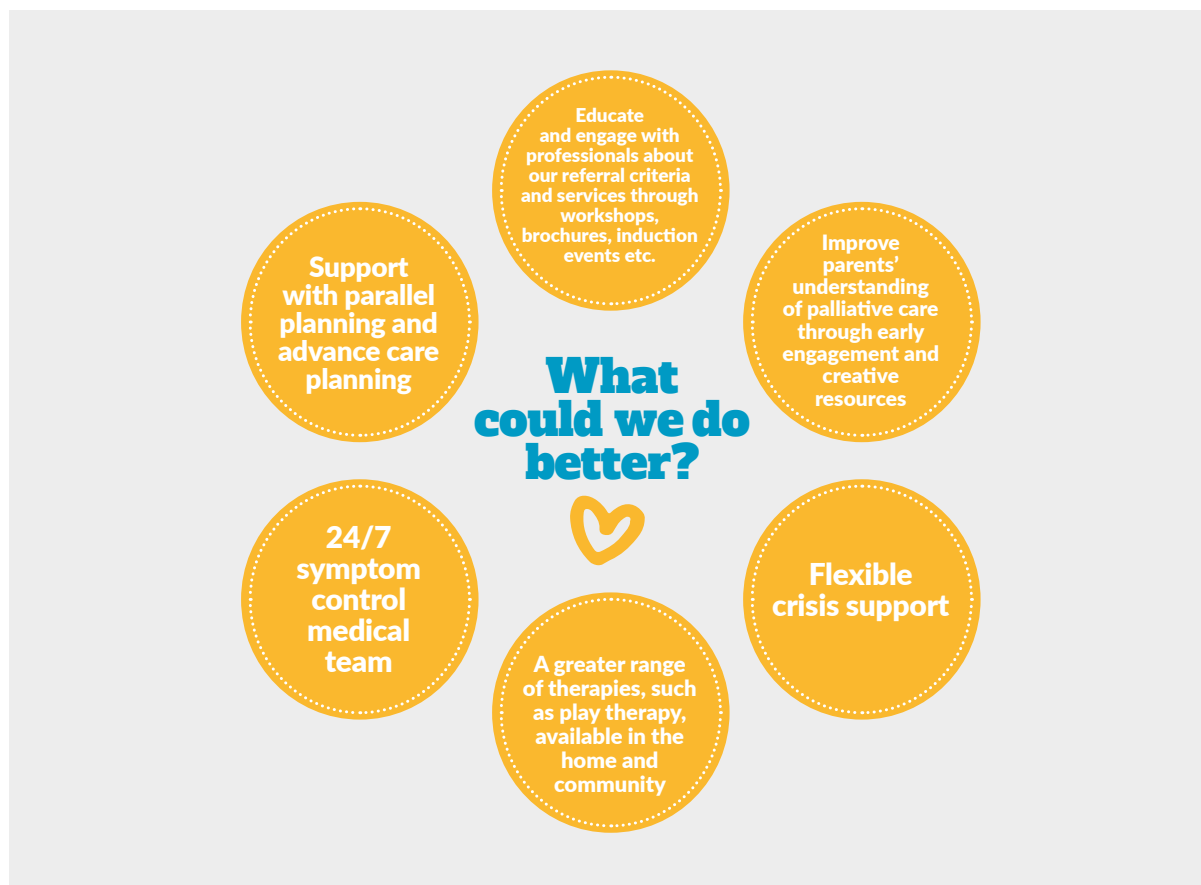
## Our partners' views

We also asked professionals about their experience of our care. Feedback from these sessions further highlighted the value of in-house respite stays, the importance of medical cover, and the value of working together across the health and social care system to support children and their families, for example through crisis respite care. In particular, engagement with our professional partners has highlighted that going forward, we need to be flexible and responsive in our approach if we are to meet the needs of more children and their families.

Our partners collectively identified a number of main challenges:

- There is inequity of care and support across the region for children and young people with life-limiting conditions.
- Information sharing across the system needs to be improved if we are to work collaboratively as multidisciplinary teams.
- The negative perception of palliative and hospice care in the community means families are afraid to access Chestnut Tree House which impacts upon partner referral to our services.
- Professionals do not always know our referral criteria and the process to be able to refer quickly and easily.
- The limited availability of services to transition young people with life-limiting conditions onto when they reach adulthood.

Below are some of the most important ways in which professionals said that we could support them in the future:



## Staff views

Amongst our own staff, there is a strong consensus that we are caring in our approach towards the whole family, and that our activities and community visits are particularly valued by children and their families. It was also observed that our provision of therapies and bereavement support is very good. Our staff noted that our strength lies in helping families to make as many precious memories as possible.

In the future, our staff agree that we need to be more flexible in our response and that we could be better in tailoring our care offer to the individual needs of children, young people and their families. Further, that our services are not always well understood by families or easily accessible for those who do not have access to transport.

It is recognised that transition is a particularly difficult issue for staff to deal with, and even more so for young people and their families, particularly as there are few services onto which young people can transition. The uncertainty around transition leads to families who are frightened and worried about losing the support of Chestnut Tree House when they reach adulthood.

## Responding to a changing landscape

The landscape of palliative care for children and young people with life-limiting conditions is complex, and it is changing. In comparison to adult palliative care services, children's palliative care has not developed at the same rate, resulting in a lack of commissioning, unequal access to services, and funding gaps.

A recent report by 'Together for Short Lives' has revealed the true extent of this and highlighted the postcode lottery that children and their families face when accessing palliative care services: they have found that in 79% of Integrated Care System (ICS) areas, the NICE quality standard of 24/7 access to children's palliative care at home, and access to a Level 4 Children's Palliative Care Specialist Consultant is not being met.<sup>1</sup>

Furthermore, the financial context shows that there will be an estimated £301m gap in NHS spending on children's palliative care by 2023/24. This is despite the pledge by NHSE/I to ringfence and increase the Children's Hospice Grant to £25m by 2023/24, and a commitment in the NHS Long Term Plan to match fund CCG [ICB] children's palliative care funding by up to £7m.<sup>2</sup>

These gaps are set against several medical, demographic, and system-wide challenges. Nationally, we know that both the mortality rate and the prevalence of life-limiting conditions is the highest in children under the age of one.<sup>3</sup> Whilst neonates are surviving extreme prematurity, they are doing so with a high level of clinical complexity. Further to this, the number of children with a life-limiting condition in the UK has tripled. Due to medical advancements and technological innovations, these children are living longer with significant

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<sup>1</sup> Together for Short Lives (TFSL), '24/7 Access to Children's Palliative Care in England: Key standards for seriously ill children and their families and how they are met round the clock' (May 2022), p. 2.

<sup>2</sup> Ibid., p. 2. TFSL has also identified an annual funding gap of £2.3million in education and training.

<sup>3</sup> Lorna Fraser et al., 'Make Every Child Count': Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom' (February 2020), p. 24, p. 46.

medical complexity and uncertain prognostication, requiring intensive care regimes which are often 24/7.

This results in a high burden of care for parents, caregivers and the young people themselves. There is thus an increased demand for respite provision for these children, young people and their families: a vital service upon which they rely. Yet access to this crucial care is often lost when young people transition into adult care services around the age of 18.

The experience of transition from children's to adult palliative care services is therefore often a fraught and distressing time for families. And whilst 84% of children's hospices in the UK support children and families with the transition to adult services,<sup>4</sup> there is still an urgent need for ICBs to commission age and developmentally appropriate transition services, with one in six (16%) CCGs currently not doing so.<sup>5</sup> Further still, families are experiencing more social isolation than the general population as an enduring result of the COVID-19 pandemic, with a concerning deterioration in their mental health and wellbeing.<sup>6</sup>



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<sup>4</sup> Together for Short Lives, '24/7 Access to Children's Palliative Care in England', p. 42.

<sup>5</sup> The All-Party Parliamentary Group (APPG) for Children who need Palliative Care, 'End of Life care: strengthening choice' (October 2018).

<sup>6</sup> Together for Short Lives, 'No End in Sight' (April 2021) and 'Then there was Silence' (September 2021).

## Our catchment population and patient referrals

Our catchment area is shown in figure 2.3, the population of which is approximately 2.5 million people. Around 80% of these people live in East and West Sussex, with the remaining 20% living in the adjoining counties of Hampshire, Surrey and Kent.

We have around 250 active referrals at any one time covering the postcodes in figure 2.1.

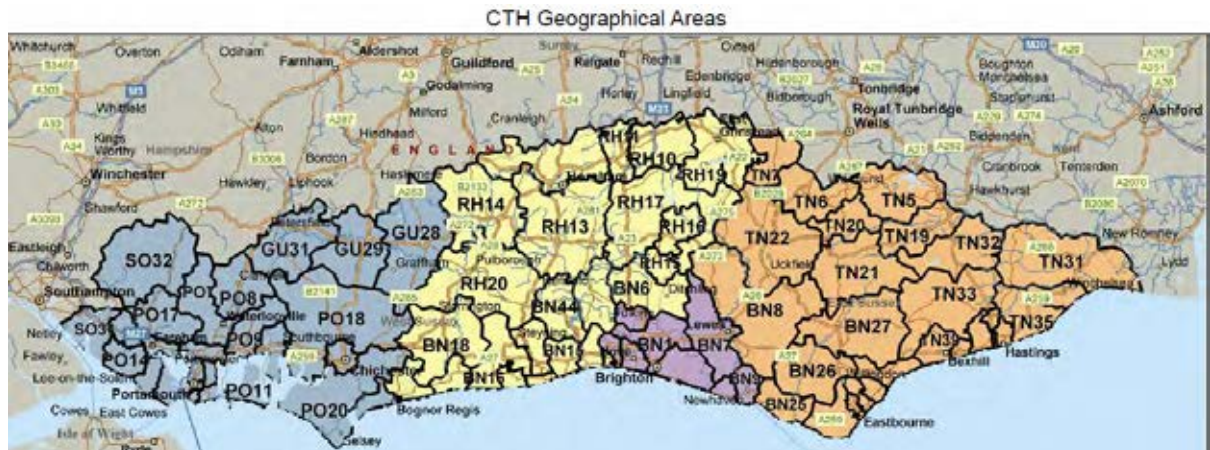


Figure 2.1: CTH geographical areas (postcodes)



Figure 2.2: CTH referral footprint



Figure 2.3: PHE Fingertips (Local Health Tool) best-fit catchment area using Lower Tier Authority areas (LTLA 2021)

Furthermore, our referral data from 2018 onwards shows that:

- Accepted referrals have averaged at 47 per year.
- There was a small reduction in referrals during the COVID-19 pandemic in 2020/21, which impacted the size of our caseload and reach (see figure 2.4: CTH referrals 2020–2022). During this time, there was less networking with professionals, and we were unable to meet referrals and offer first stays and respite. However, we anticipate an increase in referrals going forward.
- The majority of referrals are from a medical setting, however approximately 10% come from social services and 7% directly from families themselves.
- Diagnosis of children is split approximately evenly between Congenital, Neurological, Oncological, and other diseases, although this fluctuates annually.

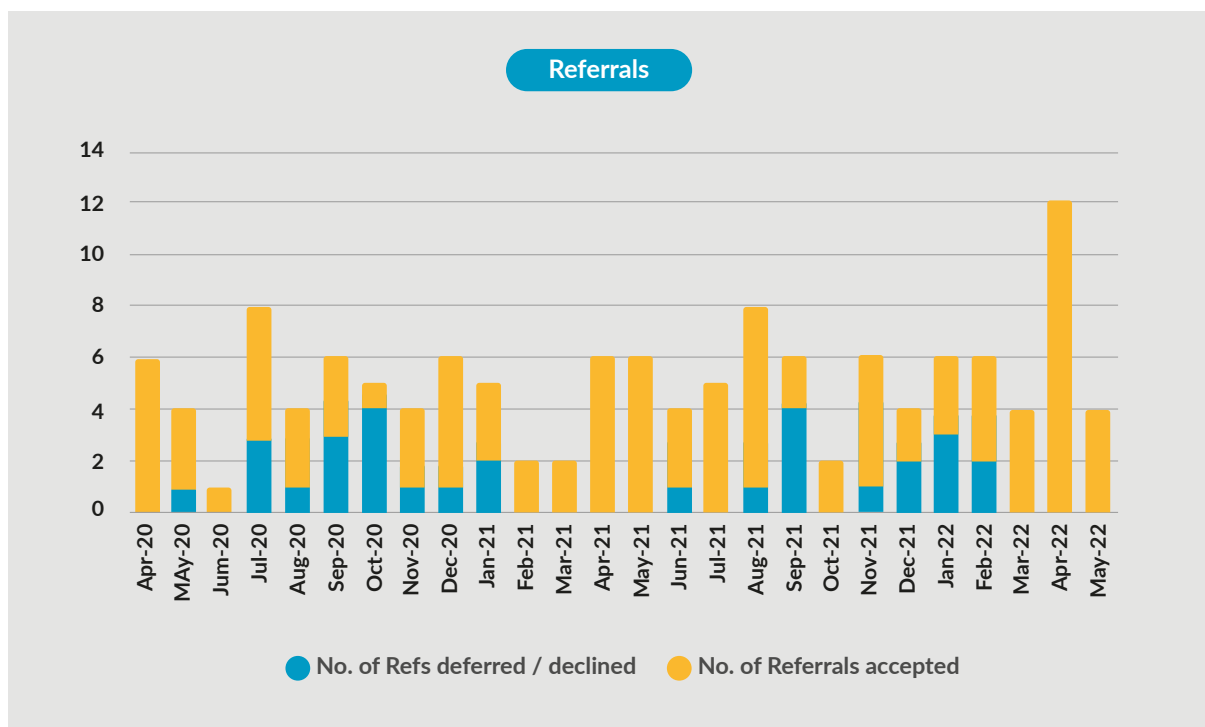


Figure 2.4: CTH referrals 2020–2022

### 3. Palliative and end of life care needs of children and young people in East and West Sussex and South East Hampshire

The national data shows that there has been a steep rise in the number of babies, children and young people with life-limiting or life-threatening conditions. This figure has almost trebled in the last 17 years from 32,975 in 2001/2 to 86,625 in 2017/18. The national prevalence of children and young people with life-limiting conditions has risen from 26.7 per 10,000 in 2001/2 to 66.4 per 10,000 in 2017/18, with prevalence being higher in boys than it is in girls. Furthermore, prevalence is by far the greatest in babies under one year, as is the number of deaths. Finally, the number of young people with life-limiting conditions living to 19 years has increased from 921 in 2001/2 to 3,075 in 2017/18.<sup>7</sup>

Our local context reflects the national picture. There are approximately 560,000 children and young people of 19 years and under in our catchment area (see figures 3.1 and 3.2). The prevalence in the South East of children and young people with life-limiting conditions is estimated to be 70 per 10,000 (increasing to 76 by 2030).<sup>8</sup> This means that there are currently an estimated 3,920 children and young people with life-limiting conditions in our catchment area – a number which is set to rise to 4,256 by 2030. With our current referrals (250), this means we are reaching less than 7% of these children. We know that Sussex is the 13<sup>th</sup> highest out of 42 ICS areas for the number of children and young people with life-limiting conditions and its prevalence is the 16<sup>th</sup> highest.<sup>9</sup> Despite this, the NICE quality standards of 24/7 access to children’s palliative care at home, and access to a Level 4 Children’s Palliative Care Specialist Consultant, are not being met in the Sussex ICS area.

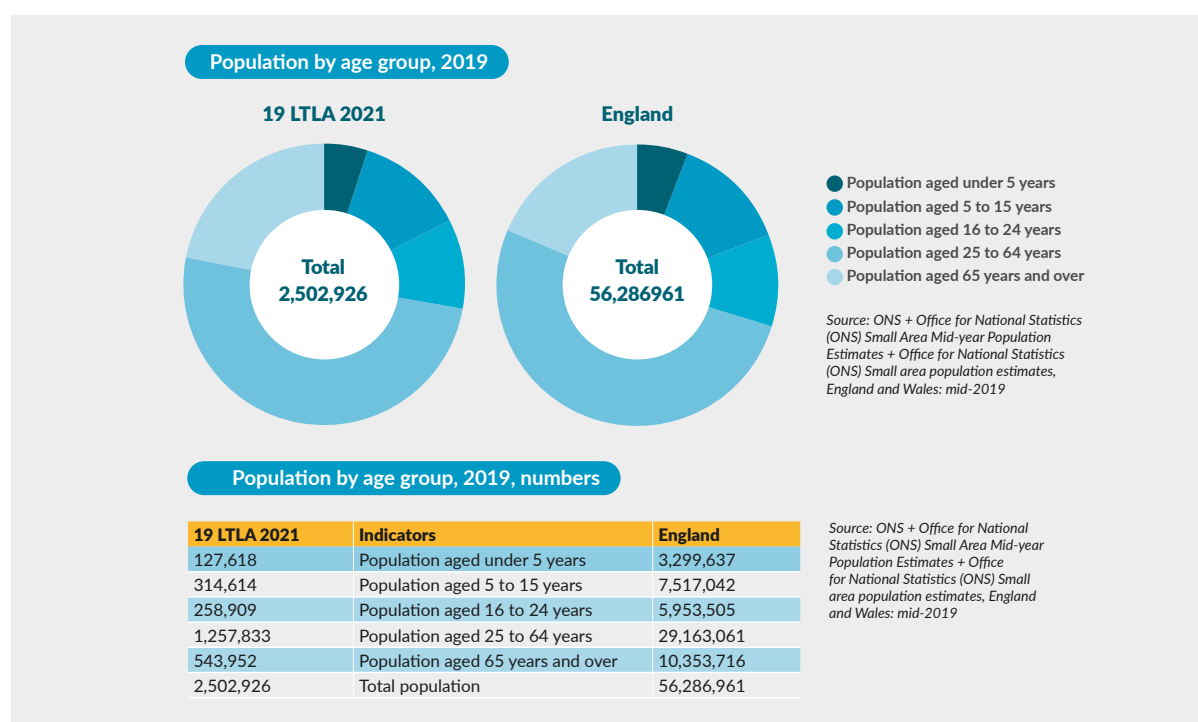


Figure 3.1

<sup>7</sup> Lorna Fraser et al., ‘Make Every Child Count’: Estimating current and future prevalence of children and young people with life-limiting conditions in the United Kingdom’ (February 2020).

<sup>8</sup> Lorna Fraser et al., ‘Make Every Child Count’.

<sup>9</sup> Together for Short Lives, ‘24/7 Access to Children’s Palliative Care in England’.

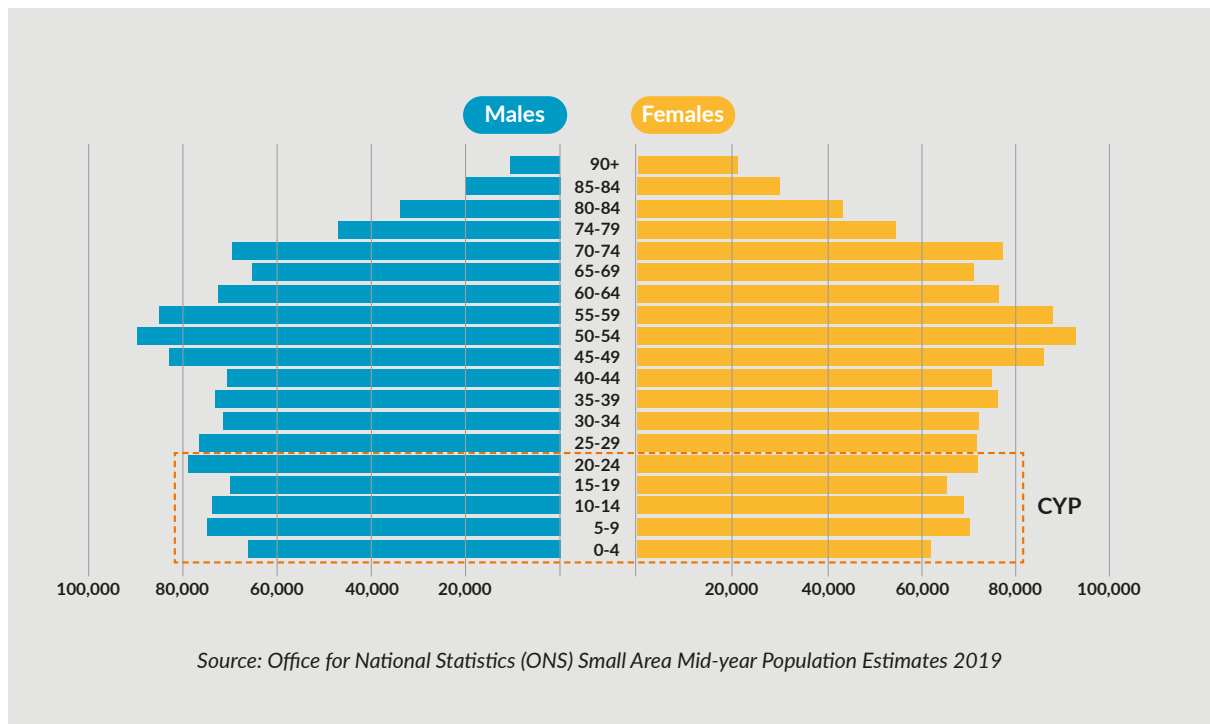


Figure 3.2

The following table shows the estimated prevalence by condition, based upon projections for the South East within the estimated catchment area of Chestnut Tree House.

CYP with LLC Group	Year			
	2022		2030	
	Prevalence	Number	Prevalence	Number
All	70.0	3920	79.0	4424
<b>Congenital</b>	29.2	1633	35.0	1958
<b>Respiratory</b>	11.6	647	13.9	776
<b>Neurological</b>	11.0	616	13.2	738
<b>Haematological</b>	8.3	465	10.0	557
<b>Perinatal</b>	8.0	447	9.6	537
<b>Genitourinary</b>	7.3	411	8.8	493
<b>Oncology</b>	4.8	270	5.8	323
<b>Metabolic</b>	4.4	246	5.3	295
<b>Gastrointestinal</b>	4.0	223	4.8	268
<b>Circulatory</b>	2.6	148	3.2	177
<b>Other</b>	2.2	121	2.6	145

Figure 3.3: Estimated prevalence and numbers of CYP with LLCs in the CTH catchment area



### **What we know about children and young people with these conditions**

There are approximately 400 life-limiting conditions which can affect children and young people.<sup>10</sup> However, 15% of children never receive a diagnosis, which not only has implications for the planning of service delivery, but also for those families managing an unknown lifespan.

Secondly, advances in medicine and science mean it is difficult to predict the illness and lifespan trajectory for the child. This in turn has implications for referring professionals, for whom it is difficult to know when to refer the child to palliative care services.

Further to this, there is also a variance between palliative care services and the conditions which they recognise as life-limiting. Due to scientific and medical advancements, many children are now outliving paediatric palliative services. For example, although cystic fibrosis is still listed as a life-limiting condition, people are now living into their 40s with this condition<sup>11</sup>.

Finally, palliative care service offers and end of life care arrangements vary greatly between conditions and localities, contributing to inequity of care. For example, children in Sussex with oncology conditions benefit from end of life 24/7 medical provision, whereas children with other life-limiting conditions do not have access to the same level of service.

However, the most prevalent conditions in the region are estimated to be congenital, followed by respiratory and neurological. Oncology conditions are estimated to be the 7<sup>th</sup> most prevalent among children and young people with life-limiting conditions. Children with congenital conditions and their families often live with a great deal of uncertainty due to the unpredictable nature of their disease trajectory, fluctuating needs, and uncertain prognosis. For these children, the availability of 24/7 medical provision and effective parallel planning are essential.

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<sup>10</sup> Hain and Devins, *Directory of Life-Limiting Conditions* (Cardiff, 2011).

<sup>11</sup> Kimberly A McBennett, Pamela B Davis and Michael W Konstan, *Increasing life expectancy in cystic fibrosis: Advances and Challenges* (February 2022) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9004282/>



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**A few years ago, Chestnut Tree House wasn't able to care for children with complex conditions like Mikey's. But now they can. Mikey needs a ventilator regularly to help him breathe and until a couple of years ago, Chestnut nurses didn't have the training to work the equipment that kept him alive. But when the big-hearted care team at the House saw there were children who urgently needed specialist care, they trained their nurses to look after those who needed long-term ventilator support. With the help of generous supporters, they were able to care for children with needs as complex as Mikey's. Not just at Chestnut Tree House itself, but in children's own homes, and even on fun trips out which would have been impossible in the past.”**

Chevonne, Mikey's mum



## What this means for our care strategy

As a result of the 'Together for Short Lives' report, as well as analysing our local context and own engagement work, we have identified that addressing **medical complexity**, improving **equity of access** to our services across the area, and developing **transition services** will be key future priorities for us and our system partners:

### 1. Medical complexity

In our catchment area, there is a high prevalence of children and young people with congenital conditions (see figure 3.3), meaning that there is a significant population of children and young people with life-limiting conditions who are living with a high degree of medical complexity and uncertainty due to the nature of their disease trajectory. This is compounded with the lack of 24/7 access to children's palliative care at home and a Level 4 Children's Palliative Care Specialist Consultant in the Sussex ICS area. Addressing **medical complexity** in our strategy is important to provide children, young people and their families with choice and expert care that meets their fluctuating needs.

We propose answering the question of *medical complexity* through a new **medical model** that:

- Provides clinical expertise in children's palliative care and capacity to support 24/7 symptom control for end of life care in-house and in the community.
- Supports a wide range of crisis and step-down care which require medical review and prescribing.
- Supports respite admissions with the ability to provide robust medical reviews and treatment for children experiencing illness and discomfort.
- Hosts clinics across Sussex to support earlier symptom control management and supports Advance Care Planning and Parallel Planning.
- Develops nursing staff (non-medical prescribing and advance care practitioners) and delivers education to our partners.
- Develops neonatal care pathways across the region and ensures that families know of our services and have choice.

### 2. Equity of access

We know that we are currently reaching less than 7% of the children and young people in our region who could benefit from our services. Barriers to accessing our services include geographical constraints, but they can also be cultural. Palliative and hospice care can have different meanings for everyone, and when a child is diagnosed with a life-limiting condition there can be a tendency for families to view palliative care as something only to be taken up at the end of life.

We propose improving *equity of access* through a new **clinical-case finding team** that:

- Enables us to reach more children and families across Sussex and South East Hampshire, by working with our health, social care and education networks and partnerships to identify more families who could benefit from our care.
- Collaborates with our health, social care and education partners to promote a good understanding of CTH and our services throughout the region and sector.

- Places nurses into hospitals and community teams to identify new referrals and work more closely with 'harder to reach groups' to improve equity of access to children's palliative care across the region.
- Works and engages with harder to reach communities to understand need and comprehend barriers to accessing children's palliative care, in particular seeking to understand their perspectives of hospice care, previous experiences of care, cultural and religious values (such as attitudes to disability and bereavement), and preferred communication methods.
- Works to ensure that we are culturally sensitive as an organisation and offering accessible and culturally appropriate services that are bespoke to the needs of a wide range of different communities in order to improve equity of access to our services. This includes developing accessible information and ensuring our messaging is suited to diverse groups. We will do this by engaging with these communities through schools, religious leaders, and other voluntary services.
- Educates the communities we serve about paediatric palliative care and hospices and the support available in order to alleviate misconceptions about hospice services.

### 3. Transition

Whilst children and young people with life-limiting conditions are living for longer, transition services have not been developed to adequately support young people and their families when they reach adulthood. At the age of 18, their access to respite and developmentally-appropriate services provided by children's palliative care services is often lost, with the transition to adult services often being a fraught and distressing experience.

We propose answering the question of how to improve the *transition experience* of young people and their families through a new **transition model** that:

- Offers appropriate support which is tailored to the young person and their needs. For example, at the age of 18 we propose to undertake a review of their care. Those who are deteriorating and unlikely to survive the next year of life will continue to receive support from all four branches of the care model. For those who are going through a period of stability, they will be discharged from in-house and community care.
- Extends our therapeutic services and LEAF branch to all the young people we are currently supporting up to the age of 25, giving them and their families reassurance that they will continue to have access to our services in some form. For example, there are few external facilities which enable medically complex young people to swim and access to our swimming pool for hydrotherapy and leisure has been identified as being particularly important to these families.
- Provides opportunities for young adults to become ambassadors for the service and to become part of the CYP board/forum.
- Offers end of life care at the hospice for those young people with significant learning disabilities and where medically appropriate.
- Supports 18–25-year-olds and their families to make informed and empowered choices as they prepare to transition to adult services. This support will begin early: at the age of 13, all young people and their families will be invited to a transition information workshop led by CTH.

- Provides targeted support groups for young people facing transition, as well as dedicated support groups for their parents and carers.
- Works with our wider health and social care network to be a part of the solution to the national gap in transition services as it emerges. In the meantime, we will develop strong links with all adult hospices in the region, identifying ways in which young people can start to engage and access support from adult hospice services.
- Leads the way in continuing to treat each child as an individual throughout their life and deliver care in a way which is right for them as they become young adults.

Chestnut Tree House is part of a broader health and social care system, in which children and young people with life-limiting conditions are cared for by a blend of Universal Services, Core Palliative Care Services, and Specialist Palliative Care Services (see figure 3.4). We envisage a future Chestnut Tree House which operates seamlessly across all three layers and which enables us to increase the reach of our care to more children and families, as well as maintain financial sustainability. To do so, we need to be **flexible, innovative, and forward-thinking**.

Working collaboratively with our partners will be essential to our success in enacting change across the system and will enable children, young people and their families to have choice, control, and equity in their care.<sup>12</sup>

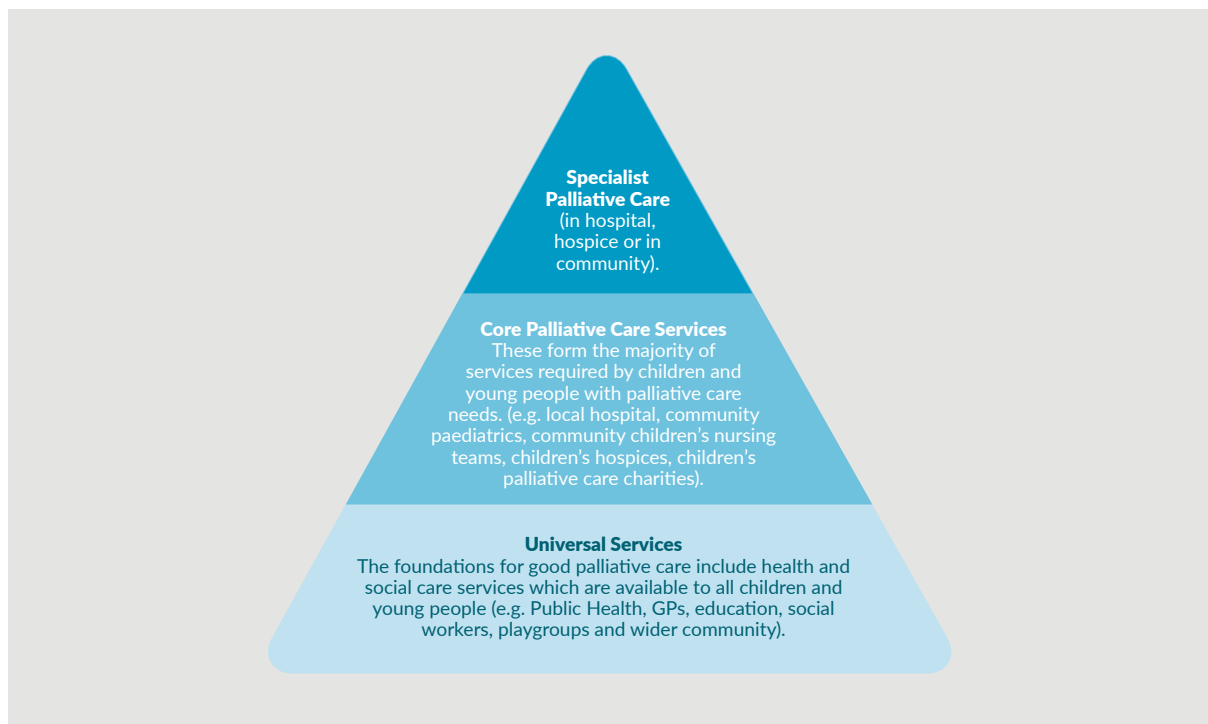


Figure 3.4: The Palliative Care System for children and young people with life-limiting conditions:

The next chapter describes our new model of care and how we will work to ensure that the needs of more children, young people, and their families across the region are met.

<sup>12</sup> A recent report from NHS England has highlighted the need for integrated working between services to provide seamless care and to ensure that the health, wellbeing, emotional, social and spiritual needs of children, young people and their families are met. NHS England, 'Specialist palliative and end of life care services: Children and young people service specification' (18 January 2023).

## 4. A new Chestnut Tree House Model of Care

Our new model of care prioritises **need, flexibility and inclusivity**. It enables us to respond to **medical complexity**, develop **transition services**, and improve **equity of access** to our services across the area. We will move away from a fixed offer of care for children who meet our medical referral criteria, to prioritising capacity based on assessed need so that we can reach as many children and families as possible. Children and their families will receive a tailored care package, from supportive through to comprehensive, which will be tailored to the child and family's needs, dependencies, and support networks. We will increase our outreach and activities so that children and young people can access inclusive events and make memories. And we will lead the way in developing a highly-skilled paediatric palliative care workforce.

Our new offer of care is based on **four key branches**:



Figure 4.1: The new CTH Model of Care

Under our previous model, all children who meet our medical criteria and come onto our caseload are entitled to a standard offer which includes 14 nights of in-house care a year; monthly community visits of 4-6 hours; and access to our activities, outreach, therapies, and family counsellors. However, we know that not only are we reaching less than 7% of children and young people with life-limiting conditions in our catchment area, but we know that this approach is not sustainable.

Under the new model, children and their families will receive a bespoke care package tailored to their needs, dependencies, and support networks, building upon the service branches according to medical and care complexity:

1. The new **LEAF service** will form the baseline of all our care offers. It provides opportunities for families to come together to form support networks; events for all family members; a comprehensive activities programme for children and young people; and access to our fully accessible facilities (i.e. the hydrotherapy pool) for all on our caseload, including those aged 18-25.
2. Building on this, all those on our caseload can access our **Child and Family Support** branch where they will be able to access social workers, specialist therapeutic support and person-centred spiritual support.
3. As medical and care complexity increases, we will build our offer to include short break **Community Care** visits for those children and families with the most complex clinical and social needs. A flexible approach will be adopted, moving away from a set number of hours of care, allowing key workers to work responsively to the needs of children and families.
4. **In-House Care** will be offered to children and young people with the highest level of clinical complexity and challenging behaviour. Many children and young people will be able to access a higher number of nights throughout the year than currently offered. Those with fewer care needs and who are experiencing stability with their condition will not be offered in-house care, leading to increased availability of bed nights to be targeted at those most in need and to support crisis care.

The following pages explain in detail each branch of the new model of care. They describe our objectives for service delivery over the next five years, the key features of each branch, the benefits to our most important stakeholders, and how we will measure our impact and success by 2028.

## Liaison, Engagement, Activities and Families (LEAF)

The **LEAF service** (Liaison, Engagement, Activities and Families) is a new branch of care and supports the child and young person, as well as their whole family, in a holistic way. This branch will form the baseline of all our care offers for children, young people and their families.

We recognise the burden of care that our children and young people experience and their need and desire to socialise with their peers and participate in fun and accessible activities. We also acknowledge the important role of the extended family in the care of a child or young person with a life-limiting condition and the difficulties they face. Through this branch, and the implementation of a lead nurse in engagement, a comprehensive programme will provide opportunities for families to come together to socialise, share experiences and address the social isolation that is being experienced.

Initial scoping projects have identified how families use these opportunities to form support networks for each other and consequently are building resilience within the community. The expansion of the activities team will support a comprehensive activities programme and our fully accessible facilities will provide accessible events across three counties supporting children to have fun – adding life to shortened years.

### Key features

- Engagement events will be run at Chestnut Tree House and across the counties for all family members recognised in the paediatric palliative care pathway, including parents, grandparents and siblings. These include opportunities to socialise, such as cheese and wine evenings and coffee mornings; and specific groups to support families at the different stages of their journey with us, such as bereavement groups.
- These engagement activities and events will also provide opportunities to gain feedback from service users and work together to codesign future events and services.
- Activities will be provided at Chestnut Tree House and across the three counties to ensure equity of provision. A programme of regular activities will include groups for different ages and will be delivered for children, young people and their siblings at times that suit family needs, including activities for younger children in the daytime; and after school, weekend and school holiday activities. A holiday programme will also be implemented, offering family days, sibling days, and fun days for our children and young people.
- Four new activity coordinator roles will be introduced to the team to support activities and the engagement work stream. These roles will be located across the three counties, allowing the activity coordinators to build up connections with the whole family and create relevant activity programmes for children and families in the area in which they work.
- The hydrotherapy pool will be used to full capacity supporting therapeutic swims. Opportunities will be provided for families to book evening and weekend swims, and the pool will be available to those on a transition caseload aged 18-25 years.
- The accessible grounds, woodland walk and playpark will be available to all families on the caseload to use without needing to be staying at Chestnut Tree House. The fully inclusive facilities will enable us to reach more children, young people and families, making life more accessible for them.

## Benefits

<p><b>For children with life-limiting conditions and their families:</b></p> <ul style="list-style-type: none"><li>• Make memories and add life to shortened years through fun, social and inclusive activities with other children.</li><li>• Children and young people are supported to make decisions, gain independence and have choice.</li><li>• Parents and carers have opportunities to meet others in similar situations and form support networks.</li><li>• Children and families are supported with specific issues with the introduction of support groups, such as bereavement and transition.</li><li>• Children, young people and their families are supported with their wellbeing.</li><li>• The increased opportunities to connect with families and children will provide more opportunities for children and families to provide feedback and help co-design services.</li><li>• The new activities roles will support activities for the whole family. Relationships will also be built with the whole family unit and the activity coordinators will support family liaison and signposting children and their families to other support.</li></ul>	<p><b>For our workforce:</b></p> <ul style="list-style-type: none"><li>• An increase and investment in activities will enable us to reach a higher number of children and families. Providing a comprehensive outreach programme will allow children to be supported holistically by activities, thus reducing reliance on clinical staff. This will allow clinical care to be targeted to those children with the highest level of clinical complexity and care needs.</li><li>• New and innovative activities roles and a period of transformation and growth at Chestnut Tree House will provide our staff with increased job satisfaction and the potential to identify new ways of working.</li></ul>
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#### For our communities:

- Bringing together parents and carers will enable the development of supportive relationships and support networks within the community, therefore providing another layer of support and resilience within the community setting.
- With the four new roles supporting across the region, a programme of activities and engagement events will be able to be offered closer to children's homes, therefore providing equity of access and allowing more children and young people across the region to access an activities programme.
- Activities will be adapted to meet the needs of those who find it harder to access hospice facilities and who are less visible to our service.

#### For our partners:

- Providing increased support in the community will reduce isolation and thus dependence on other partner services.
- The increased connection with children, young people and their families will allow for earlier identification of need and periods of difficulty which we can work responsively to support.
- Chestnut Tree House will take an active role in signposting families and children to other services, enabling children and families to manage living with a life-limiting condition in the community.
- By becoming more visible in the community and working proactively to reduce poor physical and mental health in children, young people and their families, we will reduce demands on the acute services.
- We will lead asset-based mapping across the three counties and compile information on behalf of partner services, meaning that Chestnut Tree House staff will be able to signpost families to bespoke support packages in their local community.





“

**We've met amazing animals, a bubble-pop man, been to a medieval day, made some furry friends – Zac loves it, the boys love it, and we just love watching them all make amazing memories together.”**

Dawn, Zac's mum



## Our measures of success

### By 2028...

- We will have increased the number on our caseload through increased reach and engagement with those children and families who are reluctant, afraid to use traditional hospice care, and are less visible to our service.
- We will have rolled out a full programme of activities across the three counties for children, young people, parents/carers and grandparents, providing activities at times that suit families' needs.
- We will have increased our connections and collaborative working with our partners across health, social care and education.
- We will have implemented a transition caseload for 18-25 year olds who can access appropriate activities and engagement events.
- We will have developed systems to ensure 18-25 year olds on our transition caseload can access Chestnut Tree House facilities, including the sensory room, hydrotherapy pool and our inclusive outdoor spaces.
- Through our liaison work, we will better understand and have built trust with the different and less visible communities that we serve. As a result, communities' understanding of and access to hospice care and the services of Chestnut Tree House will be greatly improved.
- We will be seen as the convener of children's palliative and end of life care in the region, building resources of available support in the community.



## Child and Family Support Branch

All children on our caseload will benefit from access to our **Child and Family Support branch** to support their emotional and spiritual wellbeing, and that of their family. Learning that a child has a life-limiting illness is distressing. Following a referral, the child and family support team will provide specialist person-centered support which is uniquely tailored to the child and family's emotional, social, and spiritual needs.

The child and family support team will be available to every child on the caseload and the introduction of a paediatric pastoral lead role to the team will ensure the pastoral care and spiritual needs of children and young people are addressed. Furthermore, whichever form of support is needed, the team will strive to be inclusive and offer various ways in which the support can be accessed. Support will be offered via the telephone, video link and face to face. Specific support such as language interpreters will be offered, and we will work with individuals to resolve any other barriers to accessing the service.

### Key features

- All children and young people on our caseload, including those staying at Chestnut Tree House, will be able to access specialist support such as music, art and play therapy.
- The offer will also include counselling and emotional support for children and young people, their siblings and parents, as well as access to spiritual support. Whether it be offering support to enable specific rituals surrounding end of life and other significant life events; providing a space where children and families can explore emotional and spiritual concerns; or working with the multi-disciplinary team to ensure that the spiritual, religious and cultural values of each child and family are accommodated as closely as possible. Spirituality is often extremely personal and unique to each person, and whether individuals describe themselves as religious or not, it can be a deeply spiritual time, both for the child and the family.
- The child and family support team will liaise with schools, GPs and other community groups to offer advice and support for children and young people.
- Social workers will provide practical and emotional support tailored to the needs of the child, young person and family. This will range from supporting with specific issues such as education, housing and carer concerns; to helping coordinate aspects of care; supporting transition to other services; or simply providing a listening ear. Social workers will further work with families to develop holistic assessments, which reflect the psychosocial needs of family members and help navigate the systems around them.

## Benefits

### For children with life-limiting conditions and their families:

- Families are supported to navigate the trajectory of a child's life-limiting condition in a holistic way.
- Children have the opportunity to talk about their worries and concerns, and they are supported through both pastoral and spiritual care to develop a range of skills to manage their condition and the challenges this brings.
- Families are supported fully in bereavement: from funeral planning through to longer-term support, including for example individual and group therapy sessions.
- Remembrance events provide opportunities to remember their children.
- With a new transition caseload, young people are guided through this difficult period with therapeutic support.

### For our communities:

- Families are supported to manage within their community by signposting to other support services within local communities.
- Through offering resources and advice, schools can support the emotional and mental wellbeing of children with life-limiting conditions.
- By working with spiritual leaders in the community, we will be able to develop a culturally sensitive outreach and support.

### For our partners:

- Partners will have a wider range of referral options into the Chestnut Tree House service.
- A reduced demand on therapeutic provision in community services.
- Providing options for therapeutic support in areas where there is no other therapeutic support for families.



## Our measures of success

### By 2028...

- We will have implemented a comprehensive therapeutic programme for children and young people in-house and in the community.
- We will be providing equity of service provision across the counties.
- We will have developed a comprehensive programme of support for children and young people, their siblings, parents and grandparents.
- All Chestnut Tree House services will work seamlessly together, ensuring a truly collaborative service provision. One example is the Child and Family Service providing therapeutic support to the youth group run by the Activities Team.
- We will have implemented a comprehensive programme for parents to access a range of support.
- We will have implemented a programme of targeted support for young people and their parents during the transition period.
- All new referrals to our caseload will be introduced to the Child and Family Service at the start of their care to ensure they are able to access the full range of support at every step of their journey.
- We will have recruited a dedicated Paediatric Pastoral & Spiritual Lead.
- We will have developed active connections with spiritual leaders in the community.

## Community Care Branch

As medical and care complexity increases, we will build our offer to include short break community visits as part of the **Community Care Branch** for those children and families with the most complex clinical and social needs. A flexible approach will be adopted, moving away from a set number of hours of care, allowing key workers to work responsively to the needs of children and families that may fluctuate over time.

### Key features

- The child will be allocated a key worker, a community nurse or care support worker who will provide a respite visit in the home or take them out for the day in the community.
- The Community Care package will be bespoke and tailored to need, meaning that not all children and young people will receive community care if this is not required for their particular needs.
- Community nurses also work in liaison roles with the acute and community sector, increasing the awareness of our services and referral criteria.

## Benefits

<p><b>For children with life-limiting conditions and their families:</b></p> <ul style="list-style-type: none"><li>• Care at home makes a difference to children and their families as this is often where they feel most comfortable.</li><li>• A key worker establishes a professional relationship with the family, allowing for identification of need and tailoring the support where it is required. Through this relationship, the key worker is able to advocate for the child at key points, i.e. multidisciplinary team meetings.</li><li>• Respite visits at home or outings in the community mean making memories and having fun. These important visits also support parents and carers to either have a break, go out, or spend time with the child's siblings.</li><li>• Community care also supports 24/7 end of life nursing care, allowing children and their families the choice to have end of life care at home. The care that is provided is wraparound: supporting symptom control and providing emotional and spiritual support.</li></ul>	<p><b>For our workforce:</b></p> <ul style="list-style-type: none"><li>• Chestnut Tree House will provide 24/7 nursing support during end of life care, which is often in collaboration with children's community nursing teams. Sharing this role and on call between the teams supports staffing demands across the workforce and reduces pressure on existing services.</li><li>• In East Sussex, respite provision in the home can be shared with another children's hospice. The sharing of resources and skill mix of staff between two hospices increases the resilience of the workforce and provides an excellent service for children and their families.</li><li>• The Chestnut Tree House community team supports palliative care teaching in the acute and community sectors, thus enhancing the knowledge and skills of the wider workforce.</li></ul>
<p><b>For our communities:</b></p> <p>Working in liaison roles across the counties, our community nurses are raising important awareness of our services and referral criteria. This will support the increased identification of children and young people who may benefit from palliative care services.</p>	



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**When Maisy-Leigh is with Amie [her key worker], we have a few hours to just be Hayleigh and Luke. Chestnut gives us the time and strength we need to carry on, so we can be the best team for our daughter.”**

Hayleigh, Maisy-Leigh's mum



## In-House Care Branch

In-house short breaks will be offered to those children and young people with the highest level of clinical complexity and challenging behaviour. Many children and young people will be able to access a higher number of nights throughout the year than currently offered. However, children and young people who have fewer care needs and are experiencing stability with their condition and symptoms will not be offered standard in-house respite care. This will lead to increased availability of bed nights to be targeted at those most in need and to support crisis care.

### Key features

- In-house care will provide families with important respite provision. Children and young people can stay on their own at Chestnut Tree House, giving families a break from care.
- The whole family is also welcome to stay at the hospice for a break where they can take part in inclusive activities, have fun, and make cherished memories.
- There will not be a standard number of allocated nights given to each child and young person. Instead, an offer of care will be allocated to the family for one year which will be reviewed annually, or sooner if circumstances change significantly. This will allow for a more flexible and responsive offer to be made to families, which is bespoke and needs-based.

### Benefits

<p><b>For children with life-limiting conditions and their families:</b></p> <ul style="list-style-type: none"><li>• Short break respite provision provides children and young people with opportunities that they may not otherwise have to spend time with other children, to have a break themselves, and to gain independence.</li><li>• Whilst staying in house, children and young people will be supported to make decisions about their care, and to plan activities and outings.</li><li>• Access to inclusive and accessible activities whilst staying at the hospice, such as the hydrotherapy pool, sensory room, and outdoor playpark.</li><li>• Children are able to socialise and gain confidence from being with other children and young people.</li><li>• Gives families a break; time to recharge, and spend time with siblings. These breaks can provide a valuable lifeline in supporting families to cope with and manage their child's condition.</li></ul>	<p><b>For our partners:</b></p> <ul style="list-style-type: none"><li>• Chestnut Tree House wants to work collaboratively with partners to ensure our resource is targeted to the right child and young person, and at the right time. In-house care can support some acute providers with earlier discharge, step down care, or to provide end of life care.</li><li>• We will work with social care and continuing care commissioners to develop care packages for the most complex children and where possible, to support crisis care.</li></ul>
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## Our measures of success

### By 2028...

- We will ensure those with the highest level of clinical complexity and care needs can access in-house care when they need it the most.
- We will maximise our occupancy for these children by extending our capacity, continuing to run at a high level of bed occupancy.
- We will have developed care packages that suit children and young people, and their families' needs.
- We will support increased funded nights provision.
- We will support an increased number of step down care.
- We will have more flexibility to provide crisis care.



## 5. Delivering our Care Strategy 2023/24

This strategy was shaped by the views of the children, young people and families for whom we provide care, as well as our professional partners and staff. We will deliver our new Care Strategy in the same inclusive way, ensuring that we engage with everyone who is impacted by our new Model of Care at every stage of the implementation process.

Our Care Strategy will be delivered in three stages during the first year:

**1**

We will improve our support to children, young people and their families by building capacity for activities and spiritual support as part of the LEAF and Child & Family Support branches of care.

**2**

During 2023/24 we will review the medical model of care by undertaking a scoping exercise with partners in the healthcare system.

**3**

We will work with families and undertake a programme of continuous engagement to understand the impact of the changes we have introduced as part of our new model of care.

