

## Shooting Star Children's Hospices

# Christopher's Children's Hospice

### Inspection report

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This report describes our judgement of the quality of care at this service. It is based on a combination of what we found when we inspected, information from our ongoing monitoring of data about services and information given to us from the provider, patients, the public and other organisations.

### Ratings

#### Overall rating for this location

Outstanding 

Are services safe?	Good 
Are services effective?	Good 
Are services caring?	Outstanding 
Are services responsive to people's needs?	Outstanding 
Are services well-led?	Outstanding 

# Summary of findings

## Overall summary

Our rating of this location stayed the same. We rated it as outstanding because:


- Staff treated children and young people with compassion and kindness, respected their privacy and dignity, and helped them understand their conditions. They provided emotional support to children and young people, families and carers and went above and beyond what was expected to provide support. Children, young people and families were truly respected and valued and empowered as partners in their care. Staff were highly motivated and inspired to provide care that is kind and promotes dignity. Staff found innovative ways to meet the totality of children, young people and their family's needs. Children, young people and families were active partners in their care and staff empowered them to have a voice and realise their potential.
- The service planned care to meet the needs of local people, took account of children and young people's individual needs, and made it easy for people to give feedback. People could access the service when they needed it and did not have to wait too long for treatment. There were innovative approaches to providing integrated person-centred pathways of care that involve other service providers.
- Leaders ran services well using reliable information systems and supported staff to develop their skills. Staff understood the service's vision and values, and how to apply them in their work. Staff felt respected, supported and valued. They were focused on the needs of children and young people receiving care. Staff were clear about their roles and accountabilities and committed to improving services continually. There were consistently high levels of constructive engagement with children, young people and their families. Services were developed with the full participation of those who use them, staff and external partners as equal partners. The service took a leadership role in its health system to identify and proactively address challenges and meet the needs of the population.

We also found the following areas of good practice;

- The service had enough staff to care for children and young people and keep them safe. Staff had training in key skills, understood how to protect children and young people from abuse, and managed safety well. The service controlled infection risks well. Staff assessed risks to children and young people, acted on them and kept good care records. They managed medicines well. The service managed safety incidents well and learned lessons from them.
- Staff provided good care and treatment, gave children and young people enough to eat and drink, and gave them pain relief when they needed it. Managers monitored the effectiveness of the service and made sure staff were competent. Staff worked well together for the benefit of children and young people, advised them and their families on how to lead healthier lives, supported them to make decisions about their care, and had access to good information. Key services were available seven days a week.

# Summary of findings

## Our judgements about each of the main services

Service	Rating	Summary of each main service
Hospice services for children	Outstanding 	Our rating of this service stayed the same. We rated it as outstanding. See the summary above.

# Summary of findings

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# Summary of this inspection

## Background to Christopher's Children's Hospice

Christopher's Children's Hospice is provided by Shooting Star Children's Hospices, which is a registered charity caring for babies, children and young people with life-limiting conditions, and their families. Christopher's Children's Hospice provides support from babies to young people up to the age of 21, they support families from diagnosis to end of life and throughout bereavement with a range of nursing, practical, emotional and medical care. Their care service includes overnight short breaks, family support, day care, symptom management, end-of-life care, bereavement care and a comprehensive range of therapies and support groups for the whole family.

The hospice is a multidisciplinary led service and children and young people's health needs are met by a range of health professionals during their stay. This includes specialist children's nurses, a medical director, clinical fellow, a physiotherapist, social workers, counsellors, therapists and the care team.

The hospice has nine rooms for children and young people and five flats for family members to stay.

At the time of the inspection the hospice cared for five children and young people within the unit.

The head of hospice services was in the process of applying to be the registered manager.

The service is registered with the CQC to provide:

Treatment of disease, disorder and injury

## How we carried out this inspection

We visited the unit and spoke with staff delivering services. We observed a home visit by the specialist paediatric palliative care (SPACE) team and interviewed staff working in the family support team. We held interviews with service leads and executives. We spoke with 17 staff and volunteers including registered nurses, support staff, catering staff, housekeeping and facilities staff, reception and non-clinical staff. We also spoke with one young person and two relatives who were receiving support from hospice staff. We also received written feedback from a relative who had been unable to speak to us during the inspection. We observed care and treatment provided in the unit, reviewed data about the service and reviewed nine patient care records.

We undertook this inspection as part of a random selection of services rated Good and Outstanding to test the reliability of our new monitoring approach. We previously inspected Christopher's Children's Hospice in 2016 using our adult social care framework. This was the first inspection of the hospice using our healthcare framework.

You can find information about how we carry out our inspections on our website: <https://www.cqc.org.uk/what-we-do/how-we-do-our-job/what-we-do-inspection>.

# Our findings






## Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
Hospice services for children	Good	Good	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>
Overall	Good	Good	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>



# Hospice services for children

Safe	Good 
Effective	Good 
Caring	Outstanding 
Responsive	Outstanding 
Well-led	Outstanding 

## Are Hospice services for children safe?

Good



Our rating of safe stayed the same. We rated it as good.

### Mandatory training

**The service provided mandatory training in key skills to all staff and made sure everyone completed it.**

The mandatory training was comprehensive and met the needs of children, young people and staff. Training included paediatric and adult basic life support, fire safety, infection control, moving and handling, data protection and health and safety. Clinical staff completed training on recognising and responding to children and young people with mental health needs, learning disabilities and autism.

Managers monitored mandatory training and alerted staff when they needed to update their training. In-house clinical staff training compliance was a 94%. For community staff compliance was at 100% and for the family support team it was at 96%. Managers monitored training compliance using a spreadsheet and this was reviewed by the clinical governance lead, with action plans developed where issues with compliance were identified.

### Safeguarding

**Staff understood how to protect children, young people and their families from abuse and the service worked well with other agencies to do so. Staff had training on how to recognise and report abuse and they knew how to apply it.**

Staff received training specific for their role on how to recognise and report abuse. This included training up to level three for both child and adult safeguarding for care staff. Safeguarding leads were trained up to level four. Safeguarding training compliance was high. Compliance for in-house clinical staff was at 94%, for community staff it was at 100%.

Staff could give examples of how to protect children, young people and their families from harassment and discrimination, including those with protected characteristics under the Equality Act. Staff understood their responsibilities and there were clear safeguarding procedures. Staff understood who the safeguarding leads were and how to seek advice.



# Hospice services for children

Staff knew how to identify adults and children at risk of, or suffering, significant harm and worked with other agencies to protect them. The hospice had a safeguarding team, led by the head of hospice services and included the hospice social workers. There were clear reporting processes and criteria that included alerting the safeguarding team within an hour and completing a written form by the end of the shift.

Staff knew how to make a safeguarding referral and who to inform if they had concerns. There were ongoing audits of safeguarding processes to ensure compliance. Results showed there had been improvements in reporting and record keeping compliance. For example, in June 2021 compliance had been at 65% in relation to record keeping, this improved to 92% by March 2022.

Staff followed safe procedures for children visiting the ward.

## Cleanliness, infection control and hygiene

**The service controlled infection risk well. Staff used equipment and control measures to protect children, young people, their families, themselves and others from infection. They kept equipment and the premises visibly clean.**

Ward areas were clean and had suitable furnishings which were clean and well-maintained. The hospice was free from clutter and visibly clean.

The service generally performed well for cleanliness. An annual infection control audit included monitoring of cleanliness and was carried out with clearly identified actions for improvement when necessary.

Cleaning records were up-to-date and demonstrated that all areas were cleaned regularly. Each room or area within the hospice had a dedicated cleaning schedule and we saw that these were completed and indicated that cleaning had been completed. Shared areas, such as soft play were cleaned in between use.

Staff followed infection control principles including the use of personal protective equipment (PPE). We observed staff using PPE appropriately, including donning and doffing. Staff wore face masks appropriately in line with Covid-19 guidance. Monitoring of the use of PPE was part of the hospice's hand hygiene audit which was carried out every three months and an annual infection control audit.

Staff cleaned equipment after patient contact and labelled equipment to show when it was last cleaned.

## Environment and equipment

**The design, maintenance and use of facilities, premises and equipment kept people safe. Staff were trained to use them. Staff managed clinical waste well.**

Children, young people and their families could reach call bells and staff responded quickly when called. Staff were seen to respond quickly to calls for assistance and children were closely observed.

The design of the environment followed national guidance. Processes for managing the environment included regular maintenance checks and upkeep of the premises. There were environmental risk assessments regularly carried out and a dedicated team of facilities / maintenance staff responsible for addressing environmental risks and maintenance.





# Hospice services for children

Staff carried out daily safety checks of specialist equipment. For example, emergency equipment was checked daily. Other specialist equipment such as hoists, assisted baths, clinical equipment and wheelchairs were subject to a regular preventative and reactive maintenance programme.

The service had suitable facilities to meet the needs of children and young people's families. This included the use of a swimming pool and there were appropriate risk assessments and mitigating actions in place for this. For example, daily water checks and monthly bacteriological testing, safety training for staff and volunteers and preventative maintenance. Staff and volunteers had received training in keeping children and young people safe while in the pool. Other facilities included individual bedrooms, family rooms, a sensory room and appropriate washing facilities that enabled children and young people to maintain their independence as much as possible.

The service had enough suitable equipment to help them to safely care for children and young people. For example, there were hoists in individual rooms and safety beds for children and young people who experienced seizures. Staff received training in the use of equipment as part of their induction and annual training updates.

Staff disposed of clinical waste safely. Waste was stored securely and there were appropriate segregation procedures. Waste was appropriately labelled, and bins were regularly changed.

## Assessing and responding to patient risk

**Staff completed and updated risk assessments for each child and young person and removed or minimised risks. Staff identified and quickly acted upon children and young people at risk of deterioration.**

Staff used recognised risk assessment processes and tools to identify children or young people at risk of deterioration and escalated them appropriately. This included assessment of pressure areas, nutrition, falls risk and seizures. The practice education team also worked with a local university to develop a half day training course for clinical staff on the recognition and action to meet the needs of deteriorating children and young people. The course included the use of a simulation doll to support the use of scenarios for learning. At the time of the inspection approximately 70% of staff had completed this training.

Staff knew about and dealt with any specific risk issues. Staff had received training in recognising and dealing with sepsis. They had also received training in basic life support and managing seizures. Children and young people with specific risks had individual care plans with agreed escalation plans. In an emergency staff called 999 and the child or young person was transferred to the local acute NHS trust.

Staff completed, or arranged, psychosocial assessments and risk assessments for children or young people thought to be at risk of self-harm or suicide.

Staff shared key information to keep children, young people and their families safe when handing over their care to others. Daily safety huddles were held on the unit and information about safety risks was shared and discussed among team members to ensure that clear and up to date information was shared across the clinical team. Huddles were held with varying frequency in other departments, for example, the specialist palliative care (SPACE) team held bi-weekly huddles and the family support team held them weekly.

Shift changes and handovers included all necessary key information to keep children and young people safe.



# Hospice services for children

## Nurse staffing

**The service had enough staff with the right qualifications, skills, training and experience to keep children, young people and their families safe from avoidable harm and to provide the right care and treatment. Managers regularly reviewed and adjusted staffing levels and skill mix and gave bank staff a full induction.**

The service had enough nursing and support staff to keep children and young people safe. Children and young people receiving in-patient care, received care on a minimum of a one to one basis and additional care needs were assessed on an individual basis. This included a ratio of two staff to one child or young person when behaviour or manual handling needs required it. The service had a minimum of two qualified paediatric nurses on shift, with more on during the day. On the day of inspection there were five staff caring for four children and young people. This included three paediatric nurses and lead nurse cover.

Managers accurately calculated and reviewed the number and grade of nurses, nursing assistants and healthcare assistants needed for each shift, in accordance with national guidance. Senior staff could adjust staffing levels daily according to the needs of children and young people. At the time of the inspection the service had enough staff to safely care for six children or young people on the unit. Service leads monitored staffing and identified potential gaps in advance, for example, where they knew that staff were leaving or on leave.

The number of nurses and healthcare assistants matched the planned numbers. There was additional flexibility built into the rota for changes in individual needs and dependency. The hospice had a bank of flexible staff who could provide additional cover. In addition, the service had recruited a paramedic with appropriate skills to work within the in-patient service.

The service had nurse vacancies of 1.6 whole time equivalent (WTE) and healthcare assistant vacancy of 2.5 WTE. Recruitment was ongoing and we saw that a new member of the nursing team was due to start in the coming months.

The service had a clinical on-call system from 5pm to 9am every night. This provided expert senior cover to the unit staff for advice as needed. In addition, the community service provided a 'silent' on call service. This was only activated as needed, usually when a child in the community was receiving end of life care and had a syringe driver in place (providing continuous medicine through a pump to ensure that the comfort of the child or young person was maintained).

## Medical staffing

**The service had enough medical staff with the right qualifications, skills, training and experience to keep children, young people and their families safe from avoidable harm and to provide the right care and treatment. Managers regularly reviewed and adjusted staffing levels and skill mix and gave locum staff a full induction.**

The service had enough medical staff to keep children and young people safe. The hospice had a clinical director in a substantive post who was a paediatric palliative care consultant and based at the hospice two days a week. In addition, a clinical fellow (senior doctor) worked at the hospice five days a week and was directly employed by the hospice.

The service always had a doctor on call during evenings and weekends. They had a contract with a local GP practice to provide day to day medical cover as needed. GPs were on call through the day and overnight. They visited children and young people staying at the hospice as required and provided telephone support as appropriate.



# Hospice services for children

## Records

**Staff kept detailed records of children and young people's care and treatment. Records were clear, up-to-date, stored securely and easily available to all staff providing care.**

Patient notes were comprehensive, and all staff could access them easily. Records were accessed through the hospice's record system. Staff had individual access with a two step authentication process to ensure security. Records were stored securely. Paper records were in use and were stored in a dedicated locked room that was only accessible to staff with the authority to access them.

When children and young people transferred to a new team, there were no delays in staff accessing their records. All hospice care staff could access individual care records across departments.

## Medicines

**The service used systems and processes to safely prescribe, administer, record and store medicines.**

Staff followed systems and processes to transcribe and administer medicines safely. Medicines were brought in by families and recorded on medicines administration records (MAR). These medicines had previously been prescribed and were checked by staff to ensure they were suitable for continued use. This process was risk assessed and a second nurse check occurred for children who required it. A parent or guardian also signed the MAR chart. The visiting GP prescribed any additional medicines that the child or young person required.

Staff checked routinely with parents that children and young people had their correct medicines when they were admitted, but full medicines reconciliation was not embedded within the service. Medicines were not routinely cross checked with the information held by the child's GP to ensure the child's medicines were all correct. This had already been identified by the service as a risk. Quality improvement work was already underway to ensure medicines reconciliation was in line with NICE guidance.

Staff completed medicines records accurately and kept them up to date. Instructions for the administration of medicines on the MAR chart were clear, safe and child centred so that each member of staff knew exactly how to give a medicine. Where medicines involved administration by feeding tube, staff accessed recognised national references sources to ensure this was done safely. If a child had more than one feeding tube, there were clear instructions about which medicines to give by which feeding tube. A MAR chart audit was completed quarterly.

Staff followed children's medicine care plans which were detailed and individualised with clear step wise treatment escalation to be able to respond to symptoms. However, we found that one medicine included in a care plan was not prescribed and was not available. The service spoke with the family during our inspection and assured us that the care plan would be updated.

Timings were adjusted appropriately to allow the young person to take their medicine at a time that suited them. Medicines were not used to control behaviour.

At discharge the person's medicines and a letter detailing any changes was being provided to families. This was developed in response to a family survey on communication and families expressing a wish to have more information about what had happened during the child's stay.



# Hospice services for children

A separate discharge letter was being sent to the child's regular GP to inform them of any changes that had taken place whilst under the care of the hospice

Staff stored and managed all medicines and prescribing documents safely. There was no recording of the room temperature where medicines were stored. Emergency medicines were available should they be required to treat anaphylaxis. Although the dose of adrenaline available did not match the current policy, but this was rectified immediately after our inspection.

Young people who received medicines through patches on the skin were monitored closely. This included checking the patch remained in place, was removed when a new one was applied and the site of application rotated. Staff also checked whether the patch was adequately controlling pain or secretions and whether the young person had any adverse effects from the use of the patch.

There was a procedure in place to allow young people to be involved in the administration of their medicines if they wished, but currently no one had chosen to be involved in administering medicines in this way.

Staff learned from medicine safety alerts and incidents to improve practice. Staff reported medication incidents which were reviewed by medicines management group and we saw evidence that actions had been completed. Learning was shared with hospice staff by a Safety and Learning newsletter.

The hospice completed medicine audits. The hospice completed medicine audits including looking at the quality of the prescribing and transcribing onto prescription charts and learning from incidents. The service used Help the Hospices toolkits annually for audits in Medicines Management and Controlled Drugs and had identified areas for improvement.

The service had access to a pharmacist for 8 hours per month who was involved in medicine management meetings, incident review and audit.

## Incidents

**The service managed patient safety incidents well. Staff recognised and reported incidents and near misses. Managers investigated incidents and shared lessons learned with the whole team and the wider service. When things went wrong, staff apologised and gave children, young people and their families honest information and suitable support. Managers ensured that actions from patient safety alerts were implemented and monitored.**

Staff knew what incidents to report and how to report them. There was an electronic reporting system in place, and we saw that a range of incidents had been reported. Staff understood their responsibilities in reporting incidents and near misses.

Staff understood the duty of candour. They were open and transparent, and gave children, young people and their families a full explanation when things went wrong. Managers investigated incidents thoroughly. Children, young people and their families were involved in these investigations as appropriate.

There was evidence that changes had been made as a result of feedback. This included improvements to care planning in relation to child behaviour following concerns/incidents raised. A quarterly safety and learning newsletter was produced, summarising learning and improvement priorities. In addition, we saw that safety data displayed within the unit showed the top three safety risk areas as a result of reporting. This included the risk of pressure ulcers, medicines incidents and issues with equipment. We saw that individual incidents had been appropriately addressed. In addition,



# Hospice services for children

there were agreed identified actions to ensure ongoing improvements. This included amendments to annual medicines training and competency assessments to reflect learning from incidents. Also, learning around pressure area care and increased risks for the children and young people being cared for was discussed and shared across the team. Forums for this included daily safety huddles.

Managers took action in response to patient safety alerts within the deadline and monitored changes. Managers debriefed and supported staff after any serious incident.

## Are Hospice services for children effective?

Good



Our rating of effective stayed the same. We rated it as good.

### Evidence-based care and treatment

**The service provided care and treatment based on national guidance and evidenced-based practice. Managers checked to make sure staff followed guidance. Staff protected the rights of children and young people subject to the Mental Health Act 1983.**

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. Care and treatment were evidence-based, and staff managed end of life care in accordance with the National Institute of Health and Care Excellence guidance NG61 (End of life care for infants, children and young people with life limiting conditions). Staff followed policies based on guidance in 'Together for short Lives'; guidance for children and young people who are expected to have short lives. Leads monitored compliance with national guidance and evidenced-based practice as part of their quality and governance arrangements.

The hospice had a research group and identified as a research active hospice. They worked in partnership with other organisations including academic institutions. They ran a regular journal club where research was reviewed to ensure they kept up to date with evidence-based practice.

Staff protected the rights of children and young people subject to the Mental Health Act and followed the Code of Practice.

At handover meetings, staff routinely referred to the psychological and emotional needs of children, young people and their families. This was a central focus of the care provided.

### Nutrition and hydration

**Staff gave children, young people and their families enough food and drink to meet their needs and improve their health. They used special feeding and hydration techniques when necessary. The service made adjustments for children, young people and their families' religious, cultural and other needs.**

Staff made sure children, young people and their families had enough to eat and drink, including those with specialist nutrition and hydration needs. Meals were provided free of charge for all children, young people, their families and visitors.



# Hospice services for children

Staff fully and accurately completed children and young people's fluid and nutrition charts where needed. Staff used a nationally recognised screening tool to monitor children and young people at risk of malnutrition. There were care plans in place that incorporated nutrition and hydration needs. We saw evidence of training for care staff in relation to different aspects of nutrition and hydration, including artificial feeding. Staff involved in the use of artificial feeding methods undertook competency assessments to ensure their practice was up to date and effective.

Specialist support from staff such as dietitians and speech and language therapists was available for children and young people who needed it. Staff closely liaised with other professionals involved in the child or young person's care.

Nursing and catering staff worked together to ensure the cultural and religious needs of children, young people and their families were met in relation to nutrition and hydration. We saw there was a range of food available and catering staff tailored this to meet individual needs.

## Pain relief

**Staff assessed and monitored children and young people regularly to see if they were in pain and gave pain relief in a timely way. They supported those unable to communicate using suitable assessment tools and gave additional pain relief to ease pain.**

Staff assessed children and young people's pain using a recognised tool and gave pain relief in line with individual needs and best practice. We viewed audit results and saw that an issue with incomplete pain assessment records had been identified. An action plan was implemented that included increasing the information about pain assessments being shared among staff on the unit and additional training sessions. Repeat audits were part of the hospice's annual audit plan. We saw that pain assessments were completed appropriately.

Children and young people received pain relief soon after requesting it. In addition, they had access to complementary therapies to help with comfort measures. We viewed feedback from one young person who experienced chronic pain, stating that the therapies helped to relax their muscles and that they were able to create scent sticks with staff by blending aromatherapy oils which improved their sleep.

Staff prescribed, administered and recorded pain relief accurately. When children and young people were approaching the end of life, anticipatory medicines were prescribed to ensure symptoms could be managed as effectively as possible.

## Patient outcomes

**Staff monitored the effectiveness of care and treatment. They used the findings to make improvements and achieved good outcomes for children and young people.**

The service participated in relevant national clinical audits. For example, we viewed a national audit of care at the end of life template that had been completed retrospectively to review the care of two children/young people who had died whilst under the care of the hospice. The audit was in progress and focused on aspects of care such as the recognition of dying, care planning and involvement in decision making. As the audit was in progress, benchmarking results were not available, however, there was evidence of good practice in areas such as involvement in decision making and care planning. Outcomes for children and young people were positive, consistent and met expectations, and in line with national standards.



# Hospice services for children

Managers and staff carried out a comprehensive programme of repeated audits to check improvement over time. Audits included areas such as pain management, advance care planning, consent and records audits. Audit results were collated by the clinical governance lead and reported on quarterly. We saw evidence of audits leading to improvements, particularly around safeguarding processes and we saw evidence of audit results leading to improvement activities with a view to demonstrating improvement later once a repeat audit had been carried out.

Managers used information from the audits to improve care and treatment. Audit results were shared with staff and reviewed in the clinical governance meetings. Managers shared and made sure staff understood information from the audits.

## Competent staff

**The service made sure staff were competent for their roles. Managers appraised staff's work performance and held supervision meetings with them to provide support and development.**

The practice educators supported the learning and development needs of staff. They developed bespoke training programmes in response to identified need. This included specialist palliative care training, enhanced communication and managing challenging behaviour training. They worked collaboratively with other providers to deliver a range of internal and external training. In addition, they had developed a deteriorating child training programme that involved working with actors on scenarios and simulation with the use of a doll that breathed, spoke and simulated pulses. The team worked with the simulation lead at a local university to develop training scenarios for the half day programme. The focus of the training was on communicating with family members as well as clinical decision making and actions.

Staff were experienced, qualified and had the right skills and knowledge to meet the needs of children, young people and their families.

Managers gave all new staff a full induction tailored to their role before they started work. There were structured induction plans for each role that included mandatory training and working shadow shifts.

Managers supported staff to develop through yearly, constructive appraisals of their work. Appraisal rates were 100% across the clinical staff teams. Staff had appraisals booked for the anniversary of their start date and in the first year of employment met with managers to set objectives.

Clinical staff completed competency assessments in specific areas such as medicines, ventilation, enteral feeding. Short session training was provided by the specialist palliative care team in areas such as pain, nutrition and respiratory issues.

Specialist nurses working in the specialist palliative care (SPACE) team included two band six nurses as development posts. The lead for the SPACE team used the Royal College of Nursing (RCN) competencies: Caring for Infants, Children and Young People requiring Palliative Care to support them in their development.

Managers made sure staff attended team meetings or had access to full notes when they could not attend.

Managers made sure staff received any specialist training for their role. All nursing staff completed palliative care training as part of their induction. Specialist training in relation to areas such as ventilation, artificial feeding and tracheostomy emergency care.





# Hospice services for children

Managers identified poor staff performance promptly and supported staff to improve. There were clear performance processes in place and staff were supported to develop their capability within their roles.

Managers recruited, trained and supported volunteers to support children, young people and their families in the service. Volunteer inductions were tailored to the individual roles. These included roles in areas such as care support, gardening and pool safety.

The hospice worked with local universities to support practical placements for student nurses. They had recently undertaken a pilot to expand the capacity for students. This involved a rotational programme through the different departments within the hospice.

## Multidisciplinary working

**Doctors, nurses and other healthcare professionals worked together as a team to benefit children, young people and their families. They supported each other to provide good care.**

Staff held regular and effective multidisciplinary (MDT) meetings to discuss children and young people and improve their care. An MDT was held weekly with involvement from the care leadership team, care service staff, physiotherapist, social workers, the transition coordinator, a children's psychological therapist, a counsellor, family support staff and community symptom control service. The meeting focused on children and young people supported within the hospice and in the community where there were concerns and attendance from across departments enabled a more holistic review of their care. Staff reviewed new referrals after an initial assessment to define what support could be offered. In addition, a multidisciplinary referral meeting was held monthly, which included input from one of the GPs, this was where decisions were made about which children and young people to admit onto the service.

Staff worked across health care disciplines and with other agencies when required to care for children, young people and their families. This included the specialist palliative care (SPACE) team who worked closely with colleagues in neonatal and paediatric intensive care services to deliver specialist care. This included attendance at acute MDT meetings.

Staff referred children and young people for mental health assessments when they showed signs of mental ill health, depression.

## Seven-day services

**Key services were available seven days a week to support timely patient care.**

The in-patient unit was open seven days a week and community specialist palliative care services were available seven days a week, including through an on-call system to support children and young people receiving end of life care in the community.

GPs provided daily medical cover through an on-call rota, including evenings and weekends. They would visit the hospice daily to review children and young people as needed. The hospice had a paediatric specialist palliative care consultant who supported the specialist palliative care nurses and GPs to provide support in terms of symptom management at the end of life.

Staff could call for support from doctors and other disciplines, including mental health services and diagnostic tests, 24 hours a day, seven days a week.





# Hospice services for children

## Health promotion

**Staff gave children, young people and their families practical support and advice to live well until they died.**

Staff worked closely with children, young people and their families, as well as other professionals to maximise health and wellbeing. Care was planned on an individual basis and took account of individual health needs.

Staff assessed each child and young person's health when admitted to the service and provided support for any individual needs to live a healthier lifestyle and support end of life care as appropriate. Staff received training on supporting children, young people and their families in the last year of life. Training included advance care planning to facilitate conversations and involvement of those close to the child/young person.

## Consent, Mental Capacity Act and Deprivation of Liberty Safeguards

**Staff supported children, young people and their families to make informed decisions about their care and treatment. They knew how to support children, young people and their families who lacked capacity to make their own decisions or were experiencing mental ill health.**

Staff understood how and when to assess whether a child or young person had the capacity to make decisions about their care. We viewed care records that demonstrated this, including where involvement of the parents and family in a situation where a young person did not have the capacity to make decisions about their care.

Staff made sure children, young people and their families consented to treatment based on all the information available.

When children, young people or their families could not give consent, staff made decisions in their best interest, taking into account their wishes, culture and traditions. Staff understood the core principles of the Mental Capacity Act (2005) and there was evidence of best interest decision making in line with the act. Staff received and kept up to date with training in the Mental Capacity Act and Deprivation of Liberty Safeguards.

Staff clearly recorded consent in the children and young people's records. This included consent to participate in activities within the hospice such as hydrotherapy and social outings.

Staff understood Gillick Competence (where a young person had sufficient understanding and maturity to enable them to understand fully what is proposed) and supported children who wished to make decisions about their treatment.

Staff understood the relevant consent and decision-making requirements of legislation and guidance, including the Mental Health Act, Mental Capacity Act 2005 and the Children Acts 1989 and 2004 and they knew who to contact for advice.

## Are Hospice services for children caring?



Our rating of caring stayed the same. We rated it as outstanding.



# Hospice services for children

## Compassionate care

**Staff treated children, young people and their families with compassion and kindness, respected their privacy and dignity, and took account of their individual needs.**

Staff were discreet and responsive when caring for children, young people and their families. Staff took time to interact with children, young people and their families in a respectful and considerate way. They demonstrated the highest level of compassion in their interactions. We observed strong interpersonal relationships between young people and the staff caring for them. There were clear bonds and trust had been built to support the children and young people to meet their needs. We observed one young person interacting with their nurse and saw that a deep sense of trust and support had been built between them.

Children, young people and their families said staff treated them well and with kindness. Feedback was consistently positive about the quality of care and support that was offered.

Staff followed policy to keep care and treatment confidential. Staff understood and respected the individual needs of each child and young person and showed understanding and a non-judgmental attitude when caring for or discussing those with mental health needs. Care was personalised and planned with the involvement of the child or young person. Staff understood the need for them to be involved in planning their care to ensure their needs were met. They demonstrated high levels of respect and openness and we observed close bonds that had been developed, including with children and young people with complex needs.

Staff consistently worked together to provide compassionate care tailored to individual needs. They went above and beyond to find ways to comply with children and young people's wishes at the end of life. We were told of numerous examples where staff had arranged outings and experiences for children, young people and their families. For example, staff arranged to take one young person to London on the train, meeting their family so they could have a family day out. The trip was not without its challenges due to mobility and communication issues; however, staff recognised the importance of the trip and were determined to make it happen. A young child unable to fly because of a heart condition wanted to sit in a plane, therefore staff worked with a local light aircraft owner to make this happen. A young person expressed a wish for an 'ice cream van' ice cream, so staff contacted local ice cream merchants and one visited the hospice the same day and supplied ice creams to all children and young people staying at the hospice. Other examples of activities staff organised tailored to individuals included shopping trips, cinema trips, and visits to beauty/nail salons. They also arranged activities within the hospice such as visits from animals, celebrities and entertainers.

Staff understood and respected the personal, cultural, social and religious needs of children, young people and their families and how they may relate to care needs. This included an understanding of care after death and how particular cultural or religious needs impacted this. We saw that staff worked with other services to ensure that these needs were met, for example, in relation to burial within 24 hours. Social and spiritual support services were available, and staff could access staff and volunteers who supported this work.

The hospice regularly held memory days for bereaved families. This provided a safe space for families to join other families in treasuring the memories and life of their child. Three memory days were held a year and families could choose which one to attend. They were provided with refreshments, attended a memorial service and had the opportunity to create a craft in memory of their child. The hospice also offered bereaved families an engraved star or leaf for the memory tree in the memory garden at the hospice and to add a page about their child to the hospice's memory book.



# Hospice services for children

## Emotional support

**Staff provided emotional support to children, young people and their families to minimise their distress. They understood children and young people's personal, cultural and religious needs.**

Staff gave children, young people and their families help, emotional support and advice when they needed it. We observed staff taking time to provide emotional support to families. The hospice had a range of approaches to help children, young people and their families. This included activities such as art, music and drama therapy to work through emotional issues. They provided support sessions and group support for siblings of children and young people who were being cared for by the hospice. They also offered a bereaved sibling's group and groups for parents and grandparents. There was a range of additional support available for families, including practical support and pamper days, family support sessions, interactive play, coffee mornings and therapeutic swim sessions.

Staff supported children, young people and their families who became distressed in an open environment and helped them maintain their privacy and dignity. We observed staff supporting children and young people and being mindful of their dignity.

Staff undertook training on breaking bad news and demonstrated empathy when having difficult conversations. Care staff had received enhanced communication skills training. We observed staff communicating with care and understanding during a home visit. They were sensitive in their approach to discussing advance care planning and involved the whole family, including the child. They took time to listen, answer questions and demonstrated advanced communication skills and an ability to sit with families and give them time to process the information and situation they were dealing with.

Staff understood the emotional and social impact that a child or young person's care, treatment or condition had on their, and their families, wellbeing. There was a comprehensive approach to care, where emotional and social support was treated with equal value to medical and comfort measures. The family support service had a primary focus of supporting the whole family who were impacted by the condition and care of the child or young person. The family support worker service had been developed at the start of the pandemic to provide additional support to families in the community. They provided support such as a sitting service so that families could go out, including when a child or young person was in hospital and the family needed a break but wanted a person familiar to stay with them.

Staff supported children and young people to maintain their social networks. This included inviting siblings to the hospice to undertake activities and inviting family and friends to join in a swim session in the hospice hydrotherapy pool.

Family support workers took on advocacy work for families, supporting them with whatever issues they needed and entailed support workers attending meetings and liaising with other services to put support in place. Staff described this is a way of joining up services to ensure that family needs were appropriately met.

Talking therapies were available to children, young people and families and included drama, art and music therapy, as well as counselling. Feedback on the service was consistently positive. Bereavement support was provided for three years and three months following the loss of a child.

## Understanding and involvement of patients and those close to them

**Staff supported and involved children, young people and their families to understand their condition and make decisions about their care and treatment. They ensured a family centred approach.**



# Hospice services for children

Staff made sure children, young people and their families understood their care and treatment.

Staff talked with children, young people and their families in a way they could understand, using communication aids where necessary. We observed staff communicating in age appropriate ways and creatively responding to communication issues so that the needs of children and young people were met and that they could understand. There was a range of creative therapies available to children and young people to help them to understand what was happening to them.

Children, young people and their families could give feedback on the service and their treatment and staff supported them to do this. They were encouraged to give feedback both formally and informally. Staff reviewed feedback to identify learning from this and we saw that opportunities for learning were regularly discussed at meetings and shared with the wider staff team through newsletters and daily huddles.

Staff supported children, young people and their families to make advance decisions about their care. Staff consistently took a lead role in supporting children, young people and their families to be involved in advance care planning and planning for the future. We observed nursing and medical staff discussing plans with a family and supporting them to be involved in decision making. We saw that while a plan to manage the child's complex symptoms had been agreed, staff assured the child's family that the plan could be amended, and they could call the hospice at any time if they had concerns. We saw that the child receiving the care was central to the conversation and a draft of the plan was sent to the family for further input before being finalised. Staff took their time to allow for questions, discussion and providing emotional support as needed.

Children and young people gave positive feedback about the service. We spoke with one young person receiving 24 hour care on the unit and they were very positive about the service received. They told us they would change nothing about the service, and they loved everything about it. They told us they had been supported by staff to go on trips, including to London and visiting adventure and animal parks.

We read feedback comments from family members, such as; 'There is so much support for your child and the whole family – all the services offered are like the scaffolding, literally holding up your life so you can keep going, knowing you have that safety net is just crucial.' A comment from a sibling; 'I feel I had 15 mothers at the hospice – it's the simple things that make it the best, just being a friend, like a family member, being a shoulder cry on – that's the greatest gift that Shooting Star Children's Hospices has ever given us. Having someone on our side.'

A parent told us that 'they have gone out of their way to support us by dealing with other institutions and attending off-site meetings. They constantly want to tailor gifts or experiences to our personal preferences'.

The family of a baby who died suddenly in hospital provided feedback on the service they received when accessing the hospice's willow suite. They described the 'kindness, openness and welcome' from staff, enabling them to say goodbye to their baby in a homely environment. They described how it gave their extended family an opportunity to say goodbye and how staff fed them and looked after them at this time. They also told of how staff helped with practical arrangements such as paperwork and funeral arrangements, enabling them to focus on the time spent with their child.



# Hospice services for children

## Are Hospice services for children responsive?

Outstanding



Our rating of responsive stayed the same. We rated it as outstanding.

### Service delivery to meet the needs of local people

**The service planned and provided care in a way that met the needs of local people and the communities served. It also worked with others in the wider system and local organisations to plan care.**

Managers planned and organised services, so they met the changing needs of the local population. In March 2020 hospice leads consolidated in-patient services to the Christopher's hospice site as these had also previously been provided from their hospice site in Hampton. This enabled them to provide day services at one site and focus on in-patient and community services at Christopher's, thus reducing the footfall at Christopher's and 'bubble' the care team during the pandemic. They added a transport service to help mitigate any transport issues for families as a result of the changes. The in-patient service provided planned respite and responsive end of life care support to children and young people.

In 2020 hospice leads reviewed their hospice at home service, recognising traditional respite visits may not be fully meeting the needs of families. The review included feedback from the parent user group to ensure their views were central to the service development. From this review the family support service was developed with healthcare assistants trained as family support workers and skilled up to provide social, emotional and crisis support as needed. This was through a dedicated helpline that operated Monday to Friday 9 am to 5 pm. Staff provided a listening ear and responded to requests for social support. In addition, the family support service provided a hospital sitting / visit service where staff would visit families with a child in hospital and sit with the child so the family could have a break. Family support workers acted as advocates to children, young people and their families, including attending meetings on their behalf.

The inpatient and family support services provided care for children, young people and families across NHS integrated care systems in South West London, Surrey, North West London and Frimley.

The specialist palliative care (SPACE) team and community nursing team had been developed to provide a more comprehensive service to meet the needs of children, young people and families. The development of the service in 2020 led to an expansion of provision to include NHS funded contracts to provide services in Surrey and South West London. The vision of the service was 'to deliver high quality specialist paediatric palliative care to infants, children and young people with life limiting conditions.' This included working with NHS paediatric and neonatal intensive care services to integrate specialist palliative care provision into the acute services to better capture infants and children who would benefit from specialist palliative care. There was a three year expansion plan in place. Specific action included improving collaboration with NHS neonatal and paediatric providers by attending multidisciplinary meetings and networking to raise awareness of the services. Activity relating to this saw an increase in referrals, for example, six new referrals had been received from April 2022 through engagement with the regional foetal medicine group. These referrals were for support for families where a baby had been identified with a life limiting condition prior to birth.

There was recognition of the inequalities and meeting the needs of the diverse populations served by the hospice. Service leads had mapped deprivation against the region and identified areas for improving the reach of services. For example, there were plans to develop a North West London outreach service and we saw that the community team were



# Hospice services for children

20% over target in their face to face contacts in this area. A key driver to meeting the needs of more deprived communities was working in partnership with other services, this included the community team undertaking joint visits with district nurses to provide more specialist input. Service leads and staff were committed to engaging with diverse communities and recognised the impact of different cultural and socio-economic factors in relation to ensuring equitable access to palliative and end of life care for children, young people and their families.

Facilities and premises were appropriate for the services being delivered. Care facilities were on the ground floor and were accessible to children and young people using wheelchairs. They had bathrooms and equipment that were designed for when assistance was required and so that independence could be maximised. Hoists were integrated within bedrooms and different beds were available to meet individual needs, such as high sided beds for those children and young people with additional risk factors.

Additional space included sensory rooms, play areas, counselling rooms, a television lounge, art and therapy rooms, an outdoor classroom, therapy pool, a teenage gaming space and family flats so that family members could stay overnight. There was a range of outdoor spaces, including a sensory courtyard and outdoor play areas where toys were accessible for all children with mobility issues. A waterbed was in use within the sensory room where music was piped through and the child or young person could feel the vibration through the bed.

There was a multi-faith sanctuary room for use by children, young people and family members. There were two 'willow' suites where children and young people could stay after death. Cooling blankets and air conditioning were used in these rooms so that the children or young person could stay for several days, giving family members time to spend with them before they were transferred to a funeral director. We saw that the rooms were available for use irrespective of whether the child or young person died at home, in the hospice or in hospital. Staff told us there was not a requirement for the families to be known to the hospice as they recognised a need for a space away from a clinical or mortuary environment. We were told that staff worked with the family members in the transition from the willow suite to a funeral director and enabled families to spend as much time as they wished with the child or young person. In addition, staff took on a carer role when family members were unable to be there, responding to requests to sit with the deceased child or young person, reading their favourite story or playing a movie or favourite music. Of the children and young people who had died while in the care of the SPACE team in 2021/22 64% had received after death care within the willow suites.

Staff could access emergency mental health support 24 hours a day seven days a week for children and young people with mental health problems and learning disabilities.

The service had systems to care for children and young people in need of additional support, specialist intervention, and planning for transition to adult services. The hospice was designed to meet the needs of children and young people with complex needs. Staff understood the support needs and had a solution focused approach to meeting these. They worked together with other services to ensure that the transition to adult services was appropriate to meeting the needs of the young people in their care. The provider had set up a transition network in 2017. The network had representation from all local adult palliative care services and Christopher's specialist palliative care team. More recently, the collaboration had been expanded with a further group established to cover the South London region. Each group met twice a year and shared best practice in transition.

In addition, a transition triage partnership had been set up in each region (Surrey and South West London) and was chaired by the hospice's transition coordinator. Their purpose was to bring together consultants and senior nursing staff from adult hospices with Shooting Star Children's Hospices to specifically discuss young people who were transitioning and to make decisions about which adult hospices were best placed to offer services.



# Hospice services for children

## Meeting people's individual needs

**The service was inclusive and took account of children, young people and their families' individual needs and preferences. Staff made reasonable adjustments to help children, young people and their families access services. They coordinated care with other services and providers.**

Staff made sure children and young people living with mental health problems, learning disabilities and long term conditions received the necessary care to meet all their needs. Staff supported the family of a child who was having difficulties sleeping at home due to anxiety. They supported the family to access a grant and helped them to re-design the child's bedroom, including sourcing sensory toys and items that would help the child to sleep and worry less.

The environment was designed to meet the needs of children, young people and their families. Wards were designed to meet the needs of children, young people and their families. There were facilities to support children and young people to maximise their independence. All children and young people were cared for in their own room and all facilities including bathrooms, dining areas and therapy rooms were accessible to patients in wheelchairs and hoisting facilities were available throughout the hospice.

Staff used transition plans to support young people moving on to adult services. They had a transition worker in post who worked closely with families and adult services to support the transition and had plans to recruit a second worker imminently. The hospice had comprehensive transition arrangements in place. We saw that young people were supported through the transition process by the transition coordinator and other staff. We were told of a young person who had recently transitioned to adult services at the age of 21. The young person and their family had been supported through the process with help introducing them to adult services. We saw that part of the transition included a celebration of the young person's time at Christopher's. This included staff arranging for a Ferrari to be brought to the hospice and for the young person to be hoisted into it.

There were clear plans to expand the service to free up more time for networking and further development of the transition pathway. Young people transitioned to adult services aged 21 and support from Christopher's staff included accompanying them to visit adult services and supporting overnight stays.

Staff supported children and young people living with complex health care needs by using individual care records and advance care plans. The records we reviewed consistently included advance care plans, detailing ceilings of treatment and the wishes of the child, young person and their families at the end of life. Data from the specialist palliative care team annual review showed that 80% of children and young people in their care had an advance care plan in place. One parent told us 'I don't think I have experienced any other place that is more focused on the care of the individual' and 'they try to tailor all support to the supported child and the surrounding care structure around them'.

We saw that support provided to children, young people and their families at the end of life was comprehensive and responsive. For those in the community and hospital settings the specialist palliative (SPACE) service worked together with the family support service to meet the needs of individual children and those close to them. For example, support was provided to a neonatal intensive care department for a baby who was in the last days of life. SPACE staff met with the family to identify their needs and how best to support them and they visited the unit to provide specialist palliative care input to care planning. They also began the process of planning after death care. The family support worker team visited the baby and family to undertake memory making activities (where mementos of the child such as foot or handprints were made). When the baby died, hospice staff transferred them to the Willow suite at the hospice and worked with the family to support their goodbyes and plan for a funeral in line with their religious beliefs. This included staff working out of hours to ensure arrangements could be made within 24 hours.





# Hospice services for children

Staff responded to crisis requests for support with urgent social issues and worked to find creative solutions. For example, workers responded to a request for urgent support for a family of a child admitted to hospital as they had found themselves homeless. Support workers responded within 15 minutes and gathered clothes and toiletries and found storage space for the family's belongings. They arranged weekly support sessions for the child to have hydrotherapy and for the mother to have complementary therapy and a meal while their social issues were being addressed over time.

Staff understood and applied the policy on meeting the information and communication needs of children and young people with a disability or sensory loss. Staff were creative in meeting the communication needs. We spoke with one young person who was unable to communicate verbally and saw that staff had created a communication board that enabled them to spell out words. Staff also used tools such as picture cards and visual prompts when needed.

The service had information leaflets available in languages spoken by the children, young people, their families and local community.

Managers made sure staff, children, young people and their families could get help from interpreters or signers when needed.

Children, young people and their families were given a choice of food and drink to meet their cultural and religious preferences. Care staff worked closely with catering staff to ensure needs were met.

## Access and flow

**People could access the service when they needed it and received the right care promptly. Waiting times from referral to treatment and arrangements to admit, treat and discharge children and young people were in line with national standards.**

Managers monitored referral activity and made sure children, young people and their families could access services when needed and received treatment within agreed timeframes and national targets. Referrals for the unit were reviewed at monthly referral meetings that involved input from senior care staff, service leads and a GP. More urgent referrals were reviewed as needed.

There was a maximum of nine beds available. In 2021 assessed bed nights were 100 a month and in 2022 these had been increased to 105 bed nights a month. Bed occupancy was 92% of assessed nights in 2021. Data showed that between April 2021 and March 2022 84 referrals had been made to the unit, of these 35% were for end of life care, 56% for general care and 7% for bereavement care.

Referrals to the specialist palliative care (SPACE) team had a target of 48 hours to first contact. We saw that this had been achieved in 95% of referrals, with 81% seen within 24 hours. The remaining one referral where contact was not made within target was due to professionals involved in the child's care asking that contact be deferred. Between April 2021 and March 2022 73 children and young people had accessed the SPACE service. Of these, 21 had died, all in their and their families' preferred place of care.

Managers and staff started planning each child and young person's discharge as early as possible. There was a clear focus on increasing support to children, young people and families within the community and their own homes. The multidisciplinary meetings with input from across hospice and community services enabled discussion about discharge planning at the earliest opportunity. Within the SPACE team there was a clear remit to provide care within the home and





# Hospice services for children

we saw that arrangements were in place, including locked boxes with end of life care medicines stored within the homes of children and young people at the end of life. The team supported the rapid discharge home at the end of life and provided a 'silent' on call rota that could be activated when a child or young person was identified as being in the last days of life, therefore providing 24 hour support within the home.

Staff supported children, young people and their families when they were referred or transferred between services.

## Learning from complaints and concerns

**It was easy for people to give feedback and raise concerns about care received. The service treated concerns and complaints seriously, investigated them and shared lessons learned with all staff. The service included children, young people and their families in the investigation of their complaint.**

Children, young people and their families knew how to complain or raise concerns. The service clearly displayed information about how to raise a concern in patient areas and on the service website.

Staff understood the policy on complaints and knew how to handle them. Staff understood the hospice's policy for focusing on immediate responses to concerns and working with the complainant to find a solution. We saw that verbal complaints were investigated and recorded so that any themes could be identified.

Managers investigated complaints and identified themes. There were limited complaints received, therefore no themes were identified. However, complaints were thoroughly investigated and reviewed by the hospice leadership team and as part of the quality governance and risk committee functions.

Staff knew how to acknowledge complaints and children, young people and their families received feedback from managers after the investigation into their complaint. We reviewed the outcome of an investigation and response to a family who had complained about their child's admission. We saw that the manager investigating the complaint had reviewed records relating to the child's admission and had sought statements from staff to ensure a comprehensive investigation. The written response to the complaint was in depth and addressed each point that had been raised. There was evidence that the response included a reflection on learning and potential areas for improvement.

Managers shared feedback from complaints with staff and learning was used to improve the service.

Staff could give examples of how they used patient feedback to improve daily practice. This included addressing concerns as they arose. The hospice's complaints appeals process included a review by a panel appointed by the chairman of the board of trustees, that included an external advisor.

## Are Hospice services for children well-led?



Our rating of well-led stayed the same. We rated it as outstanding.

## Leadership

**Leaders had the skills and abilities to run the service. They understood and managed the priorities and issues the service faced. They were visible and approachable in the service for patients and staff. They supported staff to develop their skills and take on more senior roles.**



# Hospice services for children

The hospice was led by a senior leadership team. This included the chief executive, medical director, director of strategy and partnerships and a director of care services. The director of care services post was vacant at the time of inspection and being recruited to. Other senior staff were the head of hospice services (CQC registered manager), head of specialist palliative and community nursing and the head of family support.

The senior leadership team led by the chief executive reported to the board of trustees who were accountable for the governance of the hospice. Trustees came from a range of backgrounds including clinical, legal, business and finance.

Day to day management of the hospice services was the remit of the clinical and service leads. Staff we spoke with told us that leads were accessible, approachable and supportive.

There was a focus on succession planning in relation to leadership of the service. The hospice provided senior nursing staff with senior nurse development training that included aspects of leadership and focused on developing them within their roles. In addition, we saw that within the specialist palliative care team (SPACE) there was a development role where the post holder was supported to develop their skills using the Royal College of Nursing competency framework.

## Vision and Strategy

**The service had a vision for what it wanted to achieve and a strategy to turn it into action, developed with all relevant stakeholders. The vision and strategy were focused on sustainability of services and aligned to local plans within the wider health economy. Leaders and staff understood and knew how to apply them and monitor progress.**

The hospice had a clear vision and a developing strategy. Their purpose was that ‘every life-limited or dying child and their family should have the opportunity to make every moment count and get the support they need’. They had an ambition to ‘support every family with a life-limited child or whose child has died, when they need us.’

The services had been restructured at the start of the COVID-19 pandemic to reduce risks to sustainability. The leads had taken a ‘modelling the future’ approach to provide a framework for the redesigned services. Aims were identified as; providing a specialised medical centre with family values, a multi-professional approach – can’t do palliative care with just nurses, and, working as a whole team, role modelling behaviour, and holding everyone accountable.

Built into the plans, were quarterly process reviews for the current year. For example, in quarter one there had been a focus on the review of initial assessment and outcome processes, in quarter two there was a focus on external communications and referrals, in quarter three there was a focus on the family support line and education and in quarter four there was a focus on research.

Strategic initiatives had been identified and these included increasing participation and engagement of children and families, education and advocacy, create productive partnerships that promote better outcomes for children and families. Specific ‘people’ initiatives included building a workforce representative of the communities served and creating empowering career development for staff and volunteers to grow.

Alongside this, the hospice leads had processes for the ongoing review of the needs of the local communities and worked in partnership with other services and stakeholders to ensure the hospice strategy was relevant and aligned with the wider health economy.



# Hospice services for children

The development of the strategy involved away days and meetings with trustees, families, staff and volunteers. Clear objectives had been identified, including increasing the provision of community services; strengthening skills, capabilities, diversity and inclusion of staff and volunteers; strengthening links with national, regional and local networks; and, making family support more outward facing and including support to families not currently known to the hospice. There were ongoing processes for reviewing objectives and stakeholder input, with a plan for final ratification of the strategy by the board of trustees in September 2022.

## Culture

**Staff felt respected, supported and valued. They were focused on the needs of patients receiving care. The service promoted equality and diversity in daily work and provided opportunities for career development. The service had an open culture where patients, their families and staff could raise concerns without fear.**

The hospice had an equality and diversity policy and staff had received training relating to this. Prior to the pandemic the hospice had an equality, diversity and core values working group, however, the group had not been active in the last two years due to the pandemic and staffing changes as a result of the service restructure. However, leads told us there were plans to rejuvenate the group and we saw that equality, diversity and inclusion were key aspects to the strategic planning for services and workforce mapping. Staff recognised issues relating to diversity and inclusion and promoted equality in their daily work.

Staff were focused on the needs of children, young people and families receiving care. There were clear arrangements to gather information on the experience of those using the service and use this to ensure ongoing improvements as necessary. There was a strong collaboration and team-working culture and a common focus on improving the care experience for individuals and service users.

Staff we spoke with were happy in their work, describing services that were focused on responding to the needs of children, young people and families. Staff were consistently seen to be kind, caring and inclusive in their interactions with those in their care.

Staff told us they felt able to speak up if they had concerns about the service or the delivery of care. There were clear reporting guidelines within the hospice whistleblowing policy with internal and external contacts should staff wish to raise concerns.

## Governance

**Leaders operated effective governance processes, throughout the service and with partner organisations. Staff at all levels were clear about their roles and accountabilities and had regular opportunities to meet, discuss and learn from the performance of the service.**

There were effective governance structures, processes and systems of accountability and a clear governance framework to support the delivery of the hospice strategy. The hospice leadership team were accountable to the board of trustees through various committees. For example, a quality and governance committee, care advisory, finance and business and corporate governance committees. Senior leaders reported back to the board, providing summaries, meeting outcomes and action points.



# Hospice services for children

Quality assurance and leadership meetings were regularly held. Specific meetings included research governance, senior care leadership team quality and risk, medicines management, mortality and morbidity and safeguarding. A range of monitoring and quality performance data including quality improvement and assurance audits, safety incidents and risks, training compliance, staffing, complaints and service user and family experience feedback were reviewed at these meetings.

Staff were clear about their roles and accountabilities and who to report to. Staff were committed to improving the quality of service and maintaining high standards of care. They were involved in discussions about the performance of the service and were encouraged to report issues and work together to learn and develop the service.

There were arrangements in place to manage and monitor contracts and service level agreements with partners and third-party providers. Contract reviews were informed using quality indicators and feedback. A sharing good governance and risk group for hospices was attended by the hospice's clinical governance facilitator where best practice, governance and care quality issues were discussed.

## Management of risk, issues and performance

**Leaders and teams used systems to manage performance effectively. They identified and escalated relevant risks and issues and identified actions to reduce their impact. They had plans to cope with unexpected events. Staff contributed to decision-making to help avoid financial pressures compromising the quality of care.**

There was a quality improvement, governance and risk framework in place. There were also business continuity arrangements in place.

Risk registers were in place for each area of the hospice. This included corporate, care and clinical governance and estates. Risks were assessed and mitigating actions identified. For example, risks relating to the swimming pool were mitigated with staff training, water testing, strict supervision and compliance with Health and Safety Executive requirements.

Performance was reviewed using data. This included service dashboard data that included relevant referral and admission data, outcomes and finance.

Service reviews were regularly held, and performance was a part of this. We saw that reviews included collating staff and service user feedback and were followed up with comprehensive plans for improvements.

The hospice had an audit programme in place that was reviewed annually. Audit findings were used to make improvements and provide assurance about the management of risk and quality.

## Information Management

**The service collected reliable data and analysed it. Staff could find the data they needed, in easily accessible formats, to understand performance, make decisions and improvements. The information systems were integrated and secure. Data or notifications were consistently submitted to external organisations as required.**



# Hospice services for children

The hospice used a bespoke patient information system and they collected data on the services delivered, including referral, activity and improvement data. They used IT systems to collate information and this was analysed and used to report activity to the board of trustees, partners and inform staff of areas for development. Information on performance was shared with children, young people and families and we saw that safety data was displayed on the unit.

There were clear arrangements to submit notifications to external organisations and service leads understood the requirements of this. The hospice had been trialling an initiative to provide discharge summaries to professionals and families, to summarise assessment, care and treatment changes following an admission to the unit.

## Engagement

**Leaders and staff actively and openly engaged with patients, staff, equality groups, the public and local organisations to plan and manage services. They collaborated with partner organisations to help improve services for patients.**

The hospice worked in partnership with other services to ensure the palliative and end of life care needs of children, young people and families were met within the communities they served.

The hospice valued collaborative partnerships with both clinical and academic services, both locally and nationally, including government, NHS, statutory, education and voluntary agencies. They had a philosophy of working together to provide the best care and support for babies, children and young people with life limiting conditions, and their families.

They were involved in academic partnership with universities in Southampton, Kingston, London and Surrey. These partnerships involved the hospice providing placements for student nurses, participating in clinically based research projects and participating in a project to develop the children's palliative care outcome scale.

The hospice was a founder member and hosted the South West London and Surrey paediatric palliative care network which was co-chaired by the paediatric palliative care consultant and head of symptom and community services. The paediatric palliative care consultant was also the chair of the Association of Paediatric Palliative Medicine. In addition, the hospice was in the process of setting up a paediatric palliative care network in North West London and were currently interviewing for a partnership / network manager. The hospice was a member of the Together for Short Lives Research Group and a national sharing good practice hospice group. The hospice set up a Children's Hospice Transition Network which had representation from all local adult palliative care services and the hospice's specialist paediatric specialist palliative care team. The hospice's transition coordinator chaired a transition triage partnership to bring together consultants and senior nursing staff from adult hospices to discuss young people who were transitioning to adult services.

Hospice staff actively engaged with children, young people and their families. The hospice had an active parent and family user group. This ensured that parents and families had a voice in both the strategic and operational aspects of the service. They had been invited to engage with the development of the strategy and involved in consultations. In addition, parents and families were encouraged to share their experiences of the service and make suggestions for improvements. Staff acted on the suggestions. Specific changes included the provision of independent day visits for children and young people with a parent and carer, online booking arrangements and streamlining of family surveys to make them shorter and more frequent.

We saw examples of innovative ways of engaging with children and young people, including siblings. Examples included the use of sweets in tubes to indicate a score out of five for specific services, or the use of building blocks to indicate an answer to a question.



# Hospice services for children

Staff were engaged using surveys, meetings and discussions. A 2020 staff survey identified areas for improvement around communication with staff, the impact of the pandemic on training opportunities and the visibility of trustees. Specific action taken to improve on these areas included monthly briefings, staff receiving additional one to one meetings with managers to identify continuing professional development opportunities post Covid-19 restrictions, and, trustee walkarounds to visit the services and meet staff.

The specialist paediatric palliative care (SPACE) team worked closely with NHS paediatric and neonatal intensive care teams as part of a newly funded service in 2020/2021. They engaged with the teams they worked with on a regular basis as part of the development of the service. They regularly attended meetings and conducted surveys with staff to gain feedback. Action as a result of engagement included setting up a working group with representation from the trusts, the provision of a central NHS email for communication with the SPACE team and the provision of training and hospice visits for the NHS teams as part of their learning and development.

## Learning, continuous improvement and innovation

**All staff were committed to continually learning and improving services. They had a good understanding of quality improvement methods and the skills to use them. Leaders encouraged innovation and participation in research.**

There was a culture of learning evident within the hospice services. There were processes for learning and continuous improvement, with a range of quality assurance and improvement methods in place. These were used to identify where improvements were needed and to measure improvements. Examples included improvements to the completion of body maps for children and young people cared for on the unit, a reduction in medication errors and improved safeguarding processes.

'Learning to improve' case studies were used to identify areas of good practice and areas for improvement. Mortality and morbidity meetings were held to review the care of children and young people receiving care.

We saw examples of innovation in relation to the development of services. We saw that the family support service adapted at the beginning of the pandemic to meet the needs of children, young people and families. This included the development of the family support worker role to support families with social and emotional issues. Examples included responding rapidly to families in crisis and staff delivering interactive play sessions for children in their own homes after long periods of isolation at home.

The specialist paediatric palliative care (SPACE) service was developed following successful funding negotiations to expand the provision of specialist care and support to families with new-born babies and children with life limiting conditions. This involved the development of a neonatal palliative care pathway and increasing in utero referrals where life limiting conditions were identified prior to birth.

The hospice had a lead role in developing transition services across the region. They had set up and chaired a network meeting involving adult services and a triage meeting where the care for young people transitioning was discussed with relevant services and professionals.

The hospice worked to provide bereavement support for bereaved families, to include access to the hospice's bereavement 'willow' suite, irrespective of where the infant, child or young person died.