James Hopkins Trust

Kites Corner

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

Summary of findings

Overall summary

Kites Corner is operated by James Hopkins Trust. This is part of the James Hopkins Trust. The service offers respite care for children who are severely disabled, have life limiting, or life-threatening conditions.

We last inspected the service in July 2019 when we issued 3 requirement notices. These related to breaches of the essential standards of safe care and treatment in relation to transporting children, good governance and staffing in relation to supervision, appraisal and training. This inspection found those requirements had been met.

We inspected the service under our framework for Hospice services for children, young people and families using our comprehensive inspection methodology. We carried out a short notice announced inspection on 18 October 2022. To get to the heart of children' experiences of care and treatment, we ask the same 5 questions of all services: are they safe, effective, caring, responsive to children's needs, and well-led?

We have not previously rated this service. We rated it as good because:

- Staffing levels met children's needs. Staff were well trained and knowledgeable about their roles and the care the children needed.
- Systems and processes were in place and closely monitored so the service was safe and well run. The registered manager and staff had robust risk assessments in place and acted appropriately to mitigate identified risks.
- Children's rights were upheld. Parents and carers were involved in all discussions pertaining to the care of their child and staff ensured that children, parents and carers were given choice.
- Staff effectively reported safeguarding matters and the registered manager thoroughly investigated all concerns and complaints and ensured that lessons learnt were embedded into practice.
- Staff and parents' views were gathered and used to inform developments for the service
- There were clearly defined and embedded systems, processes and standard operating procedures to keep children safe and safeguarded from abuse, using local safeguarding procedures whenever necessary.
- Staff recognised and responded appropriately to changes in the risks to children who used the service.
- Staff involved partner agencies and parents / carers when sharing information.
- Staff managed medicines consistently and safely. Medicines were stored correctly and disposed of safely. Staff kept accurate records of medicines.
- Openness and transparency about safety was encouraged. Staff understood and fulfilled their responsibilities to raise concerns and report incidents and near misses; they were fully supported when they did.
- Childrens care and treatment was planned and delivered in line with current evidence-based guidance, standards, best practice, legislation and technologies. This was monitored to ensure consistency of practice.
- Staff were supported to deliver effective care and treatment, including through meaningful and timely supervision and appraisal. Where relevant, staff were supported through the process of revalidation. There was a clear and appropriate approach for supporting and managing staff when their performance was poor or variable.
- The service had effective policies and processes for recruiting, training and supporting volunteers where necessary. These were implemented and volunteers felt supported and understood their roles and responsibilities.
- The children were treated with dignity, respect and kindness during all interactions we observed with staff and relationships with parents were positive.
- Staff communicated with parents / carers and provided information in a way that they could understand. Parents and staff worked together to plan care and there was shared decision-making about care and treatment.
- Facilities and premises were innovative and met the needs of a range of children who used the service.

Summary of findings

- Care and treatment were coordinated with other services. This included liaising with schools and community services ensuring that all stakeholders were informed of any diverse needs to be addressed.
- The board and other levels of governance in the organisation functioned effectively and interacted with each other appropriately. Structures, processes and systems of accountability, including the governance and management of partnerships, joint working arrangements and shared services, were clearly set out, understood and effective.
- The service made full use of multimedia assisted technology in its sensory room and we were shown a sensory appliance that had been developed with an assisted technology company to meet the needs of the children.
- During the pandemic when the centre was closed, the service kept regular contact with the families, ensuring that families were provided with personal protective equipment (PPE), undertaking welfare checks and delivering food hampers.
- The service made use of multi-media technology both within the building and in the garden area to enrich the child's experience. We were shown a multi-sensory garden which included a sound wall and a forest walk that provided the children with a multi-sensory experience.
- The service had very close connections with the local community and local businesses. These were involved in the maintenance of the environment and contributed to the development of the service.

However:

- The staff supervision records were accurate and up to date however a central matrix would make reviewing records more efficient.

Summary of findings

Our judgements about each of the main services

Service	Rating	Summary of each main service
Community end of life care	Good	We have not previously rated this service. We rated it as good overall. See the summary above for details.

Summary of findings

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Summary of this inspection

Background to Kites Corner

Kites Corner is operated by the James Hopkins Trust. Alongside its registration with CQC, it is registered with The Charity Commission and Ofsted.

The organisation is based in Gloucestershire and primarily serves the local community, and reports that since its founding in 1989, the charity has helped and supported over 600 children across the county.

The service is registered with the CQC for the treatment of disease, disorder or injury, with the aim, through respite care, of improving the quality of life for children who are severely disabled and have life limiting conditions.

The James Hopkins Trust provided day respite care Monday to Saturday from 9.30am to 2.30pm at Kites Corner, known as Little Kites, with overnight respite care on a Friday for up to four children. The service was planning to extend this overnight service to Thursday nights. A school holiday club for older children was provided during holidays and a stay and play group had been started for carers and parents.

The charity also facilitated 1 to 1 respite care in the child's home. A service that was also provided if the child moved to hospital.

The service operated all year round except for bank holidays and Christmas week.

There was a registered manager in post. The service had a caseload of 105 children and 4 families were provided with 1 to 1 support in their home.

What people who use the service say

We spoke with the parents of 4 children who used the service. All the statements were very positive about the service and the help and support that both the children and the parents had received from the staff.

The manager showed us thank you cards and compliments that had been received from parents together with the response of a parent / carer survey that had been carried out in July 2022. All these complimented staff on how caring they were, and that the management had kept them informed of developments in the service.

How we carried out this inspection

The team that inspected the service comprised of a CQC lead inspector, and a specialist advisor with experience in paediatric nursing. The inspection was overseen by Catherine Campbell, Head of Hospital Inspection.

This inspection took place on 18 October 2022 and we gave a 5-day notice period. This was because it is a small respite service and we needed to be sure that the service or registered manager would be in the office to support the inspection.

Summary of this inspection

We spoke with 4 parents of the children attending the unit on the day of the inspection. Reviewed 8 sets of care notes, interviewed 6 members of staff and looked at 5 staff files. After the inspection, we requested and reviewed further information.

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.

Areas for improvement

Action the service MUST take is necessary to comply with its legal obligations. Action a service SHOULD take is because it was not doing something required by a regulation, but it would be disproportionate to find a breach of the regulation overall, to prevent it failing to comply with legal requirements in future, or to improve services.

Action the service SHOULD take to improve:

- The service should review how they record staff supervisions to ensure that the leaders have oversight of when supervision are due and the numbers of supervisions that have been carried out.

Our findings

Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
Community end of life care	Good	Good	Good	Good	Good	Good
Overall	Good	Good	Good	Good	Good	Good

Good

Community end of life care

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

Are Community end of life care safe?

Good

We had not previously rated this service. Safe was rated as good.

Mandatory training

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

The service employed 9 contracted members in the charity team, a nurse who was lead in clinical governance and quality, a nursing lead, 3 senior respite nurses, 4 full time and 3 bank respite nurses, a play leader and a deputy play leader, and 4 contracted and 1 bank healthcare assistants.

We reviewed 5 sets of staff notes which evidenced all had completed a structured induction programme on commencement of employment. We spoke with 6 members of staff who all stated they had received an induction.

The service had an online training programme and conducted face to face training. Outside sources were utilised, an example being the paediatric palliative care team from the local NHS community service arranging to undertake a workshop session for the service.

Staff spoke positively about training opportunities that had been offered, for example training on the deteriorating child, and all clinical staff have received training in basic life support specific to children. Staff told us that leaders actively encouraged and supported them to develop their skills and knowledge.

The service maintained a training matrix of all training undertaken by staff, and the figures for these are reported to the board of trustees for the monthly meeting. We looked at 31 staff training files with records showing that 91% of all staff groups, including bank staff and charity staff, had completed their training. The results are reported in the services Key Performance Indicators (KPI) to the Trust Board and is discussed at the nursing and governance meetings.

Staff we spoke with, stated that they had received additional training for their roles and were encouraged to attend training. We saw 5 sets of staff files which evidenced further training specific to staff roles.

Staff completed training on recognizing and responding to children with mental health needs, learning disabilities, and autism.

Good

Community end of life care

Safeguarding

Staff understood how to protect children 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.

Nursing staff received training specific for their role on how to recognise and report abuse.

Staff we spoke with could give examples of how to protect children from harassment and discrimination, including those with protected characteristics under the Equality Act.

Staff we spoke with knew how to identify adults and children at risk of, or suffering, significant harm and worked with other agencies to protect them and knew how to make a safeguarding referral and who to inform if they had concerns.

The service has a safeguarding children and young people policy, reviewed in May 2021 which provides detail on the service lead, how to raise a concern and employment practices. The staff had an awareness of safeguarding for adult's policy which detail types and indicators of abuse of adults and procedure to follow when abuse is disclosed or suspected, for example that of a spouse.

Parents acted as advocates for their children. Parents we spoke with stated they felt their views were listened to by the leaders of the service.

We were informed all contracted and bank staff including the charity team and volunteers had completed safeguarding training to Level 3. Training was recorded in the staff files and the charity team training matrix. The courses completed were Safeguarding Children & Young People and Safeguarding and Protection of Adults. Manager and the three additional deputy safeguarding leads complete Child Protection Inter-Agency Level 3. The registered manager was the designated safeguarding lead and staff spoken with knew how to raise a concern.

All staff who are involved in recruitment had completed the National Society for the Prevention of Cruelty to Children (NSPCC) course on Safer Recruitment in Education.

All the nursing team and charity team who may have contact with children during their work complete the Safeguarding Children with Disabilities Training.

The trustees are also trained to Level 3 and have completed Safeguarding Children & Young People.

Training records of 26 nursing staff, full time and bank, showed 18 had completed safeguarding training, 2 staff were due for renewal and 5 staff were due to commence training. Training records of 13 charity staff and volunteers showed that all staff had received safeguarding training.

Staff attended multi-agency Child in Need (CIN) and Team Around the Child meetings (TAC) meetings which are described as a group that provide family support through the group of professionals that are involved in the child's care. We saw minutes of the CIN meeting April 2022, and the TAC meeting minutes of February 2022. Both minutes recorded attendance of multi-agency representatives and parents invited to attend and representation by an advocate. The minutes of the Operational / Governance meetings, Nursing departmental meetings, and monthly Trust Board meeting evidence discussion of safeguarding cases and overview of safeguarding training throughout the service

Good

Community end of life care

We saw a safeguarding audit tool which had been prepared for the Board of Trustees meeting for September 2022. This audit was to be completed every 2 years under Section 40 of the Children's Act along with the Department of Education guidance on safeguarding children, safer recruitment and keeping children safe in education. The audit consisted of 12 standards with 94 components. The service scored 2 as outstanding, 81 as good, 0 requires improvement, 0 inadequate and 11 marked as not applicable. No action plan was completed with this document.

Cleanliness, infection control and hygiene

Staff followed infection control principles including the use of personal protective equipment (PPE)

All areas were clean and had suitable furnishings which were clean and well-maintained. Cleaning records were up-to-date and demonstrated that all areas were cleaned regularly. Staff followed infection control principles including the use of personal protective equipment (PPE).

The service had a comprehensive infection control policy with evidence of recent review. The service used comprehensive audit tools which were undertaken weekly and monthly. The monthly observation audit of infection control precautions had been performed on 16 times during the period May to October 2022 and covered 11 items, personal and environmental. The items included observations on whether staff were bare below their elbows, all PPE had been put on, taken off and worn correctly and hand hygiene was carried out. Over this period the average score was 97% compliance.

We were provided with 2 months records of the weekly standard operating procedure for cleaning which detailed the task and requires a staff signature on completion. These were all signed and completed and a further monthly audit of these had been completed, which evidenced that the weekly audit had been carried out effectively.

Standard operating procedures, compliance audit, and weekly IPC precautions and observational audit, were shared at morning briefing meetings and weekly Nursing Management Team meetings. They were also discussed at the operational / governance meetings and the Trustees Board meetings.

Audits were converted into graphs and displayed in the Medication Room.

Staff had responsibility for the cleaning of toys, surfaces, floors etc. at the end of each day and the service employed contract cleaners 3 times a week, for deeper cleaning.

On inspection of the environment, we saw hand washing facilities with posters showing correct technique and hand gel dispenser around the unit. We observed staff using these as they moved from area to area.

Staff received training in infection control. The nursing and charity team training metrices showed that all staff had attended infection control training

Environment and equipment

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

We saw records of regular fire drills being held. The last fire drill was held in August 2022, and a log is kept for the weekly, monthly and annual testing of fire safety equipment which was up to date. The last regulatory reform (fire safety) order 2005 fire risk assessment was completed in June 2019 and reviewed in November 2020, and October 2021.

Good

Community end of life care

The design of the environment followed national guidance. The service had suitable facilities to meet the needs of children' families. A room was available for families to meet in privacy. The communal play area had been designed with furniture and fixings to allow easy cleaning and its lay out can be changed to ensure social distancing can be maintained.

The garden area had been designed with the child's experience central to the planning. The outside space had multi-sensory areas and the play areas have been designed to be accessible for children with a disability.

There was building work being undertaken in the garden area to update a quiet space for parents to meet and reflect. We were informed that the service hosts an annual memorial afternoon. This area was safely cordoned off while work was being undertaken.

The service had a room that is used for clinical procedures such as changing of a percutaneous endoscopic gastrostomy (PEG) button. The room is a designated clean room that can also be used as an isolation room if a communicable infection is suspected.

Staff carried out daily safety checks of specialist equipment. All hoists had regular lifting operations and lifting equipment regulations (LOLER) assessments. We saw evidence of portable appliance testing and mandatory water checks, including those for legionella, were carried out regularly.

The service carried out an annual health and safety inspection, the last one was carried out on the 4 May 2022. Further to this an interim health and safety inspection was carried out in August 2022 and actions were detailed for the findings. These included a recommendation to share the report with the Trustees, water temperature checks to be added to action plan.

The service had enough suitable equipment to help them to safely care for children. Staff disposed of clinical waste safely. We saw a service level agreement with a clinical waste company. All clinical waste bins seen were secure and clean. Sharps bins were clearly labelled and dated, and there was evidence of mandatory water checks being undertaken.

The service had a resuscitation trolley on site which was in the medication room. We saw evidence that this trolley was checked weekly.

Assessing and responding to child risk

Staff completed and updated risk assessments for each child and removed or minimised risks. Risk assessments considered children who were deteriorating and those who presented with challenging behaviour that presented a risk to safety.

The service used a nationally recognised paediatric early warning score chart (PEWS) which had adaptations for the 0-3 Months, 4-11 months, 1-4 years, and 5-12 years old child. Training was provided for all clinical staff on identifying the deteriorating child, as well as on sepsis, paediatric and emergency first aid and these were included in the induction competency list.

Staff completed risk assessments for each child on admission / arrival, using a recognised tool, and reviewed these regularly, including after any incident. Notes seen contained evidence of risk assessments being reviewed.

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

The service had a deteriorating child policy, and baseline observations were routinely taken 4 times a year on all children prior to the child visiting the service. This assessment, undertaken in consultation with the parents and carers is to ascertain whether there has been any deterioration and if a child is unwell. This is then scored into a Red Amber Green (RAG) rating system.

Should a child become unwell at the centre the parents / carers would be called and following discussion would either attend to pick up their child or, in an emergency, 999 would be called to arrange an ambulance to attend.

Staff were booked into attending a recognition of the deteriorating child course.

Nurse staffing

The service had enough nursing and support staff with the right qualifications, skills, training and experience to keep children 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 a staffing policy which was reviewed regularly. This policy set out the staffing levels for the service and staffing numbers were monitored monthly and were submitted as key performance indicators (KPI) to the Trustees. The KPI tracking document reports that for September the staffing target was 90%, this was exceeded and stood at 97% with 1 nursing vacancy. Absenteeism rate averages 3.4% across all staff groups against a target of 3% overall.

Nurse staffing is discussed at the Nursing Team meetings, the operational / governance and the Trust Board. The September minutes of the Trust Board records that the service was employing an advanced nurse practitioner on a 6-month contract to provide guidance and expertise on clinical policies and carry out supervision. This was to provide additional support to a new Clinical Lead due to start in October 2022.

We saw copies of the staffing rota which showed that shifts were fully staffed. By night there were 2 qualified nurses and 1 healthcare assistant for a maximum of 4 children. On our visit each child had an allocated member of nursing staff. In the event of unforeseen staff absence, the service could call upon a bank group of staff. Staff files and training records evidenced that these staff had undergone employment checks, induction and mandatory training

Medical staffing

We were informed that one of the Trustees is a pediatrician who advises the services on clinical policy aspects. All other medical responsibility remains with the child's consultant.

Records

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

We reviewed 4 sets of patient notes which were found to be comprehensive, and all staff could access them easily. There was evidence that these were discussed with parents and updated regularly. All documents were signed and dated, and consents seen and signed by parents.

There was a system in place to flag concerns about a child and this was discussed during the daily nurse meeting.

Good

Community end of life care

The service undertook a comprehensive monthly and an annual audit of documentation. We saw the monthly audits from January to September 2022 and the annual audit, completed in March 2022. Recommendations included areas where less than 70% was achieved should be reviewed as a priority. We saw evidence of learning implemented through audit and governance meetings.

Documentation was a standing agenda item on the Nursing department meeting and the care plan audit was discussed in the audit section of the operational / governance meetings.

When children transferred to a new team, there were no delays in staff accessing their records. The service used the ‘all about me’ document to aid in the transferring of children to school services. The all about me booklet provides pictorial easy to read information about all aspects of the child's life.

The service used a paper recording system and stored children records in secure filing cabinets which had access restricted to appropriate staff. The documentation audit covered the physical condition of the files to ensure that the paper files were not damaged or lost.

Medicines

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

The service’s only permanent stock of medication was paracetamol, ibuprofen / piriton. These medications are only given on an as required basis and after discussion with the parents / carers all other medication was brought in by parents.

All medicine charts were checked and found to have double signatures; all details were complete. Personal details also included the weight of the child.

Staff learned from safety alerts and incidents to improve practice. Incident log showed actions undertaken following a medication error and learning points discussed with staff.

Regular weekly and monthly audits of medication were undertaken, results were reviewed and acted upon. The medicine fridge was found to be locked, temperature logs for room and fridge were being kept daily and were within expected ranges.

Medication charts were reviewed with the parents on every occasion the child visited the unit, with the parents signing the medication charts.

Staff gave an example of a medicines discrepancy that had been reviewed by the clinical lead and the registered manager, and subsequently discussed at Trust Board meeting. This was then fed back to staff involved in a 1 to 1 supervision and discussed with the staff team.

The service had a management of medicines policy that had been regularly reviewed and medication practice was included in the mandatory training for nurses and training matrix showed all nursing staff had completed the training. Further training was provided for the use and administration of specialist medication such as buccal midazolam.

Good

Community end of life care

Incidents

The service managed child 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 apologized and gave parents and carers honest information and suitable support. Managers ensured that actions from child safety alerts were implemented and monitored.

Staff spoken with knew what incidents to report and how to report them. Incidents were logged and discussed at the monthly Operational Governance meetings, Nursing meetings, Trust Senior Management team meetings, and Trustees Board meetings. Staff we spoke with stated that learning from incidents was shared and staff knew how to report an incident. From October 2021 to October 2022 there had been 84 reported incidents. Of the incidents, 83 were classed as no harm / low harm, 1 moderate harm which was described as a child becoming upset and scratching themselves. Falls made up the highest number of incidents, with general incidents and medication incidents accounting for the next highest reported.

The service had no never events

Managers investigated incidents thoroughly. Children and their families were involved in these investigations, and this had been recorded in the incident records.

Staff understood the duty of candour. They were open and transparent and gave children and families a full explanation when things went wrong. The leaflet provided to parents on compliments, concerns and complaints included a section which explains the service’s duty of candour and describes the action that the service would take.

Staff met to discuss the feedback and look at improvements to childcare. There was evidence that changes had been made as a result of feedback. An example of how a safeguarding allegation led to a change in practice was seen. The changes followed an investigation by the Local Authority Designated Officer (LADO), and several learning points were acted upon. The service changed procedures in their policy and adjusted the child’s care plan accordingly. Staff involved were provided with support and the learning points disseminated.

Are Community end of life care effective?

Good

We have not previously rated this service. We rated it as good.

Evidence-based care and treatment

The service provided care and treatment based on national guidance and evidence-based practice. Managers checked to make sure staff followed guidance.

The service had a Respite Care Policy which had been reviewed regularly. This document detailed the referral and initial assessment process, the types of respite care, monitoring, care agreement and care planning and the end of respite.

Children referred to the service had a comprehensive initial assessment. The referral form included personal details, medical history, agencies involved in the care of the child, the child’s diagnosis / medical details. Referrals were completed by a professional involved in the care of the child with the parents.

Community end of life care

An in-depth holistic assessment of the child and family's physical, mental health and social needs was carried out which included an assessment of how the child's condition impacted on the family. The assessment was scored using the National Framework for Children's Continuing Care framework (DOH 2016) together with the service's bespoke vulnerability rating scale. The child was then re-assessed at least once a year or sooner if there were changes in the childs or family circumstances. There were also regular meetings with parents, carers and agencies involved in the child's care to discuss the child's progress.

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance. Staff received training in specialist procedures applicable to the care of the children in the service. This included the care of children with epilepsy, use of buccal midazolam, care of a child with a tracheostomy and the care of a child requiring intermittent catheterization.

At handover meetings, staff routinely referred to the psychological and emotional needs of children, their relatives and carers.

The service referenced the National Institute for Clinical Excellence (NICE) standards in policies and procedures for Epilepsy, urinary tract infections in children and young persons, infection prevention and control, medicines management in care homes, sepsis, end of life care for children and infants, cerebral palsy in children and young persons, child abuse and neglect, children's attachment and health workplaces.

Nutrition and hydration

Staff gave children 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' religious, cultural and other needs.

The service did not have catering facilities on site, this was not required as all feeds for the children were provided by the parents / carers and stored appropriately onsite.

On the initial assessment, nursing staff in consultation with the parents / carers, undertook a comprehensive review of the child's feeding requirements, both enteral and oral. A detailed plan was entered into the child's care plan. Those children who receive enteral feeding were monitored by hospital-based dieticians and the service followed the plans provided by those dietician services. All food stuffs usually bottled were appropriately stored in an allocated fridge with breast milk stored separately in a secured fridge. All items seen were clearly labelled and dated.

A review of training records showed that all nursing staff had received training in nutrition and hydration, food hygiene, enteral feeding and the use of the enteral feeding pumps together with the care of the child with the gastrostomy tube and management of a nasal gastric tube.

Pain relief

Staff assessed and monitored children 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.

The service used a nationally recognised pain rating scale, incorporated into the care plan, that had been specifically designed to help children communicate about their pain and is based on non-verbal cues.

Good

Community end of life care

Parents were asked about the child's pain management, and what methods were being used to alleviate pain / discomfort and this was entered into the child's care plan. Children received pain relief soon as staff became aware that the child was in pain or discomfort.

The service stocked paracetamol, Ibuprofen / Piriton and these are administered following consultation with parents and as directed on the medicine's administration chart. Parents we spoke with confirmed that the service discussed the administration of medication with them.

Child outcomes

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

The service collected data using audits for the Trusts key performance indicators. Audits were discussed at the operational / governance meetings and at the nursing meetings.

We were informed child outcomes were monitored using family questionnaires. Outcomes were also reviewed as part of a child's annual review, in collaboration with their family; the child and family's needs for future care were also discussed at these meetings.

On admission a baseline assessment was completed with the family and each time the child had a respite session there was an informal assessment of the child's current needs. We were informed the service used an educational secure online diary where the play leader could share content with the family, and they could also share content.

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.

Five sets of staff notes were seen. All notes showed evidence of a comprehensive induction and training specific to roles, in addition to mandatory training. Staff were provided with an induction workbook on starting with the service which included sections on policies and procedures, working practices, types of respite, daily tasks, roles, care of the children and equipment.

Nursing staff undertook competency assessments under the supervision of a senior nurse, as part of their role. These included clinical competency evaluations in the administration of buccal midazolam (a medication used in the treatment of seizures), manual handling and medicines management.

The service had a regularly reviewed supervision policy. Supervisions were carried out regularly with supervision notes kept in the staff files and a timetable for appraisals and supervisions placed on the wall of the office. The supervision policy states that clinical supervision should take place regularly but does not specify an expected number over the course of the year.

Staff we spoke with confirmed that they had received regular supervision and a yearly appraisal. The service had an appraisal policy which had been regularly reviewed. The policy outlined the role and responsibilities of staff and managers.

Good

Community end of life care

The service operated a named nurse system. As part of the appraisal, the parent / carer of the child is invited to contribute by answering a questionnaire on the performance of the staff member. Further to this the service ensured its compliance under the childcare regulations 2009 by asking staff to complete a staff suitability declaration as part of the appraisal process.

Managers supported nursing staff to develop through regular, constructive clinical supervision of their work. This was undertaken by the clinical lead, who had the responsibility of ensuring that policies and procedures were updated in line with current practice and had been disseminated to all staff.

Staff sickness and absence was monitored, and we were shown an example of when the registered manager had met with staff whose sickness level was of concern and support was provided.

Multidisciplinary working

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

Information about the other agencies involved in providing support to the child was included in their care records. These included, for example, schools GP's and other health professionals.

The service delivered other services for disabled children, such as play schemes and family fun days. The registered manager told us they maintained good links with other children's services within the local authority areas where they worked. This included links with schools, social services, parents' groups and other services of support for children with disabilities and took the form of both formal case meetings, evidence through the CIN and TAC meetings, and participation in charitable events organised by the James Hopkins Trust charity team.

The registered manager and their staff had attended meetings and reviews with other services, to ensure that the service was meeting the needs of children. Staff attended the local trust paediatric palliative care group meetings.

Children's records reviewed showed detailed discussions with other agencies, including GP's, Dieticians, Specialist Nurses and Consultants.

Health promotion

Staff were consistent and proactive in supporting children to live healthier lives. There was a focus on early identification and prevention of health and wellbeing problems and on supporting children to improve their health and wellbeing.

The service had relevant information promoting healthy lifestyles available to parents. Staff assessed each child's health when admitted and provided support for any individual needs to live a healthier lifestyle.

Consent, Mental Capacity Act and Deprivation of Liberty Safeguards

Staff followed national guidance to gain consent. They knew how to support children who lacked capacity to make their own decisions.

When we inspected the service was supporting children under the age of 16. This meant that the provisions of the Mental Capacity Act did not apply.

Good

Community end of life care

Information about the child's capacity to make decisions about their support was included in the care files and parents had signed consent forms to show that they agreed with the support provided by the service.

All clinical staff had undertaken training in the Mental Capacity Act and Deprivation of Liberty legislation together with Gillick Competence and Fraser Guidelines.

Are Community end of life care caring?

Good

We have not previously rated this service. We rated it as good.

Compassionate care

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

Information about equality and diversity needs and preferences was included in the care plans for children who used the service. The service had an equality, diversity and inclusion policy, which was reviewed regularly and included in the staff induction programme. Staff training records show that all staff have undertaken equality and diversity, dignity in care training and person-centred care as part of their mandatory training requirements.

Staff were discreet and responsive when caring for children. We observed 5 staff working and found that staff took time to interact with the children and those close to them in a respectful and considerate way.

Emotional support

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

Staff gave children and those close to them help, emotional support and advice when they needed it. The child's care plan included information on the emotional well-being of the child, whether they experienced mood swings and what strategies were adopted to support the child if they became distressed.

We were shown a report of an incident when a child had become distressed and how the staff had supported the child in an open environment, helping them maintain their privacy and dignity.

Staff undertook training on behavior's that challenge, breaking bad news and demonstrated empathy when having difficult conversations.

Staff understood the emotional and social impact that a person's care, treatment or condition had on their wellbeing and on those close to them.

Understanding and involvement of children and those close to them.

Staff supported and involved children, families and carers to understand their condition and make decisions about their care and treatment.

Good

Community end of life care

Staff made sure children and those close to them understood their care and treatment. Staff were observed talking with children, families and carers in a way they could understand, and using communication aids where necessary.

Children and their families could give feedback on the service and their treatment and staff supported them to do this. Feedback on the named nurse caring for their child was included in the staff supervision and appraisal framework.

Parents gave positive feedback about the service. Parents we spoke with were positive about the way that staff interacted with the children and themselves. Five parents spoken with stated that they felt supported, and that the service involved them in decision making and one parent stated that they couldn't say enough positive things about the service.

Are Community end of life care responsive?

Good

We have not previously rated this service. We rated it as good.

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

On the initial referral / assessment the language needs and preferences of the families were ascertained, and translator services were available. Information was available in different languages.

Managers planned and organised events and activities, so they met the needs of the local population. An example of this is when, during the Covid-19 outbreak Kites Corner was shut for several months due to parents being anxious about leaving their homes and the children receiving respite.

During this period of lockdown, the service contacted every family at a specific, agreed time each week to offer emotional support and practical support. The service undertook the role of advocate with other professionals, as well as organising shopping deliveries, pharmacy deliveries etc. The service was able to assess the families psychological and emotional wellbeing remotely ensuring the safeguarding of children and was able to share concerns with other healthcare professionals.

The service also ensured that hampers were sent to all families and created a reopening manual to share with families and staff before Kites Corner was open to address any anxieties that families / staff may have. The service organised the procurement of PPE for families, created safe systems of working and risk assessments on how Kites Corner would reopen and provide safe respite during COVID-19. Child friendly moveable furniture to create child friendly zones within Kites Corner was purchased to ensure that on re opening children remained 2 meters apart.

The service hosted 'Stay & Play sessions', which had 3 to 5 families attending each week, and had plans to start booking in feature sessions such as music therapy to assist with growing interest in these.

Managers monitored and took action to minimise cancelled respite sessions and ensured that the parents of children who did not attend respite sessions were contacted.

Good

Community end of life care

The service utilised information from the child's education, health and care plan's (EHC) and MyPlan+ health and educational needs assessments as part of the child's individual care plan.

The charity provides support to parents who have lost a child, through the hosting and facilitating of meetings of parents and carers in the memorial garden area. The service ensures that parents receive support in accessing bereavement counselling and statutory agencies.

Meeting children's individual needs

The service was inclusive and took account of children' individual needs and preferences. Staff made reasonable adjustments to help children access services. They coordinated care with other services and organisations.

Staff we spoke with understood and applied the policy on meeting the information and communication needs of children with a disability or sensory loss. The service had information leaflets available in languages spoken by the local community.

The care plans included guidance for staff members about how to support individual communication requirements, for example what signs the child uses and for what, and detailed information about how a child expresses pleasure and dislike. The service had used a variety of visual, audio and sensory aids to communicate with the child. These included use of tablets, interactive furniture which responded with coloured lights to the child's touch and sound walls that had touch controls to enable the child to choose sounds and lights.

Managers made sure staff and children, parents and carers could get help from interpreters or signers when needed.

The daily routine of the child, including cultural and religious preferences, were discussed with the parents / carers and included in the child's care plan. The service supported children to participate in social and play activities according to their preference.

Access and flow

Children could access the specialist palliative care service when they needed it. Waiting times from referral to achievement of preferred place of care and death were in line with good practice.

Managers monitored waiting times and made sure children could access services when needed and received treatment within agreed timeframes and national targets.

The Trustees Board report for September 2022 gives figures for vacancies, referrals and leavers with percentage figures of attendance for overnight respite, day respite and summer club. Three new referrals were reported as going through the assessment process and no delays were reported.

Learning from complaints and concerns

It was easy for children 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 in the investigation of their complaint.

Parents we spoke with knew how to complain or raise concerns. The service clearly displayed information about how to raise a concern in child areas.

Good

Community end of life care

A leaflet had been produced by the service, called 'compliments, concerns and complaints' and was given to parents / carers as part of the welcome pack and copies of the leaflet was available in the reception area. The leaflet details the complaint process, what further actions could be taken by the complainant if not satisfied with the outcome of the internal investigation and contact details were provided for the Care Quality Commission, Office for Standards in Education (Ofsted) and the Parliamentary and Health Service Ombudsman.

Staff understood the policy on complaints and knew how to handle them. Complaints handling training was 1 of the mandatory training modules that all staff had undertaken.

Managers investigated complaints and identified themes. We were provided with copies of complaint investigations. We saw that complaints had been dealt with in a timely manner with the involvement of the parent / carer. There was evidence of the results being fed back to the complainant and learning points disseminated to staff through staff meetings.

We reviewed the complaints and concerns log, there were 8 complaints over the period August 2020 to July 2022 and 5 concerns. There was evidence that these had been discussed at senior management level and action had been taken to resolve the complaints. In reviewing the complaint data, we noted that of the 8 complaints 2 referred to concerns about changes of practice following the Covid -19 outbreak, 3 were raised by staff concerning human resource issues, and three related to children.

Are Community end of life care well-led?

Good

We have not previously rated this service. We rated it as good.

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 children and staff. They supported staff to develop their skills and take on more senior roles.

We found that the service was consistently managed and well led.

From discussions with staff and parents we found the service promoted a positive culture that is child centred, open, inclusive and empowering, which achieved good outcomes for children.

Parents told us that they were informed about and involved in discussions about their child's support.

All new staff received an induction to the service which included a description of the staff roles and responsibilities in the service and the importance of ensuring that regulatory requirements were met. CQC and Ofsted regulatory compliance were standing items on the monthly operational / governance meeting agenda.

The registered manager was aware of their role and responsibility in making notifications to the CQC and the duty of candour requirements.

Good

Community end of life care

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 service and aligned to local plans within the wider health economy. Leaders and staff understood and knew how to apply them and monitor progress.

The service had developed a mission, vision and values statement that outlines the forms of support that the service offers, its vision to provide access to specialist respite care for every young child living in Gloucestershire who is severely disabled, has life limiting or life-threatening conditions and that sets out the charity's values. These have been incorporated into a poster and information cards that are disseminated to parents, carers and visitors. Day 1 of new starters induction programme included a module on mission vision and values and are included in the induction welcome pack and discussed in supervision and the yearly appraisal.

The service is a registered charity and had funding from the local authority in addition to funds raised by the charity team. The Board of Trustees received monthly updates on the charity's finances.

Culture

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

Staff we spoke with described a culture of openness and continuous learning in the organisation.

The service had a regularly reviewed lone worker policy for those staff that work on their own providing respite care in the child’s own home or in hospital. Lone working policy and procedure was covered in mandatory training

The service had a whistleblowing policy that was regularly reviewed which detailed how an employee could raise a concern, the response of the employer and what actions the employee could take if unhappy with the response. Staff spoken to were aware of how to raise a whistleblowing concern.

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 are clear lines of accountability through the service. As part of the governance framework the service has several management committees that monitor quality, risk, issues and performance to the organisation.

The Board of Trustees met bimonthly and comprises of Trustees, the registered manager and the charity manager. Reports were reviewed from the nursing department, which included percentage of children receiving respite, attendance, referrals, safeguarding's, concerns / complaints / compliments, staffing, operational activities, incidents, risk register. KPI’s were reviewed, policies ratified and feedback from the family involvement group. The treasurers report included discussion on fundraising and operational issues. Health and safety were a standing agenda item.

Good

Community end of life care

The Operational / Governance group met monthly and reviewed the risk register using a RAG rating system. General updates were provided, a review of current workload, operational issues, safeguarding's, infection prevention and control, manual handling, medication management, human resources and staffing, regulatory compliance, and volunteer / nurse management.

These meetings were augmented by a Nursing department team meeting and charity team meetings which reviewed operational challenges, changes to the nursing team, audits, reviews of individual children's care, regulatory requirements, training and dissemination of lessons learnt, health and safety, fundraising, management of volunteers and any other business.

We were shown examples of minutes of all meetings which showed reviews taking place of incidents, safeguarding's, audits and complaints and the information being feedback to staff through supervision and minutes being made available post meetings.

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.

The service had a risk register and a separate risk status list. The register had been regularly reviewed by the senior leaders of the organisation. Further to this the service had developed a 2022 -2023 Winter Preparedness Plan which detailed risks such as outbreaks including flu and Covid-19, the likely impact on the service and the actions to be undertaken by staff to address these. This included the introduction of further infection control, procedures and staff wellness / wellbeing interventions. This plan also included a presentation on monitoring the deteriorating child using the PEWS, and RAG rating the child on arrival, using an escalation algorithm to action the results of the assessment.

In assessing when a child can attend the centre, the service referenced guidance provided by the government's, 'health protection in schools' document and the NHS, is my child too ill for school guidance'.

The service had a business continuity plan policy, which had been reviewed regularly by the senior management team and was next due for review in November 2022. This document outlined the roles and responsibilities of staff, provided service continuity and recovery arrangements and covered the training testing and exercising of staff.

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.

The service had an information security retention and disposal policy which was reviewed regularly and included the roles and responsibilities of staff, data breach incident management, training and review.

Information governance was part of the employees mandatory training which all staff had attended and is included in the new starter induction programme.

Engagement

Good

Community end of life care

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

The service undertook a staff satisfaction survey in 2022. Results show a 68% response rate up from a 63% response rate in 2021. Questions included 'your engagement with JHT, Leadership, Enablement to do your job, personal perception and development. There were 49 comments from staff, 41 of these were positive with the 8 remaining comments expressed concern about morale and communication.

Staff were also able to deposit cards with their thoughts, ideas, concerns in a receptacle that could be accessed by the manager. These cards were unsigned and 3 of these cards chosen at random made positive statements about the service, the service and their co-workers.

A family / Carer survey was conducted in July 2022 with a response rate for completed surveys of 12%. Of these 92% of responses were a yes answer/positive response, 2% of responses were no and were identified as areas that needed to be addressed, and 3.5% of responses were don't know. All parents and carers were written to, explaining the results of the survey and what actions the service intended to take to address the identified shortfalls.

The service produced 2 newsletters, 'Fly the Kite' for the general public and visitors which provided an update on the charities activities and biographies of staff, and a family newsletter that detailed the sessions offered, the results of regulatory visits and an introduction to the Tapestry online journal, where parents can contribute to with photographs of activities. This newsletter also contained reminders of important service information for parents and carers.

Learning, continuous improvement and innovation

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

The registered manager attended service meetings where they could discuss and agree actions in relation to service learning and improvements. An example of this is the link that was made with a local children's hospice charity, for staff to undertake further training on the management of the deteriorating child and their assistance in developing a policy for the use of carrying out of resuscitation for a child with an advanced care plan in place.