

Julia's House Limited

# Julia's House

## Inspection report

Wiltshire Childrens Hospice  
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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?	Good 
Are services well-led?	Outstanding 

# Summary of findings

## Overall summary

This is the first time we have inspected this location. We rated it as outstanding because:

- 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 and adults from abuse, and managed safety well. The service-controlled infection risk well. Staff assessed risks to children and young people, acted on them and kept good care records. They mostly managed medicines well. The service managed safety incidents well and learned lessons from them. Staff collected safety information and used it to improve the service.
- 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, supported them and their families to make decisions about their care, and had access to good information.
- Staff consistently treated children, young people and their families with compassion and kindness. They always respected their privacy and dignity. Staff recognised and respected the totality of children's needs and that of the whole family. Staff helped children and their families to understand their conditions and supported them fully to be involved in their care. There was a strong, visible child-centred culture and staff provided emotional support to patients, families and carers in every way they could. Children and their family's social needs were highly valued by staff and embedded in their care and treatment. Families consistently and overwhelmingly told us they felt truly cared for by the service.
- The service planned care to meet the needs of local people, took account of children's individual needs, and made it easy for people to give feedback. People could access the service when they needed it.
- Leaders had an inspiring shared purpose to deliver outstanding care. They had created, developed and used reliable information systems to monitor and consistently improve the service. Leaders consistently motivated and supported staff to develop their skills to enhance the care they provided. The vision and values of the service were central to the whole organisation and visible to staff who understood them and applied them in their work. Staff felt respected, supported and valued and told us of the supportive and caring nature of staff at all levels of the organisation. The service was passion led and clearly held the child and their family at the centre. Staff were clear about their roles and accountabilities and staff felt they were encouraged and engaged. Constructive challenge was consistently sought by leaders and they strived to improve services continually for the benefit of children and their families. The service engaged well with children, their families and the community to plan and manage services and all staff were involved and committed to improving services.

However,

- The medication policy did not contain clear guidelines on the timescales for review of medication administration charts and some children had not been weighed in line with the service's medication policy.

# Summary of findings

## Our judgements about each of the main services

Service	Rating	Summary of each main service
Hospice services for children	Outstanding 	

# Summary of findings

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# Summary of this inspection

## Background to Julia's House

Julia's House is operated by Julia's House Limited. The charity provides care to children and young people with life-limiting or life-shortening conditions within the Wiltshire area.

Julia's House provides a respite service consisting of day care sessions at the hospice as well as community-based respite in the child's own environment. There is also access to multi-disciplinary end of life care provided for children who are currently using the service. Support to bereaved families is provided up to five years following the death of a child. During the COVID-19 pandemic, the service accommodated up to two children at one time within the hospice and provided an increased service within the community. Admission criteria for the service focuses on a modified version of Together for Short Lives guidance. Care to families is provided for free. Each family receives an allocation of care hours for their child and parents can 'spend' these hours as they wish.

The charity also provide care at another hospice based in Dorset. The two locations work as one team and consists of nurses, carers, family support and sibling support workers. They work closely with existing community services including community nurses, the local authority and other hospice services within the area. The service had recently recruited an additional medical doctor to provide increased medical support to the service to support choices over where end of life care could be provided. The hospice had created a bedroom suite to enable children and their families to be together at the end of life.

At the time of our inspection the charity was supporting approximately 52 families. This included 10 bereaved families. The service supported families from pre-birth and the eldest service user being supported at the time of the inspection was 18 years old.

The service is registered with the CQC to provide the following regulated activities:

- Personal Care
- Treatment for Disease, Disorder and Injury

The current registered manager has been in post since 24 August 2017. The location was registered in August 2017. This was our first inspection of this location.

## How we carried out this inspection

This was a short notice announced, comprehensive inspection. The service did not know we were coming until two days before our visit. This allowed staff to arrange patient consent for community visits.

We visited Julia's House and spent time with staff in the community. We spoke with nine members of staff including nurse team leaders, nurses, support workers and facilities staff. We also held a focus group with another eight members of staff. We spoke with six parents of children who had experienced support from hospice staff. We observed care and treatment provided in children's own homes and in the unit, reviewed data about the organisation and reviewed 24 patient care records. We held interviews with senior leaders and the chief executive officer. We spoke with one trustee through a video call.

# Summary of this inspection

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>.

## Outstanding practice

We found the following outstanding practice:

- Staff were proactive and innovative in the way they responded to the child's needs and family wishes. During the COVID-19 pandemic they sought new ways to support families in line with government guidelines and family wishes. Many families wished to shield during this period, the service supported them by providing shopping, medication collection, virtual storytelling and play therapy through the use of technology.
- The service had completed an audit that identified a high number of families wished for their child to die at Julia's House which was not anticipated. This had triggered a focus on developing medical support within the service to be able to provide and develop end of life care services. This in turn led to a memorandum of understanding being established with another local hospice to enable access and expert guidance from paediatric specialist palliative care consultants as well as appointing two hospice doctors.
- The specialist end of life suite had been designed sensitively with children and their loved ones at the centre. In doing so it was hoped they could provide more end of life care to children and young people and develop a service that met the needs of the communities it served and adapt to changes in healthcare in the future.
- The service had two parent trustees on the board to ensure accountability and transparency and that families were kept central to purpose of the board.
- Leaders encouraged innovation and participation in research. They proactively looked for ways to engage the wider national debate and policy on respite services for children.
- Families overwhelming told us of the support provided to them when other services had not been present.
- Leaders told us they were not just resilient during the COVID-19 pandemic, but they had "thrived" and supported the organisation to respond to the pace of change.
- Leaders and staff were passionate about the care they provided and kept the child and family central throughout.

## 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 MUST take to comply with its legal obligations:**

- Notifications to CQC must be completed when abuse occurs, or allegations of abuse are raised concerning a person who uses the service.

### **Action the service SHOULD take to improve:**

- The service should ensure the medication policy is clear on when medication administration record charts are reviewed.
- The service should follow their own medication policy and ensure children and young people's weights are recorded every three months.

## Summary of this inspection

- Risks should be reviewed in the time stated on the risk register and documented.

# 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>	Good	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>
Overall	Good	Good	<div>☆ Outstanding</div>	Good	<div>☆ Outstanding</div>	<div>☆ Outstanding</div>



# Hospice services for children

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

## Are Hospice services for children safe?

Good



We rated safe as good.

### Mandatory Training

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

Mandatory training was comprehensive and met the needs of children and staff. Training included modules in infection, prevention and control, basic life support, manual handling and paediatric emergency first aid. Staff had a personalised list of training they would need to complete dependent on their job role. Staff told us they were given support and time to complete these modules and those we spoke with had completed their required learning.

Staff received and kept up to date with their mandatory training. The service used an electronic training tracker to monitor mandatory training which alerted staff by email when they needed to update their training. Reminders were sent out at 28, seven and three days before the due date.

Staff training compliance was monitored on a weekly basis by the clinical development leads and reported to the senior leadership team. Leads told us clearly what needed to be completed and when and had a thorough overview of all staff compliance. Compliance levels in each staff group were rated as red, amber or green to demonstrate where training had not been attended. A report for 13 October 2021 showed staff compliance of 100% across all staff groups for each course, except for moving and handling which was at 50% for nursing staff and 88% for care staff. We discussed this at the time of the inspection and learned the training compliance target had not been met as the training had only recently returned to being delivered face to face and an additional training video had also been added. Leads were confident this would be completed imminently. We were also informed that the moving and handling team ensured practice was assessed when staff were observed on respite sitting services to reinforce good practice. This was documented and support given where further training was necessary.

### Safeguarding

**Staff understood how to protect service users 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.**



# Hospice services for children

Safeguarding training was provided for staff to level three in adults and children for nursing staff and level two in adults and children for all other staff including facilities and administrative staff. This was in line with national guidance Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff, January 2019. In October 2021 90% of nursing staff had completed safeguarding level three for both children and adults. Ten percent of staff were on maternity leave.

Staff were confident in being able to identify adults and children at risk of abuse or neglect and felt able to raise concerns according to the service's safeguarding policy. Staff were aware of how to complete the concern form and share it with the senior leader who was on call on the day. From there, the safeguarding team had links with the local authority in each area to report concerns to multi-agency safeguarding hubs. Safeguarding leads had been identified and received level four safeguarding training to support them in their role. Staff knew who these leads were and found them approachable and supportive.

Senior leaders ensured all safeguarding concerns and actions required were reviewed each day. Leaders kept detailed records of which children were subject to safeguarding concerns. The safeguarding team met monthly and analysed weekly reports on all safeguarding actions.

Staff worked with other agencies to protect adults, young people and children at risk of, abuse or neglect. We saw examples of how staff had supported and protected children by working with the other health and social care professionals involved in their care. A trustee was also a member of the national children's safeguarding board.

Senior leaders told us there had been a sharp increase in staff raising safeguarding concerns internally during the COVID-19 pandemic. Two reports were referred appropriately to the local authority as Julia's House were the lead providers. During the inspection it was noted these referrals had not been notified to the Care Quality Commission in line with Regulation 18, Care Quality Commission (Registration) Regulations 2009. Senior leaders ensured notifications were retrospectively completed and are now aware of their responsibilities in this respect to be compliant.

## Cleanliness, infection control and hygiene

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

At the beginning of the COVID-19 pandemic the service initially found it difficult to source personal protective equipment (PPE). Once a week they called upon volunteers to drive some distance to be able to collect any PPE which was available. The service then set up an ordering system for staff to book and collect PPE as and when they needed it with an allocated individual to check stocks and order more as needed. Since the introduction of this system availability of PPE had not been an issue. The service ensured all staff were tested for specific masks they needed and trained four staff members to be able to undertake these tests.

The service had a comprehensive infection, prevention and control (IPC) policy which we reviewed. The document was updated in March 2021 and covered all aspects of IPC including PPE, hand hygiene, cleaning, waste management and laundry.

A COVID-19 frequently asked questions document had been created and emails sent out to all staff regularly to update them on current guidance. We viewed two of these emails for July and August 2021. They contained information on testing, PPE, contacts and isolation, hospice opening and staff office working.



# Hospice services for children

The hospice environment and all equipment were visibly clean. The service had developed a 'COVID-19 secure hospice-based site cleaning checklist' which was completed before and after every respite session at the hospice. This was in addition to daily housekeeping staff completing a deeper clean. We viewed cleaning schedules which included the tasks that needed to be completed, when and by whom as well as method and frequency needed. We saw these were visible in all areas of the hospice and were completed in full.

Audits of cleaning were completed on a three-monthly basis. We saw results of the audit undertaken on the 9 July 2021 which showed 97% compliance. Compliance targets were set at 85% and audits had never noted any compliance below 95%. The audit identified areas such as painting which needed to be completed and action was taken with facilities to ensure these were completed.

Staff segregated clinical waste and stored it securely away from unauthorised access until contractors removed it for final disposal.

We observed staff in the hospice and within the community were bare below the elbow, in line with good practice, followed hand hygiene protocols and changed PPE, such as masks regularly. Staff were expected to undertake two rapid tests and a PCR COVID-19 test weekly. Additionally, staff were required to complete a rapid test before undertaking direct work with children or entering the hospice.

The service had taken steps to ensure only two children at one time accessed the hospice to reduce the risk of transmission and these children were within a specific bubble. Families told us they felt very safe by the measures taken and the hospice could not have done more.

Families we spoke with told us the precautions taken to protect children from infection were thorough and the amount of work that had gone into processes were described as "immense". One parent noted the hospice had "very high standards" and took the pandemic "incredibly seriously".

Incidence of infections was monitored and there had been no incidences of hospice acquired infections from January – October 2021.

## 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.

The design of the environment followed national guidance and provided a pleasant and stimulating environment for children and young people. All areas had floor coverings which were easy to clean. All bathrooms were fully equipped with height adjustable sinks. Hoist equipment was integrated throughout the building to allow for children to be supported easily and discretely. There were mobile hoists available should there be a malfunction of an integrated hoists. Bathrooms were colour coded to ensure children could easily identify their own facilities. Each room within the hospice had pictures as well as words to describe the use of room.

There was a sensory room available for children to access when they visited the hospice as well as a music room and a space with computer equipment for older children to access. All cupboards including a craft cupboard could be easily moved on wheels to be able to move around the hospice to where the child wanted to play.



# Hospice services for children

The hospice had a sensory garden which included a large ramped area where we heard children liked to race around in cars on their visits. The garden was well kept and maintained and also included an integrated trampoline suitable to be used whilst in a wheelchair.

The service had enough suitable equipment to safely care for children. Staff carried out monthly safety checks of equipment. We saw records of these checks and any issues noted and actions taken. This included mattresses and soft furnishing checks. Equipment used for emergency situations was appropriate and in an accessible location for staff when needed. We checked these emergency bags and found all equipment to be within their 'use by' dates. Equipment within these bags was checked in full on a monthly basis and we saw evidence they were completed on all items within' between January and September 2021. We saw bags had tamper evident tags on to ensure safety. However, we did note staff required scissors to open the bags which may delay access in an emergency. We raised this with the service at the time of the inspection who then provided evidence tags had been replaced with ones which could be pulled apart by hand for quick access.

In the community prior to and following any respite sit, a thorough checklist was completed with families which included checking of all equipment in the child's own home. We observed staff checking equipment during our inspection.

Electronic and mechanical equipment was maintained through a service level agreement with a local NHS trust or other service providers. All equipment we reviewed was within their service dates. The service had a comprehensive register of all equipment which included the service provider responsible as well as dates of previous and next service and review. Any repairs needed between service dates were carried out promptly.

The service had suitable facilities to meet the needs of children's families. Rooms were spacious, air conditioned and easy to access for all levels of mobility. The outside garden was available for quiet reflection if needed. A suite had been developed for any child or young person receiving end of life care. This room had been sensitively developed to allow families to be near their children but also included a separate room where they could have some time alone. These rooms were adjoining and had access onto the garden area directly.

## Assessing and responding to patient risk

Staff completed and updated risk assessments for each patient and removed or minimised risks. Risk assessments considered patients who were deteriorating and in the last days or hours of their life.

Staff completed comprehensive and numerous risk assessments for each child on admission to the service. These risk assessments were child specific and individualised. Assessments included the identification of environmental risks, risks to wellbeing, COVID-19, and risk assessments around other children within the family. Staff reviewed risk assessments annually or when there was a change regarding care needs. We saw a spreadsheet which evidenced when reviews had been completed or were due for completion. This spreadsheet was audited for compliance by service leads.

All children were allocated a named nurse and had a small team of four to five nurses and carers who provided their care. There was regular communication within those teams as well as more formal monthly meetings where all children were discussed. Named nurses were responsible for reviewing risk assessments and were updated at least once a month through a care update meeting held with all members of the multi-disciplinary team to discuss any changes to the child's needs.



# Hospice services for children

Staff told us all children and young people had an advanced care plan and this was discussed in collaboration with the other medical, clinical and social care professionals involved in the child's care externally to the hospice.

Staff told us they felt safe and well supported when working in the community as there was always a senior or on-call nurse for support with additional back up provided by one of the strategic leadership team who were on call.

The hospice did not use a nationally recognised tool such as the Paediatric Early Warning system (PEWS). PEWS is a system which provides an indicator and advice for action in acutely unwell children at risk of deterioration. The action taken depends upon children's vital signs such as blood pressure, respiration and heart rate. Staff informed us work on using this tool within the service was being looked into but was not being used at the time of the inspection. The service had a 'Seeking Urgent Medical Support and Transfers' policy. This policy included a comprehensive process in relation to actions to be undertaken if a child's health deteriorated in their own home or in the hospice. This included contacting emergency services and undertaking baseline observations

## Staffing

The service had enough staff with the right qualifications, skills, training and experience to keep patients 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.

Senior leaders monitored rates of sickness, staff turnover and vacancies and reported these figures to the board. The COVID-19 pandemic and maternity leave had presented challenges for staffing the service. At the time of the inspection the service had an overall vacancy rate of 17% across the organisation. Clinical vacancies included three full time equivalent (FTE) senior nurse vacancies and six (FTE) nurse vacancies.

The service provided was flexible and therefore arranged to reflect the staffing resource available. The care needs of each child were assessed by a nurse and if there were no complex procedures or medication to be given then one member of care staff could provide care for the child if a family member remained in the home. Staffing was therefore safe.

Senior leaders recognised the national shortage of care and nursing staff and the impact this had on recruitment. However, they had taken proactive measures by advertising maternity cover posts as permanent, networking with NHS providers and introducing flexible contracts. A staff introduction payment was recently increased to encourage staff to promote recruitment.

The service had been able to recruit two registered nurses and had supported two existing members of staff to qualify as nurse associates through an apprenticeship scheme.

In October 2021 the service appointed a second hospice doctor to support the medical care provision and to hopefully establish capacity to undertake more end of life care provision. Specialist Paediatric Care Consultant cover was provided through a memorandum of understanding with another local hospice provider.

The service employed bank staff when needed to ensure staffing needs were met. Senior leaders told us agency staff were never used. All bank staff were included in training and all received a full induction before commencing work.



# Hospice services for children

Senior leaders arranged rotas six weeks in advance to be able to support staff with flexible working in a way that met the needs of the service. Leaders wanted to ensure staff were supported as far as possible to undertake regular commitments such as exercise classes or childcare arrangements and work for the service in a way that suited them. The service had introduced an agile working framework to allow staff to choose when they wanted to undertake other work activities, aside from clinical shifts, and worked with them to determine the best way to do this.

## Records

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

Patient notes in the community and the hospice were comprehensive and all staff could access them easily. Records we reviewed had individual assessments and care plan documents which were personalised and included child and family choice and consent to share information. We reviewed three sets of paper records and audited 22 sets of notes on the computer system. We found they were all secure, complete and legible. However, we did note an out of date policy on infection control was in an individual child's home. The policy had been updated and when we raised this with the provider, they took action to remove and replace. Senior leaders carried out monthly audits of care records and noted where actions were needed to improve.

Care plans we reviewed were child and family specific, comprehensive and personalised. They included the well-being of the whole family. Records also named relevant medical and social care professionals involved in the child's care in all notes we reviewed.

Paper copies of records were kept in children's homes and information transferred to an electronic recording system. This system was bespoke and tailored to the needs of the hospice. Staff told us the computer system recorded everything in an easily accessible way which helped with communication between staff members. The service was looking at the possibility of using a different electronic record system for the future which would link with other health care services to improve information sharing.

## Medicines

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

Staff mostly managed medicines in line with their policy. The service did not routinely give medicine unless that medicine was time specific or would be needed in an emergency. Where medicine was given staff checked all medicines with families before each respite session and had a process to sign in and out all medications. We saw this happened during each session we observed. Medicines were only given by carers where the carer had been trained and assessed as competent for each individual medicine. Where complex or multiple medicines were needed a registered nurse would attend.

A medication administration record (MAR) was completed for all time specific or emergency medicines which needed to be given. The Julia's House doctor would transcribe MAR charts on a weekly basis as needed and the named nurse was responsible for ensuring the MAR chart was up to date before a respite session was undertaken. We reviewed MAR charts during the inspection on the 13 October 2021. We found that one child had been prescribed medication on the 3 April 2021. However, their weight was last recorded on the 30 November 2020. This was not in line with the provider's policy which stated the weight of the child should be recorded in the last three months as this may affect the dosage of medicine needed.



# Hospice services for children

The service kept records of medicine prescribed to children. All current medicine for the child or young person was documented on the electronic care record even where the service was not administering them.

The medicines management policy was comprehensive and set out how medicines should be prescribed, recorded, administered and stored. The policy referred to relevant guidance such as 'Together for short lives TFSL (2020) APPM Master Formulary 2020 (5th Edition)'. However, A TFSL safe use of medicines toolkit had been introduced in June 2021 and this had not been added to the medication policy at the time of the inspection as the policy was not yet out of review date. The toolkit gave information and guidance to professionals working in children's hospice and palliative care settings about using medicines safely. Senior leaders informed us they were aware this had been published since the last review of the provider's policy and would be included at the review of the medication policy due in October 2021.

Staff stored medicines safely. Medicines were stored in locked medicine cupboards or in a designated medicine fridge. The registered nurse in charge of the session was responsible for the keys to the cupboards. We saw daily checks of the fridge temperature were consistently undertaken and recorded. The medicines policy noted the accepted range of temperature for the fridge and what staff would need to do if the temperature fell outside of these ranges. We were told if medicines were in the fridge, they would be checked for the high and low ranges at the time medication was in the fridge. However, the fridge had not been needed to store medication for a number of years.

In the community regular medication for each child was kept in their own homes and stored by parents. The service did not provide guidelines on how medicines should be stored in the child's own home.

Staff had access to the British National Formulary for Children (BNFC) via an application on their mobile phones. However, we found copies of out of date BNFC reference material within the hospice. This was a concern because it could lead to mistakes being made in the prescribing of medications. We raised this at the time of the inspection and senior leaders disposed of all out of date copies at once.

The service was supporting two nurses to undertake non-medical prescriber courses to enhance the ability of the organisation to prescribe medicines.

## Safety Performance

The service used monitoring results well to improve safety.

Staff monitored safety performance to indicate how safe the service was in providing care. The service had reported zero never events, zero hospice acquired skin pressure damage and zero healthcare associated infections.

## 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 patients honest information and suitable support. Managers ensured that actions from patient safety alerts were implemented and monitored.

Staff recognised and reported incidents through the use of a clear reporting structure. Incidents were escalated to the on-call senior nurse and could be escalated to the strategic lead from there as necessary.



# Hospice services for children

The service had recently changed the incident reporting process from Care, Accident, Incident, Complaint, to a Listen, Educate, Apologise, Reflect, Notify (LEARN) form. Senior staff told us this had been well received by all nurses and care staff enabling the emphasis to be on what the organisation could do differently when incidents occur rather than lay blame. Staff told us the form was used as a reflective tool and nurses used the learning to develop solutions to issues as they arise. The change had seen an increase in incident reporting. Staff informed us of incidents they had reported and feedback they had received regarding actions taken.

Staff told us there was a very open culture around learning from incidents. Staff received feedback during team meetings. Learning and outcomes were fed back in this way and also individually. Staff told us information sharing was carried out sensitively and did not focus on individual errors but on what could be learned from the incident.

Staff received feedback from investigation of incidents, both internal and external to the service. Managers shared learning about incidents with their staff and included learning from other services. The chief executive informed us there was a strong emphasis on learning through incidents that had been investigated nationally to ensure similar incident do not occur at the organisation and shared examples of this.

Incidents, actions and learning was discussed at the clinical governance committee and a report presented to the organisational board meeting, so executives had oversight of incidents. Information was cascaded to staff at team and department meetings. We saw actions that had been taken following incidents. These included liaising with other services for more information, learning outcomes and further training and changes to care plan templates to add prompts. Managers debriefed and supported staff after incidents.

Staff understood the duty of candour. They were open and transparent and gave patients and families a full explanation if and when things went wrong. We saw how patients and relatives were kept informed of actions taken after incidents.

Lead nurses were responsible for managing patient safety alerts and ensuring staff were aware of any changes. We saw evidence of communication with staff regarding a patient safety alert around ventilators with an ask for equipment to be reviewed and parents informed.

## Are Hospice services for children effective?

Good



We rated effective 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.

National guidance and evidence-based practice was used to create policies and deliver patient care. The service monitored guidance provided by the National Institute for Health and Care Excellence (NICE), Together for Short Lives and Public Health England amongst others. We saw this guidance was embedded in policies. Clinical audits were completed to ensure staff were following guidance. The service followed the NICE principles in best practice for clinical audit to ensure their audits met the five stages of clinical audit cycles to be effective.



# Hospice services for children

The service assessed themselves against the NICE quality standard QS160 End of life care for infants, children and young people. We reviewed a document from October 2021 outlining how the quality standards were being met and if not, how they were planning to meet them in the future.

Policies were updated within their review dates and staff followed them to plan and deliver high quality care according to best practice and national guidance. The service kept a spreadsheet documenting when policies were due to be reviewed and had good oversight of this. We reviewed a number of policies and found them to be thorough, comprehensive and in date.

## Nutrition and Hydration

Staff gave patients 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 patients' religious, cultural and other needs.

Staff made sure children and young people had enough to eat and drink, including those with specialist nutrition and hydration needs. Staff supported children with eating and drinking during their respite community or hospice sits.

Staff completed feeding, nutrition and hydration care plans. We reviewed these and found them comprehensive and clear to follow. We observed clear communication between staff and families regarding children's preferences and needs.

Staff were able to support families with cleaning and changing of specialist equipment such as tubes required for feeding. Families told us they appreciated this level of support and specialist care. One family noted the nurses were able to encourage their child to eat where others had failed so they felt comfortable to leave their child to be cared for.

## Pain relief

Staff assessed and monitored patients 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 monitored children for pain or discomfort and the hospice doctor could prescribe pain relief if required.

Care was provided to each child individually within small teams to provide continuity of staff. Due to this, care staff developed close relationships with the children they cared for which allowed them to be very aware of the child's needs and cues relating to pain. We observed care being provided where the member of staff was aware of very subtle non-verbal communication regarding the child's discomfort. The staff member was able to support the child to change their position to improve their comfort and move to another activity based on this observation.

## Patient Outcomes

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

There was a clear approach to monitoring and auditing the quality of the service. In the absence of any nationally agreed outcomes framework for hospice care for children and young people, the service leads used a range of measures to ensure the quality and effectiveness of the care and treatment provided.



# Hospice services for children

Managers and staff carried out a comprehensive programme of repeated audits to check improvement over time. The service had a plan of annual audits which were reported to the executive team. Improvement actions were identified following these audits. Senior leaders shared the outcome of audits with the board through the clinical governance committee papers.

Senior Team Nurses audited community nursing notes. The named nurse resolved any issues identified on an individual basis and would be continuing to carry out rolling audits. A medication audit was completed which showed an 86% compliance rate. Themes identified included a lack of photograph and weights not being recorded within a three-month timeframe. Individual actions were being addressed.

Hand Hygiene audits were completed at every hospice session and additional training provided to remind all care staff the importance of hand hygiene.

Infection control audits were carried out and issues identified were discussed with the facilities team. The lead nurses for the hospice service met with the facilities manager each week to highlight issues and remedy them to ensure issues were dealt with promptly.

The service audited advance care plans for children receiving support in October 2019. The audit had noted a number of gaps within care records for children and young people in relation to end of life care decisions. Several actions were taken following the review of the audit. These included meetings with local community children's nursing services to discuss the children who did not have advanced care plans. A change to the electronic records system to record these decisions. Additionally, a prompt was added to documents for discussion at the monthly meetings.

The audit highlighted many families did not wish to enter into formal discussions around end of life care for their children or if there was evidence of no annual review it was due to the fact families did not want to revisit these discussions each year. The service was sensitive to this.

The audit did identify that a high number of families wished for their child to die at Julia's House which was not anticipated. This had triggered a focus on developing medical support within the service to be able to provide and develop end of life care services. This in turn led to a memorandum of understanding being established with another local hospice to enable access and expert guidance from paediatric specialist palliative care consultants as well as appointing two hospice doctors.

The service recognised further work was required around transition of care between children and adult services and was in the process of setting up a group to undertake a piece of work on this and support children in this situation using Together for Short Lives – A Transition Pathway for young people with life-threatening and life-limiting conditions.

## 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.

Staff were experienced, qualified and had the right skills and knowledge to meet the needs of children. All staff including bank workers underwent a comprehensive induction period when they first commenced their role at the service. This induction was comprehensive and formally documented. It included spending time with various people throughout the



# Hospice services for children

wider organisation such as fundraising or retail to ensure a good understanding of the workings of the whole service and where the individual staff member fitted. Line managers had clear responsibilities set out to support new staff including frequency of meetings and review of progress. Staff were supported to shadow other staff members for approximately four to six weeks or until they felt confident in undertaking their own role.

Staff were provided with a formal one to one meeting with their line managers roughly every six weeks. The service was reviewing this to see if there were any changes that needed to be made. These meetings looked at the wellbeing of staff, caseload discussions as well as keeping track of progression and training needs.

Each child was individually assessed to determine what competencies staff would need to provide care to that child. The named nurse for the child would then assess and “sign off” staff who were able to demonstrate to required skills to provide care for that individual child.

Staff competence was monitored and formally reviewed during annual appraisals of their work. Senior leaders monitored staff appraisals and rates of completion. The organisation as a whole had an appraisal completion rate of 98% in October 2021, with only three members of staff not having received their appraisal in the last year.

Staff were supported to maintain and update their knowledge and skills. In addition to mandatory training the service had identified additional training which supported their individual roles and specialities. This included sessions in, but was not limited to, respiratory, neurological, renal and cardiac, clinical skills as well as play workshops, end of life care and bereavement training.

Managers encouraged staff to attend external and university led education and training. The Director of Care told us staff were supported with training they wished to undertake, be that financially or being enabled to take time off to attend courses which could be used to improve the overall service provided.

Staff told us how they had received additional training in Makaton, a system of communication and senior leaders told us training courses had been identified by sibling support staff on undertaking difficult conversations with siblings, which they were then enabled to attend.

The service was supporting two staff members to start a nurse prescribing course and were developing the skills of care staff into nurse associate roles.

## **Multidisciplinary working**

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

Staff held regular and effective multidisciplinary meetings to discuss children receiving support and improve their care. Full “Care Update Meetings” were held on a monthly basis and attended by all disciplines within the service. Staff provided updates on all children in their care and discussed how they could best support them.

Senior leaders told us they worked across other providers of hospice care to provide services. This collaboration was based on mutual respect and clear and honest discussions about expectations of what could be provided. For example, the team worked with other providers who may be able to provide end of life care within a hospice, where that was the wish, and Julia’s House provided staff within the community to support that provision.



# Hospice services for children

Staff told us communication with the wider community of healthcare professionals was embedded. Nurses regularly met with community children's nurses to discuss the needs and care of the child being supported.

## Health promotion

Staff gave children and families practical support to help them live well.

We saw numerous examples where the holistic needs of all the family were considered and the health and well-being of the whole family were promoted. Complimentary therapies were provided which included massage and reiki. A counselling service was also being introduced for families. Sibling support was a well-regarded aspect of the service provided by the organisation and supported siblings of those with a life limiting illness to have time for themselves as well as recognition of young carers.

Families told us the provider had helped them to link with other services such as continence support, education, supporting hospital visits and encouraging parents to raise issues with services when they felt certain elements of care were not being provided.

## 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 followed national guidance to gain children's or their parent's consent. They received training in supporting people who lacked capacity to make their own decisions.

Staff gained consent for care and treatment from young people, where appropriate, or their families, in line with legislation and guidance. Conversations about care included the whole family. Records showed consent was gained and documented in relation to multiple decisions including access to medical records, sharing of information, medication, therapies and care planning. The records we reviewed showed detailed conversations taking place with children and families to ensure people were informed with all the relevant information needed to make decisions.

Staff understood and kept up to date with training in the Mental Capacity Act and Deprivation of Liberty Safeguards which related to young people aged 16 and over and establishing consent from children, their parents or their legal guardians.

## Are Hospice services for children caring?



We rated caring as outstanding.

## Compassionate Care

Staff treated patients with compassion and kindness, respected their privacy and dignity, and the totality of their individual needs.



# Hospice services for children

All staff demonstrated genuine empathy and an understanding of the totality of both the child's and the family's needs. Staff spoke with passion about their work and went above and beyond to ensure the care provided was excellent each time they visited a child. We observed interactions between staff and children was always sensitive, engaging and compassionate.

We observed care being provided within the hospice and the community. Staff were always patient and encouraging. We saw support being provided to children to achieve tasks at their own pace. Care staff offered encouragement to enable children to remain independent.

Children told us they liked coming to the hospice. We observed children being excited and engaged when receiving care from the service. Due to the small size of teams working with children, every child had developed close relationships with their care team and knew every person caring for them. One child we observed responded energetically to care staff when they visited them. Another child was happy to be left at the hospice and showed no sign of being upset when their parent left.

Staff were discreet and responsive when caring for children and their families. Parents told us staff were consistently sensitive to their needs. Parents said staff picked up on subtle cues that they may be finding things difficult and instead of asking in front of the child, they would receive calls following the sits to check in with them and give them time and space to talk.

The child's needs and wishes led the care that was provided. Personal care was completed in a private and sensitive way. We observed staff using private areas to undertake care and speaking to the child sensitively to ensure their comfort throughout. We reviewed 24 care plans, and all were comprehensive and personalised to each child.

We spoke with six parents of children using the service and reviewed feedback provided by families. Parents were overwhelmingly positive about the caring nature of the staff and the service as a whole. One parent told us the service was "wonderful", another noted the staff "are great and I love them".

Parents told us the service was consistently respectful of family choices. They felt listened to, cared for and respected.

One family told us their child was always happy and excited when the care team arrived, and this was a good indicator to them of the level of support and care the service provided. The team were described as being thoughtful, practical, thorough and that they always thought ahead and planned activities to get the most out of the time they spent with children to make it as good an experience as possible.

Families told us the talking, helping and giving of time was immensely important. Staff would go out of their way to support children. For example, some staff were able to style hair and one family described how their children loved this. One family told us how staff had celebrated their child's birthday by bringing balloons and they were moved by this personal touch.

During the COVID-19 pandemic services were adapted to ensure children and their families could still access support. The service set up online play sessions which included dropping off baskets of ingredients and kitchen equipment to children and their families so they could then bake together with staff over video calls. A virtual story time was offered which children could access, and work went into setting up a virtual sibling club, online gaming events for children to get together, as well as scavenger hunts and even playing cards. This provided an opportunity for children and their siblings to have a chance to speak with other people outside of their family and for parents to have a break whilst still being in the home under lockdown conditions.



# Hospice services for children

Named nurses visited children and their families from the end of the garden path. Staff told us they did this so families would not feel alone and to provide a face to let them know they were there, and they cared about them. Staff took shopping and collected medicines for families whose children were shielding.

Staff told us of a situation where a member of a family had to undergo emergency surgery. The service was able to step in at short notice and provide respite to that family to ensure the child could be cared for at home rather than have to move to foster care. The family were supported by the service when the family member returned home and was cared for until ready to begin caring for their child again.

## Emotional Support

Staff went over and above to provide emotional support to children, young people and their families to minimise their distress. They understood children's personal, cultural and religious needs. There was a strong child-centred culture.

Staff consistently told us they felt "privileged" to be trusted by families to look after children but especially so, when that child was experiencing a life limiting illness with often complex needs. They recognised the unique position they were in to provide emotional support and strived to go the extra mile for children and their families.

Staff took time when working with children and their families to build relationships and recognised the importance of their role in being available for children and their families. During lockdown periods, staff felt this even more acutely and were sensitive to the increased levels of stress families faced. They offered opportunities to discuss anything the family wished to relieve anxiety.

The service provided counselling support and complimentary therapies. We reviewed feedback which showed parents felt able to access these services and being able to have a cry and time for a massage, provided them with relief and an opportunity to reflect.

Staff told us they cared for the whole family and described their care as being a "hug around the family", another noted we "wrap services around them all".

One parent told us the service always seemed to know how they were feeling as parents and when they were under increased stress. However, they would be sensitive to this and always call or email rather than speak about anything in front of their child. They were given time and space for themselves which they appreciated.

One parent told us "they have been amazing" and they would "not want to be without them". Another told us "they really are amazing, everything they do is amazing, they really know and care and give us time as a family".

The service provided a quilt to every child who spent time in the hospice and also their siblings. This was to support the connection with the hospice and to provide comfort to children when moving between home and the hospice.

The service supported families for up to five years following the death of a child. This was longer than other services who generally provided support for up to three years. The service contributed £1,000 towards the cost of funeral services to support families financially at the most difficult time. Carers and nurses put together memory boxes for families to be able to remember their loved one.



# Hospice services for children

Every year a “remembering day” was held for all bereaved families as a chance to “reflect together on happy times shared with some very special children”. During the COVID-19 pandemic these days were unable to take place within the hospice for infection prevention reasons. Instead, the chief executive recorded a personalised video which was shared with all families to provide a connection with the hospice. Remembering days would usually involve the provision of food, and arts and crafts. Instead the service sent out a “doorstep” cream tea for families to enjoy at home.

In August 2021 a sky dive was undertaken by one of the sibling support workers and a sibling of a young person that had been supported by the service. The sky dive was undertaken in memory of their sibling. They appealed for donations for the hospice and stated “they have always been like family to us, I’m so grateful for everything they have done. Without them I would not of had the most amazing childhood. From their help and support we’ve been able to create our own happy memories that will last a lifetime”.

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

Staff consistently supported and were committed to involving children and their families in decisions about their care and how this was provided. They sought out ways to communicate effectively with children and their families. Families were central to decisions about care and staff sought out their views when changes needed to be made in light of the COVID-19 pandemic.

Staff made sure children and their families understood their care and treatment. We reviewed care plans and found them to be comprehensive and holistic and included the well-being needs of the whole family. Staff took time to get to know the family. For example, the play team delivered six face to face or video sessions to really get to know the child or young person. They then delivered a personalised red, spotty play bag. The bag contained tools for families and staff to be able to interact and play with the child in a way that was unique to them. They wrote a personalised communication, development and play plan for that child which was then followed by the small team of staff involved in their ongoing care. We saw feedback from families who were touched and impressed by the personalised nature of these items and it demonstrated a real awareness of the needs of the child.

Involvement of siblings of the unwell child was equally considered. We heard of numerous examples where siblings had been supported by the sibling support workers in a personalised and caring way. For example, we heard of staff taking one sibling out for walks in the countryside whilst dressed in dinosaur pyjamas as that was what the child wanted to do. All activities were based on the likes and preferences of the child to produce the best environment for supportive relationships to be built.

Staff talked to children and their families in a way they could understand, using communication aids and different methods of communication where necessary. We observed excellent communication between staff and the children they cared for. Staff picked up on very subtle non-verbal communication and it was evident the child was at the centre of all engagement. Staff undertook training on Makaton which is a language programme that uses symbols, signs and speech to enable people to communicate. Staff also made suggestions to leaders of other communication methods that could be used and sought out training on these methods with support from senior leaders. Each interaction with the child was completed in a considered manner to support them to have the greatest involvement.

Families told us the service communicated in the best way for them be that through email, text or by telephone. We spoke with one parent who told us they had requested communication only by text message and this had always been acted upon.



# Hospice services for children

Families were actively encouraged to give feedback on the service. The provider conducted a “Family Survey” in August 2020. The feedback showed 18 people out of the 22 people who responded noted they were satisfied with the service being provided. The survey allowed families to make comments and we saw families had missed family events where Julia’s House would organise community activities or days out. The service was acting on this and actively working on organising a family event for 2022.

## Are Hospice services for children responsive?

Good



We rated responsive as good.

### Planning and delivering services which meet people’s needs

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.

Julia’s House worked with other hospice providers within the area to provide care for individual children. They had a memorandum of understanding with another local hospice and held regular meetings with them.

When providing end of life care as part of a wider team of care providers senior leaders acknowledged this was based on understanding their own and other providers boundaries and managing expectations honestly from the beginning. Senior leaders were clear that communication was key in this.

In March 2021 the provider took part in a system wide, CQC led, provider collaboration review (PCR) into how cancer services were delivered to people living in Bath, Swindon and Wiltshire during the COVID-19 pandemic. The provider was able to provide examples of how they had worked with other key stakeholders, such as local NHS trusts. The chief executive officer had contacted local hospitals and offered standby capacity of beds, facilities and staff to support the wider system in response to the pandemic.

The service worked closely with children’s community nurses and paediatric oncology outreach nurse specialists. A new Wiltshire wide meeting had recently commenced which included the children’s commissioner for Wiltshire, other local children’s hospices, paediatricians and commissioners. Senior leaders attended these meetings to make connections with the wider system.

Senior leaders acknowledged they were not actively generating referrals from the local community but were able to meet the needs of those children referred to them at the time of the inspection. They noted their strategy was to increase their understanding of local prevalence within the community to plan and deliver services for the future.

### Meeting people’s individual needs

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



# Hospice services for children

Leaders explained that all respite sits were pre-planned with families and this was a key part of the lead nurse role. This involved regular contact with families to discuss what service they would most benefit from. Families were able to choose whether respite was provided in the home or within the hospice the times and days they preferred. For example, some families wished to go out of an evening whilst others wanted time to spend with their other children in the day. This was all determined on an individual basis.

All families could access the same set number of hours and used them as they wished. Due to this the service could plan their rotas for approximately six weeks ahead of time and ensure they had the staff availability.

When the hospice building was reopened the service approached all children and the families in their care and recorded their requests of what services they wished to take up. This was paying respect to the fact many families were shielding and did not wish for staff to visit their children at home. The service used this information to provide a personalised service and allowed them to plan the delivering of their care when lockdown restrictions were eased.

The hospice building itself was designed to meet the needs of children and their families. There were kitchen facilities to cater for refreshments. The Pegasus suite had been redesigned thoughtfully to support children at the end of life. The suite had an adjoining room where families could be close to their child and yet still have space for reflection. The suite led directly on to the sensory garden.

The service provided translation services for care documents and interpreters where needed at meetings for families to take part in meetings. Care staff were educated in cultural differences and diverse requirements in end of life care. This included how different faiths were accounted for in bereavement support.

## Access to right care at the right time

People could access the service when they needed it and received the right care promptly.

The service provided respite support to children and young people and were beginning to develop their end of life care services. The service received direct referrals from families and from other health care professionals. Families could access the service even prior to the birth of a child where a life limiting illness had been diagnosed in an unborn child. This allowed them to provide support to families at the point of diagnosis.

Referral criteria were based on the nationally recognised “Together for Short Lives” categories of life limiting conditions. In addition to this the child had to be under 18 years of age, resident in Wiltshire and the family, or where applicable, the young person was able to give consent for that referral.

Following acceptance of the referral, the child would have initial contact with the lead nurse. A separate visit was then undertaken to complete a comprehensive care plan and contact with the other health professionals involved in that child's care to provide an overview of all services involved. A named nurse was allocated, and this nurse would visit the family on a monthly basis.

The service monitored the times between initial referral and providing services. The service did not necessarily start providing a service at the time of initial referral if this was the wish of the family. There was a fast track framework for children who needed services quickly. The panel was able to meet seven days a week to discuss referrals and make decisions on the children they accepted.



# Hospice services for children

We heard some families had found it difficult when services were adapted to meet the government regulations in relation to COVID-19 restrictions. However, parents felt well informed about why the changes were necessary. Some families told us they would benefit from more overnight stays and queried if the service could commence this support in the future.

## 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 families in the investigation of their complaint.

Families knew how to complain or raise concerns. There was a clear complaints policy which staff understood. Staff told us they knew how to handle any concerns, felt confident in dealing with any complaints and knew how to escalate to senior leaders.

Families told us they felt able and comfortable to raise any concerns they had with any member of the care team and were confident actions would be taken to resolve any issues. One parent told us of having to make a request that a carer not use gel, and this was respected and acted upon. They also received a call from a member of the senior leadership team to confirm the arrangements. We heard of one complaint from a number of years prior to the inspection which had been immediately responded to and acted upon. The family noted they felt completely confident in the actions taken to prevent the incident happening again and it never did.

A suggestions box was located in a prominent position in the hospice and there were clear details on how to raise a concern on the provider's website.

The service had not received a formal complaint since 2018, however, when a concern was raised these were acted upon in the same way as a formal complaint and investigated in line with their policy. This included a complaint investigation and a follow up letter sent with the outcome of the investigation and an apology.

Leaders used information provided to them as an opportunity to improve the service. As a result of concerns being raised actions had been taken and learning shared with all members of the care team.

Complaints were a standing agenda item for each team meeting as well as the clinical governance meeting and for discussion at the board.

## Are Hospice services for children well-led?

Outstanding



We rated well-led as outstanding.

## Leadership of service

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 leadership structure of care services within Julia's House consisted of trustees, executives, a director of care and lead nurses. There was strong, compassionate, inclusive and effective leadership at all levels. Leaders demonstrated the required levels of experience, integrity, capacity and capability needed to deliver high quality and sustainable care which centred on the child.

Leaders understood the challenges to quality and sustainability and took proactive action to address them. Senior leaders told us they were aware of the risks the national nursing shortage posed to the service. They were sensitive to the impact this was having on staff and recognised the flexibility and "good will" of staff supported the service at a difficult time throughout the COVID-19 pandemic. They were introducing innovative methods to increase recruitment in an attempt to address these issues. For example, incentive referral schemes for existing staff, offering maternity cover positions as permanent positions and payment which was in line with NHS staff.

Leaders were approachable and visible. Staff consistently told us leaders were visible and approachable. The service had a senior nurse on call 24 hours a day for staff to call upon but also a strategic lead who was a member of the senior leadership team. Staff told us the on-call availability of senior staff was excellent and there was always someone to call upon at any time.

Senior leaders had good relationships with trustees and trustees strived to function effectively and add value to the service. Trustees were 'buddied' with members of the leadership team and we were told these relationships were helpful and provided a critical overview of the service. Senior leaders and trustees had a good understanding of their governance responsibilities. We viewed meeting minutes of the board and found trustees had questioned their roles and asked for further confirmation on how they could provide added value to the service and how this could be measured. The board were about to undertake a governance review to ensure they were carrying out their role as effectively as they could. An evaluation tool was being used to support this and the review was being undertaken by the human resource trustee to ensure the board were working as effectively as possible.

There was a leadership strategy which included succession planning. The COVID-19 pandemic had demonstrated the importance of the service's succession plans. Senior leaders told us every position in the service had the ability to be led by any member of the senior leadership team. This was formally laid out in contingency plans. This had been invaluable during the pandemic when some staff had not been present. Staff were supported to develop into senior roles and the leadership team were aware of the importance on being a sustainable service.

Leaders within the organisation were being trained in coaching skills to ensure they were leading as effectively as possible.

Leaders were involved in effective operation of the local system and national priorities and looked beyond their own service.

Leaders discussed being incredibly proud of their staff and the organisation. They told us the whole organisation has grown and developed despite the COVID-19 pandemic. They described how they had "thrived" and continued to be "overwhelmed" by the "support and drive" the organisation had. The board of trustees reached out to staff during the pandemic to express their thanks for their work. We saw communication had gone out to staff during a time of immense challenge which noted; "your commitment, desire, hard work and compassion has been truly exemplary, and you should all be so proud. You are a credit to the charity and everything it stands for".

## Vision and Strategy for the service



# Hospice services for children

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 service had a clear vision and set of values with quality and sustainability as the top priorities. The vision for the service was formally set out in its strategy. The overall vision for the service was incorporated into the sentence “Care for the Child, There for the Family”. Everything we saw during our inspection indicated leaders and staff were passionate about the service and put the child and their family at the centre of the care they provided. Staff felt strongly about this and the vision was clear for all staff. The values of the organisation were clear and set out in the strategy and visible during our time at the hospice. The values were set out at the entrance of the hospice and all staff were aware of them and found them meaningful. The CHILD values were set out as:

- Compassionate and caring
- Honesty and Integrity
- It's up to all of us
- Listen and learn
- Determined to excel.

Staff told us the values were an integral part of the recruitment process with staff being assessed not just on their skills and experience but on their core values and what “makes them tick” to ensure they were the right people with the right attitude to work for the organisation.

The service had a clear strategy with objectives which were stretching, challenging and innovative and yet remained realistic. A four-year strategy had been developed before the COVID-19 pandemic. However, in light of the events of 2020 the organisation chose to introduce an interim policy entitled “COVID-19 Recovery 2021-22”.

The overall objectives for the organisation were ambitious and stretching. They included:

- Provide the highest quality, responsive, COVID-19 secure care and support for the whole family.
- Improve public understanding of the pressures on the families we support.
- One of the very best run charities and best workforces in the UK
- Influence and enable better care nationally.

Staff were clear about their role in achieving the strategy. The leadership had been developing a new strategic plan and was about to unveil this at the time of inspection. Staff, children and families were being provided with the new strategy ready for 2022-2025. The new strategy had the following objectives:

- Support growing numbers of children
- Enhance end of life services
- Broaden family support
- Be the best run charity with the best people.

The strategy was being presented in a child friendly manner and set out as a monopoly board with a picture of a family who used the services of the hospice at the centre. For each year there was a corresponding set of clear actions mapped out on the monopoly board with the strategic objectives at the centre. For example, securing enhanced medical cover, increasing board and staff diversity and recruitment of additional nurses and carers. This was laid out in a very clear and simple form and in a way that progress could be monitored.



# Hospice services for children

The strategy was aligned to both local and national plans for the wider health and social care economy. Leaders attended the pan Wiltshire commissioning meeting and outcomes from this led into the new strategy. The organisation was involved in lobbying of government and undertaking a pilot of respite care for families. The strategy included the need for national mass market media coverage of family mental health and respite breaks based on the report completed on behalf of Julia's House.

The organisation had a number of internationally known celebrity patrons who were supportive of the media campaign and undertook regular work in promoting the charity.

## Culture within the service

Staff felt respected, supported and valued. They were focused on the needs of children receiving care and their families. 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.

We spoke with a range of staff during our visit, including members of the leadership team, a trustee, nurses, support workers and facility team members. Without exception, all staff we spoke with told us they were incredibly proud to work for the organisation. Staff told us they had never worked anywhere else where there was such a strong emphasis on care for children but also for each other. Staff commented that the organisation was “amazing”.

Senior leaders went to lengths to ensure staff felt valued. In November 2020 each member of staff received a handwritten letter of thanks from senior leaders for their hard work and dedication throughout the pandemic. Staff told us this was well received and made them feel special. All staff also received a travel mug with an inscription of a poignant quote written by a member of the family of a service user.

During the COVID-19 pandemic the chief executive had personally called some 200 volunteers, many of them older and some shielding due to ill health, to ensure they were supported during that time.

Senior leaders recognised the impact of staff vacancies on staff wellbeing. Staff told us their wellbeing was considered when rotas were arranged. They noted it could be difficult to refuse to work when they knew the child and family well but felt comfortable and able to speak up when they felt overstretched. Leaders recognised the good will of staff members and had developed flexible ways of working to be able to support staff.

There was a strong focus on the safety and well-being of staff. This included effective emotional support to staff who worked with children experiencing end of life care or life limiting conditions. Leaders recognised the emotional toll the work the service undertook could have on individuals. Staff told us they felt well supported and never worried or felt alone because of the effort leaders and the whole staff group put in to support them. This support included regular one to one conversation with line managers. Staff had access to a confidential staff helpline which was utilised and provided independent information and counselling services on a 24-hour basis.

The chief executive described the importance of wellbeing and the emphasis they placed on this as a service. A wellbeing programme had been set up as well as initiatives including a menopause awareness group, adapting to working from home training, yoga sessions and relaxation techniques.

The monthly staff bulletin sent to staff entitled “Our House” demonstrated the service’s emphasis on health and wellbeing. It included videos of exercises demonstrated by the service’s complementary therapist. The October



# Hospice services for children

newsletter included exercises for the eyes and the hips and was inclusive and considerate of people's abilities. The newsletter contained information about the employee assistance provision including contact details and resources. There was also a section on the "mood boosting power of pets" where staff shared images and details of their pets to promote positivity and a sense of community.

Equality and diversity were promoted within the organisation. The service had an ambition to be a "beacon of diversity" within the sector. A key aim of the organisation's COVID-19 recovery strategy was to improve the diversity of staff and the leadership board. The organisation had the aim to "recruit representatively from the local community, playing our part in correcting disadvantage, giving everyone equal opportunity and ensuring diversity of background, experience and opinion in the charity". As part of this board members, leaders and line managers undertook diversity and unconscious bias training in 2021. All staff were encouraged to complete independent training sessions provided in "equality and diversity" and "bullying and harassment". Two board diversity champions had been identified to provide a forum for healthy debate.

The service had published an "equality, diversity and inclusion statement". This included an overview of census statistics of the Wiltshire population and how this related to the number of children from black and minority ethnic (BAME) backgrounds receiving services. In addition to this they monitored the number of staff from BAME backgrounds and within the senior leadership team. 17% of the senior leadership team and 8% of children using the service were from a BAME background. This compared favourably with the national population of people from a BAME background which was 14.6% and above the Wiltshire population of 3.4%.

The service was leading a board level process to measure and address any imbalances of representation on the board as well as examining best practice guides for diverse recruitment.

There were well embedded mechanisms for providing all staff at every level with the development they needed. This included high quality annual appraisal and career development opportunities. All staff we spoke with had received an appraisal in the last year. They all commented on how there was opportunity to discuss carer developments within this process but also with managers at any time throughout the year. We heard how the organisation had supported two members of staff to progress to the nursing associate role. Members of the care staff team had left the organisation to undertake nursing degrees and then returned as registered nursing staff.

Staff and families told us they felt comfortable to raise concerns with any member of the team including the chief executive or board members. There were two parent trustees who sat on the board. Trustee's told us this focused the board on the issues pertinent to those who used their services and provided a good check on the issues being discussed and ensured openness. We spoke to a nurse trustee of the board. They were clear about their role and felt able to ask for support as necessary. They described the culture of the organisation as being "open" and recognised the value of people. They felt they hospice went above and beyond to support children and their families and standards were very high.

## Governance, Risk Management and quality management

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.



## Hospice services for children

There was an embedded, effective and clearly defined governance structure within the service. This ensured individual, team, and overarching accountability and delivery of the strategy was maintained. Senior leaders told us the effectiveness of the system was regularly reviewed. A human resource trustee was due to carry out an evaluation of the board level process to measure and address the effectiveness of the board and to ensure roles and accountabilities were clear and trustees aware of their purpose.

A range of board committees fed into the board of trustees. Each board committee was chaired by a named trustee with other trustees and senior leaders were allocated to each committee depending on their skill set. The clinical governance committee was responsible for reporting on the safety and quality of care services to the board.

The board of trustees met on a formal basis six times a year. Prior to the board meetings board reports were presented from each committee. A trustee told us there was ample time prior to the meeting for these to be reviewed. This allowed for informed conversations and debate at those meetings.

The governance structure included board meetings, committees, senior leads, nurse and team meetings. The board committees covered different areas of accountability including; clinical governance, finance and risk, health and safety and trading. We reviewed meeting minutes from the clinical governance committee and saw that performance, policy ratification, audits, staffing and incident information was discussed.

Levels of governance and management functioned effectively and interacted with each other appropriately. There was a programme of clinical and internal audit to identify areas of risk and improvement and actions were taken to improve performance.

The service had plans to ensure continuity of care in the event of an emergency. We reviewed the business continuity policy and the winter plan. The business continuity policy was kept on paper as well as a computer system so it would still be accessible in the event of technology failure. Responsibilities were clearly outlined by role and there were clear actions that would be needed in a range of scenarios which could impact the service.

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 were clear and accountable arrangements for identifying, recording and managing risks. They identified and escalated relevant risks and issues and identified actions to reduce their impact.

The senior leadership team and the trustee we spoke with were able to describe the service's main risks, and these matched the risks identified on the service risk register. We reviewed the risk register and found it was comprehensive and covered all areas of the service. The risk register was laid out in a way that risks were listed by the lead responsible for overseeing the risk. Risks were rated by the likelihood, exposure and the impact it could have upon the safety or provision of the service. We saw clear, documented actions taken in mitigation to control the risk. However, some ongoing risks had not been reviewed on the review date of January 2021.

Staff we spoke with were aware of the main risks to the service with staffing and COVID-19 restrictions being the main concerns. Staff could describe the actions taken to mitigate the risks these posed to the service.



# Hospice services for children

An emergency planning group was set up during the pandemic and operated efficiently to manage risk. This group had been running weekly for around five months but at the time of our inspection the frequency had decreased. Leaders told us this meeting worked well, it brought the right people together to ensure information sharing was effective and could be convened again very quickly if needed in the future.

## **Public and staff 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 service engaged well with patients, staff, the public and local organisations to ensure people's views and experiences were gathered and acted upon to improve services.

A family survey was undertaken in August 2020 to establish the views of families using the service. Areas covered included satisfaction, cultural needs and suggestions for shaping the service amongst others. This was at a time of national lockdown and many of the services usually provided by the organisation were restricted or families were cautious about letting people into their homes. Despite this 18 out of the 22 people who responded noted they were satisfied with the service being provided. The survey allowed for comments to be made and we saw where these comments were acted upon.

The family survey also included a question around whether the service was meeting the family's needs in respect of race, culture and ethnicity. Ninety-five percent of people responded they felt their needs were met and 5% were not sure. Suggestions by families for the virtual story time to include more culturally diverse stories was taken on board.

When the hospice building was reopened following the lifting of government restrictions a survey was sent out to all families. This allowed the service to understand and establish each family's views and personal circumstances so they could plan services and provide support in the best way possible for those who wished to attend.

An employee forum was well established. The forum was chaired by the chief executive and the human resources director. Elected management and employee representatives attended on a quarterly basis. We reviewed the minutes of these meetings and saw they were well attended, minuted and included a review of actions. The forum covered topics on diversity, wellbeing and business updates amongst others. Minutes were made available for all staff.

Staff were encouraged to nominate individuals for CHILD values awards. These nominations were made by staff for those who embodied the values of the organisation. Anyone in the organisation could be nominated including those in the fundraising or finance teams. We saw nominations for members of the care team for "professionalism when speaking to other services" and showing "outstanding patience and dedication to the family". A member of the leadership team was nominated for all their "hard work ensuring we are kept safe during this pandemic".

In May 2021 Julia's House had achieved an "outstanding best company" ranking and ranked 12 in the top 30 charities nationally recognised in the independent Sunday Times 2021 Best Companies survey. They were the highest ranked hospice or palliative care charity in the UK.

"Best Companies" were an employee engagement specialist that measured and improved workplace engagement. The best companies to work for lists were the standard of employee engagement and were compiled annually. The results came from an independently conducted, anonymous and confidential annual survey of Julia's House staff about their well-being, pay and benefits, personal growth, team, leadership and other aspects of the organisation.



# Hospice services for children

## 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.

Staff throughout the organisation told us they were committed to continually learning and improving. One member of staff told us they were “swimming with ideas” and felt they could raise ideas with leaders at all levels and they would be supported to put these plans into action as there was a real appetite for learning. There was a strong focus on clinical development with clinical development roles clearly embedded in the service and used well. Training was a high priority and staff told us they could suggest new ways of working which would be listened to and acted upon.

Leads of the service were committed to improving services by learning from when things went wrong, not just within the service, but other organisations, in a bid to improve safety and quality. The service had refreshed their incident reporting system to ensure the main focus was on learning and improvements. This was well received throughout the organisation and established a clear no blame culture.

The service participated in research projects and took part in national debate. In 2017 Julia’s House completed a piece of national research in conjunction with Bournemouth University. This research highlighted the impact respite breaks had on parental stress and separation. Following this, Julia’s House undertook further research with Pro Bono Economics. This provided evidence of the savings that could be made to the state if respite breaks were provided and the impact this would have on parent’s mental health and economic productivity. This research was concluded in 2020. The organisation was using this information to present the long-term benefits of increased respite breaks and presenting evidence to the government seeking national government policy improvement in the support given to parents of disabled children.

This section is primarily information for the provider

## Requirement notices

### Action we have told the provider to take

The table below shows the legal requirements that were not being met. The provider must send CQC a report that says what action they are going to take to meet these requirements.

Regulated activity	Regulation
Treatment of disease, disorder or injury	<p>Regulation 18 CQC (Registration) Regulations 2009 Notification of other incidents</p> <p>Senior leaders told us there had been a sharp increase in staff raising safeguarding concerns internally during the COVID-19 pandemic. Two reports were referred appropriately to the local authority as Julia's House were the lead providers. During the inspection it was noted the provider had notified the CQC of these referrals in line with Regulation 18, Care Quality Commission (Registration) Regulations 2009 . Senior leaders ensured notifications were retrospectively completed and are now aware of their responsibilities to be compliant in future.</p>