

Julia's House Limited

Julia's House

Inspection report

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

Ratings

Overall rating for this location

Outstanding 

Are services safe?

Good 

Are services effective?

Good 

Are services caring?

Outstanding 

Are services responsive to people's needs?

Outstanding 

Are services well-led?

Outstanding 

Summary of findings

Overall summary

We last inspected this location in 2014 when it was rated outstanding overall

We found this rating had not changed and we rated it outstanding overall 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 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 managed medicines well. The service managed safety incidents well and learned lessons from them.
- Staff gave children enough to eat and drink and gave them pain relief when they needed it. Managers monitored the effectiveness of the service and made sure staff were competent. Staff worked well together for the benefit of children and young people, advised them and their families on how to lead healthier lives, supported them to make decisions about their care, and had access to good information. Key services were available seven days a week. The service actively contributed to issuing bodies of best practice guidance.
- Feedback from staff, children and their families demonstrated children and young people received outstanding care from highly motivated staff who developed exceptionally positive, caring and compassionate relationships with them. Staff treated patients and their loved ones with compassion and kindness, respected their dignity and privacy, and went above and beyond expectations to meet their individual needs and wishes. Staff were devoted to doing all they could to support the emotional needs of children, families and carers to minimise their distress. Staff helped children and young people live every day to the fullest. Families and those that mattered to the person were supported to spend quality time with them.
- Services were planned and tailored to meet the complex needs of individual children, and the local population, in partnership with the wider health economy. The hospices' services were delivered flexibly, by a responsive and passionate multidisciplinary team, providing choice and continuity of care for children and young people, their families and carers. The service made it easy for people to give feedback. People could access the service when they needed it. The service helped families access help with the rising costs of living.
- Leaders operated effective governance processes and ran services well using reliable information systems and supported staff to develop their skills. Staff understood the service's vision and values, and how to apply them in their work. The service had an open and positive culture that placed people at the heart of everything they did. Staff felt respected, supported and valued. They were focused on the needs of children and young people receiving care. Staff were clear about their roles and accountabilities. The service engaged well with children, young people and the community to plan and manage services and all staff were committed to improving services continually.

Summary of findings

Our judgements about each of the main services

Service	Rating	Summary of each main service
End of life care	Outstanding 	See overall summary above.

Summary of findings

Contents

Summary of this inspection

Background to Julia's House

Page

5

Information about Julia's House

5

Our findings from this inspection

Overview of ratings

7

Our findings by main service

8

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 Dorset area.

Julia's House provides care for children with life-limiting and life-shortening conditions, consisting of sessions at the hospice, in the child's own home or out in the community. All care is provided free of charge. The family support service organises social activities that enable families to spend quality time together, this includes a dedicated sibling group.

For children at the end of their lives the service offers emergency respite and overnight care 24 hours a day from a multi-disciplinary team. The hospice had a bedroom suite to enable children and their families to be together at the end of a child's life. The service provides bereavement support for up to five years following the death of a child. Care is provided based on Together For Short Lives guidance.

The organisation consisted of two hospices; the other hospice was based in Wiltshire. The two locations worked as one team and shared all administration records, policies and procedures. Staff worked closely with other healthcare professionals

At the time of the inspection the charity was supporting approximately 119 families. This included 25 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 June 2019. The location was registered in February 2014 and was last inspected in August 2014.

How we carried out this inspection

We carried out a comprehensive inspection of the service under our regulatory duties. The inspection team comprised of a lead CQC inspector and a specialist nurse in palliative care and was overseen by a CQC inspection manager. A further lead CQC inspector carried out the follow up visit in January 2023. The service was undergoing refurbishment on the day of our inspection, so we could not observe care in the hospice. However, we looked at children's care plans on the day, then spoke with their families and spoke with staff who looked after the child after the inspection.

We conducted a further onsite visit in January 2023 to specifically look at care being delivered both in the hospice and the community. During this visit we spoke to eleven members of staff and observed care of three children.

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>.

Summary of this inspection

This inspection took place on 06 September 2022 and was unannounced. After the inspection, we held telephone interviews with key people we were not able to speak with during the unannounced inspection.

The follow up visit on 30 January 2023 was announced.

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:

- The service was holistic with the child and family central throughout. Staff consistently went above and beyond to support families. Other healthcare providers praised the work staff had done supporting children.
- Staff went above and beyond supporting siblings to develop resilience and confidence and have time for themselves.
- The service supported bereaved families longer than other services, providing care for the family for up to five years following their child's death.
- The provider actively engaged in research and presented their findings nationally to influence Government policy.
- The service provided help, support and guidance for families to access both material and financial support with the rising costs of living.
- The service had developed specialist learning disability training in response to the CQC 'Right to be heard' report.
- The service participated in research into the causes of family breakups and actively worked to keep families together.
- The service was an active participant in the development best practice guidance and was listed as a contributor.

Areas for improvement

Action the service MUST take is necessary to comply with its legal obligations. Action a provider 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.

There were no areas identified for improvement.






Our findings

Overview of ratings

Our ratings for this location are:

	Safe	Effective	Caring	Responsive	Well-led	Overall
End of life care	Good	Good	Outstanding 	Outstanding 	Outstanding 	Outstanding 
Overall	Good	Good	Outstanding 	Outstanding 	Outstanding 	Outstanding 

End of life care

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

Are End of life care safe?

Good 

We previously rated safe as good. This remained the same on this inspection.

Mandatory Training

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

Medical and nursing staff received and kept up-to-date with their mandatory training. The mandatory training was comprehensive and met the needs of patients and staff. All staff completed a range of mandatory training which included fire safety, infection control, safeguarding, moving and handling, Mental Capacity Act, equality and diversity and information governance. Most of the training courses had completion rates above 85%. Where training statistics were not 100%, the provider had training courses arranged and staff were made aware of the need to complete all training. 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.

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 57, 28, and seven 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. Leaders 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.

The service ran simulation training for staff to gain competency in not only setting up essential equipment in each scenario run, but to have experience in compassionate extubating.

Since July 2022 it has been a mandatory requirement for healthcare providers to provide specific learning disabilities training. The service was rolling out access to tier one of the training in March 2023.

Safeguarding



End of life care

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.

Safeguarding training was provided for all staff at an appropriate level for their role. Nursing staff were trained to level three in adults and children and all other staff, including facilities and administrative staff, were trained in level two in adults. This was in line with national guidance Safeguarding Children and Young People: Roles and Competencies for Healthcare Staff, January 2019. In September 2022 94% of nursing staff had completed safeguarding level three for both children and adults.

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. Staff had access to an up-to-date safeguarding policy. Staff we spoke with were able to clearly articulate signs of different types of abuse and the types of concerns they would report or escalate to the registered manager. 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.

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. The service had made 19 safeguarding referrals between April 2022 and September 2022. 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.

The provider had a recruitment policy which stated all staff had to have a Disclosure and Barring Service (DBS) check before starting their employment at the location. All staff had an up-to-date DBS check. We reviewed staff personnel files and all staff had proof of identification, full employment history and an up-to-date curriculum vitae on file. The service had obtained two references for all staff in line with their policy. We also saw employment offer letters, evidence of induction training, qualifications, and professional memberships were kept on file.

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.

The service set up an efficient system to manage shortages of personal protective equipment (PPE) during the COVID-19 pandemic and 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 staff members to be able to undertake these tests.

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



End of life care

At the time of our inspection, the building was undergoing extensive renovation and there were no children on-site. However, we looked at cleaning records and audits of the environment and spoke with families. Families we spoke with told us staff took every precaution to protect children from infection and were very thorough. On our follow up visit in January 2023 we saw cleaning records were consistently completed with no gaps or omissions.

Changes were being made to the building to improve the entrance areas and improve the children's play facilities, as well as removing wallpaper and replacing with washable surfaces. The service was investigating the costs of creating a designated clinical treatment room and a sluice room. This work had been completed when we returned for our follow up visit in January 2023.

Cleaning audits were undertaken monthly and any areas of development or non-compliance was addressed with the facilities team and solutions sought. Any additional training or resource requirements required were put in place to address any issues found.

Staff undertook monthly audits of cleaning. The audits identified who was responsible for the cleaning, for example the cleaning company, estates or nurses. The provider set compliance targets at 85%, though the service did not have any audits below 91%

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

Staff assured us, when they worked in the hospice and within the community, they were bare below the elbow, in line with good practice, followed hand hygiene protocols and changed PPE, such as masks regularly.

Incidence of infections was monitored and there had been no incidences of hospice acquired infections from August 2021 to August 2022.

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 building was a rented property which had been converted, it 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 integrated hoists. Each room within the hospice had pictures as well as words to describe the use of room. Building risk assessments were in place and were in the process of being transferred to a new risk assessment format.

Staff carried out monthly safety checks of specialist equipment. Service contracts were in place to ensure medical equipment, such as beds and wheelchairs, and equipment such as fire extinguishers and fire alarms, were all serviced in line with manufacturers recommendations. Staff had access to emergency bags which were also checked monthly. All items in the emergency bags were within their use by dates.

Clinical equipment was serviced by servicing contractors on an annual basis unless the manufacturer specified more frequent servicing. Staff and parents told us how staff completed a thorough checklist with families which included checking all equipment in the child's own home prior to and following any respite sit.



End of life care

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.

A named nurse and small team of four to five nurses and carers were allocated to each child. A multi-disciplinary team met monthly to discuss any changes to the child's needs. Parents and staff told us there was regular communication within the teams.

Each child had a comprehensive risk assessment when they were admitted to the service. These risk assessments were individualised for the child. Risk assessments included the identification of environmental risks, risks to wellbeing, COVID-19, and risk assessments around other children within the family. If children/young people had their sits away from their home, for example at Brownies, Cubs or trips out, then additional risk assessments were completed to ensure the safety of the patient and staff during that episode of care. Staff reviewed risk assessments annually or when there was a change regarding care needs. Staff updated a spreadsheet which evidenced when reviews had been completed or were due for completion. This spreadsheet was audited for compliance by service leads.

Most children had an advance care plan, which was discussed with other professionals involved in the child's care including local NHS Trusts. The service aimed to have an advanced care plan for each child when providing end of life care however for reasons such as the parent or child not wanting to complete a plan or the feeling it was the wrong time, the service did not always have one, aligned to patient wishes.

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. However, staff identified the need for an early warning system for deteriorating children and young people and this led to the development of a sepsis teaching programme for care staff, which covered baseline observation skills and action in the event of a deteriorating child.

Risk assessment training was available to all staff undertaking risk assessments to ensure a safe and consistent approach. Significant risks were recorded on the organisational risk register.

Staff told us they always had a lead nurse or doctor on call for support when working in the community.

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.

The service employed two doctors and the director of care was also a qualified nurse. The service also employed family support workers, playmaker assistants and sibling workers. A complementary therapist was also available. Staff were supported by administrators and IT specialists. An 'Emotional Health and Wellbeing Practitioner' had started in December 2022.



End of life care

The service employed 29 nurses, with 24 nurses having a contract and five nurses having bank contracts. The service employed 33 care staff, with 30 care staff having contracts and three care staff having bank contracts. 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.

Senior leaders monitored rates of sickness, staff turnover and vacancies and reported these figures to the board. Clinical vacancies included one team nurse, and an offer had been made for this post. Other vacancies included a nurse associate and two care team members, and the service was actively recruiting for these.

Every child/young person's needs were assessed at their initial assessment, followed by annual and half-yearly reviews or if there were any significant changes to their needs in between these reviews. Each child/young person was given a care score which was based on the level of support the young person needed, their clinical complexity, their social and safeguarding needs and if they were bereavement or end of life.

The service provided was flexible and therefore was arranged to reflect the staffing resource available. Visits were mostly carried out by two members of staff. However, the service paused referrals for July 2022 and August 2022 in house as this was the busiest time and they had been unable to recruit more staff to allocate new referrals to. Any end of life and fast track referrals were treated differently. Any one person visits were risk assessed in advance.

To enable staff to work flexibly, rotas were arranged six weeks in advance. The chief executive told us they wanted staff to work for the service in a way that suited them and be able to have regular commitments, such as attending exercise classes. This flexible working included working with staff who wanted to undertake other work activities, not just clinical shifts.

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. We looked at two sets of paper records and four sets of notes on the computer system. Care records were personalised and comprehensive. The records had individual assessments which included the child's and the family's choices. The well-being of the whole family was considered and consent to share information was clearly recorded. Staff had information about other professionals involved in the child's care. Care records were audited monthly and any actions identified to improve records were followed up. Records were kept securely.

In January 2023, the service had rolled out electronic access to include home based carers with a remote desktop dashboard (toolkit), which allowed electronic access to latest SOP's, Policies, and children's information, which had previously been paper based.

Staff used paper copies of records kept in children's homes, then information was transferred to an electronic system. Staff told us the systems gave them all the information they needed. During our inspection staff told us they were considering a different system which would link with other health care services to improve information sharing.

Where children were cared for in hospital as well as in the hospice, all records were copied and transferred to the care team at the hospital following each episode of care, so all involved had the most up to date information, care plans and assessments. Documents used followed the same format for all care providers.



End of life care

Medicines

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

Staff managed medicines in line with their policy. 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) safe use of medicines toolkit 3rd edition (2021) and the APPM Master Formulary 2020 (5th Edition)'. The toolkit gave information and guidance to professionals working in children's hospice and palliative care settings about using medicines safely.

Staff did not give medicines routinely unless that medicine was time specific or would be needed in an emergency. Children's medicines were kept in their own homes and stored by parents. Medicines were only given to children by carers where the carer had been trained and assessed as competent for each individual medicine. Registered nurses attended to give medicines where children had complex or multiple medicines.

Staff told us and parents confirmed staff checked medicines with the parents before any respite sessions. Staff followed the providers policy to sign medicines in and out.

The service kept records of all medicines prescribed for children, this included medicines staff did not administer. Children's electronic records had all medicines for the child recorded

Staff completed medicine administration records (MAR) for all medicines, including time specific or emergency medicines. The child's named nurse was responsible for ensuring the MAR chart was up to date before any respite sessions. A senior nurse and a doctor transcribed and checked the medicines transcribed onto the MAR charts which occurred twice a week. We reviewed MAR charts during the inspection on the 07 September 2022 and found they were all fully and correctly completed.

Any medicines on the premises at Julia's House were stored safely in locked medicine cupboards or a designated medicines fridge. Staff checked the fridge temperatures daily. Staff had guidance in the medicines policy what to do if fridge temperatures were outside the acceptable range of 2–8 degrees Celsius.

Staff had access to a current copy of British National Formulary for Children (BNFC) reference material within the hospice and access to the BNFC through an application on their mobile phones.

The service completed an audit of medicine records in February 2022 from 67 children's records who were receiving active Julia's House care. Overall, average compliance against all standards was 83%.

Although data showed that overall compliance to standards were high, for example GP details and children's photographs being included on medicine records, the audit did identify low compliance with recording the child's weight within the six-month date period and additional instructions not being dated. Several recommendations were made, and these were followed up. In response, the service had carried out an audit of records of children's weights.

Safety Performance

The service used monitoring results well to improve safety.



End of life care

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 we spoke with described how they reported incidents using a clear reporting process. The on-call senior nurse was informed of any incidents and could escalate incidents if necessary.

The chief executive told us, and staff confirmed there was a very open culture around learning from incidents. Incidents that happened elsewhere nationally were shared with staff to ensure similar incidents did not happen in this organisation. A medicines management group looked at ways of improving the service and learning was discussed. For example, learning shared with staff from the July meeting included reminding parents to bring the original packaging and prescription labels. Staff received feedback from learning through emails, individually and team meetings.

The clinical governance committee looked at incidents, any actions and any learning identified was then reported to the board of trustees. Minutes of meetings showed actions were followed up following any incidents and external services were included in meetings. This enabled the service to maintain good communication with other services, share learning and identify additional training. Minutes of staff meetings showed information was shared with staff. Staff told us they were supported and debriefed after any 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. Staff ensured patients and relatives were kept informed of any actions taken following incidents. For example, staff apologised for marks which occurred as a result of using a sling and as a result, slings were replaced.

Lead nurses ensured staff were updated if there were any patient safety alerts.

Are End of life care effective?

Good



We previously rated effective as good. We found this had not changed on this inspection.

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.

Staff followed up-to-date policies to plan and deliver high quality care according to best practice and national guidance provided by the National Institute for Health and Care Excellence (NICE), Together for Short Lives and Public Health



End of life care

England, amongst others. A process was in place for policies to be updated with any new or amended guidance and all policies were up to date. We reviewed a range of policy documents held by the hospice. For example, the service used the standards required for a children's hospice were laid out in "Together for Short Lives, A Guide to Children's Palliative Care." The service had processes and protocols in place to ensure they monitored children and responded appropriately, for example deteriorating children were transferred to hospital if that was appropriate.

The hospice undertook a comprehensive range of audits throughout the year to ensure care was being provided in line with standards. The hospice used the audits as a quality improvement process to improve patient care and outcomes through systematic review of care against explicit criteria. Staff ensured audits met the five stages of clinical audit cycles by following NICE principles. Staff also assessed themselves against the NICE quality standard for 'End of Life Care for Infants, Children and Young People.' The service also audited preferred place of death to ensure families and patients were given 'real options and choices when patients were close to the end of their life.

The service was an active participant in the development of NICE guidance and received guidance for comment before it was issued for wider dissemination. The service was listed as a contributor to the guidance.

Staff represented Julia's House at the National Children's Hospice Neonatal Special Interest Group which shares best practice and innovative ideas nationally across all Children's Hospice.

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 who supported children with specialist nutrition and hydration needs were trained to do so.

Parents told us staff listened to them and their children regarding their child's preferences and needs. Staff recorded the support they provided in feeding, nutrition and hydration care plans. We saw staff incorporate food and food familiarisation into play activities delivered in the hospice.

Parents told us they appreciated the support staff gave them with cleaning and changing of specialist equipment such as tubes required for feeding.

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 and used nationally recognised tools where necessary.

Children received individualised care from a small team of staff. Staff told us and we saw staff looking for distress cues, for example non-verbal signs which might indicate discomfort and how they would support the child to reduce their discomfort.



End of life care

Patient Outcomes

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

Managers and staff used audits to improve patients' outcomes. Using the five stages to the clinical audit cycle, audits were planned. The standards identified were based on up-to-date evidence of best practice and the actual performance was measured against this standard. If a standard was not being met staff identified why and how practice should be improved to ensure that the standard was met in the future. Results of audits were shared with the board of trustees.

The range of audits completed included infection prevention and control, hand hygiene, records and documents, medicines, moving and handling. Audits were scored for compliance; for example, hand hygiene audits were completed both in the community and in the hospice and results were consistently 100%.

The service had completed further work around transition of care between children and adult services. A nurse led transition group presented at a regional transition group and shared activity in this area. This included developing a care plan which identified when a child entered the transition phase (year 9 or the year they turn 14) and was used at bi-annual reviews to encourage discussion around transition and awareness of completing the Together For Short Lives checklist. Reports were generated for quarterly review by the transition group. Other activities included compiling a directory of all adult hospices in Dorset and Wiltshire with a description of the resources they offered.

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. Hospice staff had a range of skills and experience and received access to thorough training and opportunities for ongoing professional development. All new staff including bank staff and volunteers underwent a thorough induction, which gave them the skills and confidence to carry out their roles.

Managers gave all new staff a full induction tailored to their role before they started work. New staff spent time with other staff throughout the organisation to gain an understanding of the whole organisation. Staff were also able to shadow other staff members until they felt confident to work alone.

Managers supported staff to develop through regular, constructive supervision of their work. Staff met with their line managers every 6 weeks. Staff also had formal appraisals of their work annually.

Staff were allocated to the care of a child depending on the care the child needed. The named nurse for the child assessed and signed staff once they had the required competencies to care for the child.

The Director of Care told us staff were supported to undertake additional training such as university courses if the training was beneficial to the organisation. The support provided to staff could be financial support or time off to attend courses.

Staff supported each other to peer review tasks such as care of and administering fed through nasogastric tubes. All staff, regardless of experience participated in regular peer review.



End of life care

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 patients and improve their care. Links with other healthcare services were well established. Senior leaders told us how they collaborated with hospitals and other hospice care providers to give families choices. This meant children who were at the end of their lives could choose where they wished to be when the time came. Julia's House staff supported children wherever they chose to be.

Parents told us staff were always up to date with any changes required as their child's needs changed. Staff regularly met community children's nurses and other professionals to discuss the needs of the child. One parent said, "When nurses come in, they're up to date. [Name's] needs change regularly, they keep in touch with other professionals and school." They told us how 2 nurses had gone to the child's school so they could replicate anything that was good at home.

One family described how nurses attended meetings with funding providers and social workers and how they advocated for the family. They said, "As a parent we've got a voice, but they bring a professional voice, they do this really well."

Health promotion

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

Staff assessed each child and young person's health when admitted and provided support for any individual needs to live a healthier lifestyle. Staff considered the health and well-being of the whole family when completing assessments. A range of complimentary services were available for families, such as massage, reiki and counselling. Parents told us the support provided for siblings was extraordinary and described how much of a difference it made for everyone. The service was expanding support to include art and music therapy.

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 understood how and when to assess whether a child or young person had the capacity to make decisions about their care.

Staff gained consent from children, young people or their families for their care and treatment in line with legislation and guidance. Staff understood the principles of Gillick competence. Staff made sure children, young people and their families consented to treatment based on all the information available. Families, including siblings where appropriate, were included in discussions about care.

Staff clearly recorded consent in the children and young people's records. Staff held conversations with families and recorded consent for all aspects of a child's care, such as giving medicines, sharing information and any therapies.



End of life care

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.

Are End of life care caring?

Outstanding



We previously rated caring as outstanding. We found this had not changed.

Compassionate Care

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

All staff were aware of the importance of providing compassionate care and the impact their actions had on the child and their families during this time of their lives. Support was always given by caring and empathetic staff who put children and those close to them at the heart of everything they did. Parents said, "It's an amazing service" and, "It's awesome how it all works."

We spoke with parents and children about the care they received within the hospice and the community. Everyone was overwhelmingly positive about the support they received and gave us many examples of how staff went above and beyond. Parents said, "It's a very bespoke tailored service, not one size fits all. They come out and ask us how do we want them to do things, what works best for the child, how do they provide the best and work around our life" and, "Medically they're brilliant, social aspects of the care are really good as well because they don't just come and sit, they play, entertain, make it so its special time for the family" and, "When staff are here it's extra special for [name], they do her nails, massages, she feels like a princess."

Consultants in NHS hospitals praised the work the service had done supporting children at the end of their life. The service released one member of staff the child knew and trusted to work full-time on a ward to care for a child. It was noted the member of staff worked above and beyond in terms of their commitment to deliver this care. The consultant thanked the teams involved and said, "It really was done with medical expertise, compassion, skilful negotiation and excellent communication and team-working. It has been an absolute pleasure working with Julia's house teams through the whole of [name's] care - you've really made my role as a new consultant managing a patient with lots of complex medical and social needs so much easier." Staff were thanked for the ongoing bereavement support they provided. Another consultant said, "It was such a pleasure working with all the team at Julia's House. You are an exceptional group of nurses with such a committed work ethic and it was lovely getting to know everyone. The family and [name] were so well cared for by the team that I don't think I could have asked for more for one of my patients." A third consultant said, "A huge thank you from myself and our paediatric team in relation to the incredible support your nursing team have provided to one of our patients. Caring for this family was particularly challenging, not only due to the medical complexity but also significant social complexity. The continuity provided by your nursing team was instrumental in ensuring that the child received the very best care and parents and families were appropriately supported."

One young person told us how much they enjoyed coming to the hospice. They told us, "It's a home away from home, everyone there is perfect." They told us about the close relationships they developed with their care team and how they knew every person caring for them.



End of life care

One family told us how when their child was in hospital, nurses went into hospital to sit with the child so parents could have a break. This was especially important to them throughout COVID-19 when hospitals only allowed one visitor and they said, "It goes above and beyond what you'd expect from a service that provides respite care."

Parents told us staff were discreet and responsive when caring for children and their families. Parents told us staff were consistently sensitive to their needs. We were told staff picked up on subtle cues that parents 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.

Families were supported to spend quality time together and form friendships with others in similar circumstances. For example, one family was happy for the service to use their story on the provider's website and said, **"It's nice to speak to other parents of children with a life limiting condition – it feels so relaxed when you're all there together and you don't feel like you're being judged by anyone. It's like you don't want that day to end."**

Staff worked to help siblings build confidence and resilience. Staff recognised the impact having an unwell child in the family had on siblings and provided a sibling group to help brothers and sisters enjoy fun times. Siblings could choose what activity they wanted to do; this could be a quiet cup of hot chocolate or taking part in week-long residential trips. The service organised two of these a year and said, "these events were great at helping children find the courage to feel comfortable talking about their situation." The service provided events throughout the year, such as craft days, water sports weekends, dry slope skiing or other activities siblings wished to try.

We spoke with 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. One parent told us the service was "absolutely amazing", and "it was the most compassionate and kind, difficult to put into words."

Parents told us the service was consistently respectful of family choices. They felt listened to, cared for and respected. During COVID-19 the sibling team were furloughed. Within 6 weeks families said they needed sibling support as children were home schooling and parents needed support. Named nurses visited children from the end of their garden path. Staff and parents told us the sibling team worked to provide support in an innovative way by delivering bags to every family with sensory items, baking items, sweets and other items. The team organised quizzes, bug hunts, games and activities on-line. Staff provided online play sessions, for example everyone could bake together following the leader demonstrating. Staff provided an online bedtime story read each evening. Staff provided four versions of the goody bags, to cover Christmas and Easter 2020 and 2021. These activities were provided for children, siblings and families. The sibling team have returned to doing in person events and group activities.

When families were isolating during COVID-19, staff took them bags of shopping.

The child's needs and wishes led the care that was provided. Parents told us personal care was completed in a private and sensitive way. Parents told us how staff spoke very sensitively to their child to ensure their comfort throughout. We reviewed 6 care plans, and all were comprehensive and personalised to each child.

We saw staff interacted with children in a compassionate, tender and genuinely caring manner. Children were responsive and happy when interacting with staff and actively participated in tasks and activities tailored by staff to each child.

Emotional Support



End of life care

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 and family-centred culture.

Parents told us, “Staff are very special people, they enjoy and are brilliant at what they do. They provide end of life care and this might be several years for some nurses, the support is exceptional.” Staff listened to what children wanted at the end of their lives and made it happen. For example, one child wanted to go to the beach. Staff arranged a beach hut for the child to visit, but as the child was in hospital and too poorly to go to the beach, staff recreated a beach scene/ experience at the hospital. Staff arranged for a child to attend a show at a theatre and meet the cast afterwards. One of the service’s patrons is the lead guitarist and singer with a hit band and arranged for a group of children to be VIP guests at a concert. Staff created social bubbles for small groups of young people, so they could enjoy gaming and pizza sessions with their friends from other families, or make new friends, while still staying safe.

Staff were proud of the relationships they built with children, young people and their families. Parents told us how staff all kept in touch during and after times when their children were very poorly. One parent said, “When anything happens, it’s not just ‘it’s happened, we’ll make a note’, they’re there with you throughout” and, “[Name] is very poorly several times a year, so having someone who knows how to hold our hand through this is such a comfort.”

Staff recognised the unique position they were in to provide emotional support and strived to go the above and beyond for children and their families. Parents told us how staff cared for the whole family and said, “They scooped us up and put their arms around us, supported us in every way” and, “They take hold of you and hold you by the heart for the time you have with your child.” The service provided support for anyone regularly involved in the care and support of a child through ‘Great Mates’ sessions, where family members such as grandparents, aunts and uncles could take part in activities such as dinner dates, spa days and arts and adrenaline-packed activities such as quad biking, go-karting and clay pigeon shooting. Families could also access counselling support and complimentary therapies.

One parent told us staff always seemed to know how they were feeling and when they were struggling. They said, “the family support worker has a way of turning up with things for the children, done in such a way we don’t feel they’re taking pity and gives us dignity. Without them we wouldn’t be as happy as family and we’d be lost.”

Staff told us every child and their siblings were given a quilt; this homely gift helped to comfort children and was a connection with the hospice.

One parent told us about the support activities, away days and annual ‘remembering days’ staff provided and said they gave “really nice opportunities” to remember their child. This gave bereaved families an opportunity to reflect together and share happy memories of their children. Carers and nurses put together memory boxes for families to be able to remember their loved one.

Staff supported families for up to five years after the death of a child; this was longer than most other services who provided support for up to three years. The service also recognised the financial impact of funeral services on bereaved families and contributed £1000 towards the cost.

Understanding and involvement of patients and those close to them



End of life care

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 were needed.

Staff made sure children, young people and their families understood their care and treatment. Care plans were written for the individual and staff told us they had all the information they needed. Care plans contained information about the needs of the whole family and demonstrated staff knew the child and their families well.

Parents told us how a member of staff visited them and had a chat to find out what their child liked and enjoyed, then put together a bag of sensory toys specific to the child in a 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. Staff wrote a personalised communication, development and play plan for the child which was then followed by the small team of staff involved in their ongoing care. One parent said, "It's a complete service for the whole family. They treat [name] as a child not a list of conditions. That's how they are. To them she's a happy little girl who has a difficult life but still has fun and likes to be entertained." 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.

One parent told us, "They went above and beyond to support the whole family so I could go abroad for a whole week for a family funeral. They released extra care hours to cover the week."

At the time of our inspection, many of the rooms in the hospice were being refurbished. However, staff described how they brought a second bed into a room so a child could have a sleepover with a friend if they wished, as this was something children often liked to do but didn't get many chances. Staff arranged movie nights for the friends if they wished, or they could have gaming nights using the services gaming equipment. All rooms in the hospice were personalised for the child, before the child moved in.

On our follow up visit in January 2023 we saw rooms had been refurbished and had taken into account patient feedback, including removal of a mural some patients had found unsettling. Rooms were large, light filled and could be adapted to each child. For example, in one of the larger bedrooms and projector had been installed and had been utilised by an older child to having a gaming night with friends.

Staff talked with children, young people and their families in a way they could understand, using communication aids where necessary. One parent told us how staff spotted very subtle non-verbal communication and how well their child responded to staff. Staff undertook training on Sign along which is a language programme that uses symbols, signs and speech to enable people to communicate. Staff had picture cards and children could point to the picture on the card to tell staff what they wanted.

Staff explained that through the close relationships they held with patients and families, they had been able to see a patient had been trying to tell staff (not just in Julia's house) when they were going to have a fit. Staff identified this and shared the information with other care givers and the young persons school.



End of life care

Are End of life care responsive?

Outstanding



We previously rated responsive as outstanding. We found this had not changed.

Planning and delivering services which meet people's needs

The hospice, and its multidisciplinary team, proactively planned its services and provided care in a way that considered and, quickly and responsively, met the preferences and needs of local people and the communities it served. The hospice, and its team, worked with others in the wider system and local organisations to plan individualised and highly responsive care that promoted equality, including for those with protected characteristics.

Managers planned and organised services, so they met the needs of the local population. The service published their 'Impact Report 2021' which identified the growing need for services for children with life-limiting or life-threatening conditions. The report also highlighted the growing gap in funding, which resulted in only four in ten children receiving support from their local authority, and only when they reached crisis point. The impact report showed the 4 key areas the provider aimed to achieve by 2023; these included supporting growing numbers of children, enhancing end of life support, broadening family support and being the best run charity with the best people. Julia's House staff supported the NHS during COVID-19 and staff remained on stand-by to support the NHS if required.

Julia's House worked with other hospitals and hospice providers in the area to care for children. Children who were approaching the end of their lives could choose where they wanted to be at the end of their lives. At the time of our inspection, there were no children on a waiting list for a place.

Research conducted with 'Together for Short Lives' found respite care reduced stress and led to fewer visits to the family doctor for parents of terminally ill children. This reduced the demand for NHS services and the number of days parents needed to take off work.

The service looked at how they could improve communications with external services. In response to feedback from the service's own teams and discussions with other healthcare professionals, the service employed a clinical administrator. The clinical administrator had reduced multiple communications with professionals and has provided the service with one point of contact for external professionals with regards to obtaining clinical documents and information such as clinic letters, protocols and arranging assessment and review dates. The clinical administrator had improved this communication, in turn streamlining the service's processes and reducing the administrative work of care teams so they are able to focus more on the clinical aspects of care.

The service worked with other organisations to review and update a Transition to Adult Services Pathway with an associated Standards framework called "Stepping up", due to be published in Spring 2023. The service contributed to the guide which sets standards at each stage of the journey to enable a good transition to adulthood for young people with life-limiting and life-threatening conditions.

Meeting people's individual needs



End of life care

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.

Parents told us how staff provided individual care for everyone in the family to meet their individual needs. Parents said, "Staff are always up to date with everything going on in [name's] life, their communications are excellent" and, "Nurses and play therapists, they all mean the world to us. We managed on our own for 10 years and spent most of the time in hospital, we became institutionalised, and Julia's House helped us become more normal."

Parents praised the work staff did for the whole family. They told us how they had family days out together as a family, how staff provided activities for the whole family, such as tea and cake, and games. One parent told us how the service provided support activities, away days and provided them with some "really nice opportunities to remember our son", including a Remembrance Day.

The sibling work was highly valued by the family. Parents told us how the support for siblings was specific for their needs. For example, one sibling was picked up from school and had time to do what they wanted. Another sibling wanted to go to events, have hot chocolate and muffins. Parents were delighted siblings had weekend activities such as surfing, canoeing and other outdoor events. Staff arranged for siblings to have a film night in a museum, then slept overnight in the museum. Parents told us older siblings found the opportunities to talk with other siblings valuable. Parents said this helped their children understand everything and feel they had a place.

Families appreciated being put in touch with other families. They said, "It gives us a social circle where we've all got similar circumstances, but don't have to explain anything." Parents appreciated the support provided to them as well, such as the 'Dining Divas' social group for Mums to have a treat, meal or coffee and cake. One parent told us about the 'dads and sons' group where dads and siblings could do activities such as archery and outdoor activities.

Parents also appreciated the way the counselling service was provided for siblings. They told us siblings were able to have play therapy, which they said was not as intrusive as speaking with someone on the phone. One family told us following the passing of their child, the sibling support continued, and the sibling saw the hospice as a positive place to be, because they knew they were not on their own.

The service offered whole family sessions so every member of the family could benefit from respite care. Different members of the care team worked collectively to offer a range of care and support to meet individual family members' needs, so siblings could have one to one time with sibling workers while parents enjoyed a massage with a complimentary therapist.

The service shared a caravan with another hospice, so families using their services could take a holiday. One family were so happy to have had an opportunity for a holiday they wrote a letter of thanks to express how grateful they were for "this time away from home, routines, hospital appointments and admin."

One young person who had used the service before their 18th birthday told us staff started to prepare them for the transition to adult services from a young age. Staff told us the transition period began from the age of 14-years when staff started to work alongside adult services and

social services.



End of life care

Parents told us how important it was for them to have a named nurse and told us about the benefits for them. One parent said, “Our named nurse is a shining star, they saw [name] in hospital, they were a brilliant link to doctors so any medical language we didn't understand, she explained.” Families were allocated 200 hours and could use these respite hours how they wished. For example, respite could be provided in the child’s own home or at the hospice, daytime or evening. The service planned rotas six weeks ahead to ensure staff were available.

Staff told us how they had received additional training in Makaton, a system of communication. Sibling support staff had completed training around undertaking difficult conversations with siblings.

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.

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. Rooms were equipped with televisions and gaming equipment and which made them comfortable and homely.

The hospice had a sensory garden which included a variety of play activities children could use on their visits. The garden was well kept and maintained and included an integrated trampoline suitable to be used whilst in a wheelchair.

The hospice had a Mermaid suite for families whose child was at the end of their life. The suite had an adjoining room where families could be close to their child and have space for reflection. The suite led directly on to a secluded sensory garden, and the child’s bed could be wheeled outside if they wished.

Managers made sure staff, children, young people and their families could get help from interpreters or signers when needed. Translation services were also available. Staff received training in how to meet the needs of families from different cultures. For example, care plans recorded spiritual preferences and if the family wished staff to arrange a visit from a cultural leader, or if the family had their own leaders. Staff were trained how different faiths wished to receive bereavement support. Although data showed 4.4% of Dorset’s population were an ethnic minority, over 8% of the children receiving support were from ethnic minorities.

The service had a team of administrative staff who researched and supported families to access all available grants and funding they were entitled to. In addition, staff could access and make referrals 24 hours a day to a local food bank if needed. The hospice had provided food hampers to families over Christmas and had given support to families in researching and applying for grants which may cover utility bills and essential equipment, especially where the children they cared for needed specialist equipment charged up in the home.

Access to right care at the right time

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

The provider’s website gave information for families how to access the care provided. The website said, “Anyone could make a referral to Julia’s House: mums, dads, friends, and health professionals – even the child themselves. If your child has been diagnosed with a life-limiting or life-threatening condition they may be eligible for our care.” The child had to be resident in Dorset, under 18 years of age and the family or young person if applicable was able to give consent for that referral.



End of life care

Once the referral had been accepted, a named nurse was allocated to the family who then made contact. Health care professionals involved with the child's care were contacted and a comprehensive care plan developed. Staff were allocated to the care of the child based on the competencies required.

Staff told us how they provided support from the point of diagnosis. This included families accessing the service prior to the birth of a child if the unborn child had been diagnosed with a life-limiting condition. The service also worked with hospital paediatric intensive care units (PICU) and neo-natal units.

There were no delays making decisions about accepting children because the panel who discussed referrals were able to meet daily. There was also a fast track process for children who needed services quickly. The service monitored the times between the initial referral and providing services, though not everyone who was accepted for the service wanted the care to start immediately.

The service had developed a counselling service for any child, parent or grandparent to use. Families could identify their own counsellors if they wished and the service would pay for it, once they had checked the counsellor's accreditation. The service also provided one-to-one support for siblings.

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.

Children, young people and their families knew how to complain or raise concerns. Everyone we spoke with said they could raise any concerns with any member of staff. Parents told us staff were diligent and communicated with families very well. There had not been any formal complaints since 2018, however if any concerns were raised these were taken seriously and dealt with in line with the provider's policy.

Managers investigated complaints and identified themes. Families said they had no concerns or complaints about the service.

Staff knew how to acknowledge complaints. Staff told us they would follow the complaints policy, which gave clear guidelines to staff.

Staff could give examples of how they used families feedback to improve daily practice. For example, after the family survey, feedback had been reviewed and actions had been taken in response. This included overnight respite, more hospice sessions, extended sits and longer handover times for sits of complex children.

The board of trustees had oversight of complaints. Complaints were discussed during team meetings, at the clinical governance meeting and board meetings.

Are End of life care well-led?



We previously rated well-led as good. We found this had increased to outstanding on this inspection.



End of life care

Leadership

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

There was compassionate, inclusive and effective leadership at all levels. Julia's House was led by a dynamic and purposeful senior executive team and board of trustees.

The leadership structure of care services within Julia's House consisted of trustees, executives, a director of care, heads of clinical services and governance and lead nurses. The leadership team promoted strong values of person-centred care and worked in partnership with other organisations for children to receive high quality care based on best practice. Parents told us how the Chief Executive Officer (CEO) attended events and spoke with everyone. One parent told us they got emails from the CEO, and when their child was in hospital, they got an email from them asking how they were doing as a family. Another parent said, "The chief exec is the most down to earth, level-headed person who cares for everyone, we're so lucky to have him at the helm."

Staff consistently told us trustees and senior leaders were accessible and approachable. Trustees were selected according to a skills matrix to use their expertise to develop the organisation. For example, there were 2 trustees with nursing experience, 2 parent representatives and other trustees with backgrounds in finance and business, law and HR and medicine.

Staff told us they could seek help at any time from senior staff and trustees. Staff said, "It's not a detached management style. During our debriefs they reflect with us to look at how we can do things better next time, they give us multi-faceted support, anything we need."

An evaluation tool was used to support this to identify how trustees could provide added value to the service. The evaluation tool looked at an area where the trustees had expert knowledge, some experience, an understanding or identified as a development need. As the board of trustees had people from a range of backgrounds and experience, there were some areas where trustees didn't need any knowledge or understanding, because other trustees had this background.

Board minutes summarised how leaders within the organisation were being trained in coaching skills to ensure they were leading as effectively as possible.

Vision and Strategy

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

The service had a clear mission, which was "to reach more children with life-shortening and life-threatening conditions and to set the gold standard in flexible, bespoke care that supports the whole family."



End of life care

The service had a clear vision and set of values, published on their website, with quality and sustainability as the top priorities. The website said, “The vision for the service was for local families of life-limited and life-threatened children to be able to access the help they need, when and where they need it and for every member of the family to feel supported, valued, cherished.”

The provider’s values were based on the word CHILD. This mnemonic stood for Compassionate and caring; Honesty and integrity, It’s up to all of us, Listen and learn, Determined to excel.

The chief executive told us the values were the core basis for everything done in the organisation. The values were used in staff inductions, appraisals, training and would be used in any disciplinary meetings. All staff we spoke with knew the values and told us how they underpinned everything they did.

The provider published their impact report 2021 with their strategy and objectives clearly defined. The provider’s strategy included four strategic objectives; support growing numbers of children, enhancing end of life services, broadening family support and being the best run charity with the best people.

To achieve this strategy, the service identified the need to remain able to respond in case NHS hospitals should become overwhelmed and had several goals in place.

The provider presented their strategy in an easy to understand manner, set out as a monopoly board. The centre of the board identified the four strategic objectives. Each side of the monopoly board represented a year, from 2022 to 2025 and had the objectives for that year.

For example, 2023’s objectives included having greater board and staff diversity and recruiting nurses and carers. The objectives for 2024 included providing longer respite stays and employing a third hospice doctor. The objectives for 2025 included a research project on the impact on siblings and growing corporate partnerships. The monopoly board was very easy to follow, and staff all understood their role in achieving the objectives.

Culture

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

Leaders had an inspiring and shared purpose and strived to motivate staff to succeed. All staff promoted a positive culture that was open, inclusive and empowering. The senior leadership team set high standards of caring for staff and told us how they nurtured staff to ensure low turnover. This also enabled them to build on the experience in the team. Staff were committed to care that placed children, young people and families at the centre of the service. Staff told us, “Everyone understands the emotional challenges and support is second to none” and, “I’ve never felt on my own, even if I’m in a situation know there’s someone there”.

Staff told us they felt supported, respected, and valued by their managers. They enjoyed coming to work and were proud to work for the service. Staff told us there was strong collaboration, team-working and support between staff and a common focus on improving the quality and sustainability of care. Staff at all levels were actively encouraged to speak up and raise concerns, and all policies and procedures positively supported this process. Staff completed equality and diversity training. Staff were encouraged to raise concerns openly and without fear of recrimination.



End of life care

Staff were given a cost of living increase in August 2022 and staff wrote many letters of thanks for this. Staff said, “This gesture and financial gift is such a clear example of how compassionate this organisation is. I consider myself very lucky to work here, as the principle behind this gift is that as employees, we are looked after, thought about and helped in whatever way we can be and I very much appreciate that” and, “I already feel and tell everybody I work for the best organisation that truly care about their team, I now just want to shout it from the roof tops. I have already received several phone calls from the staff saying thank you and how this is going to help pay the energy bills.”

The chief executive told us about the forward-thinking ways they were looking at staff recruitment and retention. The board of trustees were considering options such as training their own staff and looking at sharing staff with other providers. For example, staff might work part-time in a hospital and part-time in the hospice. Senior leaders had introduced self-rostering for staff, so staff had more control and said this was working well.

The chief executive told us how there was a strong focus on the well-being of staff. The board commissioned an external staff survey to enable staff to provide feedback. The feedback staff provided rated the provider as a world-class employer. Any staff member or a member of their family could phone an advice line for counselling. Staff could speak with a counsellor for as long as they needed. The chief executive told us the board recognised the emotional impact on staff of the work they did and while they would normally expect the counselling service to have an 11% annual usage, this rose to 14% during the pandemic. Staff had access to a well-being programme which included yoga sessions, relaxation techniques, meditation and complimentary therapies. Staff were able to meet in groups or individually to reflect. The provider issued a monthly bulletin which contained a ‘praise column’; any member of staff could praise anyone else. There were also links to a helpline and videos staff could access.

The chief executive told us he had personally telephoned every volunteer, around 200 volunteers during the COVID-19 pandemic to ensure they were supported. In recognition of the work the service had done to ensure staff well-being was a priority, they won the ‘Workplace Health and Wellbeing Award’ in 2022 presented by the Thames Valley Chamber of Commerce Group.

The senior leadership team published their equality, diversity and inclusion statement on their website. The statement said, “Everything we do in the provision of care at Julia’s House is about treating people equally as individuals, and seeing their potential rather than their limitations: maximizing their opportunity to play, live, love and thrive within the family and the wider world.” The provider undertook an anonymous survey to assess how they could be more inclusive of people from BME backgrounds and received very high satisfaction responses. Although census figures show Dorset’s population is 4.4% ethnic minority, they estimated that 8% of children using the service were from BME backgrounds. Seventeen percent of the senior leadership team were from a BME background. Staff completed independent training sessions in equality and diversity as well as bullying and harassment training. The board had two diversity champions. Board members, leaders and line managers had completed unconscious bias training.

Governance

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

We found a clear line of governance to communicate information throughout the service, and to escalate and cascade information up and down lines of management and staff. Staff were clear about their roles and understood what they were accountable for and to whom. Staff could describe the governance processes for incidents and complaints and how they were investigated.



End of life care

The board of trustees held 6 board meetings a year. We reviewed minutes of board meetings. The board received reports from the two sub-committees, finance and risk and clinical governance. Minutes of meetings clearly recorded the discussions and showed it was an effective way to monitor, promote and maintain standards at the hospice.

The board of trustees invited independent professionals to complete a governance review to ensure they were carrying out their role as effectively as they could. The governance review identified a high number of trustees with certain skills such as collaborative working and leadership and found the meetings to be well managed by the chairman.

During COVID-19 an emergency planning group was set up. The chief executive told us this had proved to be a very effective and efficient way of working and the organisation had kept aspects of this way of working to maintain efficiency.

Management of risk, issues and performance

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

Staff improved service quality and safeguarded high standards of care by creating an environment for excellent service to flourish. All staff were fully committed to patient safety. The service had an effective risk register and the board of trustees had oversight of this. The three main challenges for the service were data interruption, recruitment and bringing services back after the changes as a response to the COVID-19 pandemic when children were stopped from meeting each other.

The service had a contingency plan with identified actions to be taken in the event of an incident that would impact the service, for example, extended power loss, severe weather events, short notice staff sickness and equipment failure. The contingency plan included contact details of relevant individuals or services for staff to contact.

The chief executive told us how the national shortage of care and nursing staff affected recruitment. Measures the board had taken included making posts permanent where staff had covered maternity leave, networking with NHS providers and introducing flexible contracts. A payment was made for staff who introduced a new member of staff as another way to promote recruitment.

The board was actively looking at succession planning and had written succession plans for all management roles. These identified what skills staff needed to develop and if they were ready now or up to four years ahead. The chief executive 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. For example, the contingency plans identified whether a successor had been identified or whether the service would need to recruit or restructure. Staff were supported to develop into senior roles.

The board of trustees had effective oversight of the quality and safety of care which enabled them to make sure decisions were in keeping with the strategy and values of the hospice.

Staff contributed to decision-making to help avoid financial pressures compromising the quality of care.

Information Management

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



End of life care

The service engaged well with families, staff, the public and local organisations to ensure a wide range of views were captured. 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.

Family surveys were undertaken to establish the views of families using the service. Areas covered included satisfaction, cultural needs and suggestions for shaping the service amongst others. A recent survey, conducted in 2021, asked families about the impact of COVID-19 and what aspects stood out, good or bad. For example, parents appreciated the continuity of the service through COVID-19, especially staff collecting prescriptions for parents. However, the impact of COVID-19 where families were shielding meant some families felt lonely, so having someone to talk with during sits was a great relief for them. The survey allowed for comments to be made and we saw where these comments were acted upon. A further survey had been conducted in 2022 which showed 87.5% of the 24 respondents were either quite satisfied or very satisfied with the service.

The service was ranked 2nd in the top 30 charities nationally in the 2022 Best Companies survey and was 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.

The board sent congratulations to the team in May 2022 for being awarded Charity of the Year from the Great British Business and Community Awards.

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.

Families were asked in an anonymous survey if the service met their needs in terms of race, culture and ethnicity, with 100% agreeing their needs were met. The service supported 8% of the children who were from ethnic minority backgrounds and 17% of the provider's senior leadership team were from an ethnic minority background. Dorset had an estimated ethnic population of around 4.4%, which is much lower than the population as a whole.

The service had a disability working group to ensure appropriate support was provided and raise awareness within the workplace. The working group were mindful of seen and unseen disabilities as well as the impact of stressful events such as family break-ups. The working group were looking at best practice in other organisations and identified wellbeing conversations with managers and mental health first aiders as important.

The hospice had developed strong collaborative partnerships with hospitals, another hospice and other health and social care providers. They demonstrated a commitment to developing joined up, innovative, flexible services and to developing sustainable models of care that improved the health and wellbeing of those using the service.



End of life care

The chief executive told us about the provider's rising stars programme. Staff were provided with the training and development they needed and were able to discuss their career developments either during their appraisals or with managers at any time. One member of staff told us how they joined and worked their way through to a position of seniority.

We spoke with the chair of the clinical governance committee. They told us the provider was very forward thinking and felt very positive about the work being undertaken. They told us how staff attended conventions and looked at research into changes in treatment and new devices to stay at the forefront of clinical provision. All parents and staff we spoke with said the service provided the highest level of support to children and their families.

The organisation had several internationally known celebrity patrons who supported them and undertook regular work in promoting the charity.

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.

The executive team supported leadership and management development at every level. Management and leadership education and training was provided in house and by accessing external courses, expertise and support.

The service was an active member of a paediatric palliative care network education group. This membership ensured the provider was aware of the national agenda in terms of education in paediatric palliative care. As a result, the provider drove improvements such as continuity of education and training within the region and shared expertise and resources. The provider was working to establish a similar education group in a different region, where they also provided care for children. The chief executive told us training and improving was a high priority and staff confirmed this. Staff had access to thorough training, updating and opportunities for ongoing professional development.

All new carers were required to complete the Care Certificate, any existing staff were supported with this process. The Care Certificate is an agreed set of standards that define the knowledge, skills and behaviours expected of specific job roles in the health and social care sectors.

Julia's House had a strong 'no blame culture' and this ensured staff had confidence to report accidents and incidents. All were investigated and staff had specific 'debrief' meetings involving all relevant staff when needed. The incident reporting system focussed on learning and improvements.

The board noted there was an ongoing concern about the national shortage of nurses and were taking actions to mitigate this, such as more support for families from family support services. Three initiatives had been signed off by the board; a third part-time Doctor (Wiltshire based), a Family Wellbeing post, and (subject to negotiations with the NHS) two Shared Nursing 'gateway' posts. The provider was considering taking on newly qualified nurses with preceptorship programme and keeping them hospice based. The provider also offered to pay nurses for returning to nursing.

Julia's House has led on two national research projects looking at how respite can prevent relationship breakdown and its role in mental wellbeing, using these results to lobby parliament in partnership with Together For Short Lives. This



End of life care

research highlighted the importance of respite breaks for parents. The results of the research were presented to the government to show the emotional and cost-benefits of supporting parents of disabled children because it showed parents who were supported had better mental health and were economically more productive. The chief executive told us they were seeking meetings with opposition parties to get shadow policies in place as well.