The Whittington Hospital NHS Trust

RKE

Community end of life care

Quality Report

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Date of inspection visit: 8-11 December 2015
Date of publication: 08/07/2016

Summary of findings

Locations inspected

Location ID	Name of CQC registered location	Name of service (e.g. ward/ unit/team)	Postcode of service (ward/ unit/ team)
RKE	The Whittington Hospital	End of Life Care	N19 5NF

This report describes our judgement of the quality of care provided within this core service by The Whittington Hospital NHS Trust. Where relevant we provide detail of each location or area of service visited.

Our judgement is based on a combination of what we found when we inspected, information from our 'Intelligent Monitoring' system, and information given to us from people who use services, the public and other organisations.

Where applicable, we have reported on each core service provided by The Whittington Hospital NHS Trust and these are brought together to inform our overall judgement of The Whittington Hospital NHS Trust

Summary of findings

Ratings

Overall rating for the service	Outstanding ☆
Are services safe?	Good ●
Are services effective?	Outstanding ☆
Are services caring?	Outstanding ☆
Are services responsive?	Outstanding ☆
Are services well-led?	Outstanding ☆

Summary of findings

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Summary of findings

Overall summary

We gave an overall rating for end of life care as outstanding because;

Whittington Health had their own children's palliative care service called Lifeforce. The service was a multi-disciplinary team delivering care and support to families who have a child with a life limiting or life threatening condition living in the boroughs of Camden, Haringey and Islington. We found that the service were providing a very high quality of care to the children and families on their caseload. The few areas where there was room for improvement was recognised by the team and plans were in place to make further improvements.

Staff were aware of the processes for reporting any incidents and there was a strong culture of learning from incidents and complaints to improve the quality of the service provided. Staff were fully aware of the safeguarding policies and procedures and could clearly tell us what they would do if they had any concerns. Staff reported there was good access to further training specific to their roles and all mandatory traning targets had been met. We observed risk assessments and emergency care planning. These were managed on an individual basis as needs changed.

Standard documentation based on the 'Together for Short Lives' protocols was used across the service and was shared with relevant stakeholders.

Relatives reported that they found staff very caring and supportive and we reviewed some excellent feedback especially from the services' exceptional Memory Day event. Patients' needs were looked at on an individual basis and the service showed us and we observed good examples of responsive care.

Staff were very passionate about their roles and local leadership was excellent. Staff felt supported in their roles and could discuss any issues they had with senior leaders. The teamwork was evident throughout the visit and staff often mentioned how they supported each other. The supervision offered by the team psychology members was essential in enabling staff to provide effective end of life care in difficult circumstances. All the staff we spoke with had been in their roles for many years and were justifiably proud of the end of life care they provided, whilst always looking for further improvements to be made.

Summary of findings

Background to the service

Children's Palliative Care services served by Whittignton Health are provided within the community across the boroughs of Camden, Haringey and Islington. The service forms part of the Integrated Care Specialist Children's Unit and is delivered across various localities closely aligned to Clinical Commissioning Groups and GP providers.

Palliative care, which aims to achieve the best quality of life for patients and families affected by life limiting illnesses, encompasses the important phase of End of Life Care. The General Medical Council considers patients to be approaching the end of life when they are likely to die within the next twelve months.

During our visit to Whittington Health, we inspected services delivered into the community by Lifeforce. The team were based at the Northern Health Centre on Holloway Road and travelled across the boroughs as required. The Lifeforce team held a contract with Great Ormond Street NHS Trust for input of medical services from a paediatric specialist consultant. The team further consisted of paediatric specialist nurses, respite play nurses, a play specialist/ youth worker and psychologists. The team liaised in the community with specialist children's nurses, other health professionals such as dieticians and occupational therapists and GPs. The children's hospices offered support to the service but their provision was not reviewed as part of this inspection and their services not reported on. However, it was clear that they impact on the overall care needs of the children and their families approaching end of life care in a positive way.

The inspection team included a CQC inspector and an end of life care specialist advisor. We spoke with 1 patient, 2 relatives and 5 members of staff. We attended 1 visit in the community observing the care given and were able to observe interactions over the telephone whilst in the office.

The Whittington Hospital NHS Trust

Community end of life care

Detailed findings from this inspection

Good

Are services safe?

By safe, we mean that people are protected from abuse

Summary

We rated safe as **good** because;

There was evidence of good initial care planning supported by high levels of specialist palliative care input from very well qualified and skilled nurses and doctors. Clinical staff were further supported in their roles by the respite nursery nurses and the play specialist who fully understood the importance of their roles in providing safe care.

The staff we spoke with were aware of the process for reporting any incidents and what to do with the information. There were effective systems in place to learn from any incidents.

We saw there were arrangements in place to minimise risks to people receiving the service and this was managed on an individual basis.

Staffing levels were good across the service, although staff were concerned about the increasing demand for their service and no specific plans in place to expand the workforce

We saw no issues with storage of notes or any breaches of confidentiality.

Incident reporting, learning and improvement

- There have not been any never events (serious largely preventable patient safety incidents that should not occur if proper preventative measures are taken) in the Lifeforce service within the past 12 months.
- The Trust had an up to date incident reporting policy and the staff were all aware of the required process. Staff were positive about incident reporting and saw this as a way of improving the service and learning from incidents. We were told of a recent incident indirectly involving the team where they had reviewed and changed their practice for requesting medication.
- We saw that learning from incidents was a regular agenda item at staff meetings. Staff described to us how information was cascaded through regular meetings and via email.

Duty of Candour

- The Trust had promoted duty of candour and this was seen to be cascaded through the regular team meetings.
- One staff member told us that duty of candour had been looked at by the team as to what was appropriate to communicate at the end of life stage.

Good

Are services safe?

- All staff we spoke with were aware of the policy and how it should be used.

Safeguarding

- The Trust had policies and procedures in place in relation to safeguarding adults and children. Staff told us they had received appropriate training and were confident in reporting concerns to the relevant teams. Staff were able to explain what constituted a safeguarding concern and the steps required for reporting on these concerns.
- One member of staff told us they have always had an excellent, supportive response from the safeguarding team.
- All members of the Lifeforce team had completed Children's Safeguarding level 3 and were 100% compliant with training targets.
- Level 2 Safegaurding Adults training was also provided for the team. Records showed that all members of the team had completed this training.

Medicines

- The specialist nurses we spoke with were able to prescribe independently and were fully trained.
- Staff told us that the management and administration of medicines was simplified as much as possible to prevent any undue pain or distress. We looked at symptom management plans and saw the medicines management was clearly described for the families to understand.
- Staff used a combination of national and local guidelines when prescribing such as the Association for Paediatric Palliative Care Formulary 2015 (APPCF) and the Palliative Care Formulary (PCF5).
- The consultant told us there was a good system in place for ensuring the right medications were always in the home for current symptoms and any anticipated symptoms. They used advanced care planning and had good working relationships with local hospitals.
- We saw the anticipatory medications and the emergency care plans were dually signed to avoid any medication errors.
- Staff told us the families were taught how to administer medication appropriately.
- We observed medicines being prescribed appropriately to prevent nausea and vomiting.

Environment and equipment

- Staff told us that they were able to access equipment seven days per week.
- Staff told us that robust processes were in place to ensure the equipment was safe and fit for purpose.
- All of the teams we spoke with did not express any concerns with the equipment contracts and were satisfied that they were given a safe and effective service.
- Whilst accompanying staff on home visits we observed appropriate equipment was available for the patient.
- The service used ambulatory syringe drivers. We looked at the last audit of the equipment undertaken in 2014 and saw the syringe drivers were checked.
- All staff using a syringe driver were audited and found to be competent in their use and operation of the devices.

Quality of records

- We looked at six patient records on the electronic system. The electronic notes were completed sensitively and with sufficient detail to describe the personalised care required for the patients. There were a full range of care plans individualised to patient need such as care of a naso-gastric tube.
- Records included conversations of where a patient wanted to be when unwell, at end of life and after death. Good systems were in place to discuss the information with parents and young people and for sharing this across the teams. Staff told us the records were shared with the ambulance service, other hospital providers, accident and emergency departments and Great Ormond Street. The parents also had a copy.
- All the records we looked at showed a discussion had been held around 'Do Not Attempt Cardio Pulmonary Resuscitation.' (DNACPR) The staff told us it was a discussion that was revisited when appropriate. The records clearly showed the family had been involved in the discussion.
- Staff told us the templates were regularly reviewed to ensure they were effective as possible.

Good

Are services safe?

- We looked at the emergency care plans and these were all fully completed and signed

Cleanliness, infection control and hygiene

- We observed good infection control and hygiene on the community home visit.
- There were good levels of Personal Protective Equipment such as gloves and aprons available in the home for delivering any personal care.
- Staff told us they took their own personal hand gel on home visits.
- Staff had 100% compliance with the mandatory training for Infection Prevention and Control.

Mandatory training

- Mandatory training rates provided by the Lifeforce team showed a consistently high level of compliance of staff completing the training.
- We saw the training matrix of mandatory training for the Lifeforce team. This included subjects such as safeguarding, equality and diversity, information governance and infection control.
- Staff told us they had good access to mandatory training and felt supported by their managers in being able to access it.

Assessing and responding to patient risk

- Staff told us that risk assessments were completed on a regular basis or as required. These included risk assessments for pressure ulcers and nutrition.
- The shared care working arrangement with Great Ormond Street NHS trust offered the service a specialist palliative care telephone advice line 24 hours a day, seven days a week. The consultant told us they also tried to involve the families' GP as much as possible to support any out of hours home visits that might be required.
- Staff shared some concern of out of hours response to syringe drive issues between 10pm and 8am. They were able to describe their contingency plans if there was ever a problem.
- The need for specialist support for coping with current or anticipated distress was offered within the team via a variety of methods based around the child and families need. This might include respite care , basic and therapeutic play therapy and psychology support. The staff members were able to describe many interventions that had helped assist with the patient need.

Staffing levels and caseload

- The team reported a full complement of staff.
- The team consisted of 8 whole time equivalent posts. This included a matron, senior specialist nurses, a play specialist/youthworker, clinical psychologists, respite care nursery nurses and a band six nurse on secondment from the children's complex care nursing team.
- Medical consultant input was provided via an agreement with Great Ormond Street. This included eight hours of direct input per week with a full 24/7 on call advice line cover.
- The matron was concerned about increasing demand on the service. One of the full time nurse specialist posts was externally funded with funding ending in January 2017. They told us they was a need to complete a full business case to ensure the staffing levels remained at a safe level to continue to provide the quality of service that is needed.
- Staff told us the caseloads were reviewed on a weekly basis. We saw the caseload review template. Matron told us a full review was done every three months to ensure all the records were complete and correct.
- All of the staff we spoke with had worked in the service for many years. The turnover was very low which demonstrated a commitment to the service.

Managing anticipated risks

- Staff told us they worked closely as a team to address any anticipated risks.
- We spoke with one member of staff who told us they managed anticipated risks by knowing the individual needs of their patients and risk assessing them accordingly.

Outstanding ☆

Are services effective?

By effective, we mean that people's care, treatment and support achieves good outcomes, promotes a good quality of life and is based on the best available evidence.

Summary

We rated effective as **outstanding** because;

We found the service provided outstanding, effective services to children, young people and their families. We saw examples of very good multidisciplinary working and effective partnerships with the local GPs, other providers and hospices.

The service was fully staffed with highly competent staff across a range of disciplines. The team respected each other highly and valued the input each role could bring to the service.

Feedback from patients and families was overwhelmingly positive about the care and resources available to them from the team.

Care plans had been developed taking into account the 'Together for Short Lives' eight priorities of care for children with life threatening and life limiting conditions. Symptoms and emergency care planning was well managed.

We observed excellent care in the home which provided the family and the patient with comfort and reassurance. The team were able to review the patients needs to ensure they could continue with meeting their own particular wishes in the face of great difficulty.

Evidence based care and treatment

- Lifeforce worked very closely with the UK Charity, 'Together for Short Lives' in order to achieve the eight priorities of care that were presented to Parliament in November 2013.
- The team referred to up to date information from the regular 'Policy Matters' newsletter issued from the charity.
- Clinical standards for the Lifeforce team were set using the National Service Framework for Children Young People and Maternity Services, the Nursing and Midwifery (NMC) Code of practice and standards,Trust policies and guidance and 'Together for Short Lives' End of life pathway. We saw these standards embedded in the care planning documentation.
- The care plans were regularly updated through literature search and examination of best practice and current evidence base.
  The team had a Standard Operating Procedure (SOP)
  The SOP was revised in November 2015 and provided a framework to cover all aspects of care provided by the service.
- The SOP was monitored by appraisal sessions with the Matron, clinical supervision sessions with professional colleagues, investigation of complaints and user views to improve the quality of the service and by clinical audit projects.

Pain relief

- Patients in the community received good pain relief.
- The team had established good relationships with local pharmacy teams for an effective response to medication needs.
- We noted that anticipatory drugs were prescribed to ensure pain relief was administered to patients in a timely manner.
- We did not observe the patient in any pain during our inspection.
- Specialist palliative care advice for pain control was available 24/7 via the specialist telephone advice line.
- The emergency care plan contained details of pain relief.

Nutrition and hydration

- Nutrition and hydration was well managed.
- Discussions were held with families about needs for nutrition and hydration specific to the patients needs. We observed a discussion with a family around hydration needs during a particular phase of the patient's week. Recommendations were made to ensure the patient had enough nutrition and hydration to maintain required energy levels.

Are services effective?

- Staff told us they worked closely with the community dieticians and speech and language therapists to support nutrition and hydration needs. We observed referrals had been made and recorded correctly in the care plans.

Patient outcomes

- The service took part in the Palliative Care Funding Review during 2013 and 2014. Data was submitted during these two years in order to gain a better understanding of the resources utilised and required in the provision of palliative care services.
- Staff within the service regularly attended the weekly multi-disciplinary team (MDT) review meeting of the shared caseload at Great Ormond Street. Staff also attended MDT meetings at other local providers. We were told that dicussions took place at these meetings to look at the plans in place for timely discharge into the service.
- We looked at the Preferred Place of Death audit of the service from January to December 2015. All of the patients had achieved their preferred place of death.
- The Trust had Neonatal and Paediatric End of Life Decision Making Guidelines in place in line with local and national policies and guidelines.
- The team worked closely with the children's ward at the Whittington to ensure effective rapid discharge planning into the Lifeforce service. We looked at the documentation which covered areas such as relevant contact details, family and child wishes and care after death.
- The family we spoke with said, "we could not have coped without the team. They support us fully."

Competent staff

- The Lifeforce service had developed a competency framework for the respite care nursery nurses. This underpinned the skills required to deliver high quality end of life care such as gastrostomy button feeding, oxgen therapy and oral suction.
- The palliative care nurse specialists were well qualified. Two of the staff members had completed a Master Degree in Palliative Care which meant there were high levels of expertise and good understanding of current issues within the team.
- Staff regularly attended training days held by 'Child Bereavement UK.'One staff member had just started a course with them looking at bereavement in children and young people.
- The matron had completed 'Sage and Thyme' training. This training looks at helping staff to respond to patients/carers who are distressed or concerned. They told me this training would be delivered to all the team.
- All new starters to the service attended a three day foundation course in palliative care led by Great Ormond Street. The nurse on secondment told us this had been very helpful in developing her knowledge and understanding.
- All new staff were provided with a comprehensive induction period.
- Staff attended the death reviews and weekly teaching sessions held at Great Ormond Street on a rotational basis.
- All the staff we spoke with were very positive about the training received.
- Staff told us they received annual appraisals and regular supervisions. They told us they could identify training needs within these sessions.
- There was a clear team approach to sharing learning.

Multi-disciplinary working and coordinated care pathways

- There were good local working arrangements with hospice provider organisations.
- The relevant teams worked in an integrated and multidisciplinary way. We were told that the local multidisciplinary team meetings (MDTs) held at local hospitals were attended by the team and very productive to ensure improved communication and coordination of care.
- We observed shared care with Great Ormond Street. We saw good working relationships had been established to ensure an effective coordinated approach to end of life care.
- We discussed the involvement of a physiotherapist at one visit and saw in the care records that referrals were made to other health professionals.

Outstanding ☆

Are services effective?

- Staff felt the multidisciplinary way of working was very strong and effective.
- We looked at notes from the Paediatric Oncology Shared Unit team meeting in November 2015 where a meeting had been held to discuss and agree management plans for a particular patient.
- We looked at the minutes from Community Children's Nursing Team. The Lifeforce team attended this meeting on a monthly basis. We were told there were strong working relationships with this team, particularly in Islington where the two teams were co-located. We observed interactions across the teams as regards home supplies that needed to be delivered.

Referral, transfer, discharge and transition

- The service offered a single point of access for referral from health and other key professionals and families.
- Staff told us the discharge from hospital into the community service was good. Where possible the staff would visit the patient and family on the ward prior to discharge.
- Referral criteria were available for the service on the website and in leaflets about the service.
- The team also considered short term respite support of six weeks for children being discharged home from neonatal intensive care units or hospital ward with a nursing need, to assist and support with transition to home from hospital, for example with oxygen and naso-gastric tubes.
- Transition processes were embedded within the service although numbers were low. Staff told us they had transitioned two patients to adult services within the last 18 months. We were told that when a young person reached 17, the adult services were contacted so that the relevant paperwork and handover process could be completed in a timely manner. The Lifeforce team would stay involved with the patient until the age of 19 if that was the wish of the patient and family. They would attend joint meetings with adult services.
- The service worked closely with the Children's Complex Care nurses. (CCN) Each patient on the Lifeforce caseload was allocated a CCN. The CCN service offered care throughout the day when required and until 10pm at night.
- Information was shared with the Great Ormond Street medical team to ensure the staff had enough information to make safe and correct decisions out of hours.

Access to information

- The palliative care team used an electronic system for recording information. Other clinicians, allied health professionals and the ambulance service were able to access the records. A copy of the emergency care plan was also held on the children's ward and within accident and emergency at the Whittington.
- We looked at the electronic patient notes and it was easy to navigate around the care plans to access information.
- A copy of the patient's emergency care plan was kept in the home.
- Information for patients and relatives and carers such as out of hours contact numbers were readily available.
- We saw examples of patient information leaflets that were routinely used. They were written in plain English and easy to understand.

Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- Staff had received training on the Mental Capacity Act (MCA) as part of their mandatory training. This was up to date.
- Staff we spoke with were aware of the MCA and the implications for their practice. One staff member told us they were due to discuss this further in a team meeting. We saw a poster was displayed for staff on the information board.
- Staff told us they asked for the patients' consent prior to delivering any care.
- Staff were aware of the patients' DNAR decisions and the information that was recorded within the care plans.
- We saw the consent forms had all been completed correctly on the electronic records.
- We observed consent being sought from the patient in the home visit. The staff communicated excellently with children and they were at the centre of discussions.

Outstanding ☆

Are services caring?

By caring, we mean that staff involve and treat people with compassion, kindness, dignity and respect.

Summary

We rated caring as **outstanding** because;

Throughout our inspection, we heard how patients were treated with compassion, dignity and respect by all staff. We observed a home visit which was exemplary in terms of care, respect and dignity at all times. Everyone we spoke with told us they had entirely positive experiences of the service. Two relatives told us they were so happy with the care given to their child. All staff we spoke with were passionate about their work and acted in a professional and sensitive manner at all times. Staff were committed to providing not only good care but being aware of the wider family needs. There was a high recognition of the importance of family and friends as life ended. We heard many stories that demonstrated compassion and kindness and this ethos underpinned the team's day to day working. Staff told us about attending funerals and visiting schools after a young person had died.

Compassionate care

- During the inspection we saw a patient treated with compassion, dignity and respect in their own home.
- We observed staff interactions with patients and their families demonstrating a 'can-do' attitude to solving problems to help support the young person involved.
- We saw patient choice was fulfilled where possible, taking into account a person's culture, beliefs and values.
- It was evident that a trusting relationship had been established with the patients and their families. The families were very relaxed with the team.
- There was evidence of on-going support for relatives after a child or young person's death, such as the annual Memory Day held in a local park to support bereaved families. Families could attend for many years after their bereavement. A multi-faith chaplain was involved in the event.
- We received direct feedback from some relatives. One said, "They are excellent. We couldn't ask for more."
- We saw feedback from various patient questionnaires. It was all positive with comments such as, "there is a total focus on my child's needs" and "they couldn't do anything better".
- Staff told us they had worked closely with the accident and emergency department to ensure that a high quality of care was given to families if their child died in the department. They told us how important it was for the families to receive compassionate care at all times such as not receiving belongings in a carrier bag but in a more suitable format to demonstrate care and compassion in a practical way.

Understanding and involvement of patients and those close to them

- Time was given to patients and relatives to discuss their concerns. During a home visit, we saw that the community nurse specialist and the consultant took time to discuss the changes in medications with the relative and ensured there had been a good understanding of the reasons why. A discussion was held around the next steps for the involvement of other health professionals such as the respiratory physiotherapist. The relatives told us they had been involved at all times and consulted about any decisions.
- We found that staff delivered person-centred care and knew the patients and families extremely well. Staff were able to tell us many stories about the patient and their wider family with their individual likes and dislikes.
- Patients and families were encouraged to give feedback on all aspects of the service.
- We saw examples of information leafets available to families and carers.

Emotional support

- We observed a good assessment of emotional needs during a home visit at a particularly difficult time for the patient. Support was offered in a constructive and flexible way to meet the needs of the patient.
- The team gave good support to the parent group called 'Surviving Loss of Our World.' The consultant and

psycologist from the team attended the steering group and gave support and supervision as required. There was also support for a monthly evening group and a sibling group.

- The play specialist/youthworker delivered bereavement workshops for the families. The feedback from these workshops was very positive with comments such as , “excellent workshop” and “a thousand times, thank you”.
- Bereavement support was given by the team with a visit within the first two weeks following death, after one month, after three months and a follow up phone call after six months. Families were encouraged to attend the annual Memory Day. It was evident the team set no limits on bereavement support and acknowledged that families needed differing amounts of time.
- The play specialist/youth worker told us about making family memory jars and using masks as a way of exploring feelings and emotions.
- Emotional support was also offered to friends of the child/young person by the team offering to attend the school. They offer a two hour session with making memory jars and answering any questions.
- The psychologist told us they worked with families to offer support around accepting the diagnosis.
- The team were also well supported with regular weekly supervision sessions. The respite nursery nurses were given a monthly group supervision session to share solutions and ideas as they often did not manage to meet as a group but would share the same patients.
- The team were given a pre-death brief by the psychologist looking at how the team felt and any solutions for offering the best death possible. A de-brief was also given to the team after each patient on the caseload had died to talk about feelings. This gave excellent support to the team to enable them to work so positively in difficult circumstances.

Outstanding ☆

Are services responsive to people's needs?

By responsive, we mean that services are organised so that they meet people's needs.

Summary

We rated responsive as **outstanding** because;

Patients and families were able to access 24 hour 7 day per week help and advice for end of life care.

There was a commitment to offering an equitable service across the three boroughs. Staff were aware of individual diverse needs. Data was collected on the patient's preferred place of death and discussed at the Great Ormond Street MDT.

The service worked well with the local hospice to make the best use of day care and hospice at home services in response to patient need.

The team responded to families' needs with their ongoing bereavement work, Memory Day and annual party. The team demonstrated a flexibility of service provision and an attitude of going above and beyond to ensure the patients and families received the best service possible.

Patients and relatives told us they were very happy with the service provided and knew how to make a complaint if necessary.

Planning and delivering services which meet people's needs

- The service we inspected was delivered in people's homes by the specialist Lifeforce team working closely with Great Ormond Street, community nurses, therapists and other key professionals.
- The times of the respite service was changed in response to patient and family feedback and is now offered later into the evening.
- Short term respite was also offered for children leaving hospital with for example, a nasal stent or naso-gastric tube. The team assessed the care package offered after four weeks. Staff told us the parents really appreciated this service as it is responsive to their needs at that particular time.
- Lifeforce have been working with the London Neonatal palliative care nurse consultant to deliver teaching at all the neonatal units in Camden, Islington and Haringey. Regular teaching sessions were given at the Whittington Hospital and other local NHS providers. This meant that healthcare staff across a wider geographical area and working within various departments were made aware of the needs and how the service was delivered.
- The team worked closely with a local hospice to provide a mortuary room for one week so that families and friends could sit with their child.
- There were strong links with other hospital providers of specialist care. Staff sat on a range of steering groups to contribute to the service planning of children's palliative care.

Equality and diversity

- Staff had received training in equality and diversity.
- Staff told us they had access to an interpreter service if required.
- Spiritual support was discussed with the patients and families and staff told us they had good access to local resources. Staff were willing to undertake research to meet the varying spiritual needs of the diverse community, for example, contacting the local mosque. They were able to access the chaplaincy service from both Great Ormond Street and the Whittington.

Meeting the needs of people in vulnerable circumstances

- The psychology staff supported patients and families with first line psychological support.
- Strong multi-professional working arrangements meant support could be accessed from a variety of sources such as the children's community nurses, therapists, local hospices and medical input from Great Ormond Street and other specialist providers. We observed care being given to a patient utilising a wide range of resources to meet their needs. A discussion was held about the unsuitability of the current wheelchair and a referral was made to the community occupational therapy team to undertake a review.
- Staff told us they were able to access Trust services to support patients with learning difficulties.

Outstanding ☆

Are services responsive to people's needs?

- We observed a telephone call trying to arrange help and support for a patient whose mother needed to attend hospital in an emergency. Staff contacted the relevant people to ensure the patient was safe and cared for appropriately.
- Leaflets had been developed by the team for parents on things to consider when a child dies at home.
- The play specialist /youthworker told us they attended a hospice visit with a patient to introduce her to the staff and help her with this difficult experience.

Access to the right care at the right time

- The team told us they worked closely with other members of the multidisciplinary team in order to ensure patients received timely access to services.
- The hospice at home can be contacted so that the patients had access to care overnight.
- Patients and relatives told us they had contacted the service out of hours and were given the right advice when they needed it.
- There were rapid discharge protocols and processes in place that were seen to be effective in getting people to their preferred place of care prior to their death.
- Staff in the accident and emergency department and on the children's ward had access to the emergency care plan.
- Staff in the Lifeforce team had recently completed work with the local hospital providers to raise the profile of the service to ensure children and young people were referred as soon as possible. The team told us they preferred to visit the patients on the wards prior to discharge to start the relationship and offer individualised care and support as soon as possible.

Learning from complaints and concerns

- Staff we spoke with were all aware of the Trust complaints process.
- One relative said, "I have no complaints at all."
- There were no complaints to the service in the last year.
- It was clear that the team welcomed feedback whether positive or negative to help improve the service.

Outstanding ☆

Are services well-led?

By well-led, we mean that the leadership, management and governance of the organisation assure the delivery of high-quality person-centred care, supports learning and innovation, and promotes an open and fair culture.

Summary

We rated well-led as **outstanding** because;

The children's community palliative care service, Lifeforce, was exceptionally well led. The service was committed, adaptable and flexible to meet the needs of the patients and their families. The term going, 'over and above' was used on many occasions to describe the team's approach to their work.

Staff complimented the leadership at a local level without reservation. They felt well supported and were very happy to be part of the team.

Staff knew the vision and values of the wider organisation although they felt there was more work to be done to be fully integrated into the trust as a whole. There was a good governance structure in place and the matron was aware of their service risks. The chair of Whittington Health executive board had recently taken on the lead for end of life care.

Staff demonstrated innovation and were proud of ways they had developed the service and were keen to do more.

Service vision and strategy

- The matron was encouraged that representation and leadership was now at executive level to integrate and progress the end of life vision and strategy for children.
- There was strong local leadership and the teams were clearly able to articulate their own particular service area's service delivery model. There was no specific strategy in place but the team referred to their standard operating procedure for guidance and were able to collectively present team objectives for service improvement.
- The team had a strong vision for the future to keep providing high quality care to their patients and their families.

Governance, risk management and quality measurement

- Staff told us that complaints, incidents, learning from incidents, safeguarding and policy reviews were discussed at team meetings. We looked at the minutes from across the teams and confirmed that issues relating to governance were discussed and recorded.
- The matron was aware of the risks to the service and these had been highlighted via the correct governance processes.
- The matron attended the Paediatric Quality Board and bi-monthly matrons' meetings. Information was shared with the team via monthly meetings and emails.
- The end of life care team based at the Whittington will be meeting with Lifeforce every six weeks starting from January 2016 to facilitate stronger integration and governance.

Leadership of this service

- Staff spoke very positively about their team leaders and senior management including the relationship with the medical staff from Great Ormond Street.
- All staff said they felt supported and could discuss any issues. There was an evident team based approach with great respect amongst the various roles and what they could bring to the service.
- The matron chaired the 'North Central London Palliative Care Network' and the Royal College of Nursing 'Children and Young Peoples' Palliative Care Community'.
- The matron was presented with an award for services to palliative care 'over and above' by the Well Child charity. The award was presented by Prince Harry in 2014.

Culture within this service

- We found the culture was very positive and staff felt empowered to do their job and be involved in the service delivery.
- One staff member said "I love my job."

Outstanding ☆

Are services well-led?

- The team worked well with others and there was a great level of respect for other services involved in palliative and end of life care.
- All staff we spoke with were passionate about their roles and this promoted a caring culture within the service.
- The consultant told us the team have a 'can-do' approach and 'they are an incredibly welcoming team where everyone's view is heard and valued.'

Public and staff engagement

- Staff were engaged through the regular supervision sessions and able to give feedback to senior staff at any time.
- The Friends and Family Test (FFT) was used within the service. The results from the survey from August 2015 to November 2015 showed 100% of respondents agreed this was a good service for the family and friends.
- One FFT comment said, "we have been treated with compassion."

Innovation, improvement and sustainability

- Staff felt their extended knowledge and skills and their team approach provided a quality service.
- The staff were able to provide us with numerous examples of innovative practice such as The Memory Day, a toy loan library and securing a piece of land in the local park for families and friends to visit. All staff we spoke with were committed to delivering a high quality service both now and in the future.
- The service have recently become part of a pilot project to develop volunteer project support for families known to Lifeforce. This is a national pilot and provides a unique opportunity to shape a volunteering programme in this sector in London.