

Lincolnshire Community Health Services NHS Trust

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End of life care

Quality Report

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This report describes our judgement of the quality of care provided within this core service by Lincolnshire Community Health Services 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 Lincolnshire Community Health Services NHS Trust and these are brought together to inform our overall judgement of Lincolnshire Community Health Services NHS Trust

Summary of findings

Ratings

Overall rating for End of Life Care	Good	
Are End of Life Care safe?	Good	
Are End of Life Care effective?	Good	
Are End of Life Care caring?	Good	
Are End of Life Care responsive?	Good	
Are End of Life Care well-led?	Good	

Summary of findings

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Summary of findings

Overall summary

Lincolnshire Community Health Services NHS Trust delivered community based services to people requiring palliative and end of life care and their families, throughout Lincolnshire. It provided a range of palliative and end of life care services within different care environments including hospice, hospital and care in people's own homes.

At the time of our inspection we judged community end of life services were safe. There was awareness amongst staff to identify and consider patient incidents and most staff we spoke with were aware of incidents within their areas. Staffing levels were generally safe in the services we inspected, although some staff reported often feeling under pressure.

Community end of life services were judged as effective at the time of our inspection. Staff used evidence based guidance and focussed on achieving a positive outcome for patients.

Community end of life services were caring. Throughout our inspection staff demonstrated good clinical practice and spoke with compassion, dignity and respect regarding the patients they cared for. We received positive feedback from all the patients and most of the relatives we spoke with.

End of life services were responsive to patient's needs. There were systems and processes in place to ensure people from all communities could access services and 24 hour arrangements in place for access to palliative and end of life services.

Overall we found community end of life services were well-led. Staff shared a common vision for end of life services and demonstrated a commitment to delivering good, safe and compassionate care.

Summary of findings

Background to the service

Lincolnshire Community Health Services NHS Trust delivered community end of life care services to adults throughout Lincolnshire, and covered a population of over 700,000.

Palliative care aims to achieve the best quality of life for patients and their families who are affected by life limiting illnesses. End of life care is an important part of palliative care and refers to the care of patients and their families throughout the last phase of their life. This could be a period of months, weeks, days or hours.

End of life care services were delivered within people's own homes, in addition to The Butterfly hospice at Boston and The Tulip Suite, a palliative care unit, situated on Welland ward at the Johnson Community Hospital at Spalding, as well as other locations.

Care was delivered by community GPs, a specialist palliative care consultant, nurses, community nurses, clinical nurse specialists (palliative care nurses), health care assistants and allied health professionals.

The teams worked closely with other health professionals in nearby trusts, charitable organisations and the community to ensure that all appropriate patients, including those with non-malignant disease, achieved the best possible quality of life.

Our inspection team

Our inspection team was led by:

Chair: Stuart Poynor, Chief Executive, Staffordshire and Stoke on Trent Partnership NHS Trust

Head of Inspection: Adam Brown, Care Quality Commission

The team included CQC inspectors, and a variety of specialists; school nurse, health visitor, GP, nurses, therapists, senior managers, and 'experts by experience'. Experts by experience have personal experience of using or caring for someone who uses the type of service we were inspecting.

Why we carried out this inspection

Lincolnshire Community Health Services NHS Trust was inspected as part of the second pilot phase of the new inspection process we are introducing for community

health services. The information we hold and gathered about the provider was used to inform the services we looked at during the inspection and the specific questions we asked.

How we carried out this inspection

To get to the heart of patients' experiences of care, we always ask the following five questions of every service and provider:

- Is it safe?
- Is it effective?
- Is it caring?
- Is it responsive to people's needs?
- Is it well-led?

The inspection team always looks at the following core service areas at each inspection:

1. Community services for children and families – this includes universal services such as health visiting and school nursing, and more specialist community children's services.

Summary of findings

2. Community services for adults with long-term conditions – this includes district nursing services, specialist community long-term conditions services and community rehabilitation services.
3. Services for adults requiring community inpatient services
4. Community services for people receiving end-of-life care.

Before visiting, we reviewed a range of information we hold about Lincolnshire Community Health Services NHS Trust and asked other organisations to share what they

knew about the provider. We carried out an announced visit between 9 and 11 September 2014. During our visit we held focus groups with a range of staff (district nurses, health visitors and allied health professionals). We observed how people were being cared for and talked with carers and/or family members and reviewed personal care or treatment records of patients. We visited 23 locations which included 4 community inpatient facilities and one walk-in centre. We carried out an unannounced visit on 10 September to one of the inpatient units.

What people who use the provider say

We spoke with six patients and six relatives during our inspection and received 12 comment cards from patients and relatives across the trust before and during our inspection. All of the patients and most of the relatives we spoke with were very positive about the quality of the care and treatment they were receiving.

Patients were complementary about the quality of facilities for inpatient units and the support they received from staff.

Good practice

We found the care and treatment of patients and support for their families, within the hospice, the palliative care suite and throughout palliative care and community nursing services to be good. Across end of life services all staff demonstrated compassion and commitment.

Areas for improvement

Action the provider **MUST** or **SHOULD** take to improve

- The provider should review end of life training across the trust for all grades of staff.

- The provider should consider submitting National Minimum Data Set (MDS). This would allow the trust to benchmark against a national agreed data set.
- The provider should consider specialist leadership in the form of a dedicated and experienced lead nurse for the trust wide palliative care team.

Lincolnshire Community Health Services NHS Trust

End of life care

Detailed findings from this inspection

The five questions we ask about core services and what we found

Good 

Are End of Life Care safe?

By safe, we mean that people are protected from abuse

Incidents, reporting and learning

All staff were aware of, and had access to, the trust's online incident reporting system. This allowed staff to report all incidents and near misses where patient safety may have been compromised. Staff were aware of what should be reported and were encouraged to do so. Some staff said they received feedback from incidents they had raised and gave examples of email feedback and feedback at team meetings. During our inspection we saw minutes from team meetings where incidents had been discussed. However some staff did not receive feedback and were unaware of any actions or interventions that may have been put in place to prevent incidents reoccurring. For example information we received prior to our inspection had identified two patient incidents resulting in harm that were directly related to end of life care. Root cause analysis (RCA) investigations had taken place on both occasions. When we discussed these at a specialist staff focus group not all staff were aware of the details or outcomes of either incident.

Cleanliness, infection control and hygiene

The hospice and the palliative care suite we visited were both clean and well maintained. There were procedures for

the management, storage and disposal of clinical waste, environmental cleanliness and prevention of healthcare acquired infection guidance. In both areas we observed staff using personal protective equipment appropriately. During visits to patient's homes we observed nurses sanitising their hands before and after patient contact.

Maintenance of environment and equipment

The hospice and the palliative care unit we visited were both modern well maintained buildings providing single room accommodation throughout. Both areas had access to specialist equipment for example pressure relieving mattresses and moving and handling equipment.

Community staff told us they had sufficient equipment to enable end of life patients to be cared for safely. They told us they had no problems accessing equipment. All the patients and relatives we spoke with told us there had been no delays in accessing equipment where needed. At the hospice we visited, staff told us equipment ordered before 2pm would be delivered to patients the same day.

The former National Patient Safety Agency (NPSA) recommended in 2011 that all Graseby syringe drivers should be withdrawn by 2015. We were told by staff, and

Are End of Life Care safe?

saw where syringe driver equipment met the requirements of the Medicines & Healthcare Regulatory Agency (MHRA). This meant that patients were protected from harm when a syringe driver was used to administer a continuous infusion of medication because the syringe drivers used were tamperproof and had the recommended alarm features.

Medicines management

Information we received following our inspection indicated within community services there were 311 nurse prescribers with five nurse prescribers within palliative care services. Staff told us this improved the quality of service to patients and improved clinical outcomes. Within end of life services nurse prescribers were able to prescribe medicines for the treatment of pain and other symptoms associated with end of life care. This allowed for a timely response to the patients symptoms and meant patients did not have to wait for a GP to write up a prescription.

We observed in the hospice and the palliative care suite where medicines were stored safely, controlled drugs (CDs) were managed according to legal requirements and, anticipatory medication [medicines that are prescribed just in case they are required] were prescribed appropriately.

We attended five home visits. At each home visit we saw where the nurse carried out a comprehensive review of all the patients' medications. This review included discussing the effects of the medications and, on one occasion, the side effects that may have contributed to the patients' current symptoms.

Safeguarding

Information received prior to our inspection outlined safeguarding training amongst staff, across the trust, to be 98% for level two safeguarding adults and, 96% for level two safeguarding children. Staff we spoke with demonstrated a good understanding of how to protect patients from abuse and could describe what safeguarding was and the process to refer concerns. Team meeting minutes we saw showed where safeguarding incidents had been discussed.

We saw there was a safeguarding procedure on display in the hospice and the palliative care unit. Further information and guidance was also available through a staff information folder.

Records systems and management

Throughout community end of life services patient records were held within the trusts electronic care record system.

Staff told us and we saw where there was shared access across the trust and patients GP's. However access was limited for local collaborative partners. For example out of hours end of life services were provided by a rapid response team funded by a registered charitable organisation. This team had limited access to patient records and could only see information on a 'read only' basis. This meant staff within the out of hours service could not update the electronic care records in a timely manner if a patient visit or communication had taken place.

The palliative care nurses told us they had access to remote working technology but chose not to use it because they felt the use of a laptop device may cause a barrier or distraction between themselves and the patient. As a result staff were making written notes in the patient's home and updating the electronic care records once they had returned to their base. This meant the electronic record was not always contemporaneous and there was a risk the paper notes may not always be identical to the electronic care record.

During our inspection we looked at 12 do not attempt cardio pulmonary resuscitation (DNACPR) forms within the hospice and the hospital ward and found that ten had been completed in line with the resuscitation council (UK) guidelines. The forms indicated that the decision had been made and recorded by the appropriate clinician. We saw evidence that discussions around DNACPR had been undertaken as appropriate with patients and their families. Of the two that had not been completed correctly one had been photocopied and one had not been discussed with the patient's relatives. In both instances the nurse in charge was made aware.

Lone and remote working

Staff were aware of the trust policy for lone working. To minimise the risk of lone working they told us there was a procedure for checking in and checking out when they had arrived at and were leaving a patient's home. They also told us they had access to a work mobile phone.

The hospice we visited was situated in its own grounds. We were told the manager had an agreement with the local police to complete a 'nightly' check of the building and surrounding area. A closed circuit television security system was also in place.

Are End of Life Care safe?

Assessing and responding to patient risk

Palliative and end of life care took place in the patient's own home, a hospice and palliative care beds delivered from inpatient wards. Ward teams and hospice staff operated local risk assessment protocols to reflect the type of service and where care was being delivered. In the hospice the manager maintained an 'issues log' to record risks on a daily basis. This would then be discussed with the team at team meetings. Examples of risks were low staffing and access to end of life training. Within palliative care nursing services some of the nurses were unable to identify any local risks relating to the service they provided, whilst others suggested lone working and access to training as their immediate risks.

All the nursing teams completed risk assessments for patients receiving end of life care. These included risk assessments for falls, pressure ulcers and a pre-bereavement risk assessment. In all the care records we reviewed we saw where these risk assessments had been carried out. We also saw where care plans were regularly evaluated and revised as appropriate.

Within community end of life services staff were using the NHS Safety Thermometer. This is a national improvement tool used for measuring, monitoring and analysing patient harms and 'harm free' care. Within the hospice and the palliative care suite the results of the safety thermometer were clearly displayed or readily available to staff and the public.

Staffing levels and caseload

Throughout end of life services, we were told of issues around shortages of staff and increased caseloads as a result. During our inspection we saw no evidence that staff shortages were having a negative impact on care delivery. We attended five home visits during our inspection; at no time did we observe the visit to be rushed. Most of the patients and relatives we spoke with were positive about the amount of time the nursing staff and palliative care services gave to them, however, one relative did express concerns about accessing palliative care services in a timely manner.

Staff within palliative care services felt recent vacancies compromised the quality of their service and had directly contributed to their inability to provide specialist end of life training to the wider trust. Trust wide the head count for palliative care services was 15 nurses. Staff told us of one band six and one band seven (whole time equivalent)

vacancies and gave examples of managing caseloads of approximately 40 to 60 patients each and, not always being able to dedicate the time they wanted to their visits. Staff told us they managed these vacancies through their own teams working extra shifts or help from the community nursing teams.

We were told there was a lack of administrative support within the palliative care teams. This meant a lot of time was spent on administrative duties instead of spending time with patients and their relatives.

In one inpatient area senior managers had reduced beds to reflect the decreased number of staff available. The ward sister told us this had helped to maintain an acceptable level of care delivery. In the same area unregistered staff told us they felt the staffing levels compromised the quality of end of life care they were able to deliver and that they often felt pulled between end of life patients and the remainder of the patients on the ward. At the time of our inspection the registered nurse responsible for the palliative care beds had to leave her shift. The ward sister told us the end of life patients would be allocated to the remainder of the staff on duty. We were also told this was a regular occurrence and that the palliative care suite did not have its own dedicated group of staff. This meant that staff often could not deliver the level of care that they wished to provide and ensure that the continuity of care was maintained.

Deprivation of Liberty safeguards

Staff we spoke with demonstrated a good understanding of their responsibilities regarding the Deprivation of Liberty safeguards and Mental Capacity Act 2005 and knew what to do when patients were unable to give informed consent. Staff spoke of best interest decisions and use of the two-stage functional test in line with legal requirements in order to make an assessment of the patient's capacity before carrying out any care or treatment.

Managing anticipated risks

The trust had a risk register which identified the risks within community services. The trust board assurance framework enabled the trust to have an overview of risks which could affect the safe running of patient services. However, not all staff were aware of the risks within their area. In the palliative care team we found that staff were unaware of risks that may affect the delivery of care in end of life services.

Are End of Life Care safe?

Both the manager of the hospice and the ward sister of the palliative care suite were able to recognise risks within their areas and identified staffing and capacity as significant risks.

Are End of Life Care 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.

Evidence based care and treatment

The trust had an 'allow a natural death policy' this detailed the standards and considerations across the trust, relating to cardiopulmonary resuscitation decisions for patients and had been developed in line with the NHS Litigation Authority guidelines.

During our inspection we looked at the care records of seven patients across end of life services. All the records were stored electronically. The records were well organised and information was easy to access. Records were complete and up to date and included recordings of capacity and consent. There was evidence, to show where patients had been made aware of the details of their illness, advanced care planning and, their resuscitation status was clearly documented. All the records demonstrated that patients received care that followed the National Institute for Health and Care Excellence (NICE) Quality Standard QS13. This quality standard defines clinical best practice in end of life care for adults.

Across end of life services we saw where staff followed guidance aligned to the Gold Standards Framework (GSF). This was a way of working that had been adopted by the health care professionals involved in their care. During our inspection we attended a GSF style multidisciplinary meeting with local GP's and the palliative care nurses. We observed the staff working together as a team to help to provide the highest standard of palliative and end of life care possible for patients and their families.

The trust had responded to the national withdrawal of the Liverpool Care Pathway (LCP). At the time of our inspection whilst there was no local procedures to replace the LCP staff were following national guidance through the use of the six-step end of life pathway. The National End of Life Strategy (Department of Health 2008) produced the end of life pathway to highlight the six steps required to provide good end of life care and is based on discussions as end of life approaches, holistic assessment, co-ordination of care, delivery of high quality services, care in the last days of life and, care after death. Local agreed symptom control guidelines and existing care plans were also in use through the use of individualised patient information 'prescriptions'.

Specialist nurses at the focus group we held told us there was on-going local collaboration across the trust to agree on a framework to replace the LCP for end of life care. Minutes from the trust wide palliative care nurses meeting in July 2014 showed where discussions had taken place.

Pain relief

The specialist palliative care nursing team had developed symptom control guidance for care of the dying patient in the last days of life. We saw that guidance followed the National Institute for Health and Care Excellence (NICE) clinical guideline CG140. This quality standard defines clinical best practice in the safe and effective prescribing of strong opioids for pain in palliative care of adults. The specialist palliative care team could also be contacted for advice about appropriate pain relief if required where symptoms were more complex.

During the home visits we attended we saw where staff spent a significant amount of time during the visit reviewing and discussing the patient's pain and other symptoms. All the patients and relatives we spoke with felt the patient's pain had been managed appropriately.

Within the palliative care suite staff were due to pilot the de-regulation of a medicine which is used in relieving severe pain. Previously the trust had treated all concentrations of this medicine as a controlled drug and as such the requirement was that it required two registered nurses to administer it to the patient. A six-month pilot was due to commence after our inspection allowing one nurse to administer the medicine. Staff told us this would allow them to address a patient's pain in a timely manner.

Telemedicine (optional)

At the hospice we visited the trust was due to commence a six-month pilot involving the remote diagnosis and treatment of patients by means of telecommunications technology in response to the 3millionlives Programme (Department of Health). We were told local GP's, the local accident and emergency department (A&E) and the hospice had all the necessary equipment available for the pilot that was due to commence between two and three

Are End of Life Care effective?

weeks after our inspection. The trust project initiation document outlined the benefits of this project as improving and enhancing the patient's experience and health outcomes and reducing the number of unnecessary A&E attendances and admissions into secondary care. Staff at the hospice told us the main benefit would be a timely response to patient's symptoms through immediate visual consultation by a medical practitioner.

Approach to monitoring quality and people's outcomes (combine with below if appropriate)

The care and treatment provided achieved positive outcomes for people who used the service. All of the patients and most of the relatives we spoke with indicated they were happy with the services provided.

The trust reported that between April 2013 and March 2014 interventions involving community nurses enabled 81% of patients to die in their own home and in accordance with their wishes and, interventions involving palliative care nurses enabled 74% of patients to die in their own home and in accordance with their wishes.

Patients receiving palliative and end of life care received support from a multi-disciplinary end of life care team, which included palliative care nurses, consultants, GP's, community and district nurses and, registered and unregistered staff based in the hospice and palliative care suite. In line with the principles of the Gold Standards Framework multi-disciplinary team meetings took place weekly to ensure any changes to patients' needs could be addressed promptly. These services alongside interventions from local charitable independent health organisations contributed to the avoidance of hospital admission and enabled patients to live as independently as possible.

During our inspection we found the palliative care nursing teams across the trust were not contributing data about palliative and end of life care to the National Minimum Data Set (MDS). Whilst basic data for example, the number of patients contacted by community palliative care nursing services within two working days of referral and, preferred place of death data was collected, data such as demographic information and breakdown of diagnosis were not collected. The MDS for Specialist palliative Care Services is collected by the National Council for palliative Care on a yearly basis, with the aim of providing an accurate picture of hospice and specialist care service activity. It is the only annual data collection to cover patient

activity in specialist services in the voluntary sector and the NHS in England, Wales and Northern Ireland. The collection of the MDS is important and would allow the team to benchmark against a national agreed data set. By not collecting MDS and examining the data staff were not able to identify unmet need and develop their services to support robust palliative and end of life care within the trust.

Competent staff

We received mixed feedback from staff about end of life training. Staff working at a hospice that had opened four weeks prior to our visit had all received some form of end of life training. In other areas we visited one staff member was doing a palliative care degree and one staff member had a palliative care degree. However, some staff told us they had received little or no training in end of life care in the last year. We discussed this with the palliative care nurses who confirmed that end of life training was difficult to deliver due to staff shortages within the teams. The palliative care nurses told us they had 'mapped' the training requirements across the trust and were aware of the lack of training provided. Information received following our inspection showed an action plan the trust wide palliative care team had developed in order to work towards establishing a structured framework for education in palliative and end of life care.

To assist staff in planning care for patients an end of life resource was available online, this included symptom control guidelines, useful contact numbers and other valuable information. In the hospice a band six nurse, with specialist palliative care training was available on every shift. In the palliative care suite a band six nurse had responsibility for arranging training for the ward staff. They showed us how each member of staff had an individual folder that listed their attendance at training and, identified their future training needs.

Most staff told us they were up to date with their mandatory training. Staff told us they attended a two-day rolling mandatory training programme and gave examples of the content which included; customer care, conflict resolution, equality and diversity, safeguarding vulnerable people, information governance, basic life support and, infection control. Trust compliance figures for year ending

Are End of Life Care effective?

31 March 2014 showed that the trust wide target of 95% had been met. Figures up to July 2014 showed that 92% of staff were up to date with the trust mandatory training requirements.

All the staff we spoke with told us they had received an appraisal within the last year. Trust data for April 2013 to March 2014 showed that 90% of staff had received an appraisal. Information received prior to our inspection indicated, in end of life services, that 14% of staff had received an appraisal between April and June 2014. During our inspection we were told the trust planned to have most appraisals completed by 31 October 2014. All the staff we spoke with felt their appraisal had been a useful exercise and gave them the opportunity to reflect on their work and learning needs in order to improve their performance.

Information received prior to our inspection outlined the increased uptake of clinical supervision as one of the trusts quality priorities for 2014/2015. Clinical supervision is a way of supporting staff in the development of their practice. All of the staff we spoke with told us of their involvement in 'informal' supervision and gave examples of team debriefs, one to one support from their managers and peer group supervision. However, the palliative care team were not receiving appropriate clinical supervision in line with NICE guidance (2004) 'supportive and palliative care guidance for adults', which states level two practitioners should be formally supervised by a level three practitioner.

Multi-disciplinary working and coordination of care pathways

A multidisciplinary team (MDT) approach was evident across all of end of life services. We observed good MDT working in the hospice, the palliative care suite and throughout palliative care services. Palliative care nurses were based at both the hospice and the palliative care suite

allowing staff easy access to advice and support Monday to Friday during office hours. Out of hours support was provided through a charitable organisation based at a nearby hospice.

We were told there was good access to specialist palliative care consultant advice through a local specialist hospice. The consultant also undertook community visits and reviewed patients when required.

Multidisciplinary meetings followed the principles of the Gold Standards Framework. Within the palliative care suite we saw that weekly MDT meetings were attended by nurses, a GP, allied health professionals, a pharmacist, a ward based social worker, a chaplain and, an end of life consultant, who accessed the meeting via a teleconference link.

Communication and coordination between some health care professionals within end of life services was enabled through the use of a patient coordination system which was managed by a local registered charitable organisation. It was unclear if this could be accessed by all the professionals who were caring for the patient or, if it was utilised trust wide. Trust wide access would enable staff to record and share information necessary to ensure the ongoing needs of the patient, including decisions about their care were met.

We saw there was integrated care pathways in place to ensure people received their care in a timely manner. We saw examples of excellent holistic integrated care pathways through the use of individual patient prescriptions. These clearly detailed anticipated care that had been drawn up by the multidisciplinary team and, patients and their carers. We saw that patients were supported by members of the multidisciplinary team who worked together to ensure care was integrated.

Are End of Life Care caring?

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

Compassionate care

We spoke with six patients and six relatives during our inspection. All the patients and most relatives were consistently positive about their experiences within the end of life services. We also received feedback via comments cards. We asked the trust to make comment cards available to patients and relatives across the trust before and during our inspection. We received 12 comments cards relating to end of life services; 11 were positive and one comment card was negative and related to not having access to palliative care services in a timely manner.

We found the care and treatment of patients and support for their families, within the hospice, the palliative care suite and throughout palliative care and community nursing services to be empathetic and compassionate. Staff and volunteers across the service promoted and maintained dignity and respect of all patients and their families. We consistently found a holistic approach in the planning and delivery of care. Staff always ensured that confidentiality was maintained and we found that patients, their families and staff had confidence in the care delivery within end of life services. It was apparent that end of life care within the Trust focussed in its entirety on ensuring the patient was at the centre of all decisions made.

We attended five home visits during our inspection; the compassion we witnessed during these visits was very good. Staff were focussed on the patient and their family. During one visit the palliative care nurse arranged with the patient to meet with the patients children to discuss their needs and any additional support they may require. On another visit the palliative care nurse felt it was time to discuss DNACPR with the patient. This patient had previously refused any discussion around DNACPR however on this occasion we witnessed the nurse sensitively and empathetically 'lead' the patient through this process. At the end of the visit the patient could be reassured that the care at the end of their life would be in accordance with their wishes.

At the hospice the manager told us that relatives were encouraged to bring in patients personal items or family pets therefore enabling them to be close to things that mattered to them when they were nearing the end of their life.

Dignity and respect

We observed staff treating patients respectfully and with dignity throughout end of life services. All staff, including volunteers, were welcoming towards patients and relatives and supported them in a professional and sensitive manner. We noted that there were good working relationships between different professional groups, and there was an apparent mutual respect between staff. We observed staff introducing themselves and interacting with patients and relatives in a kind and positive manner.

At the hospice and palliative care suite patients were cared for in single rooms where their privacy and dignity could be maintained. Privacy curtains were inside the entrance to all rooms. We noted at the hospice that all the rooms were sensitively decorated to avoid a clinical feel and promoted a supportive and welcoming environment in order to have a positive effect on those who visited the hospice whether as patients or their loved ones.

During our inspection we were told of good arrangements with local undertakers who responded in a timely manner. Staff told us, whilst they liked to keep deceased bodies in the area until the families had viewed them, they were mindful of other patients and families and as such often suggested families viewed the body of their loved one at the undertakers. Staff at the hospice were considering the use of a cooling blanket in order to allow the body to remain with them for a longer period of time.

Patient understanding and involvement

During our inspection we spoke with six patients and six relatives and, attended five home visits. Patients and relatives all told us they had been fully involved in the care provided and had a clear understanding of what was happening at all times. During the home visits we observed staff not only discussing patient wishes but revisiting advanced care plans to establish if the patient's wishes had changed in any way.

Information leaflets were available about a range of end of life care subjects such as pain control and bereavement support and, leaflets relating to risks associated with the patients altered mobility. For example advice on avoiding

Are End of Life Care caring?

pressure damage and falls. The leaflets were available in other formats and languages if required. During one home visit the palliative care nurse read through a leaflet with the patient to ensure they understood the content.

During the home visits we observed positive interactions between staff and patients, we saw that staff offered patients choices and provided them with information to allow them to make informed decisions. On one home visit the palliative care nurse concluded the visit by reading back all the actions that had been decided throughout the visit, the nurse then confirmed with the patient that they still consented to the actions taking place.

During our inspection we looked at the care records of seven patients across end of life services. We saw where appropriate communication had taken place between staff, patients and their relatives and, where patients and relatives had been involved in planning and making decisions about their care. As a good example of person-centred care, there was a 'patient prescription' document which was completed by patients and their relatives in order that staff were aware of what was important to the patient.

Emotional support

Staff developed trusting relationships with patients and their relatives by working in an open, honest and supportive way. Throughout our inspection we saw that staff were responsive to the emotional needs of patients and their relatives. The palliative care team had received training to enable them to have difficult discussions with patients and their families. The palliative care team, the chaplaincy, local registered charities, clinical psychologists and psychiatrists from a nearby acute trust were all available to provide appropriate psychological support to patients, relatives and staff.

At the hospice and palliative care suite overnight accommodation for relatives was available and there were quiet rooms where emotional support could be provided. All the patients and relatives we spoke with felt their emotional needs had been well supported.

We asked staff if they assessed relative's emotional needs prior to the patient's end of life. Staff told us relatives had an assessment of their emotional status, when the nurse met the patient for the first time, using a pre-bereavement checklist. This allowed the nurse to determine what level of support may be needed in the post bereavement stage. Post-bereavement the palliative care nurse would contact the relatives a week after the patient had died and in the following two weeks to see if further bereavement support was required.

Promotion of self-care

At the hospice and palliative care suite we saw that there were no restrictions on visiting times for relatives and friends of patients who were nearing the end of their life. We saw where staff encouraged relatives to visit frequently, or stay, in order that they could spend time with their loved ones.

During the home visits we saw where nurses took an active interest in the patient and their relative's social activities and made suggestions where patients could continue to engage in social activities even when the symptoms of their illness may have restricted them. One nurse arranged for a wheelchair to be delivered 'just in case' the patient became tired whilst out shopping. Another nurse suggested to a patient that they may like to attend a nearby hospice where complimentary therapies such as massage and reiki were available.

Staff told us of The HOPE (Helping Overcome Problems Effectively) programme, a six week programme run in conjunction with a university and a registered charity. The programme was free to participants and the palliative care nurses identified patients that might benefit, the aim of the course was to enable patients to manage the day to day impact of their condition. Feedback from a course held during October and November 2013 was either good or excellent.

Are End of Life Care responsive to people's needs?

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

Service planning and delivery to meet the needs of different people

End of life care took place in a number of different settings such as a palliative care suite, hospice and people's own homes. We observed an integrated approach to the delivery of care in all of the areas we inspected. We observed that all staff were committed to ensuring patients and their families received person-centred care.

Written information was available for patients and their families and although these were written in English staff were able to obtain the information in other formats such as large print and audio as well as in different languages. Staff told us that interpreter services were easily accessible if they were required.

The palliative care team and staff working in the hospice and the palliative care suite were aware of the importance of respecting the cultural and religious beliefs of different members of society. During a multidisciplinary meeting we observed a discussion around the needs of a patient with multi-cultural needs.

The chaplaincy presence in the multidisciplinary team on the palliative care suite worked closely with local representatives of various denominations. The trust had a service level agreement with a nearby acute trust to provide a similar service at the hospice.

Both the hospice and palliative care suite had specific referral criteria and staff were not afraid to challenge inappropriate referrals to their area. On the palliative care suite a daily meeting took place to discuss all patients who had been referred but were still awaiting a bed. The ward sister, advanced nurse practitioner and nurse in charge discussed the suitability of all the referrals and, on the day of our inspection, refused two referrals due to insufficient information that had been provided. The ward sister told us this did not mean the patient would not be accepted eventually but that the referrer may have needed to be more specific with the information provided. The ward sister told us using referral criteria helped to avoid inappropriate admissions that may delay end of life services for another patient.

The palliative care nurses told us they had developed close links with specialist nurses across the trust in order to

manage non-malignant conditions. For example neurological and respiratory patients who were in the end stage of their lives. This allowed the teams to appropriately address the more complex symptoms that patients may experience. We saw, in the minutes of a trust wide palliative care nurse meeting, where the teams were considering inviting specialist nurses from these groups to join their meeting on a regular basis.

Access to the right care at the right time

End of life services delivered, safe and coordinated care throughout all of the locations we inspected. In all the areas we inspected we found that robust out of hours arrangements, involving collaborative partnership working between the trust and independent providers, met the needs of patients who required end of life care and their relatives. There was a consultant within the community palliative care team who was available 24 hours a day, seven days a week for specialist advice. A specialist palliative care advice line was available 24 hours a day operating from a local independent provider and, there was access to an out of hours GP provided by the trust.

The trust quality schedule review for quarter four of 2013/14 indicated a target of 98% for the number of patients contacted by community palliative care nursing services within two working days of referral. Data received prior to our inspection showed just below the trust target at 95% with 390 patients out of a total of 409 receiving contact within two working days. We discussed this with the palliative care nurses who told us the final figure was influenced largely by patient choice.

GP's remained the responsible clinician for the patients whether they were at home, in the hospice or, in the palliative care suite. In the hospice and on the palliative care suite GP's reviewed patients daily and were available on-site for four hours per day, this service was complemented with on-site palliative care and nurse practitioner support. A band seven community nurse practitioner would also visit both the hospice and the palliative care suite each night.

A 'green card' scheme, launched by a local registered charity supported the use of a credit card sized green card with contact details for patients for the palliative care

Are End of Life Care responsive to people's needs?

nursing team, other healthcare professionals including district nurses and details of out of hour's provision. Patients were encouraged to show this if admitted to hospital or requiring out of hours support to indicate to others that they are known to end of life services. Staff told us the green card system alerted other providers and was flagged on the patients electronic care records to identify end of life and palliative care patients to staff in other services.

Palliative care services worked closely with the 'assertive in-reach teams'. Employed by the trust but based within the accident and emergency departments and the medical admissions unit of the acute trust, the team managed presentations at the front door and worked to prevent hospital admission by identifying alternative supported discharge back into the community. Managers told us the in-reach team met with local GPs at least once a month to discuss all end of life and palliative care patients in the locality.

Discharge, referral and transition arrangements

During the inspection we saw that patients' and relatives' needs were understood throughout their care and treatment. Hospice, palliative care suite and community nursing services had robust referral criteria's for patients from the trust, the acute trust, community and, patients and their relatives. At the focus group the palliative care nurses told us they were keen to ensure their services were easily accessible to the wider community. They told us of strong links with HMP services and nursing homes in the surrounding localities and, on-going work with the trust's diversity matron to address any barriers which may prevent black and minority ethnic people from accessing the services.

Staff told us where patients were to be admitted to either the hospice or palliative care suite they would normally be admitted on the day of referral. During our inspection we saw where patients were referred and admitted on the same day. On one occasion the patient was referred,

admitted and seen by the GP within three hours. During a home visit we saw a palliative care nurse identify a palliative care emergency and, through observing a well-defined pathway, dealt with this in an appropriate manner.

We received mixed feedback from staff about 'fast track' discharge for patients. Fast track discharge is for patients who are close to end of life and in urgent need of home care services. Most staff did not identify any issues and described a process that facilitated the discharge of the patient within 24 hours of a decision to discharge being made. However, within the more rural areas of the community, staff told us of problems accessing carers to provide personal care to the patient.

Complaints handling (for this service) and learning from feedback

Reported complaints were handled in line with the trust policy. Staff encouraged patients and relatives to speak to them about concerns. If a patient or relative wanted to make a formal complaint staff told us they would consider local resolution in the first instance. All the staff we spoke with said they would refer the patient or relative to the patient advice and liaison service (PALS) if they were not happy with the care. At the hospice and on the palliative care suite we saw information about how to complain was on display for patients and their relatives. Most of the patients and relatives we spoke with were aware of how to make a complaint.

Between 01 December 2013 to 31 May 2014 the trust received 97 complaints. Four complaints were directly related to end of life care involving lack of support, delay in being seen by a doctor and attitudes of the nurse. We discussed these complaints at the palliative care nurse focus group, not all staff were aware of the complaints or service improvements as a result. We looked at the minutes of the last three trust wide palliative care nurse meetings and noted that none of the complaints had been discussed. This meant that opportunities for learning from complaints, across end of life services, within this trust were limited.

Are End of Life Care 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.

Vision and strategy for this service

All of the staff we spoke with were aware of the vision and values of the trust and described an organisation that very much focussed on the patients. Most staff described a chief executive who was approachable, visible and committed to ensuring care delivery was patient-focussed.

Within end of life services there were four palliative care teams, located across the four business units. During our inspection we met with three of the teams. Locally each team demonstrated a passionate commitment to end of life care and shared a common purpose. They described a responsive service that provided care when and where it was needed. Trust wide, the palliative care nurses had a number of ideas to improve the service and gave us examples of; reviewing the service specification, submitting to the minimum date set, developing a robust programme of training in end of life care and, reviewing formal clinical supervision. At the time of our inspection we were not told of any systematic method of planning these developments, however, information received following our inspection showed an action plan the trust wide palliative care team were working towards in order to develop services within end of life care. Within this action plan a lead nurse, time frames and expected outcomes were detailed.

Guidance, risk management and quality measurement

Across end of life services most staff demonstrated a good awareness of governance arrangements. They detailed the actions taken to monitor patient safety and risk. This included incident reporting, keeping a risk register and undertaking audits. However not all staff, within the palliative care nursing team, understood how learning from incidents was implemented and were unable to identify risks that may affect their services. For example, we asked about how two recent patient harm incidents and a recent complaint had impacted on the care provided by the teams. Although learning actions had been identified not all the staff knew how these had been considered locally.

Within the hospice and palliative care suite staff talked of team meetings and shared learning from incidents and complaints. The minutes we saw, from the team meetings

on the palliative care suite, demonstrated where discussions and shared learning had taken place. In one area an 'issues log' was used to record any risks or concerns which were then shared with the team. We also saw where a weekly newsletter was produced for staff, this had 'weekly headliners' detailing any falls, pressure damage or incidents that may have occurred the previous week.

Regular mortality meetings took place, usually following each death, where a mortality review reporting template would be completed and uploaded on to the patients electronic care record. Staff told us this gave them the opportunity to reflect and learn about end-of-life care.

Leadership of this service

The palliative care teams were based in individual business units across the trust and had a line manager for their team. We saw strong leadership at matron level. However, staff felt they were lacking specialist leadership in the form of a dedicated and experienced lead nurse for the trust wide palliative care team. Staff felt a lead nurse would allow the service to develop, grow and innovate particularly around the non-cancer field, an area of palliative and end of life care that is vital if the trust is to be able to provide quality and timely care across the community.

The NHS Staff Survey 2013 saw the percentage of staff in the trust reporting support from immediate managers and, good communication between senior management and staff as worse than average (in the worst third of community trusts). Throughout end of life services staff told us they felt supported in their roles. Staff told us of excellent support from their direct line managers and matrons and, the palliative care team described the deputy chief nurse as someone who took an interest in end of life services and, "will inject a pace of change". Across community end of life services we saw evidence of strong local leadership with managers who were aware of the challenges within their areas and supported and valued their staff.

Are End of Life Care well-led?

Culture within this service

All staff were aware of the trust 'Time to Care project' and some staff had been involved. The project, led by the executive team, involved road shows to consult staff on developments within the trust. Staff gave us examples of developments they had been involved in including reducing the amount of time staff spent on the trusts electronic care record system and, reviewing the falls risk assessment process. Staff told us, reviewing both processes, would allow them more direct patient care time.

All staff were clear about their responsibilities to end of life care services and all demonstrated caring attitudes believing that patients were at the centre of the work they carried out. All of the staff we spoke with were passionate and committed to ensuring patients received the care and treatment they needed. Mutual respect between staff was apparent during our inspection.

Public and staff engagement

Staff we spoke with assured us they understood the trust whistleblowing policy and would feel comfortable using it if necessary. This suggested that the trust had an 'open culture' in which staff could raise concerns without fear.

During our inspection we were told of the clinical senate group that had been developed in February 2014 and provided a forum for the discussion and debate of clinical and quality issues and an avenue for raising innovative ideas. The group was made up of 30 clinical representatives and had representation from palliative care services. We looked at the minutes for the last three meetings and saw where discussions had taken place around developing unregistered nurses, developing leadership skills in band

five nurses and, improving communication. We noted all the meetings were well attended and on one occasion the executive board representation came from the chief executive.

We also discussed the 'listening differently to users' pilot project developed by the National End of life Care Programme. The aim of the project was to find more effective ways to collect analyse and present data on the experience of people receiving care in their last year of life, as a basis for service improvement. The pilot had two phases, and ran over three and four months respectively between 2012 and 2013. The trust had been involved in this pilot however, not all of the palliative care nurses we spoke with had been aware of the pilot.

Innovation, improvement and sustainability

The palliative care nurses demonstrated good clinical practice and this was supported by the patients and families we spoke with during the inspection. The team were motivated to improve service provision however they were limited in their ability to do so due to resource issues.

At the focus group we held with the palliative care nurses they told us of an audit they had undertaken in November 2012 which captured the views of service users in relation to the role of the community palliative care clinical nurse specialist (CNS) in palliative care. Their aim was to ensure the results would shape the delivery of palliative care CNS services across the trust. Results from the audit had been mostly positive for palliative care services and actions had been taken as a result. Examples that would benefit patients and their relatives included; standardising their answerphone message and redesigning their service leaflet. We were told there were plans to repeat the survey but currently no date had been agreed.