

Birmingham Community Healthcare NHS Trust

RYW

End of life careEnd of life care services

Quality Report

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

Summary of findings

Ratings

Overall rating for End of life care services

Good



Are End of life care services safe?

Good



Are End of life care services effective?

Good



Are End of life care services caring?

Outstanding



Are End of life care services responsive?

Good



Are End of life care services well-led?

Good



Summary of findings

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Summary of findings

Overall summary

End of life services were good within the trust, we identified some excellent care. Staff demonstrated a level of compassion and willingness to 'go the extra mile' for patients and families. We saw that innovative work was undertaken by the service, where staff had identified areas where their input resulted in improved outcomes for the patients and or their families.

We found the service to be safe. The trust undertook via each division and department audits which enabled conclusions to be drawn about activities. Where improvement or learning was required this was undertaken and shared appropriately with staff and relatives if need be.

We found the service was effective at meeting the needs of the patients on an end of life care plan. The services were highly personalised and holistic. The trust had developed a tool called the Supportive Care Plan for use with patients with a life limiting disease to help them achieve this. Multi-disciplinary team working was used to good effect for patients.

The end of life service was caring. We found evidence of a level of care which demonstrated excellence. Staff anticipated patients and family needs. We found that other staff within the team worked to an equally high standard.

The service was responsive to patient needs. The trust understood the needs of its client base, ensuring for example that translation services were readily available to patients whose first language was not English. We saw that religious practices informed staff interactions so not to cause offence and so they were able to offer advice with these customs in mind.

We found the end of life service to be well-led. At team level staff were well supported, line managers knew their staff well and effectively managed them. Information was shared about the individual services and the trust as a whole. Staff felt they were part of the trust and represented the vision and strategy of the service. Senior management was effective; governance arrangements were in place to plan for service provision and ensured that actions were disseminated appropriately.

Summary of findings

Background to the service

End of life services, consisted of an inpatient unit called the Sheldon Unit. The unit was part of the adults and community division, therefore cared for adult patients only. It had 18 commissioned beds for people with a life limiting diagnosis in the final 12 months of life. The unit had a clinical lead nurse, an advanced nurse practitioner and a variety of qualified and unqualified staff, as well as student nurses. Some patients received end of life care in other inpatient settings, but they were not recognised as being in the last 12 months of life and requiring care in the Sheldon Unit.

Within the community in the Children's and Families Division there was a dedicated children's palliative care

service, the service had service team leaders, band 6 nurses and band 3 healthcare assistants who worked as respite workers or play therapists. There were three teams covering Birmingham area, caring for children with life limiting diseases in the last 12 months of life.

During the inspection we spoke to five patients, 12 relatives and 31 staff. We observed care and support being delivered and reviewed documents related to the running of the services. Inpatient palliative care (Sheldon Unit) for adults and community nurse and palliative care teams for children, young people and their families.

Our inspection team

Our inspection team was led by:

Chair: Dr Cheryl Crocker, Director of Quality and Patient Safety, Nottingham North and East Clinical Commissioning Group

Head of Inspection: Adam Brown, Care Quality Commission

The team included CQC inspectors, and a variety of specialists; School Nurse, Health Visitor, GP, Dentist, 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

Birmingham Community Healthcare 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.
2. Community services for adults with long-term conditions – this includes district nursing services, specialist community long-term conditions services and community rehabilitation services.

Summary of findings

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 Birmingham Community Healthcare NHS Trust and asked other organisations to share what they knew about the provider. We carried out an announced visit between 23 and 27 June 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 46 locations which included 13 community inpatient facilities and the dental hospital. The remaining locations included various community facilities. We carried out an unannounced visit on 27 June to one of the inpatient units.

What people who use the provider say

We spoke with a number of patients, parents and family members about end of life care during the inspection. All of them were positive in their remarks about the quality of care that they or their relative of child had received.

In addition the recent inpatient survey, whilst small in number had returned positive results, and the end of life team were actively seek other ways to get feedback about their services.

Good practice

- The provision of just in time medication boxes to ensure that patients pain relief could be maintain in the community
- Nurses undertaking verification of expected deaths to reduce further distress to families
- The quality of care and extra steps that staff across end of life services carried out to support patients and their families.

Birmingham Community Healthcare NHS Trust

End of life careEnd of life care services

Detailed findings from this inspection

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

Good 

Are End of life care services safe?

By safe, we mean that people are protected from abuse

Summary

At the time of inspection we judged that services were safe. Incidents that took place were recorded and any lessons learnt were shared with the staff teams.

The priority of harm free care had resulted in improved outcomes for patients. Incidents were monitored closely to indicate whether the service was achieving harm free care and to what extent.

Arrangements for medications were well planned and executed; the prescription of anticipatory medication, the use of an advanced nurse practitioner and the use of just in case medication boxes in patients' homes, meant that patients did not have to wait for medications they needed to keep them comfortable. However the arrangements for respite patient's medication needed to be improved, the Trust had recognised this and was currently undertaking work to improve.

We reviewed do not attempt cardio-pulmonary resuscitation records and found that patients and family members were part of the decision making process.

Equipment and facilities were well maintained and presented low risk to patients, relatives and staff.

Detailed findings

Incidents, reporting and learning

Incidents were reported using a trust wide system. Staff confirmed they knew how to use the incident reporting tool and that they received feedback on incidents raised. Staff told us they were made aware of incidents which took place outside of their areas of work, which could impact on their own practice, such as serious incidents and near misses. We were made aware of an incident which involved a leaking syringe driver; following an investigation staff that used the syringe drivers were given learning updates.

Learning from incidents was shared with staff at regular team meetings, ward rounds, handover and reflective

Are End of life care services safe?

practice. In children's palliative care following a death a debrief session was arranged. Staff were able to attend and discuss new experiences they had gained from the experience and share this with other staff. Staff told us they understood that incidents were investigated and used as a learning tool to continually improve the service. They understood that a "no blame" culture was promoted.

The safety thermometer measures four areas of preventable harm that could occur to patients. These are pressure ulcers, blood clots in lower limbs, falls with harm and urine infections following catheterisation. This information is recorded and shared with members of the public who visit inpatient units within the NHS. We saw within the Sheldon Unit that this type of information was on display in the reception. It had been 291 days since the last person had fallen.

Documents supplied by the trust of serious incidents showed that from August 2013 to March 2014 on Sheldon Unit four grade 3 ulcers occurred, but following investigation they were found to be unavoidable.

The trust also recorded additional information regarding patient safety; 12 months of data was on display, the trust referred to this as the 'Essential Care Indicators'. Information recorded and measured was patient observations, falls assessments, tissue viability, nutritional criteria, medicines management and environmental criteria. We saw that the unit recorded 100% compliance for the period May 2013 – April 2014 for the completion of patient observations; 92% of the time the unit had met its target with 8% recorded as close to target. The data demonstrated that it was a well performing unit having only 4 months where they had not met the targets in its entirety.

The safety thermometer was not fully utilised in children's end of life as staff felt they needed a tool that was specific to their area. Staff had developed their own children's safety indicator tool, which we saw, but was not fully in use at the time of the inspection. We saw that it sought to capture information about pressure ulcers and advanced care planning arrangements. We saw copies of monthly team meetings which demonstrated that incidents were discussed and follow-up actions agreed to prevent repeat incidents.

Cleanliness, infection control and hygiene

Audits of the infection prevention practice in line with the trusts policy was recorded regularly. We saw that the Sheldon Unit audits gave them a score of 98% for both cleanliness and infection control.

We saw cleaning rotas in place which had been signed daily and spoke with cleaning staff that were able to explain the cleaning programme they undertook. They were also able to describe circumstances in which they would increase the cleaning regimes. We observed that stickers were in place with dates to identify when equipment had last been cleaned.

Staff complied with the trust policy to be bare below the elbows during work time. Each room had hand gel, soap and sinks within them. Hand gel and information about how to prevent the spread of infection was readily available throughout the unit. We observed staff working in the community wash their hands or use cleaning gel both before and after clinical delivery. The Trust had implemented an action plan for 2013 as a follow-up to issues raised in the staff survey; 47% of staff in the 2013 staff survey believed that there were sufficient hand washing facilities, this was down from 53% in 2012.

Maintenance of environment and equipment

Patients and staff had access to the equipment they required. We observed that equipment in use had been serviced and PAT tested to ensure it was safe to use. On Sheldon Unit, we saw hoists in use. Staff confirmed there were enough for the patients who required them. Risk assessments had been undertaken for their use and appropriately sized slings were kept in each patient's room. These hoists had documentation attached to prove they had been maintained and serviced.

In the Sheldon Unit we observed that where people who had been risk assessed as requiring pressure relieving mattresses' these were available to them and in use. Within the community we observed that patients also had the equipment they required, such as specialist feed pumps and oxygen machines. Though some of the equipment was not owned or maintained by the Trust, staff still checked that it was in working order and supported families to request maintenance visits.

Medicines

Effective arrangements were in place with regard to medication management. Within Sheldon Unit fridge

Are End of life care services safe?

temperatures were recorded, medicines were kept in locked cabinets and treatment rooms. Controlled drug medications were checked twice a day which was more than required by the Trusts own controlled drug policy.

Sheldon Unit had recently started to admit patients for respite care, these patients had their brought their own medications from home. The unit stored their bags of medication in the drug trolley. This resulted in the drugs trolley being disorganised and overfull. The unit had recognised this as an issue and had agreed to supply lockable drawers in rooms. During our inspection estates were present making initial arrangements for this to happen.

People were given medication appropriately, right person right medication at the right time, which were all recorded correctly. We did see that some people had to have their meal interrupted to receive medicines, which was not compatible to enjoying a meal. However some medications are prescribed to be taken with meals, but this was not made clear to people who we observed receiving their medications at a meal time.

Both in the community and on the Sheldon Unit we saw evidence of anticipatory prescribing. Relatives we spoke to on the Sheldon Unit were aware of it for their relatives. During home visits in the community, we saw that families had been supplied with locked “just in case boxes”. These contained the medications patients may require when their condition deteriorated. Within a hospital setting medications can be acquired from the store on the unit and from pharmacy. In the community it required a little more planning as medications required could take time to access. We saw that the boxes had a combination lock for safety and when no longer required were returned to pharmacy. The boxes were dispensed and returned to the pharmacy at University Hospital Birmingham.

The trust had developed a policy, the Terminal Home Care Symptom Management Policy and Procedure to implement the just in case medication box in the community which had not been released on the intranet at the time of our inspection. We saw that the children’s community nurse and palliative nurse team had been consulted in its production and content, along with the community pharmacist. This policy was to support staff with the safe use of the “just in case boxes”.

Both on the Sheldon Unit and in the community, nurses had trained to take on the additional role of a medication prescriber. Robust systems were in place to support the nurses and for additional checks to be made on prescriptions. On Sheldon Unit this role was occupied by the advanced nurse practitioner, who prescribed medications patients required. These were further checked with the medics who came to the unit most days. Pharmacy support was also present on the unit to check medication stock and any contraindications. The advanced nurse practitioner could access support from the medics who attended the unit.

Within the community and palliative nurse teams they had nurse prescribers working within teams. They too had a robust system; it was slightly more complicated as the nurses often prescribed and dispensed their own prescriptions. Safety checks were in place by having where possible two nurses present to check the prescription. Also all new prescriptions would be checked by the non-medical prescribing lead within the trust. There was currently no palliative care medic within the community who could assist with this task, though we did identify that the role had been advertised at the time of our inspection.

Parents whose child was being cared for in the community were supported to administer medications. Often these medications were very frequent and complicated. We spoke to families who told us how well they were supported to achieve this for their children. We were given an example of a parent who could not cope and they told us they were never made to feel inadequate. The staff took over the administration for them and took the time to teach another relative how to administer.

Staff were offered bite size learning opportunities regarding medication in inpatient services. Within the community all qualified staff regardless of whether they were nurse prescribers or not received training in the principles of prescribing so they were competent to check medication prescriptions and act as an additional safety mechanism.

Safeguarding

Safeguarding adults training had been identified by the trust as mandatory for staff. Trust figures showed for adult and community services and children and family services 92% of staff had received their training in safeguarding adults.

Are End of life care services safe?

During our inspection of Sheldon Unit staff showed a good level of understanding or what they would consider a safeguard indication. Staff were able to show us where information was readily available to report a safeguard incident for both adults and children.

The trust employed a safeguarding lead who supported and trained staff and audited safeguarding information.

Staff we spoke to were able to describe Deprivation of Liberty safeguards and what safeguards needed to be put in place. We saw completed documentation where Mental Capacity Act assessments had been undertaken for patients. We saw that the Trust had in use two types of assessment tools to assess mental capacity to make day to day decisions and one for significant decisions.

The trust had a robust policy in place to support staff and it could be accessed via the intranet.

Staff on the Sheldon Unit told us of a patient who had identified a preferred place of death. This had been risk assessed and presented a considerable elevated risk to the patient. To overcome this a case conference meeting was arranged with all interested parties including the patient and relatives and friends. The outcome of the meeting resulted in the person fully understanding that the risks were too high and the patient was able to choose another safer location to die.

Records

We looked at do not attempt cardio pulmonary resuscitation (DNACPR) arrangements. Within the inpatient unit staff had printed hand over sheets with patients DNACPR status; we also observed that this information was updated on the patient information board within the staff office.

We reviewed DNACPR paperwork and found that in the majority of cases they were completed in line with the Trust resuscitation policy. We saw where patients did not have capacity; the decision was discussed with relatives.

Both an advanced nurse practitioner (ANP) and physician signed the DNACPR paperwork we reviewed, the decision making process was clear. All admissions to the unit were seen by the ANP and advanced care planning was discussed and recorded; this was confirmed by relatives we spoke with. We noted that an information leaflet was available on the Sheldon Unit which had information for both patients and relatives regarding making decisions

about CPR. Audits of DNACPR paperwork were completed; however senior staff on the inpatient unit were not aware of the results, though the records we reviewed were completed in-line with the trust policy

In the community, we saw that DNACPR records were completed; parents were fully involved in the decision. We noted that advanced decisions conversations took place over time, to give parents time to come to terms with any decision they made.

Other records maintained such observations and details of interactions were maintained in an orderly fashion. We saw that records were maintained of regular skin checks to monitor any skin changes and comments were written where required and shared with the nurse in charge.

Within the community, detailed records were maintained of each visit outlining all the advice and care delivered and when the next expected contact was to be. This ensured that if the next member of staff visiting was different there was a clear record of interactions for them to follow on from.

Lone and remote working

Lone working only occurred in the community setting. During day time hours staff operated a buddy system and diary so it was clear where each member of staff was at any given time. The buddy system operated so if a patient visit ran over and staff intended to go straight home following the visit they had to call another member of their team to alert them that the visit had concluded.

Risk assessments of families were undertaken. Sharing of information from associated authorities such as the police and local authorities was used to identify potential high risk families who presented risks to staff safety.

The community children's nursing and palliative team worked out of hours, there were always three staff on call. Staff told us that when they were visiting out of hours there would often be two members of staff in attendance. The trust operated a lone workers policy that staff were aware of. We saw that staff could access all policies and procedures via the Trust intranet.

Assessing and responding to patient risk

Risk assessments were undertaken to identify risk and put systems in place to reduce the risk to patients. Staff had an arrangement in place to recognise a deteriorating patient and what actions they would take. For example within the

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community children's nursing and palliative team staff told us on identifying a deterioration which they could not manage they would contact the child's GP or treating physician. We saw a new policy had been produced which formalised the actions in use within the community children's nursing and palliative. The policy had been produced in consultation with the lead for the team. Within the meeting minutes of May 2014 staff were told this policy had been ratified.

We saw minutes from community children's nursing and palliative team meeting which indicated that some staff were using out of date assessment tools paperwork. This was addressed by administrative staff making an electronic folder with only the most up to date assessment tools within it for staff to access.

Staffing Levels and Caseload

Caseloads were large in the community setting. Full time band 6 staff held case loads of 70-75 patients. The palliative nurses held caseloads of 20-41 patients. Staff told us they supported each other and would take over patient appointments to help another member of staff. However staff told us they felt this was unsustainable, but were hopeful of the new staff and the CCG agreeing to the extra staffing for the rapid response service.

Staff absence had a negative impact and had the potential to increase patient risk. The trust consistently had higher sickness rates than the average across the NHS in England. Absence rates for adult and communities and children and families for June 2013 to May 2014 were 6.1% and 4.9%. Which were higher than 4.7% England average. The Trust had an initiative in place "the health and wellbeing pilot" this was to drive down the staff absence rates.

Maintaining safe staffing levels was an area in which the trust performed higher than their target of 85%. Documents supplied by the trust showed that 92% of the time, they achieved the minimum number of staff to maintain patient safety within the trust. These results were trust wide and related to the period of 2013-2014

Managing anticipated risks

Risk assessments were undertaken to identify risk and put systems in place to reduce the risk to patients. The trust undertook patient and family awareness initiatives. We saw on Sheldon Unit that there were leaflets and audit results regarding infection control. Relatives we spoke to often mentioned the level of cleanliness within the unit which they thought was good. Audit results for the unit were on display and showed that they maintained a good level infection control and cleanliness too.

Documents were stored within patient files and included risk assessments for example the risk of falls. These documents were comprehensive and gave clear instruction to staff about what adjustments in care was required to reduce the risk to patients. In the community the need for "just in case boxes" which contained medications which could be detrimental if taken by other members of the family or visitors. To mitigate this risk the container had a combination lock on it to prevent unauthorised access to the medications.

Advanced care planning took place at both the Sheldon Unit and in the community. This enabled patients to make their wishes known about arrangements for their end of life and the service planned for this.

Are End of life care 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 judged the domain of effective to be good in end of life care. The systems in place supported patients, relatives and staff to deliver effective care. The service delivered evidence based care and treatment. Patient outcomes were recorded and acted on to ensure they were positive.

Pain management arrangements were robust, which meant that patients were not left uncomfortable for extended periods of time.

Patient's nutrition and hydration status were reviewed regularly and acted on as appropriate. Staff were competent and professional displaying the skills required meeting patient's needs.

The facilities for patients on Sheldon Unit scored highly and above the national average when assessed by patients.

Detailed findings

Evidence based care and treatment

Care was delivered in line with nationally recognised guidelines. We saw evidence of personalised, individual and holistic care. Documents we reviewed were written with patient and family input. Information was present regarding their current care requirements but also took into account their personal situation. Both the Sheldon Unit and community children's nursing and palliative team adopted this approach. This was in line with the Gold Standards Framework for end of life care.

The trust adopted an outward looking approach to ensuring it delivered high quality care. Senior staff took opportunities to work with other organisations and contribute to improving services. For example the Trust worked with the West Midlands Palliative Care Guidelines group and had representation at its regular meetings.

Pain relief

Anticipatory prescribing took place within end of life services. Medication was identified that patients may require to alleviate their symptoms. The service planned for this by prescribing in advance these medications. So in the event that patients required them they could be

administered with little delay. The effectiveness of pain medication was assessed using a tool developed by the World Health Organisation, this helped staff to ensure that patients were kept comfortable.

Nutrition and hydration

On the Sheldon Unit a national assessment tool was in use to assess patient's nutritional status and identify what interventions were required. Where people needed supplementation to their diet this was delivered. The tool was reviewed on a weekly basis to ensure that patient's needs were continually assessed and adjusted to their current needs. Within the community children's nursing and palliative team we saw documentation where an incident had occurred where a patient requiring complex support to take on nutrition had failed. This resulted in poor patient outcomes. During a staff meeting staff were all reminded of the safeguards in place that they should be used. Policy documents supported this action, and additional training was sought and offered.

Patient outcomes

The trust no longer used the Liverpool Care Pathway, and had researched and implemented the Supportive Care Plan. The aim of the care plan was to support people who had a life limiting diagnosis to preserve their quality of life, in this final phase. The Supportive Care Plan was comprehensive and took into account the best practice in end of life, by being personalised to the patient, taking into account their current emotional and mental status and family expectations. There was an area for the medical plan of care, and it prompted staff to ask about care planning. A policy document was in place to support staff further in its uses as well as guidance. The trust accepted that further training in its use was required.

The national bereavement survey results for 2011-2012 showed the trust was in the bottom 20% of local area teams for respect and dignity shown by district and community nurses and GPs. The area was also in the bottom 20% of local teams for pain relieved completely, all the time during the patient's last hospital admission, sufficient help and support for family at time of death. This was the latest data available at the time of the inspection.

Are End of life care services effective?

However during our inspection we saw and were told by both patients and relatives that they had been treated with dignity and respect. We also saw no evidence of patients being in pain. We were able to speak to one bereaved family, who told us that their relative was made comfortable when dying. They went on further to say how well supported they felt following the death of their relative.

Children and their families mostly achieved their preferred place of dying. Documents supplied by the trust showed for the four quarters of 2013 83% died in their preferred place. Notably in quarter three 100% achieved this. Within the Sheldon Unit, staff and relatives told us that most patients, once there, wanted to die on the unit. They had very few patients who expressed a wish to die elsewhere. We explored this further with relatives, who told us that they found the staff and facilities so good it gave them peace of mind.

Performance information

The trust undertook extensive audit activities to measure its performance and ability to deliver positive patient outcomes. The trust was working with technology companies to deliver 'real time' data to trust staff to get at a glance information about performance. Senior staff told us they had access to this data, although it was quite new to the Trust.

The community children's nursing and palliative team had undertaken some audits of their ability to meet the needs of patients and were able to build a business case, which was at the time of the inspection under review with the Clinical Commissioning Group (CCG). They had identified the need for additional palliative care nurses to be able to improve the service offering.

The trust undertook self-assessments of the environment, Patient Led Assessments of the Care Environment (PLACE). The Sheldon Unit performed above the national average for three of the four measures. These were cleanliness, food and hydration, privacy, dignity and wellbeing and appearance, condition and maintenance. The final measure was just below the national average.

Competent staff

Staff demonstrated a good level of competency within their roles. We observed numerous patient interactions for which staff were professional and knowledgeable of the needs of the patients.

Handover arrangements were comprehensive and gave staff the up to date patient status details they required. We observed the handover from early staff to late shift staff during our inspection. Staff we spoke to told us they received appraisals from their line managers and also were able to access their mandatory training without any delay.

We saw nurse competencies with regard to end of life care. Staff had to complete each one to ensure that they displayed a level of skill to meet people's needs. Staff signed learning contracts to commit to completing them. The competencies included palliative care emergencies, pain management and bereavement.

Senior staff in the community children's nursing and palliative team had good working relationships with universities to improve the job related training for staff. They were able to identify modules which related closely to the work staff were undertaking to underpin their knowledge base.

Staff survey results for 2013 showed that 78% of staff received job relevant training and learning in the last 12 months, (this is over and above mandatory training) this was down on the previous year where the result was 81%.

Use of equipment and facilities

The facilities available to people on the Sheldon Unit were very good. Carers and/ or relatives were able to use a room on site for overnight stays. The unit had a multi-faith room on site; during our inspection it was being decorated. Staff told us that at that time there was no one on the unit who wanted to use it. There was a kitchen for relatives and carers to use to make drinks and store food. The main dining room was bright and large which enabled visitors to eat with and or sit with patients at meal times. The outdoor space was well planned especially the court yard, being easily accessible to wheelchair users; there was a shop on the unit.

Both on the Sheldon Unit and within the community, we saw that equipment was readily available and fit for purpose.

The trust assessments of the environment PLACE results for the Sheldon Unit performed above the national average four three of the four indicators. For appearance, condition and maintenance of the facility this was slightly below at 87.5% (88.75% national average).

Are End of life care services effective?

Multi-disciplinary working and working with others

Multi-disciplinary team (MDT) working took place in end of life care. However the extent to which this happened between the Sheldon Unit and community children's nursing and palliative team was different. During our inspection of the Sheldon Unit we saw that the team consisted of GP medical support, pharmacy and the advanced nurse practitioner (ANP) who all worked with the unit staff to meet the patient's needs. Close links were maintained with local hospices and dietician support was used regularly on the unit. We observed that staff cared for people in an emotionally supportive way and care plans demonstrated a holistic approach. We did not see any input from psychologists, physiotherapists, or complementary therapists which could have benefitted patients further.

We were told that when one patient had expressed a preference to die at home, but was assessed as not having sufficient support to maintain their safety a case conference was held. MDT working took place to support this patient to identify an alternative place of dying. Present at the meeting were people important for the person, social worker, continuing health care representatives, GP, district nurse and care home representative.

We reviewed documents within the CCN & PM teams which demonstrated that they undertook MDT working. We saw that there was input from GP's, the treating physician, respite care workers, play workers, occupational therapy, physiotherapist, psychology input, dietician and speech and language therapist and hospice and charity support. During our inspection we observed one family receiving support from a play therapist.

Co-ordinated integrated care pathways

The trust had developed the Supportive Care Plan; it took into account the national strategy from the Department of Health 'The End of life Care Strategy' 2008. The care plan had been designed to support patients in their last 12 months of life, its use was help to identify, assess and document the needs and care delivered. The care plan was to be used for adults only. Once implemented the care plan was reviewed regularly to ensure that changes in patient needs were recognised and addressed. The supportive care plan took into account Mental Capacity Act and Deprivation of Liberties safeguards, giving staff clear guidance of actions to take to ensure patients are not being deprived of their liberty.



Are End of life care services caring?

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

Summary

We judged this domain to be outstanding for end of life care. The level of compassionate and dignified care was excellent. Staff were emotionally aware displaying a high level of communication skills to support patients and relatives to a high degree.

Staff undertook support roles which may not at first glance seem part of their role. For example writing to one parent's employer to inform them of their child's illness.

Carers having the ability to stay overnight on the Sheldon Unit and having access to open visiting and free parking was greatly appreciated by carers.

Detailed findings

Compassionate care

There were many examples of compassionate care during our inspection, which we considered to be excellent. Staff appeared to have a level of empathy that ensured that their interactions were timely and sensitive. Patients and relatives told us they thought the level of care was of a good standard. We observed that staff took as much time as each person required to ensure their needs were met. We observed the palliative nurse with families; they told us they never felt rushed by the staff and they supported them in many different activities such as accompanying parents to hospital appointments.

Notably one member of the community palliative nurse team won the Lord Mayor's award for compassionate, outstanding and exceptional service. One area in which one parent mentioned was the support of being accompanied to hospital appointments by the nurses. We observed other nurses offering to do this and relatives told us they appreciated this level of support.

One relative told us that staff on the Sheldon Unit cared for their relative in such a way that they would, make sure that they always had their "treats" available. Friends and family results for October 2013 – January 2014 averaged 75.7%. The information indicates the likelihood of the patient recommending the service to others. The England average for the same time period was 72.5%.

The Sheldon Unit had a number of patients who also had a diagnosis of dementia. Relatives we spoke to give us

examples of excellent care and understanding that their relatives received. We saw that patients had a book called "This is me"; family members completed this. It contained information about the person to allow staff to get an understanding of what is important to the person. This included information about what worries the person and their hobbies and interests.

Relatives told us that staff had a good level of understanding of their relative's behaviour. Where patients could be aggressive staff understood the underlying cause and approached patients with care and compassion being careful not to antagonise them. Relatives were extremely grateful of this approach.

The trust had undertaken some support activities for carers of people with dementia. They undertook an audit of all inpatients in 2013-2014 and found that of 1100 patients screened for dementia, 27% (over 300) were identified as having a possible diagnosis of dementia.

Dignity and respect

End of life patients received care and treatment from staff that treated them with dignity and respect to a level we considered to be excellent. Patients and relatives we spoke to said they felt theirs or their relative's dignity was maintained.

One relative on Sheldon Unit told us that when she visited her relative, she often listened to the interaction between staff and her relative through the closed door. She said that staff spoke to her relative with a high level of respect. We observed that when patients received care staff ensured that the doors to patient's rooms were closed which meant that no one entered the room and patient dignity was maintained.

Within the community we observed that staff were culturally aware. We observed that they removed shoes and were aware of religious festivals. With regard to important religious festivals which required fasting staff were aware of the physical strain that may have on the main carer and discussed how they planned to manage the period.



Are End of life care services caring?

Patient understanding and involvement

Patients and families were involved in their care. One measure of this is the amount of people who die in their expressed preferred place. Evidence demonstrated that 83% of people were able to die in their preferred place. We observed and spoke to families, who told us they felt part of the care planning. They were given ample amount of time to understand and question the care planning.

We observed that when new ways of working were introduced which could have a benefit to the child and parent; although the parent was nervous the staff gave them time by introducing the new regime slowly, explaining the benefits and seeking consent from the parent. We saw that one parent was quite nervous and the staff did not push for them to try this they allowed them the time to come to terms. The Mother told us, she never felt rushed and appreciated them (the staff) allowed her the time to get used to things.

We saw documentation which was evidence of ongoing conversations about care needs and wants. We saw that advanced care planning was undertaken, patients where appropriate and families input was sought. We saw in DNACPR paperwork that family members and patients where appropriate were involved in decisions about their care.

Emotional support

Staff recognised that end of life care is a time of complicated emotions and try to accommodate the wishes of those involved. We were told of a patient who wanted to attend a spa day with relatives, but had been commenced on a therapy which required more timely input from the community children's nursing and palliative team. To accommodate the wishes of the patient, they accompanied them so they could fulfil their wish.

Verification of death was a role which supported families at a time of heightened emotion. This was an area in which

the trust was one of few that had the ability to support relatives to this level by having trained nursing staff verifying expected deaths. This meant that staff that knew the patient and families and had had time to build a relationship were able to complete this task. The one bereaved family we spoke to told us they greatly appreciated this and to have a GP out of hours at that time who they did not know could have added to their distress.

We observed one family whom we visited in their home where one parent was so anxious they did not sit with the nurse for more than 30 minutes as the nurse spoke predominantly to the other parent. We saw as more time elapsed the first parent became more relaxed until they were able to sit with the group and take on and ask questions about the care of their child. We were told afterwards that this was often the pattern, and they needed to give that parent time, which they did.

Within the inpatient unit we saw that there was open visiting. Visitors said they appreciated that they could attend when they wanted. Car parking was free on site, so relatives could stay as long as they wanted.

Within the end of life service we were told by staff that they made contacts at least twice with bereaved families giving them the opportunity to talk if they wished. We spoke to one bereaved family who corroborated this and said they found it helpful and caring. We also saw letters from families thanking them for the service. We noted one made mention of an offer to speak with staff, but the relative declined because they felt they were well prepared by the staff prior to the death of their relative.

When relatives invited staff to funerals, the service always endeavoured to send a representative. We were told of a funeral the day after our inspection in which two staff members were intending to attend.

Are End of life care services responsive to people's needs?

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

Summary

We judged this domain to be good for end of life care. The service understood the needs of the people it provided care for, ensuring they received care where they wanted and in a timely manner. Communication issues were also overcome by the current arrangements in place.

Reviews of the service were undertaken to identify areas where they could improve and business cases had been submitted to the CCG for consideration.

Out of hours arrangements were robust, so that patients and families in the most need were attended to in a timely manner.

Complaints were few for this service but were investigated to see if any learning actions could be taken. The patient experience team were actively working towards ways of gaining more feedback from end of life patients and relatives.

Detailed findings

Service planning and delivery to meet the needs of different people

During our inspection of the Sheldon Unit we noted that signage around the unit included Braille for those with limited vision. We also noted that the site was fully accessible using a wheelchair. Both inpatients and in the community we saw that translation services were used and available. Staff were able to show us literature which had been produced, including pictures with wording in the languages of patients most likely to use the service. Staff were able to confirm times when they had used the in house translation service.

The service was culturally sensitive when entering people's homes. We observed that they were aware of customs and cultural norms and followed them whilst in people's homes. For example one family's culture was to care for their child on the floor on cushions as opposed to a cot, which we were made aware of beforehand. The trust also had an external translation company under contract. Staff we spoke to were aware of how to access this service which was predominantly telephone and covered a wide range of languages.

Patients who accessed care on the Sheldon Unit were assessed by the continuing healthcare team. If the continuing healthcare criteria was met and their illness or their circumstances meant they could not be cared for at home, patients on an end of life care plan used this facility. Patients usually stayed until they died, but sometimes improved enough for arrangements to be made for them to go to another caring facility. We spoke to one such family who told us their relative had been expected to die in weeks but had improved so much they were now looking for a nursing home for them. They felt this was wholly due to the care and treatment their relative had received on the Sheldon Unit.

In the community children's nursing and palliative team we saw that they worked closely with commissioners identifying areas of additional resources and building business cases to demonstrate the need. Two new palliative care nurses were due to start; this was because the service had shown they were over delivering. The same service had a business case which the commissioners were considering to improve the rapid response access to service, which would require additional staff to deliver on improved timescales. We spoke to staff who had added to a policy document by developing a rapid discharge checklist. This was to help staff to be certain all checks and requests were in place to ensure a smooth transition from a hospital setting to home.

Access to care as close to home as possible

The community children's nursing and palliative team enabled children to be cared for at home, this reduced the level of distress for both the child and family of being cared for in an unfamiliar place. Systems were put in place to enable the staff to care for very complex needs of patients within their own home.

Access to the right care at the right time

Patients who accessed care on the Sheldon Unit were assessed by the continuing healthcare team. This team assessed patients who had been cared for within the University Hospital Birmingham. If they met the criteria and their illness or circumstances meant they could not be cared for at home, patients on an end of life care plan used this facility. Patients usually stayed until they died, but sometimes improved enough for arrangements were then

Are End of life care services responsive to people's needs?

made for them to go to another care facility. Patients were accepted to the Sheldon Unit seven days a week. There were guidelines in place to accept emergency patients and regular referrals for staff to follow.

Referral to the community team was via any acute hospital, where the child was diagnosed with a life limiting disease. The input of the community children's nursing and palliative team meant that children received a service at home as often as they required. This was accommodated by the level of dependency and need of the child and family. Therefore if the child was very close to death, they would receive more visits and at a higher frequency to a child that was stable.

Out of hours service was available to patients. The inpatient unit was open every day 24 hours a day. Out of hours GP support was arranged, we saw the rota for the month of June 2014 which demonstrated that there were no gaps in the cover. Out of hours telephone support was offered by a local hospice. Within the community team there was out of hours cover available to families. An on call rota was produced so staff were aware when they were to be on call. They were required to respond to the out of hour's calls and give advice over the phone or attend in person if a visit was required. One member of staff told us of family they supported with a colleague where they attended twice in one evening, the final time was at 03:00hrs until midday. The child died that morning and staff were able to verify the death and make arrangements with a hospice to use a family room so that the family could stay together with additional support from the hospice until the funeral directors attended.

Flexible community services

Staff supported relatives once their relative had died. We saw that following a discussion staff gave families a bereavement booklet. It contained information such as contact details for the funeral directors, arrangements for seeing their relative's body and first steps of actions to take. The bereavement booklet also had advice regarding organ donation. We spoke to a nurse on the Sheldon Unit who was very knowledgeable about organ donation and what processes had to be in place. The unit were able to quickly access phone support for this and for people who wanted to leave their bodies for medical science. The trust did not have a mortuary, but did have an agreement with a local

funeral directors to take the deceased. If families wanted to use another the person could be taken directly to a funeral director of their choice, or be moved from this original funeral director to the one of their choice.

Meeting the needs of individuals

The end of life service was tailored to meet individual needs of patients and families. In the community setting, we were told by a relative that staff had written to her husband's employer to explain that they had a chronically ill child. This resulted in the employer giving the father months of full paid leave so he could be at home to help care for his child, without fear of losing his job.

On the Sheldon Unit we saw that a record of foods that people liked and disliked was maintained. However one patient had pointed out that despite this they were offered food they did not like when staff were going through the menu options. In response to this when staff are taking menu choices they no longer mention the foods that the person actively disliked. Furthermore a list of food likes and dislikes were maintained in the onsite kitchen.

One relative told us that his relative who was on Sheldon Unit had a number of communication issues which made it difficult for them to fully understand interactions. They told us they had explained to staff how best to approach his relative and they were happy they were doing this. It resulted in his relative remaining calm during care and treatment.

Moving between services

The trust aim for end of life patients was for them to die in their preferred place, but occasionally they did move to other services. The Sheldon Unit patients usually stayed until they died, but sometimes improved enough for arrangements to be made for them to go to another caring facility. We spoke to one such family who told us their relative had been expected to die in weeks but had improved so much they were now looking for a nursing home for them. They told us that the pace in which this was happening was good, they did not feel hurried to move their relative out, so felt they could identify the best care environment for their relative.

When patients accessed the service the trust endeavoured for this to be a smooth transition. In the community we spoke to staff who had added to a policy document by

Are End of life care services responsive to people's needs?

developing a rapid discharge checklist. This was to help staff to be certain all checks and requests were in place to ensure a smooth changeover from a hospital setting to home.

In the inpatient setting, when a patient had been assessed as meeting the criteria for care at the Sheldon Unit staff would visit with the patients beforehand. Family members could then arrange to visit the unit. When this had taken place patients were moved to the unit. Having visited the person prior to admission the unit ensured they had all the correct equipment and staffing required to meet the person's needs.

Complaints handling (for this service) and learning from feedback

Documents supplied by the trust showed from January 2013 to May 2014 the trust had received four complaints which were end of life specific. One was upheld, two were partially upheld and one is still under investigation. All four had a common theme of communication issues. The trust supplied documents to demonstrate that they responded to complaints in a timely manner. They met the target 100% of the time for the two time parameters they measured.

On the inpatient unit we saw literature in the main reception area giving people details of how to complain and the different ways this could be achieved. We also saw a "You said, We did" display. One comment had been about being able to eat in the dining room. The trust had purchased specialist movable chairs which people could use who needed whole body support to enable them to eat in the dining room supported.

Senior staff in both the inpatient and in the community gave examples of how they dealt with issues before they became official complaints. When they were made aware of an issue they met with the patient and family to discuss it and resolve it at that time.

The patient experience team have recognised that getting feedback from people in end of life is difficult. To increase the response rate from carers/ relative they now offer prepaid envelopes for the responses. For June 2014 they received four responses from carers of in patients on Sheldon Unit. All the responses were positive or very positive.

Are End of life care 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 judged this domain to be good in end of life care. The management arrangements worked well and we saw that systems were in place for information to flow from board to service and back up again.

The saw a clear vision and strategy though this had not fully been implemented. Staff involvement was such in its production that they were aware of it.

Leadership at service level was robust; the team leaders demonstrated a good level of management skills, which led to staff delivering and making suggestions about future service provision. The governance was such that this information could easily be shared with appropriate groups for discussion and action.

The trust board were visible to staff in end of life, staff said they felt part of the trust.

Detailed findings

Vision and strategy for this service

We spoke to staff and the lead for end of life care and within documents supplied by the trust; we were able to see that although a full strategy was not in place the development and implementation were underway. The strategy is a city wide one and is currently in formal consultation with a view to the procurement process taking place from October 2014 to March 2015.

The trust identified strategic objectives. One of these has been the end of life care plan (the Supportive care plan); an action plan had been developed for its implementation. The Trust had met the markers for development and implementation and in the next quarter an audit of its use was to be undertaken.

Staff told us they felt part of the trust as there were many ways to access information about current news in the Trust. Staff mentioned the chief executives video messages in particular. Staff thought the intranet was a good source of up to date information.

Governance, risk management and quality measurement

We saw that the trust collected data about service delivery. This was used to plan future service provision. We saw that staff were able to contribute to future planning at many different levels within the organisation.

Meetings took place where we saw actions were agreed and disseminated appropriately. The information and actions were fed up through a process of groups to the board level. Where action was required action plans were produced and acted on in a timely fashion.

Leadership of this service

Leadership within this service was good; staff told us that their line managers were supportive and approachable. Both services felt they were well represented at senior management level. Staff from the services were well represented at meetings which related to their service.

The leadership styles of the unit managers for both services was extremely supportive and respectful of staff. One senior member of staff told us that when they were aware of behaviours they thought could be improved they were dealt with quietly and immediately and not left for a 1:1 meeting. A more junior member of staff corroborated this. We were also given an example of staff wanting to attend pain management training. Their line manager asked them to set out their objectives and do some work to understand them by arranging to visit other palliative care settings.

Culture within this service

The culture was one where patient and family care was of a priority. We were told by patients and families that “staff could not do any more for us”. Staff we spoke to were fully committed to giving excellent service and would consider any request which resulted in an improvement in quality of life. The trust wide staff survey supports this, having an 11% point improvement to 65% for the statement “Agreed that patient/ service user care is the organisations top priority”.

Public and staff engagement

The patient experience team was in place and had only recently been actively seeking feedback from end of life care users. They had engaged with senior staff to explore

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the appropriateness of seeking this type of feedback and had been reassured that it was appropriate to do so. This was what led to the introduction of prepaid envelopes for the responses. For June 2014 they received four responses from carers of inpatients on Sheldon Unit. All the responses were positive or very positive.

We saw both in the inpatient setting and in the community that families had taken time to send thank you card and letters to the services expressing their gratitude to staff at a time of extreme emotion and distress.

Staff were given opportunity to share their thoughts about work through their line managers. Staff we spoke to told us they felt comfortable to make suggestions without fear of retribution. The trust undertook the staff survey every year to understand the thoughts of the whole staff group.

Innovation, improvement and sustainability

The safety thermometer was not fully utilised in children's end of life care as staff felt they needed a tool that was specific to their area. Staff had developed their own children's safety indicator tool, which we saw, but was not fully in use at the time of the inspection.

One of the community children's and palliative care nurses had won the Lord Mayors Award last year. She was

nominated by a group of families who wanted to express their gratitude for her willingness to go beyond the call of duty to support them in caring for their children with complex needs. Although one nurse won this award in discussions with staff it was clear they all had a huge commitment to deliver excellent care to their patients and their families.

In the community senior staff told us they were developing a safety tool in conjunction with IT (Gel Solutions). The tool was in place for adults, but staff wanted to use a similar tool that reflected the children's service. This development would also help them to identify the dependency levels and share caseloads equitably.

As noted previously qualified nurses were able to verify expected death. Relatives benefited from staff they had existing relationships undertaking this for them.

Within the community staff had used audit data and built a business case for a rapid response service to be run both in and out of hours. The aim of which was to prevent hospital admissions once a child's condition had deteriorated. At the time of the inspection it was with the CCG for review.