

# St George's University Hospitals NHS Foundation Trust

RJ01

# Community end of life care

## Quality Report

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# Summary of findings

## Locations inspected

<b>Location ID</b>	<b>Name of CQC registered location</b>	<b>Name of service (e.g. ward/ unit/team)</b>	<b>Postcode of service (ward/ unit/ team)</b>
RJ701	St George's Hospital (Tooting)	Community end of life care services	SW17 0QT







This report describes our judgement of the quality of care provided within this core service by St George's University Hospital NHS Foundation 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 St George's University Hospital NHS Foundation Trust and these are brought together to inform our overall judgement of St George's University Hospital NHS Foundation Trust

# Summary of findings

## Ratings

Overall rating for the service	Inadequate	
Are services safe?	Requires improvement	
Are services effective?	Inadequate	
Are services caring?	Good	
Are services responsive?	Requires improvement	
Are services well-led?	Inadequate	

# Summary of findings

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# Summary of findings

## Overall summary

We rated community end of life care services as inadequate because;

- The trust did not have a strategy for the delivery of community end of life care services. The lack of such a strategy could have a negative impact on the quality of end of life care and future service improvements.
- There was no end of life care strategy that described the priorities for the trust as an integrated organisation. There was no trust-wide community and acute multi-disciplinary meeting.
- There was no overall vision for community end of life care services.
- Systems or processes were not sufficiently established or operated effectively to ensure the trust was able to assess, monitor and improve the quality and safety of community end of life care services or to identify and manage risk.
- There was no embedded replacement for the Liverpool Care Pathway (LCP) that had been discontinued in July 2014 following national guidance from June 2013.
- Community nursing staff did not always feel included in decisions about service changes and felt disconnected from the acute trust. However, they felt supported by their local team leaders.
- There was inconsistent end of life care training for community nursing staff with some staff having received training in end of life care while others had not.

However;

- Staff understood and fulfilled their responsibilities to raise concerns and report incidents and near misses.
- Patients were treated with dignity, kindness and compassion and there was consistently positive feedback from patients and their relatives about the service.

- Staff worked hard to ensure that patients at the end of life were given the support that they needed, including staying beyond the end of their shift to make sure patients had in place what they needed.

We rated safe as requires improvement because;

- The community nursing staff did not always have the end of life care knowledge, skills or experience for their roles caring for end of life patients in the community.
- There was insufficient IT equipment available to meet the needs of the service.
- Community nursing staff told us they could visit patients with two staff if a risk had been identified. However, they did not always have sufficient numbers of nursing staff available to undertake such visits.
- Patients' level of dependency was not measured as there was no analysis of the types and details of care the community end of life patients received from the community nursing team.
- Staffing levels and skills mix were not reviewed regularly to ensure patients received safe care and treatment at all times.

We rated effective as inadequate because;

- The community end of life care was not consistently provided in accordance with national guidelines. There were no individualised plans of care specifically for community end of life care patients in the last phase of life that were based on national guidance or evidence based care and treatment.
- There was no replacement of the Liverpool care Pathway (LCP) following its removal from use in June 2013. Moreover, there were no audits or quality monitoring of patient outcomes in the community end of life care services.
- Community nursing team responsible for end of life care had not fully implemented the five core recommendations for care of patients in the last few days and hours of life as set out in the Department of Health's End of Life Care Strategy 2008. The community nursing team had not implemented recommendations of 'One chance to Get it Right' document published by the Leadership Alliance for Care of the Dying People 2014.

# Summary of findings

- There was no involvement of the physiotherapy, occupational therapy, dietitian, counsellor or chaplaincy services in provision of community end of life care services.
- A training needs analysis for core end of life training had not been carried out in 2015 to identify the training needs for community nursing staff working in the community.

We rated caring as good because;

- We observed community nursing staff caring for end of life care patients in their own homes with dignity, respect and compassion. Community nurses treated patients gently and checked their comfort at various stages of care and treatment. Families and relatives we spoke with told us staff were caring and had provided them with emotional support and kept them informed about their loved one's care and treatment.
- Community end of life care patients we spoke with and those close to them told us they were encouraged to be involved in their care. They told us they were routinely involved in decision-making and felt they had sufficient information to understand their treatment choices.

We rated responsive as requires improvement because;

- Due to the shortage of experienced and skilled community nursing staff, the community end of life services were planned simply to get round those patients that needed basic nursing care using newly qualified and agency nurses.

- There was no engagement between the acute end of life care team and community nursing team to plan and deliver an integrated end of life care service for patients. There was no equality and diversity champion within community nursing services to support staff.

We rated well-led as inadequate because;

- There was no overall vision for community end of life care services. The corporate management was not effectively managing and monitoring the community end of life care service.
- Community end of life care had no influence within the acute management structure and there was a lack of both strategy and resources which compromised the service's sustainability.
- Systems or processes were not sufficiently established or operated effectively to ensure the trust was able to assess, monitor and improve the quality and safety of community end of life care services. There was no governance structure which supported community end of life care services.
- All community nursing staff felt confident about speaking up and raising concerns with their line managers. However community frontline managers felt their voice was not heard by senior management in the trust. Most of the staff we spoke with in different roles, although committed to their patients felt disconnected and undervalued by the trust.

# Summary of findings

## Background to the service

St Georges University Hospitals NHS Foundation Trust provides community end of life care services for adults in the community. Community Adult Health Services (CAHS) are commissioned by the local clinical commissioning group (CCG) to provide care to people in their own homes, including end of life care. Trinity Hospice is commissioned by the CCG to provide specialist palliative medical and nursing services.

The service is provided across the London boroughs of Wandsworth, Sutton and Merton, as well as parts of Lambeth for patients who are registered with General Practitioners in Wandsworth.

Community end of life care services for people living in Wandsworth was provided by the general nurses from the trusts' community nursing team in conjunction with Trinity Hospice. However there was no service level agreement with the hospice for the provision of such services. The trust has one band seven facilitator and one band six nurse, neither of whom are community end of life specialists, working with the community nursing team.

Community end of life care is provided to patients who have been identified and assessed as having entered the last twelve months of their lives. In common with many areas of the country, cancer patients formed a high proportion of the trust's end of life care patients. The trust was not able to provide us with the actual figures for cancer and non-cancer patients receiving community end of life care.

During our inspection, we visited the community nursing teams in Brocklebank Health Centre, Balham Health Centre, Tudor Lodge Health Centre, Tooting Health Centre, Stormont Health Centre, Doddington Health Centre, Westmoor Clinic and observed care being provided by the community nurses. We looked at 18 care records for the patients we visited. We spoke with 18 members of staff including the end of life care facilitator, end of life care nurse, community nursing team leaders and community nurses. We spoke with 14 patients in their homes and eight relatives in the community.

## Our inspection team

Our inspection team was led by:

**Chair:** Martin Cooper

**HOHI:** Nick Mulholland, Head of Hospital Inspection, Care Quality Commission

The team included CQC inspectors and a variety of specialists:

The team inspecting community end of life care services included a CQC inspector, a palliative care consultant and palliative care specialist nurse.

## Why we carried out this inspection

We inspected this core service as part of our comprehensive inspection of St Georges University Hospital NHS Foundation Trust.

## How we carried out this inspection

We inspected this service in June 2016 as part of the comprehensive inspection programme.

As part of our inspection we held interviews with a range of staff who worked within the service, such as nurses, therapists and senior managers.

# Summary of findings

To get to the heart of people who use services' experience 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?

Before visiting, we reviewed a range of information we held about the core service and asked other organisations to share what they knew. Before the onsite

visit we held focus groups with a range of staff who worked within the trust (both community and acute). We spoke with people who use services. We observed how people were being cared for in their own homes and talked with carers and/or family members and reviewed care or treatment records of people who use services.

During the inspection of the community end of life care services we spoke with 18 members of staff, undertook nine home visits with community nurses. We reviewed the records of all the patients we visited and reviewed their 'do not attempt resuscitation' records.

## What people who use the provider say

Patients and relatives we spoke with told us they were highly satisfied with the quality of care they received and that staff treated them with respect and maintained their dignity.

Specific feedback included a relative who told us the support they received from the community nursing team during the time that their loved one was dying had helped them to feel like they were being 'carried' and that staff had shown them incredible kindness.

## Good practice

The trust in partnership with the local hospice and CCG had recently set up a pilot Coordination Centre based in the hospice to coordinate and manage fast track discharges and supply of equipment's and care assistants to patients requiring palliative and end of life care.

## Areas for improvement

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

#### Action the provider **MUST** take to improve

- Have an oversight of the community end of life care services.
- Have a vision, local lead and set of values for the provision of community end of life care services.
- Have MDT meetings that incorporate allied health professionals.
- Implement joint working between the community and acute end of life care services.

- Improve the governance arrangements and risk management processes to ensure they are robust and embedded throughout the community end of life care services.
- Ensure there is an evidence-based replacement for the Liverpool Care Pathway.
- Ensure there are sufficient numbers of suitably qualified, skilled and experienced nursing staff to meet the needs of end of life patients.



## St George's University Hospitals NHS Foundation Trust

# Community end of life care

## Detailed findings from this inspection

Requires improvement 

### Are services safe?

By safe, we mean that people are protected from abuse

#### Summary

We rated safe as requires improvement because;

- There was insufficient and non-functioning computers and IT equipment available to meet the needs of the service.
- There was overcrowding and inadequate office space for the number of staff in community nursing teams we visited.
- Community nursing staff told us they could visit patients with two staff if a risk had been identified. However, they did not always have sufficient numbers of nursing staff available to undertake such visits.
- Staffing levels and skills mix were not reviewed regularly to ensure patients received safe care and treatment at all times.
- There was no specific incident reporting log and risk register for community end of life patients.

However;

- The service had robust systems in place to investigate and learn from community nursing incidents.

- We found good practice around hygiene and control of infection.
- End of life care patients were provided with the required equipment and medical supplies they needed through a coordination centre based at Trinity Hospice.
- The service measured the dependency of patients.

#### Incident reporting, learning and improvement

- Staff were knowledgeable about the incident reporting process. They confirmed that there had not been any Never Events or Serious Incidents relating to end of life care. There were no record of any Never Events for community end of life care reported by the trust.
- Community nursing staff had a full awareness of the processes to follow in order to report adverse incidents or concerns. Nursing staff we spoke with understood their responsibilities to raise concerns, to record safety incidents and near misses, and to report them internally in order that they could be investigated and acted upon.
- A formal process was used for reporting, investigating and learning from incidents, errors or near miss situations. Nursing and other clinical staff described to us the system they used and the investigation process.

## Are services safe?

- Community nursing staff told us they were confident in reporting incidents and ‘near misses’ on the trust’s electronic incident reporting system. We reviewed a number of incidents reported by the community nursing team, however, we were not able to extract specific community end of life care issues that had arisen through the incident reporting process.
- We were told that there was dissemination of learning from incidents that related to community end of life care during staff meetings, team and handover meetings. We requested minutes of these meetings, but the trust was not able to provide such minutes.
- Community nursing staff were knowledgeable as to what constituted abuse and how to report safeguarding issues. However, they told us that their training was not up to date.
- Community nursing staff were aware of the trust safeguarding team that they could contact if they had concerns or needed advice or support.
- Patients and their relatives we spoke with told us they were encouraged to tell staff if they had any safeguarding concerns.

### Duty of candour

- The Duty of candour regulation, which came into force in November 2014, is a regulatory duty that relates to openness and transparency and requires providers of health and social care services to notify patients (or other relevant persons) of certain ‘notifiable safety incidents’ and provide reasonable support to that person. Staff were aware of this new regulation and understood its implementation.
- Senior nurses were able to describe how Duty of Candour formed part of their working practices. The process they followed was a verbal apology and explanation followed by a written apology and explanation of the incident and what was done by the trust. The patients were also invited to a face to face meeting with the trust. We weren’t told of any incident that warranted a duty of candour process.

### Safeguarding

- Policies and procedures for safeguarding vulnerable adults and children were accessible to staff electronically. However, when we asked staff in the community to show us the policy, it was not accessible because the computers were either not working or too slow to respond.
- Staff received mandatory training for safeguarding children and adults. The trust’s induction and mandatory training policy identified that children’s and adult safeguarding level 1 and 2, were all provided within either the corporate or clinical annual mandatory training. The community nursing service did not see children. All the community nursing staff undertook appropriate adult safeguarding training.

### Medicines

- There was appropriate access to syringe drivers, used to administer regular continuous analgesia. These were available through the medical equipment library and we found examples of when these had been retrieved without any difficulties by the nurses. All nursing staff were trained in the use of syringe drivers and this was mandatory.
- Community end of life care patients identified as requiring end of life care were prescribed anticipatory medicines. Anticipatory medicines were medicines prescribed in advance to ensure patients received prompt relief from pain and other symptoms.
- All the community nursing staff were non-medical prescribers (NMP). They told us they could not prescribe anticipatory medicines for patients at the end of life as this was not their responsibility, and they were also not trained in medicine prescribing. The GP’s and the CNS from the Trinity Hospice were responsible for prescribing anticipatory medicines.
- A policy for the management of controlled drugs was in place and could be accessed by the community nursing team via the trust intranet.
- At the time of the inspection, all the patients we visited during home visits did not require administration of controlled drugs (CD) and therefore these drugs were not prescribed. The CD administration documents were present in the patient notes should the patients’ needs change and such medication was prescribed.
- Medicine prescriptions and administration records we checked were completed clearly and legibly, detailing

## Are services safe?

the times of administration of medicines prescribed 'as required' and checks to ensure the safety and suitability of controlled drugs and other medicines kept in patients' homes.

### Environment and equipment

- All equipment required for community end of life care patients discharged from the hospital to home was accessed via the coordination centre. Community nursing staff told us the coordination centre took responsibility for the supply of equipment's for community end of life care patients.
- All the community nursing staff we spoke with told us their office area was inadequate for the number of staff in their team due to lack of space, overcrowding, poor IT infrastructure and non-functioning computer systems.
- There was insufficient IT equipment's available to meet the needs of the service. Most of the community nurses we spoke with during the focus group meetings and on inspection expressed their views on the lack of functioning IT equipment and how it negatively impacted on their work.
- Staff told us they felt unsafe in the community because they did not have a lone worker safety tracking devices with them. However, we were advised by the Trust that the issue of staff having lone worker devices had been risk assessed and it was agreed by members of the Division Governance Board that such devices were not necessary.
- Agency and bank community staff were restricted in undertaking home visits due to lack of parking permits for community home visits. However, the trust reported after the inspection, that temporary staff were able to access free parking badges for use in residential estates and were also able to reclaim expenses accrued as a result of undertaking home visits.

### Quality of records

- Patients were risk assessed. Their records were well completed and contained full details of their care needs. Whilst there was no specific end of life care plan documentation available, we were told following the inspection, that staff were expected to adapt generic care plans in order that they met the individual needs of patients.

- In a completed care record we reviewed, we found clear and concise documentation and a recorded discussion with family members about the end of life wishes of their relative.
- During an accompanied home visit with community nurses, we observed the nurses completing appropriate care records for end of life patients. They documented the visit appropriately in the patient's care records.
- We saw that risk assessments and generic nursing care plans had been completed for end of life care patients to meet their basic individual needs. There was no specialist palliative or end of life care team involvement in care planning for end of life patient care in the records we reviewed.

### Cleanliness, infection control and hygiene

- We were told the trust had an infection control policy and all community nursing staff had received training in infection prevention and control. However, the level of compliance across the community end of life services was variable among the nursing staff.
- Staff undertaking community visits had adequate stocks of hand gel and personal protective equipment (PPE) such as gloves and aprons to take out with them. All the staff had a good understanding of infection control practices.
- We saw staff washing hands appropriately and wearing personal protective equipment, for instance, gloves and aprons, during our home visits with them.

### Mandatory training

- We were concerned at the lack of records available on levels of mandatory training completed by individual members of staff. However after the inspection, we were told by the trust, that individual staff mandatory training records were available on an electronic real time system.
- Delivery of mandatory training was via e-learning and occasional face to face sessions. Topics included safeguarding, infection prevention and control, hand hygiene and risk management. New staff completed a full day corporate induction at the trust's acute hospital site and had a further local and site specific induction at their community nursing base (Health Centre).

## Are services safe?

- All staff completed corporate mandatory training and in addition, community nursing staff also completed the clinical training component of the mandatory training. Mandatory training status was monitored by line managers and was reviewed during staff appraisals.
- All new nursing staff were required to complete syringe driver training as part of their induction and were assessed for competency prior to using the syringe drivers. All the community nursing staff we spoke with told us they were trained, assessed and competent in the use of syringe drivers; however there were no written records or data of this. We requested training data for community staff training on end of life care topics, but none was provided.
- We were told that all new staff received training on end of life care within induction as a part of the Trust's mandatory training.

### Assessing and responding to patient risk

- Risks to patients who used the end of life care services were assessed, and their safety monitored and maintained by the community nursing staff providing care. Advice and support was available from all members of the community nursing team for nurses caring for patients whose condition was deteriorating.
- The trust had a system in place to alert the out of hours services where a patient's condition was deteriorating. Patients were reviewed daily in their homes by their assigned community nurse. We saw evidence of risk being assessed and risk assessments carried out for the patients.
- There were daily handover meetings within the community nursing team where they discussed all existing and new patients. The community end of life care patient list, which detailed which patients were being seen by the team, was updated. Work was prioritised and patient visits were planned at these morning meetings.
- We found the trust did not use a specific dependency assessment tool, however were told following the inspection that the service measured the dependency of patients in relation to the number of time units (1 time unit = 15 minutes). The higher the number of time units allocated to the patient, the higher the patient dependency. The service care input for a patient is

recorded in the progress notes held in the patient's home. The care required is detailed within an individualised patient care plan, held in the patient's home. The care provided is recorded in RiO, the community adult health service information system.

- We found that risks relating to patients receiving end of life care were managed as general risks for patients. For example we found managing of individual risks such as pressure care, dementia, and fluid intake was not dealt with by the multi-disciplinary team (MDT). These were being managed by only the community team caring for those patients. We were informed after the inspection that the community nursing team access the weekly MDT (led by CAHS GP) to discuss specific patients with identified risk and that the community nursing team also discussed EOLC patients at the GP Gold Standard Framework (GSF) meetings. However we specifically asked all the staff we went out with during the onsite inspection about the above and none of them could recall attending GSF nor MDT meetings about end of life care patients.

### Staffing levels and caseload

- Community end of life care was provided by community nurses together with agency and bank nurses who worked in their designated locality. Specialist palliative/end of life care was provided by clinical nurse specialists (CNS's) from the local hospice. However, there was no service level agreement (SLA) between the trust and the hospice for the provision of specialist input for the patients receiving end of life care.
- Community nursing staffing shortages due to recruitment and retention issues were problematic. Community nursing staff told us they could visit patients with two staff if a risk had been identified, but they weren't able to undertake such visits because they did not always have sufficient nursing staff available for such visits. We were told by the community nursing manager that approximately 50% - 70% of the nursing shifts were covered by agency nurses for the year ending 2014/2015.
- Community team leaders (CTL) told us they tried to ensure continuity of cover as much as possible by requesting agency nurses for block periods of time. Some agency nurses booked in the community occasionally cancelled their shifts due to non-availability of parking permits.

## Are services safe?

- We found no evidence that caseloads, staffing levels and skills mix were reviewed regularly to ensure patients received safe care and treatment at all times. However, the trust reported following the inspection, that daily reports were generated at 10am which considered the safe staffing requirements of the trust. In addition, a situation report conference call took place daily at 3pm where the dependency of patients and staffing requirements for the following day were discussed and considered.

### Managing anticipated risks

- We were told the trust had systems in place to make sure end of life care was provided irrespective of the weather conditions. Caseloads were prioritised and those patients that did not need to be seen as priority were informed and their visits re-scheduled in the event of severe weather conditions.
- Staff told us risk assessments were completed on the first visit to a patient's home to ensure compliance with the trust policies, guidelines and procedures.

## Are services effective?

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

### Summary

We rated effective as inadequate because;

- Community end of life care was not consistently provided in accordance with national guidelines.
- There were no individualised plans of care specifically for community end of life care patients in the last phase of life that were based on national guidance or evidence based care and treatment.
- There was no replacement of the Liverpool Care Pathway (LCP) following its removal from use in June 2013.
- The community nursing team responsible for end of life care had not fully implemented the five core recommendations for care of patients in the last few days and hours of life as set out in the Department of Health's End of Life Care Strategy 2008.
- The community nursing team had not implemented recommendations of 'One chance to Get it Right' document published by the Leadership Alliance for Care of the Dying People 2014.
- There were no audits nor quality monitoring of patient outcomes in the community end of life care services.
- A training needs analysis for core end of life training had not been carried out in 2015 to identify the training needs for community nursing staff working in the community.
- There was no involvement of the physiotherapy, occupational therapy, dietitian, counsellor or chaplaincy services in provision of community end of life care services.
- Community nursing staff did not always have the end of life care knowledge, skills or experience for their roles caring for end of life patients in the community.

However;

- Community nursing staff we spoke with demonstrated an understanding of the Mental Capacity Act 2005 and issues around deprivation of liberty safeguards.

### Evidence based care and treatment

- Community end of life care was not consistently managed in accordance with national guidelines. Patient's needs were regularly assessed and their preferences identified. However the delivery was not in line with best practice as demonstrated by lack of trust's specialist palliative care input.
- There was no individual plan of care specifically for community end of life care patients in the last phase of life that was based on national guidance or evidence based care and treatment. We saw care plans where an identified problem was recorded as a patient needing end of life care due to diagnosis of terminal illness' and care planning prompts were included such as symptom control, pain management, nutrition and hydration.
- The Department of Health stated that the Liverpool Care Pathway (LCP) should be phased out over 6 to 12 months from July 2013. The LCP was a care pathway covering end of life care options for patients in the final days of life. The community nursing team had not developed the replacement of the LCP following its removal from use.
- The community nursing service had not fully implemented the five core recommendations for care of patients in the last few days and hours of life as set out in the Department of Health's End of Life Care Strategy 2008. It had also not implemented recommendations of 'One chance to Get it Right' document published by the Leadership Alliance for Care of the Dying People 2014. Most of the community end of life care documentation was in draft and yet to be embedded into the community end of life care services.
- Staff were aware of the Advanced Care Plan (ACP) but we did not see any evidence of its use. ACP is a key part of the Gold Standards Framework Programmes. It should be included consistently and systematically so that every appropriate person is offered the chance to have an advance care planning discussion with the most suitable person caring for them.

## Are services effective?

- Advance Care Planning is a tool for improving care for patients nearing the end of life and of enabling better planning and provision of care. It helps patients to live and die in the place and the manner of their choice. The main goal in delivering good end of life care under ACP was to be able to satisfy patients' wishes, needs, aspirations and preferences and deliver care to meet these needs.
- The community nursing team had not participated in key national audits (e.g. NICE QS 13) to benefit from comparing its performance with other trusts.

### Pain relief

- Patients we spoke with told us their pain was well managed and staff responded to their request for additional medicines when they were in pain. We did not see patients in pain and patients and relatives told us their pain was "well managed" by community nursing staff whom they described as "very responsive".
- Where appropriate, patients had syringe drivers which delivered measured doses of medicines at pre-set times and intervals. We were told that all qualified nursing staff were trained in the use of syringe drivers, however due to the higher number of nursing staff turnover, vacancies and the high usage of agency nursing staff, there were a number of agency nursing staff who would not necessarily have attended syringe driver training. A community nursing team leader told us if this was the case, only nursing staff with syringe driver training would be assigned to attend the needs of patients on syringe driver infusion.
- Staff told us there were adequate stocks of appropriate medicines for end of life care and these were available when needed both during the day and out of hours. Anticipatory medicines were available in patients' homes where it had been identified they may require medicines to manage their symptoms quickly in the near future.
- These anticipatory drugs were prescribed in advance to allow for management of any sudden changes in patients' pain and other symptoms. Anticipatory drugs (which can alleviate and minimise pain and symptoms associated with end of life) were available at all times.

- We observed staff assessing patients' pain levels and responding quickly and appropriately, to provide pain relief if they identified the patient was feeling pain or discomfort.

### Nutrition and hydration

- During home visits, we saw the use of the malnutrition universal screening tool (MUST). MUST risk assessments were undertaken to identify patients at risk of malnutrition. Where required, food and liquid intake was recorded and patient weight was monitored. However there was no dietitian input in the nutrition and hydration assessments of community end of life care patients.
- The community end of life care patient documentation included an assessment of patient's nutrition and hydration status and guidance about the patient's choice to eat and drink, even if they had swallowing difficulties.
- During the home visits we attended, we saw staff spent a significant amount of time during the visit reviewing and discussing patients' needs including nutritional needs. All the patients and relatives we spoke with felt the patient's nutrition had been managed appropriately.
- There was a strong culture of meeting comfort requirements at the end of life and staff we spoke with were clear that nutrition and hydration needs were led by the patient's view of their nutritional needs.

### Patient outcomes

- We were told the trust supported patients to achieve their preferred place of death either through rapid discharge to home, hospice or nursing home or by ensuring appropriate end of life care for patients who wished to die at the hospital. However, there was no written evidence or data to indicate the number of patients who were supported to die at their preferred place of choice. We requested this data but the trust was not able to provide it.
- The National Bereavement Survey (VOICES) was conducted by the Office for National Statistics on behalf of the Department of Health. The aims of the survey was to assess the quality of care delivered in the last three

## Are services effective?

months of life for adults who died in England and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients.

- The trust leads for end of life care told us there were gaps in the integration of the two services (acute and community), and work was in progress for the integration of the two end of life care services. The director of nursing (DON) was the trust lead for end of life care and was based at the acute trust site. However the DON had no input in the community end of life care
- There were no clinical audits and quality monitoring of end of life care patient outcomes. We were told that was an area the community nursing team were planning to address in future.
- We asked nurses in all the community locations we visited what end of life care planning tool they were using in replacement of the Liverpool Care Pathway (LCP) which was withdrawn from use in June 2014. We were told they were using the general community nursing care plan format to produce individualised community patient care plans instead which would specifically address end of life care needs.
- We were told the Clinical Commissioning Group (CCG) had developed patient centred end of life care communication tool called the 'The Yellow Book' which was seen in patient's homes; however this had not been widely used and not completed fully by all community nurses. We were told "The Yellow Book" was a kind of end of life care communication tool, which was designed to help healthcare professionals, patients and relatives to document patient's wishes, aspirations and plan for care at an early stage. This meant end of life patients had an information and an opportunity to consider their wishes and to enable staff to plan the care pathway from an early stage of their end of life journey. The book is meant to be with the patient wherever they are going, however, this was yet to be embedded across the community end of life care service across all the trust's community locations.
- We were told community nurses could access external study days if they wished, but because of staffing constraints, it was difficult for them to access and attend these. There were no educational resources to support community nursing teams in end of life care situations.
- We found there were no training or development programs on palliative/end of life care for the community nursing staff working with end of life care patients. However, following the inspection, the trust told us that the Trinity Hospice provides training to the Trust on palliative care. Also, there were no psychology, bereavement, breaking bad news or multidisciplinary teaching and learning programs for community staff caring for end of life patients.
- Even though there was no formal end of life training programmes for community nursing staff, the lead nurse told us they encourage staff to update their skills, knowledge and experience in palliative and end of life care through ad hoc training provided by the local hospice. There was no record of how many staff were able to undertake such ad hoc training/study days. Most of the community nursing staff told us they weren't able to take up these offer of ad hoc training due to staffing shortages.
- Community nursing staff told us they had received training in the use of syringe drivers and that there was a syringe driver resource folder available in their offices. However, no training record was available to confirm that this training had taken place.
- A training needs analysis for core end of life training had not been carried out in 2015 to identify the training needs for community nursing staff. Core end of life care training currently included syringe driver training for registered nurses, advance care planning and the use of treatment escalation plans, verification of expected death and training around the five priorities of care for the dying patient.
- We found there were no formal clinical supervision arrangements for the community nurses providing end of life care.

### Competent staff

- As with mandatory training, we were concerned at the lack of formal records of training completed by individual members of staff.



## Are services effective?

### Multi-disciplinary working and coordinated care pathways

- The community nurses told us they had developed effective working relationships with GPs and they communicated in person, by phone or by fax if a patient was assessed as approaching the end of their life.
- There were no evidence of MDT meetings within the community nursing teams during the inspection, with regard to end of life care services. However, following the inspection, the trust told us that the community nursing team had access to a weekly MDT to discuss specific patients with identified risks. Minutes of MDT meetings in the last year were submitted after the onsite visit.
- We were also told the community nurses worked well with the coordination centre to provide support to community end of life care patients who were been fast-tracked home.
- The end of life care nurse had established a good working relationship with the coordination centre staff in facilitating fast track discharges for patients to their preferred place of death.
- There was no evidence of involvement of the physiotherapy, occupational therapy, dietitian, counsellors and chaplaincy services in community MDT for end of life care patients.
- There was no interaction between the acute end of life care team and the community nursing team providing end of life care and no attempt had been made to develop, establish or implement one.

### Referral, transfer, discharge and transition

- Community end of life care patients were referred and transferred appropriately between services. Community nursing staff told us patients could be referred to the hospices or to the hospital (with appropriate support from the community nursing team) when they were being transferred from the community to the acute hospital for symptom control and management.
- Community nurses were involved in the planning of discharges to an alternative place of care. This process involved the support of the coordination centre as well as other agencies in providing end of life care to patients at home or in their preferred place of choice.

- There were clear referral pathways from acute to community and vice versa. We were told there was a discharge pathway which included a rapid discharge procedure for patients approaching end of life care who had expressed the wish to die in a different care setting. We saw evidence that patients were being discharged using the fast track process through the coordination centre to their preferred place.

### Access to information

- The community nursing team kept all their records of contact with patients in a blue folder in the patient's home, along with any assessments they had completed, for ease of access by other nurses caring for the patients. In some homes, there were 2 sets of folders, a yellow folder and a blue folder, and these could sometimes be confusing for nurses as to which record they were to use to document their interventions, especially for agency and bank nurses. Most of the yellow folders we reviewed were completed, a majority of advanced care planning records had not been completed in the records reviewed. The blue folders were for normal community nursing documentation and the yellow folder was meant for end of life care patients.
- The community nursing staff kept a record of their first assessment and basic patient details for each patient in their own office location. The initial assessment and all other records were written in the blue folder and kept in patients' homes.

### Consent, Mental Capacity act and Deprivation of Liberty Safeguards

- Community nursing staff we spoke with demonstrated an understanding of the Mental Capacity Act 2005 and issues around deprivation of liberty safeguards.
- We reviewed 18 sets of patient notes and all of them contained 'Do Not Attempt Resuscitation' (DNACPR) forms, which were accurately completed and kept at home in the patient's notes. We saw evidence that staff had discussed these with patients and their families.
- Community nurses we spoke with were able to discuss decisions around resuscitation. This included discussion with the patient and family members.
- We observed verbal consent being obtained for invasive procedures and was clearly documented by the nurse carrying out the procedure.

## Are services effective?

- Nursing staff told us where possible they gained the patient's consent in planning treatment and care. We saw evidence in patient's notes to support this. A patient

we spoke with told us that staff sought their consent in sharing information and discussing treatment and that staff had ensured the patient was fully aware of their care and treatment.

## Are services caring?

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

### Summary

We rated caring as good because:

- We observed community nursing staff caring for end of life care patients in their own homes with dignity, respect and compassion.
- Community nurses treated patients gently and checked their comfort at various stages of care and treatment.
- Community end of life care patients we spoke with and those close to them told us they were encouraged to be involved in their care. They told us they were routinely involved in decision-making and felt they had sufficient information to understand their treatment choices.
- Families and relatives we spoke with told us staff were caring and had provided them with emotional support and kept them informed about their loved one's care and treatment.

### Compassionate care

- Patients were treated with kindness, dignity, respect and compassion while they received care and treatment. Community nursing staff understood and respected patients' personal, cultural, social and religious needs, and took these into account. When we undertook home visit with the nurses, we saw that nurses made sure patients' privacy and dignity was respected and closed doors where necessary.
- Community nursing staff respected patients confidentiality at all times with appropriate volumes of conversation. We saw community nurses worked with patients who were experiencing physical pain, discomfort and emotional distress, they provided care to those patients in a compassionate, timely and appropriate way.
- We observed members of the community nursing team interacting with a patient and their family. They had a good rapport with the family and responded to them with a caring attitude.

- During the inspection we visited a patient in their own home with the community nurse. The patient's daughter was present. The daughter and the patient told us they were pleased with the care they received from the community nurses.
- Patients and their families we spoke with told us the care they had received was "fantastic" and that the nurses went "above and beyond the call of duty to make them feel valued and respected". Relatives we spoke with gave us examples of where staff had gone beyond their role to provide compassionate care to patients.
- Patients were encouraged by nursing staff to create a memory box and to think about other considerations regarding their last days and hours of life. We observed a patient having a discussion with a palliative care nurse about creating a "memory box" for their loved ones.

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

- Patients we spoke with told us they felt involved in their care and treatment. Their families and carers told us they also felt involved. One family member told us nursing staff had fully explained the care and prognosis of their loved one.
- We observed interaction between the nurses and family members of a patient who was receiving end of life care. The community nurses worked hard to help relatives understand what was happening and what the patients preferred plan of care was.
- All patients we spoke with were able to describe conversations they had had with the nursing staff about their wishes and priorities for the last days and hours of their life. However, some did not know if they had an advanced care plan to support their end of life care.
- We observed discussions between patients and staff about options for alternative pain medication and other suggestions to make the patient more comfortable. Community nursing staff told us where possible family members were always involved in these discussions.
- All the relatives and patients we spoke with were positive about their involvement and understanding in

## Are services caring?

the care and the decisions that were needed to be made. We were told several times that the nurses were excellent at communicating and ensuring they had the information they needed.

- Relatives commented about the honesty of the community nursing staff and how sensitive information was communicated to them in clear terms. Relatives described how they had full and open discussions with nursing staff about the care and treatment provided to their loved ones.
- We spoke with members of one family who explained how the nurses explained to them care in the last days of life and the documentation they would be using to ensure the best care possible was provided.
- The interactions we saw between staff, families, and people using the service were kind and professional. We received highly positive comments from patients about services received from the community nursing staff.

### Emotional support

- Community nursing staff demonstrated they understood the impact a person's care and condition had on their wellbeing and their relatives. Patients and relatives told us how the nursing staff were supportive, understanding and listened to their concerns. We observed a community nurse providing reassurance and compassionate advice to two patients, both of whom were distressed about their treatment and prognosis.
- Nursing staff told us they felt they generally had the time to spend with patients and provided them with the emotional support to meet their needs. We observed community nurses assessing people's emotional needs as a matter of routine when visiting them at home.
- There was no chaplaincy support for patients receiving end of life care in the community. Community nursing staff we spoke with told us patients and their families had to arrange this privately if needed.
- Patients and relatives were given appropriate support and information to cope with their care and treatment. One relative explained how they had been supported emotionally by one of the nurses when they had become very distressed during their first visit.
- Community nursing staff developed trusting relationships with patients and their relatives by working in an open, honest, transparent and supportive way. Throughout our inspection we saw that nursing staff were supportive and responsive to the emotional needs of patients and their relatives.
- During the home visits we saw community nurses took an active interest in the patient's social needs and made suggestions to assist patients to continue to engage in social activities even when the symptoms of their illness may have restricted them.

# Are services responsive to people's needs?

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

## Summary

We rated responsive as requires improvement because;

- Due to the shortage of experienced and skilled community nursing staff, the community end of life services were planned simply to get round those patients that needed basic nursing care using newly qualified and agency nurses.
- There were no equality and diversity champions within community nursing services to support staff.

However;

- Fast track discharge procedures were embedded into the community end of life care service and were managed through the Coordination Centre.
- There was evidence of emergency care plans and treatment escalations plans in use and these were embedded in practice.

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

- The community nursing team told us it was hard to deliver a service plan because it was difficult for them to get the acute end of life care leadership to engage with them to plan community end of life care services.
- Patients with end of life care needs were referred to the community nursing team by their GPs or from an acute hospital. Patients who were referred to the community nursing team either due to the end of life care needs or due to co-morbidities were supported by the general community nursing staff.
- There was no medical consultant led multidisciplinary team which provided end of life care to patients in their own homes. End of life care services were provided to patients by generalist community nurses.
- We observed care being delivered in the community. We saw nursing staff made every effort to ensure that people's needs were met, including medicines being delivered, equipment being provided and support for relatives being provided by the community nursing staff.

## Equality and diversity

- We saw that all patients receiving end of life care were treated as individuals. The community nursing team management told us equality and diversity training was delivered to all staff during induction and then as part of the trust mandatory training programme.
- There were no equality and diversity champions within community nursing services to support staff.
- Community nursing staff were open about providing care for patients from different cultures. They said that every individual was different and that they approached situations with sensitivity to their needs.
- We were told by the community nursing team leadership, that they had difficulty accessing translation and interpreting services for community end of life patients. There were no information, posters or signs to indicate that translation and interpreting services were available either. The service relied on family members for assistance in interpreting and translating.

## Meeting the needs of people in vulnerable circumstances

- The community nursing team provided end of life care patients with generic-format care plans tailored to meet patients' end of life care needs. Patients and family members we spoke with told us that their care was individualised and we observed discussions around care and treatment decisions that demonstrated personalised care and treatment.
- Emergency care plans and treatment escalation plans were all seen to be in use and embedded in practice. The wishes, choices and beliefs of individuals were seen to be incorporated into all care plans and we saw good evidence of recorded discussions with patients and their families about their care at the end of life.
- End of life care patients living with dementia were assessed early and their treatment planned and supported by the CNS from the hospice. Community nursing staff had support and advice from a link nurse for people living with dementia and those with learning disability.

## Are services responsive to people's needs?

- There was recognition by the nursing staff that an individualised approach was needed to support patients living with dementia as well as those with learning disability when they approached the end of life. There was also awareness that time was important to ensure patients' needs and choices were identified before there was a loss of capacity and so sensitive discussions were undertaken.
- A priority for the community nursing team was to develop good quality end of life care based on the wishes and preferences of the individual and to improve care for end of life patients in the community. This included support to people in vulnerable circumstances.

### Access to the right care at the right time

- Referrals for end of life care were prioritised based on assessed patient needs and daily work activities. Patients and relatives consistently reported that the community nursing teams were able to respond quickly to their care needs.
- Community nursing staff visited patients in the morning, prioritising patient's appointments to meet their needs. Community nurses visited patients who were poorly and needed care and treatment first. Appointment times were agreed with the patient. If a patient required two visits, these were arranged by the community nurse time of visit was agreed with the patient.
- We were told that the community nursing teams completed all urgent and routine assessments and were above the target set by the trust. We requested data about this performance target for end of life care patients, but none was available from the community nursing team. The trust did not have data relating to patients receiving end of life care.
- Fast track discharge procedures were embedded into the end of life care service and were managed through the coordination centre. Wherever possible patients would be transferred home from hospital within a day, if

that was their wish, when it became apparent that care at home was appropriate or that no further interventions were available at the hospital. The coordination centre arranged for patients to go home with the required equipment and package of care needed for the patient.

- The service was piloting a new community end of life care services process, jointly with Wandsworth Council and Trinity Hospice, to facilitate discharge to the patient's preferred place of death. A band six nurse role was established, called a palliative care nurse, to work alongside the existing community nursing team structure five days a week. The role had three functions: to support all patients and carers of community end of life patients, to support the rapid discharge pathway by ensuring key equipment was provided to patients prior to discharge from acute to community teams and to follow patients home to provide ongoing support.

### Learning from complaints and concerns

- We were told community end of life care services received few complaints within the last year, and were given an explanation of the how complaints received were handled. However we were not provided with the exact number of complaints received nor were we able to review how the complaints were handled.
- All staff preferred to deal with issues immediately and endeavoured to diffuse the situation before it escalated. They spoke to patients either over the phone or directly in a face to face meeting. The trust had a policy which set out how complaints should be dealt with and timescales for responding to complaints.
- We were told that themes from informal complaints were analysed and discussed at weekly team meetings. Action plans and learning from complaints were discussed at those meetings. Staff explained that issues discussed in the weekly team meetings were to share the complaint and to see if lessons could be learnt and action plans and learning from complaints agreed.

## Are services well-led?

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

### Summary

We rated well-led as inadequate because;

- Systems or processes were not sufficiently established or operated effectively to ensure the trust was able to assess, monitor and improve the quality and safety of community end of life care services.
- The corporate management was not effectively managing and monitoring the community end of life care service.
- Community end of life care had no influence within the acute management structure and there was a lack of both strategy and resources which compromised the service's sustainability.
- There was no governance structure which supported community end of life care services.
- Many staff we spoke with in different roles, although committed to their patients felt disconnected and undervalued by the trust.
- All community nursing staff we spoke with said they felt confident about speaking up and raising concerns with their line managers. However community frontline managers told us they felt their voice was not heard by senior management in the trust.

### Service vision and strategy

- The chief nurse was the board member responsible for community end of life care services and the trust told us following the inspection, that a non-executive director had recently been nominated to take responsibility for community end of life care. Following the inspection, the trust told us that an end of life strategy had been developed.
- The service received specialist input and support from the local hospice in relation to specialist end of life care support, but it was unclear how the service was planning to develop strategically and there was no

service level agreement with the local hospice for the provision of that specialist services or the support they were providing for community nursing team providing community end of life care.

- There was no clear community end of life care strategy in operation or evident in how the acute and community services would work together to ensure quality improvement in end of life care for patients in the community.
- The community nursing team did not have a community end of life care strategy to implement the requirements of the national strategy and the 2011 National Institute for Health and Care Excellence (NICE) guidelines on end of life care. The acute end of life strategy did not reflect on the community end of life services.
- The trust's lead for end of life care, who had responsibility for community end of life care across the trust, told us the remit of the end of life care committee was to standardise the trust's approach to end of life care between the acute and the community and to provide integrated care between the community and the hospitals. However, we found no evidence of this in practice.

### Governance, risk management and quality measurement

- There was no non-executive director (NED) with specific remit and interest in the development of community end of life care services.
- There were no systems in place to facilitate governance meetings in each of the community nursing bases for end of life care. Community nursing staff we spoke with during the inspection and home visits could not identify key priorities for the community end of life care.
- There was no systematic programme of clinical audits to monitor quality of the community end of life care services been provided. There were no arrangements for identifying, recording and managing end of life of risks, along with mitigating actions.

## Are services well-led?

- Clinical outcomes relating to community end of life care were not being measured by the community nursing team who had the responsibility for providing end of life care in the community.
- The community nursing team providing end of life care services had not identified the risks of the service and there were no systems to identify where action should be taken in respect to audit improvement, quality monitoring and risk.

### Leadership of this service

- The community end of life service appeared to be led on a day to day basis by a band seven facilitator and a band 6 nurse. The leadership function, reporting and managerial structure of the trust wide lead for community end of life was unclear.
- We found community end of life service delivery depended on two staff, one band seven facilitator and one band six nurse. The band six nurse worked primarily with the coordination centre. These staff had to relate to a number of different area operational managers. We were also told that the two end of life care staff were feeding into the trust end of life work streams, however they were not leading on them and their voices were often not heard. They had no direct influence on strategy, management or commissioning arrangements for the community end of life services.
- The end of life care facilitator and the end of life care nurse we spoke with told us they found their role quite isolating and were not integrated with the acute end of life team.
- Community nursing staff told us they were still seen as being independent of the acute hospital, but they were working hard to integrate within the wider trust, however they felt that this had been a difficult transition at times.

### Culture within this service

- There was no engagement between the acute end of life care team and community nursing team to plan and deliver an integrated end of life care service for patients.
- There was a culture of good quality generalist end of life care services within the community. Community nursing staff we spoke with were enthusiastic about the care

they delivered. We saw that the nursing staff were proud of the service they delivered and there was a culture of sharing feedback from family and friends of patients who died and supporting each other.

- There was a commitment by the community nursing team in ensuring patients and their families were supported as much as possible at the end of life and we saw that staff worked collaboratively with the coordination centre to support this.
- Community nursing staff were aware of the need to support each other after a death of a patient. The community nursing team organised a debrief for nurses involved with difficult deaths.
- There was evidence that the culture of end of life care was centred on the needs and experience of patients and their relatives. Nursing staff told us they felt able to prioritise the needs of patients at the end of life in terms of care delivery.
- Community nursing staff reported an open and caring and supportive culture where they could raise and discuss any concerns with their team and managers. They felt well supported by their managers in all aspects of their work including training and supervision.
- Most of the community nursing staff we spoke with, although committed to their patients felt disconnected and undervalued by the trust, they felt they were not engaged by the trust wide end of life care team. The community nursing team were not aware of the end of life care core service inspection until two weeks prior to the inspection.

### Public and Staff engagement

- There was no formal gathering of views from the public about end of life care and there were no mechanisms to obtain feedback from bereaved relatives. Staff only knew how well they were doing through thank you cards and comments from the bereaved families.
- Community nursing staff we spoke with during the inspection and in focus groups told us they felt marginalised and not actively engaged with the Trust's acute end of life care team and felt unable to share their views with confidence of being listened to. For example, community nursing staff told us they were unable to express their view in relation to the development of community end of life care services.



## Are services well-led?

- We did not see any evidence of community nursing staff involvement in the development of any end of life care strategy. Community nursing staff told us there was no end of life strategy group specifically for community nursing.

### **Innovation, improvement and sustainability**

- We saw that the community end of life care facilitator and end of life care nurse were fully involved and

engaged in end of life care in the locality, regularly attending meetings at the coordination centre and working collaboratively with the community nursing team.

- Community nursing staff were positive and focused on how to improve the services for patients and providing a high quality end of life care services despite working in a difficult and challenging environment.

This section is primarily information for the provider

## Requirement notices

### Action we have told the provider to take

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

#### Regulated activity

Treatment of disease, disorder or injury

#### Regulation

Regulation 17 HSCA (RA) Regulations 2014 Good governance

**Systems or processes were not established and operated effectively to ensure compliance with the requirements of the regulation because:**

1. There was no vision or strategic overview of the service.
2. There was no trust wide (community and acute) end of life care integration and joint working.
3. There were no audits undertaken for community end of life care services.
4. There was no formal arrangement for specialist end of life medical input.
5. **There was no evidence that leadership, management or governance supported or enabled high quality community end of life care services.**
6. There were no individualised plans of care that were based on national guidance or evidence based care and treatment.
7. There was no replacement of the Liverpool Care Pathway (LCP) following its removal from use in June 2013.

Regulation 17 (2)(a)(b)

#### Regulated activity

Treatment of disease, disorder or injury

#### Regulation

Regulation 18 HSCA (RA) Regulations 2014 Staffing

**There were not sufficient numbers of suitably qualified, competent, skilled and experienced persons must be deployed in order to meet the requirements of this Part because:**

This section is primarily information for the provider

## Requirement notices

1. There had been no trained specialist end of life care nurses working in the community and this was having a detrimental effect on the community end of life care services.
2. The number of community nurses was half of the recommended levels which left some patients without care.
3. Actual community nursing staff was persistently below the planned levels and the service relied very much on the use of agency and bank nurses, who were often unavailable.

**Regulation 18 (1)**