healthwatch Lincolnshire

# Enter and View Report

## St Barnabas Hospice
## In Patient Care
## September 2015

# Summary

The following report looks at some of our inpatient hospice services in Lincolnshire and contains information from 2 enter and view visits undertaken during late September. The focus of the visits was on the patient journey and with the full support of St Barnabas and ULHT (within Grantham) in Lincolnshire this programme of work also includes engagement and feedback from the staff and volunteers.

Our enter and view reports, where appropriate, identify key themes which Healthwatch believe should be raised as a matter of importance not only with the organisation but also with other commissioners and providers of services.

Healthwatch is mindful that factors outside the control of the hospice services may have significant impact on the service provided and consequently the patient experience; where these occur we have included them.

In essence, there were some core themes listed below which came out of the visits, and as part of this work we have requested that the organisations to comment on the findings in the public interest, their responses are also included throughout. What is evident is that, the challenges faced are everyone's business and in order to sustain an effective health and care service for the future, partnership working and assessing lessons learned are key. What must also be recognised is the public recognition of the care and support delivered by frontline staff delivering these services.

**Key Themes from the visits and patients spoken to at the time:**

- The general feel for the hospice in Lincoln was one of a calm but vibrant team of staff and volunteers working hard to support patients and loved ones. It is clear that housing this service in such an old house has its plus points and also downsides. Capacity to develop this anymore is extremely limited and the impact of that is felt within the car park before you even access the premises.

- We noted the appreciation of the patients at Grantham for the care and compassion offered to patients by the staff team and the volunteers.

- We acknowledge some of the challenges around getting the community care packages in place at both sites and the frustration that this can bring to the patient, loved ones and the hospice as their focus is very much on ensuring the patient gets back to their preferred place of care in the most reasonable timescale possible.

- At Lincoln we noted some of the challenges the hospice faced in transporting patients from the acute hospital to the hospice setting.

- We heard at Grantham how staff were sometimes redirected to other parts of the hospital if they were short staffed. With the intention to move the Lincoln site closer to the hospital this drain on resource is a concern for them also.

- We were told that getting the help needed in the community was not always straight forward and there was limited support around the mental health element of diagnosis and treatment, we heard dealing with life limiting illness had a direct impact on mental health and that there could be more done within the community to support psychological assessment and treatment.

The suggestions and recommendations, along with feedback from the Trust can be found at the back of the report and provides a complete picture of the findings.

Thanks goes to the cooperation of the St Barnabas, its staff and volunteers, our HWL enter and view representatives, patients and carers for their open and constructive contribution to this report.

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| **Place of Visit:** | **St Barnabas Hospice (Lincoln and Grantham)** |
| **Address of Provider:** | **36 Nettleham Road, Lincoln LN2 1RE** |
| **Service Provided:** | **Acute Care** |
| **Date:** | **September 2015** |

## 1. Background

This piece of work has been carried out by Healthwatch Lincolnshire who has a statutory function to enter and view any publically-funded premises providing health and care services. These visits are carried out with the sole intention of collecting information relating to the quality of services provided and gathering the views of patients, relatives and carers of those people accessing and receiving the services.

Healthwatch carried out this work as part of its Operational Plan for 2015 but also as a direct response to some of the developments within the service such as the new facility of Hospice within the Hospital at Grantham Hospital. The work was also linked to some of the national press where it was reported that end-of-life care in the UK has been ranked as the best in the world supported by the NHS and hospice care.

In addition, we felt that culturally it would be beneficial to visit the hospice environment and help dispel some of the myths surrounding this level of acute care.

In addition to carrying out this work, we have a duty to ensure any information gathered is disseminated to the relevant organisations which have a monitoring and commissioning responsibility. We also have a duty to report to the relevant bodies any cause for concern relating to the safety and care of those in receipt of those services.

## 2. Methodology

Healthwatch authorised representatives were appointed to undertake this piece of work. A questioning framework was produced to enable the representatives to effectively talk with patients, relatives, carers and care providing staff and to make observations during the visits. The framework is not exhaustive, but does provide a background for directing theme-specific questions – *in this case the 'patient journey', exploring how the patient had arrived at the service, pre-conceived perceptions, experience of the care and the ongoing planning and support for patients and family.*

The focus of this work was to specifically look how patients experienced in-patient care within this setting.

We visited 2 sites during the programme of work, Lincoln and Grantham, and we visited during the normal working week.

In addition to our focussed piece of work, the visit naturally notes observational perspectives of the provider and where views are expressed by the service user about other elements of care or the environment these were also recorded.

In the interest of confidentiality we remove the names of those making specific comments although generic comments themselves maybe included within the report feedback.

**The Provider: About St Barnabas Hospice.**

St Barnabas Hospice is a specialist palliative care provider and have been providing free care since 1982 for over 9,000 people each year.

We were told many patients admitted to the hospice require specialist care for a short period of time and approximately 50% of all admissions are treated and discharged. Where patients are discharged they are done so with the appropriate packages of care in place. On average a patient's expected length of stay is 14 - 17 days.

The hospice aims to manage patient symptoms and to provide support that is appropriate for both the patient and the family. The aim is also for the patient to be able to return to home or the place where they had previously been receiving care.

***What does the NHS say about Hospice Care.***
*The aim of hospice care is to improve the lives of people who have an incurable illness.*

*Hospices provide care for people from the point at which their illness is diagnosed as terminal, to the end of their life, however long that may be - this doesn't mean hospice care needs to be continuous. People sometimes like to take a break from hospice care if their condition has become stable and they are feeling well.*

*Hospice care places a high value on dignity, respect and the wishes of the person who is ill and aims to look after all their needs.*

*Hospice care provides for medical, emotional, social, practical, psychological and spiritual needs, plus the needs of the person's family and carers. Looking after all these aspects is often referred to as holistic care.*

*Care also extends to those people who are close to the patient and into the bereavement period after the patient has died.*

**Myth Busters**
There are many myths and preconceived ideas around what a hospice is and is not. Here are some we have come across:

Myth: Hospice is just about dying.
**Reality: Hospices exist to enable people to live as well as possible.**

Myth: No one comes out of a hospice alive.
**Reality: The aim of the hospital is to enable patients to return home or to their preferred place of care as soon as possible.**

Myth: Hospices are places for people with cancer.
**Reality: Hospices are not just for those patients living with cancer. They provide care for all life limiting conditions including Motor Neurone disease, heart failure, Parkinson's disease and COPD to name but a few.**

Myth: Hospices are for old people.
**Reality: Hospices provide care for everyone over the age 18 and everyone is welcome to visit - family, children and friends, the family dog or cat.**

**Acknowledgement.**

Following visits to the Hospice sites Healthwatch had an opportunity to feedback and outline some of the core findings to a member of the staff team on site at the time. Many thanks to the teams who took time out of their schedule to facilitate the visits but also to listen and contribute to the conversations around the findings. In addition, we would like to thank all the staff at the Hospice sites who offered an open and honest perspective of their working environment and some of the challenges it faced and we thank the patients, family and staff who it was a privilege to meet and spend some time with and share their stories.

## 3. Respondents.

Prior to any conversation being held with a service user, we introduce Healthwatch Lincolnshire and ask permission for any dialogue to continue as we respect that not all service users will want to engage with us in this way.

During the visit we spoke to as many patients who wished and/or had capacity to talk with us. In addition and where we could, we spoke to managerial and operational staff at each site to provide a more holistic view along with volunteers.

A total of 5 patients and/or loved ones were spoken to during the visits which equated to 35% of the 14 patients at the hospices during our visits:

| Site | Number of Beds | Occupancy | Spoken to (incl loved ones)/% |
|---|---|---|---|
| **Lincoln** | 11 | 8 | 3/37% |
| **Grantham** | 6 | 6 | 2/33% |

## 4. Findings from Respondent Experience Survey.

The following overleaf provides an overview of the service from a lay-person's perspective and separates the sites for clarity. However, staff feedback, conclusions and recommendations may be duplicated across sites where organisational themes are identified. The culmination of all key findings and recommendations can be found in the table on page 19.

## 4.1 Findings for Lincoln

The following provides the detail of the visit feedback and should be acknowledged that this information was taken at a point in time. If changes have been made since the visit and the provider has commented on them, we will include those within the report for public interest and information.

### 4.1.1 General Information: In-patient Hospice - Lincoln

In 1979 a small group of people with total funds of £270, established a charitable trust with the aim of developing a local hospice based entirely on charitable support.

In 1982 the Trust purchased an existing nursing home on Lindum Terrace in Lincoln and with alterations opened their first four beds on the ground floor in June 1982 and a further two beds in 1984 and then in 2008 the inpatient unit underwent an extensive refurbishment programme and was re-opened in December 2008 as an 11 bedded facility (2, 4 bed bays and 4 side rooms).

### 4.1.2 What the Patient said.

Within this environment we aim to talk to as many patients and family and carers as possible, in Lincoln at this 11 bedded unit we spoke to 2 patients and one family member about the care received, at the time of the visit there were 8 patients receiving care.

We asked patients and family members a series of questions which related to their care and the following stories and feedback were shared.

***How did you feel about coming into the service?***

For the patients we spoke to this was not the first time they had attended the hospice, we were interested to know how patients felt when they first had to attend this environment and how they might feel on subsequent visits. Those spoken to told us that reasons for wanting to be admitted included the feelings they weren't coping well at home and feeling the time was right to come in and receive care, help provide and support for the patient and family. For those we spoke to it was an informed decision or choice to access the service. A patient told us it was a relief to come into the service, although they had previously received a lot of community support from the GP they also knew the level of support from the hospice would provide some relief.

***When staff talk to, do they always introduce themselves and staff call you by your preferred name?***

We appreciate as patients in any environment that the need for personalised care is important to the wellbeing so we asked how staff introduce themselves and whether this promoted a patient centred approach.

Those we spoke to told us that they couldn't fault the staff and volunteers, they wore name badges, introduced themselves and always referred to the patient by their preferred name. Whilst the unit is not large and there are quite a number of staff and volunteers in and around the unit, the sense of person centred care was demonstrated by the way we observed interaction between the patient, loved ones, staff members and volunteers.

***When staff provide care do they always explain what they are doing?***
We understood from the Hospice how important it was that patients and loved ones understand what was happening and would happen in a language that was clear and understandable, this included admission, treatment, discharge and end of life wishes. Those we spoke to said they were communicated with in a way they understood and even told us how specialist Doctors and staff would sometimes spend hours talking to the patient or coming back the following day to make sure everything was understood and any questions could be asked and answered.

***Do you feel there are enough staff and volunteers around to support you and if you need a member of staff to tend to your needs how quickly do you get that help?***
Sometimes when we talk to patients in other acute settings we hear that they feel the staff don't have the time to spend with them and sometimes call bells can be left, therefore we felt it necessary to explore this within the hospice setting to establish any differences and where differences occurred what impact this had on patients.
Those spoken to told us that there were always people milling around and that the environment was quite lively, they told us that the volunteers were invaluable as they were the people who made cups of tea for the patient or loved ones when they needed one; volunteers were the people who could sit and chat when the patient needed to or maybe support at mealtimes. Patients told us that call bells were normally answered immediately and there was not a problem in getting the support they needed, when there is a delay in responding to the call bell the patient told us that the member of staff always came and explained any delay which improved that patient experience.

***Overall, do you feel treated with respect and dignity while in the care of staff?***
We acknowledge how important retaining dignity and respect is for individuals and for their loved ones, even small acts such as clothing, hair, nails and a shave can make the difference to how a person feels their dignity is maintained. Without exception those spoken to said that their respect and dignity appeared to be high on the agenda for the care staff and volunteers and one citing the service as 5 Star.

***Do you feel the staff have the information/skills and train to support you in the right way?***
Confidence of the patients and loved ones in those caring for them, can sometimes be as important as the care provided. We heard on numerous occasions about how specialist Doctors took the time to talk and visit patients and how the staff were always around to help and how the volunteers offered a different but valued part of the care process all leading to the perception of patients feeling all members of the team including the volunteers had the skills, information and training to carry out care to a high standard.

***How satisfied are you with any symptom relief you receive, for example for pain or sickness?*** We asked about symptom relief as this is something many people are concerned with, and whilst talking to the staff team it was evident that there were different types of pain, emotional and physical, however it would appear that all efforts are made to support the patients and provide the most appropriate relief. The discussion with patients and loved ones showed that patients felt they were supported and also those they were fully engaged in the process.

***One patient said, "If I don't know what I want, they (the staff) discuss all the pain relief options with me which helps".***

Patients also spoke to us about the kind of pain relief they had or intended to experience, all said they had received medication but that pain relief was also supported through the advice given by the staff. In addition we were told that a patient intended to try an alternative therapy to support their care. There was also evidence that where a patient had a specific requirement that needed extra or specialist equipment they would do try and facilitate these needs.

***Do you feel you have been given enough information to help make decisions about future care and are you and loved ones involved in decisions about treatment and care?***

It is clear that patients do not always want to discuss future planning with loved ones however in the case of the people we spoke to they had said they had been engaged throughout the process, they had asked questions. Those spoken to told us they had been allowed the time to process and consider future care options and preferences, they were allowed the time and input from clinical staff to support their decision making and felt, at the point of time we spoke to them, that everything that could be discussed had been.

***One patient said*** ***"there was nothing left to ask questions about, and that it had changed them as a person and they were actually much more positive".***

***Is there enough privacy for discussions to take place between, patient/family/staff and does the premises provide good access and facilities for family, friends and visitors?***

Having family and loved ones around was clearly important for patients, pictures, cards and flowers also provided a homely feel even in the 'bays'. Patients and loved ones had opportunity to use a variety of spaces for quiet and confidential discussions a which the patients had used and found useful.

***Do you feel family, friends and carers are supported enough by staff?***

From the perspective of a loved one they felt that their views did matter and that on the whole they were supported by the hospice.

***Where information leaflets and materials have been given?***

We know that often during difficult and stressful time information can be hard to understand and retain, therefore we asked where written information had been provided whether it was felt that it was relevant, helpful and easy to understand. Of those we spoke to they said any literature they had received covered all those areas adequately.

***Pre-visit Care and Care at Home. Tell us anything you feel is relevant to your care prior to coming to the Hospice.*** Patients told us that they had sometimes experienced problems during the diagnosis and referral to treatment time, and we were also told about how packages of care were put in place to support them return home or to their previous place of care but these could sometimes be delayed.

***Finally we asked patients and loved ones to sum up their experiences to date with any wishes for future change or development, the following summarises that feedback in their own words.***

"We are not the easiest of patients to satisfy or care for, but the staff and team work is amazing".

"It is not like being in a hospital, I feel more in charge of my own care and the staff listen to my needs".

"This is not really like a hospital with all the rules and regulations to abide by".

"Parking on site can be a real problem for visiting family and friends".

"Are needs cannot always easily be met but we know the staff will do their very best".

"As a carer I cannot give enough praise for the staff and volunteers here".

**4.1.3 Observations – Lincoln.**
As part of the visit we spend a proportion of the visit observing and recording the surroundings in which the care is being given, this can be helpful in informing the provider of how the patients perceive that service at that point in time.

***Access to the premises.***
Entrance to the premises was clearly signed and access was good, however the issue raised by not only Healthwatch but also the patients and family members was the lack of capacity within the car park and that the disabled bay was quite restricted. The Hospice acknowledged these points however we also appreciate there is nothing that can be done to improve the situation and the premises is at capacity with no room for development. Hospice did talk of their future plans to move premises to a site to the rear of Lincoln County Hospital which would allow for development of a unit that was more accessible and would meet future needs better.

***Are reception/patient/caller conversations confidential?***
The reception area within the Hospice with light, low level and welcoming. We appreciate that confidentiality in the reception area is not as much an issue as it is in other clinical environments. However if privacy is needed there is a room off the reception that could be used, also other rooms are available within the unit and in addition the waiting area seating is well away from the reception desk.

***Does the premises give appropriate access for disabled patients?***
Yes the reception and clinical area are on one floor and access to the entrance and rear gardens are ramped for wheelchair and mobility support.

***Is the premises easy to navigate, signage (different languages, accessible)?***
The unit is very compact and appropriate signage was in place. Due the nature of the care, patients and loved ones would not be expected to navigate the premises for the first time without an escort. However we did suggest that in support of patients with dementia or perhaps those with English as a second language that pictorial images be used for male and female facilities. There was a clear staff board with photographs and

staff names as soon as you entered the clinical area of the hospice which was informative.

***Were the premises and facilities clean and in working order?***
The premises appeared clean and where looked at, the facilities were in working order, the only exception to this were the blinds in the conservatory area which we understand are going to be replaced.

***The patient and working environment.***
As a patient observed in their feedback, the unit can be very busy and full of clinical staff and volunteers working with and supporting patients, however we also observed quite periods when the environment was calm and relaxing. The premises provides excellent outdoor space and sensory garden for all and is well equipped for most activities from children's toys to audio books. On a previous visits to the hospice in the summer we saw children visiting and playing in the garden and staff interacting with patients as they needed to, the environment although clinical does provide a degree of homeliness and opportunities for calm spaces.

**4.1.4 Common Themes and Conclusions – Lincoln.**
The general feel for the hospice in Lincoln was one of a calm but vibrant team of staff and volunteers working hard to support patients and loved ones. It is clear that housing this service in such an old house has its plus points and also downsides. Capacity to develop this anymore is extremely limited and the impact of that is felt within the car park before you even access the premises.

We acknowledge some of the challenges around getting the community care packages in place and the frustration that this can bring to the patient, loved ones and the hospice as their focus is very much on ensuring the patient gets back to their preferred place of care in the most reasonable timescale possible.

We also noted some of the challenges the hospice faced in transporting patients from the acute hospital to the hospice setting.

On the whole the unit provides a homely, supportive and relatively calm environment for visitors whether patients or loved ones. The staff were polite, happy and helpful and the volunteers added something extra which was recognising the value of the small things which make a patient or families experiences much better and the volunteers were obviously greatly valued.

## 4.2 Findings for Grantham

The following provides the detail of the visit feedback and should be acknowledged that this information was taken at a point in time. If changes have been made since the visit and the provider has commented on them, we will include those within the report for public interest and information.

### 4.2.1 General Information: Hospice in the Hospital - Grantham

The unit opened on September 8th 2014 and is a partnership between St Barnabas, South West Lincolnshire Clinical Commissioning Group (CCG) and United Lincolnshire Hospitals NHS Trust (ULHT). The unit provides 6 'nurse led' community hospice beds for the South West Lincolnshire community and is based within Grantham and District General District Hospital.

***What do the Commissioners and Providers say about their service***

*The care is provided by a nurse led team, supported by General Practitioners and other professionals.*

*The unit benefits local people who require end of life care in an in-patient setting, assessment and treatment of symptoms or palliative rehabilitation. The unit also provides respite care for those with complex needs which cannot be met by community based services.*

*Clinical treatment provided within this new unit benefits those patients who have frequent hospital admissions for symptom management as they will receive timely, specialist intervention and then be transferred to the care of community teams for on-going support.*

*In addition to the specialist care provided within the unit, the service will also outreach into the main stream hospital services thereby enhancing the quality of care throughout the hospital.*

*There are 6 individual bedrooms, each with en-suite facilities, seating area and small courtyard. All bedrooms will be equipped with a TV / DVD. In addition, there is a general relaxation area, with a quiet room and contemplation room for use by patients and their families. There is also a bedroom with en-suite facilities for relatives who might want to stay overnight.*

### 4.2.2 What the Patient said.

***How did you feel about coming into the service?***

The patients we spoke to were either attending for the first time or had been admitted before, we were interested to know how patients felt when they first had to attend this environment and how they might feel on subsequent visits. In both instances they felt it was the right thing to do and that they felt comfortable, confident and safe being at the unit.

***When staff talk to you, do they always introduce themselves and do staff call you by your preferred name?***
We appreciate as patients in any environment that the need for personalised care is important and how staff introduce themselves and whether this promoted as patient approach is again important. Both patients said that the rapport with nursing staff was good, however it was noted that the presence of support workers for longer during the day and a presence at night would be helpful particularly when the unit it full with patients with complex needs the extra help would be beneficial.

***When staff provide care do they always explain what they are doing?***
We understood from the Hospice how important it was that patients and loved ones understood what was happening and would happen during their stay in a language that was clear and understandable, this may include admission, treatment, discharge and end of life wishes. Both patients felt that the rapport with staff was good and they said that the staff took time to explain anything that was happening to the patient, we heard how staff had spent a lot of time with patients in the night trying to get medications and pain relief right. The patients said they found the comfort and attention from the staff reassuring.

***Do you feel there are enough staff and volunteers around to support you and if you need a member of staff to tend to your needs how quickly do you get that help?***
Sometimes when we talk to patients in other acute settings we hear that they feel the staff don't have the time to spend with them and sometimes call bells can be left, therefore we felt it necessary to explore this within the hospice setting to establish any differences and where differences occurred what impact this had on patients. Patients spoken to, although said the staff would come straight away for a call bell, also said they didn't like to call as they knew how busy the staff were with complex patients and didn't want to bother them, again the issue relating to the need for extra support workers was raised in relation to this.

***Overall, do you feel treated with respect and dignity while in the care of staff?***
We acknowledge how important retaining dignity and respect is for individuals and for their loved ones, even small acts such as clothing, hair, nails and a shave can make the difference to how a person feels their dignity is maintained. Both patients said they felt there were treated with dignity and respect and that they were very much treated as individuals rather than being looked at as a condition.

***Do you feel the staff have the information/skills and train to support you in the right way?***
Confidence of the patients in those caring for them can sometimes be as the important as the care provided. Patients again made reference to the time taken to get medications and pain relief right for the patients and that knowledge and ability to discuss pain, location of pain and the options brought a lot of comfort to the patients.

***How satisfied are you with any symptom relief you receive, for example for pain or sickness?*** We asked about symptom relief as this is something many people are concerned with, and whilst talking to the staff team it was evident that there were different types of pain, emotional and physical. On the unit patients we spoke with were happy with the medication provided and whilst none had accessed any other form of therapy one patient was looking into it.

***Do you feel you have been given enough information to help make decisions about future care and are you and loved ones involved in decisions about treatment and care?*** This varied between patients. One felt that the discussion about next steps and future care plans had not been discussed so far, but had said the Dr was coming in so expected further conversations then. The other patient was fully aware of the steps being taken and was also mindful that loved ones could also be included in those conversations as much or as little as was wanted by the patient.

***Is there enough privacy for discussions to take place between, patient/family/staff and does the premises provide good access and facilities for family, friends and visitors?*** With the private bedrooms and other accessible private spaces for private discussions or a family get together/meeting the premises is very well equipped to provide adequate privacy.

***Do you feel family, friends and carers are supported enough by staff?***
Both patients felt that rapport was built between staff, patients and their loved ones and that if family members needed supported that it would be provided.

***Where information leaflets and materials have been given?***
We know that often during difficult and stressful times information can be hard to understand and retain and we, therefore, asked where written information had been provided and whether it was felt that it was relevant, helpful and easy to understand. The patient who had used leaflets said they felt they had been useful and that the timing of giving information to patients was key.

***Pre-visit Care and Care at Home. Tell us anything you feel is relevant to your care prior to coming to the Hospice.*** We were told that getting the help needed in the community was not always straight forward and there was limited support around the mental health element of diagnosis and treatment. We heard how dealing with life limiting illnesses could have a major impact on family and relationships. We also heard that whilst counselling was offered to some, it wasn't accessible due to location and therefore opportunities to take up the services were not always feasible.

***Finally, we asked patients and loved ones to sum up their experiences to date with any wishes for future change or development. The following summarises that feedback in their own words.***

*"Diagnosis and medication does have a huge impact on mental health issues, but I feel there could be improvements to better support people and families out in the community."*

*"There is a need for better out of hours support to cope with stress and anxiety."*

*"The knowledge of the staff and the time they spend with you is reassuring."*

*"I could not find fault with the staff they are wonderful to me and my family."*

*"I don't like to press my buzzer too often because there are patients more poorly than me and I know how busy the staff are."*

*"Having an extra waking night Health Support Worker and additional help during the morning and meal times would be a help."*

*"I get as much rest as I need here; it's just very relaxing."*

### 4.2.3 Observations – Grantham.

**As part of the visit we spend a proportion of the visit observing and recording the surroundings in which the care is being given. This can be helpful in informing the provider of how the patients and service receivers perceive that service at that point in time**

**Access to the premises.**
The premises are new and access now has a dedicated entrance at the rear of Grantham hospital. The doors are automatic and easily accessible for those using wheelchairs or mobility aids. The unit has a dedicated parking area - 24 hour visiting if required.

**Are reception/patient/caller conversations confidential?**
The reception is large and bright with low level reception. The waiting area is behind the reception and whilst that doesn't lend itself to confidentiality this environment is not one where there is a lot of through traffic for it to be a major concern.

**Is the premises easy to navigate, signage (different languages, accessible)?**
We felt there was appropriate signage on all the rooms which required it and, in addition, security and safety was supported via swipe and key pad *access*.

**Were the premises and facilities clean and in working order?**
All the services we saw were in good working order. The premises appeared clean and we noted that the cleaning staff were part of the hospital Trust rather than specific to the unit.

**The patient and working environment.**
The patient rooms were well proportioned and had access to television and the shared outside space. There was a family room, a quiet room and also a relatives room where loved ones could stay if they needed to.

### 4.2.4 Common Themes and Conclusions – Grantham.

The feel of the hospice is very different to that of the rest of the hospital. Once inside you can easily forget where you are. The individual rooms could feel isolating, however, patients didn't really communicate that but instead felt it provided them with the much needed rest.

Patients felt the presence of support workers for longer during the day and a presence at night would be helpful particularly when the unit is full with patients with complex needs, the extra help would be beneficial.

Patients spoken with said although the staff would come straight away for a call bell, they also said they didn't like to call staff as they knew how busy the staff were with complex patients and didn't want to bother them. Again the issue relating to the need for extra support workers was raised in relation to this. This response is also very typical of what we would expect within a normal acute setting and was not seen at Lincoln. This may suggest the staff challenges are more readily seen at the Grantham site.

We were told that getting the help needed in the community was not always straight forward and there was limited support around the mental health element of diagnosis and treatment. We heard how dealing with life-limiting illnesses could have a major impact on family and relationships. We also heard that whilst counselling was offered to some, it wasn't accessible due to location and, therefore, opportunities to take up the services were not always feasible.

## 5. Findings from Staff and Volunteers.

Talking to staff and volunteers gives an overall perspective of the service; the environment; the positives and some of the challenges being faced by the service. The following provides a brief overview from both staff and volunteer discussions from the Lincoln and Grantham sites.

### Lincoln

We were told that services had changed considerably over the last 2 years and although patients are admitted from across the county the majority are normally from around Lincoln and surrounding areas. The patients at the hospice are normally those with the most complex conditions. As treatments and technology have changed so has the environment of the hospice and the need to employ and continuously develop skilled staff.

We talked about training and were told staff attended a number of internal and external courses to support staff carrying out their clinical function but also that of looking after the whole patient emotionally. Other aspects such as pain management, falls and skin integrity are also invested in. Training in specialist palliative care is also provided.

The hospice said they took individualisation seriously and supported patients and families in any way they could whether that was celebrating birthdays, renewing wedding vows or general celebrations had all been held at the hospice.

It was clear that the families are as important as the patients and support was offered in many ways. The hospice has a book of remembrance and deliver bereavement and companions groups. The hospice also has a family flat upstairs which is used to support the patient and family unit; for example we were told of a case where a family staying in the flat supported the patient by enabling the family to spend Christmas together.

The hospice wants to make patients as welcome as possible supporting flowers, cards, pictures. Each bed also has a television and patient details are above the beds. However, patients also have the full use of the family room, quiet/relaxation/treatment room, conservatory and also the family room in the reception area. The unit uses the services of a chaplain although the space is kept non-denominational.

We were told that the majority of patients were on air flow mattresses, however, we acknowledged the difficulties this presented as it is much harder for patients to mobilise on an air flow mattresses and soft form mattresses were generally used for more mobile patients. There is a 'plan for every patient' board which details the patient's stay and their care. There is also a palliative care coordination centre based on site and at the time of the visit there was also a GP registrar trainee. The staffing ratio is one nurse to 3 patients equivalent to what you would expect on a high dependency unit. We were told that a lack of national standards creates inequalities across the country.

The hospice uses volunteers to support service delivery. The volunteers help support meal times and help maintain nutrition diaries. The hospice also has volunteer drivers and volunteer gardeners supporting the unit and has also used young volunteers from the Duke of Edinburgh schemes.

The staff told us that discharge could be difficult as there was limited availability of agency staff to provide care packages. The volunteers told us that they hold the whole team in very high regard and they felt that everyone worked well as a team. The volunteers said that they were able to have conversations with the patients as and when they needed them; they were able to fetch cups of tea and help with meal times to enable the clinical staff to do their job or to enable the patient to spend more time with loved ones when they visited. In the words of the volunteers, it was a 'home from home'.

### Grantham

The unit has 6 separate bedrooms, each with their own wet room. Whilst the individual rooms are nice, we felt they could be quite isolating. Each of the rooms, however, do open out on to the court yard garden area. Volunteers are used here both on reception and also on the wards.

The staff are employed by ULHT and supported by a Palliative Care Consultant and Specialist Nurse Practitioner. General medical care is provided by GPs.

Multi-Disciplinary Team meetings are held on Mondays which looks at each patient and their care plan. The unit has 14 staff, 11 nursing staff and 3 Healthcare Support Workers covering 24-hour care. The Health Care Support Workers work two 4-hour shifts mainly to support personal care and meal times. We were told there was a separate budget for bank and agency staff, however, it could be a challenge getting staff and they didn't necessarily have the skills. We heard how the QELCA programme had been piloted at Boston Pilgrim but hadn't included hospice staff to date. QELCA has been designed by St Christopher's Hospice to support the delivery of high quality care to patients and families at the end of life.

A Dr visits patients and adjusts medications as necessary as the unit does not currently have a nurse prescriber.

We were told that 69% of patients died at the hospice and a focus on keeping patients well and pain free was crucial whilst trying to maintain a homely environment in an acute setting. However, the clear benefits of having this facility within a hospital is the access to specialist services such as testing, transfusions and pharmacy.

One of the challenges which faces the unit is the fact the staff are employed by ULHT and can, therefore, be redirected to other parts of the hospital when needed which impacts on the unit.

The expected length of stay for a patient is around 2 weeks although there has been some longer stays and stays can be as long as a few months. We were told that discharge can be problematic with little community care that can provide complex packages of care often required within a short time frame. DST (Decision Support Tool) meetings take place to discuss patient needs and include a hospital social worker, a St

Barnabas Nurse and decisions will be made around decisions for planning and funding of care within the community setting.

## 6. General Overview of Observations and Conclusion.

- At both sites the overwhelming support of the patients and appreciation of staff and volunteer kindness and compassion was never in doubt. The sites themselves, whilst had their own challenges, provided a bright and cheery environment with the backup of specialised care.

- Both sites, although delivering the same kind of care, did have a slightly different feel. In terms of how the staff pressures came across at the Grantham site were much more akin to a normal hospital ward than that of Lincoln.

- We saw the lack of capacity within the Lincoln site - the car park and disabled bay were quite restricted. The Hospice acknowledged these points, however, we also appreciate there is nothing that can be done to improve the situation and the premises is at capacity with no room for development. The Hospice did talk of their future plans to move premises to a site nearer Lincoln County Hospital which would allow for development of a unit that was more accessible and would meet future needs better.

- We heard at Grantham how staff were sometimes redirected to other parts of the hospital if they were short staffed. With the intention to move the Lincoln site closer to the hospital this drain on resource is a concern for them also.

- Both sites struggled with the challenges of accessing community support packages to enable patients to be discharged as soon as possible.

- Staff referred to no national guidelines and inequalities and indeed, it was also felt that within the Hospital Trust relevant staff should have access to specialist training irrespective of what site or what unit they are on, specifically in relation to the QELCA.

- We were told that getting the help needed in the community was not always straight forward and there was limited support around the mental health element of diagnosis and treatment. We heard dealing with life-limiting illness had a direct impact on mental health and that there could be more done within the community to support psychological assessment and treatment.

- We also heard of the need for a robust pathway for out of hours mental health care.

In general, there were themes across both sites and some not within the gift of the provider but the general feedback from patients and loved ones was positive as was that of staff and volunteers and was a privilege to listen to.

## 7. Final Recommendations.

The table below provides the outlines of the recommendations and suggestions made and includes the responses in the public interest, it is acknowledged that the items below highlight the areas for development and comment and should in no way detract from the positive feedback and activity described within the report:

| Issue Raised/Which Site | Commentary/Recommendations Related to the Report | Responsibility |
|---|---|---|
| **Both Sites**. Access to Community Care Packages. | Both sites struggled with the challenges when accessing community support packages to enable patients to be discharged as soon as possible. | All and LCC |
| **Grantham**. Although delivering the same kind of care did have a slightly different feel. | In terms of how the staff pressures came across to the patients at the Grantham site, were much more akin to a normal hospital ward than that of Lincoln where patients could see and feel the strain on staff and the repeated suggestion that more HSW would be useful and beneficial to the unit. | ULHT/SWCCG |
| **Grantham**. Staff Movement across the Trust. | We heard at Grantham how staff were sometimes redirected to other parts of the hospital if they were short staffed. This was a clear concern to the unit and let to feelings that they were undervalued as opposed to it being a specialist facility. | ULHT/ SWCCG |
| **Grantham**. Training. | It is requested that the Hospital Trust include all relevant in specialist training irrespective of what site or what unit they are on, specifically in relation to the QELCA. | ULHT |
| **Lincoln**. Facilities. | The blinds in the conservatory were in a poor state of repair but we understand are going to be replaced. | St Barnabas |
| **Lincoln**. Signage in support of patients with dementia. | We did suggest that in support of patients with dementia or perhaps those with English as a second language that pictorial images be used for male and female facilities. | St Barnabas, Lincoln |

| | | |
|---|---|---|
| **Community**. Mental Health. | We were told that getting the help needed in the community was not always straight forward and there was limited support for mental health particularly around the point of diagnosis and treatment. We heard dealing with life limiting illness had a direct impact on mental health and a feeling more could be done within the community to support psychological assessment and treatment. | SWCCG/LPFT |
| **Community**. Mental Health Out of Hours. | We heard the need for a robust pathway for out of hours mental health care. | SWCCG/LPFT |

**Healthwatch ask that in addition to the specific recommendations above, that all the observations and recommendations made regarding Hospice provision which is directly within the control of St Barnabas or within the control of other providers or commissioners be considered and acted on in equal measure.**

Healthwatch wishes to thank everyone involved in the visit and particularly the respondents, St Barnabas, the staff and Healthwatch authorised representatives. It is acknowledged that if at any time, any patient, family member or carer wishes to talk to Healthwatch relating to compliments, concerns or complaints they can do so in confidence.

## HEALTHWATCH LINCOLNSHIRE – INPATIENT UNIT ACTION PLAN

| Issue | Action Required | Date | Responsible Person/s |
|---|---|---|---|
| Blinds in the conservatory are dated and require replacement. | Blinds to be replaced. | **January 2016** | **General Manager, St Barnabas**<br>**Facilities Manager, St Barnabas** |
| The car park is inadequate with lack of space. There are designated visiting spaces, but spaces are limited. | Reception, volunteer and clinical staff to monitor the situation and signpost visitors to off road parking nearby.<br><br>Continue to request staff and volunteers to park off site.<br><br>Wheelchair support is available to support less able visitors to access the building.<br><br>Approach the BMI hospital to try and establish if there is any spare parking capacity available. | **Ongoing with review and updates**<br><br>**December 2015** | **General Manager, St Barnabas**<br>**Ward Manager, St Barnabas**<br><br>**General Manager, St Barnabas** |
| Ensuring community care packages meet the needs of patients and families on discharge from the Inpatient Unit. | Palliative Care Co-ordination centre to continue to feedback any issues relating to care packages to the Continuing Healthcare Team<br>Patients and families to be kept informed of any delays in respect of discharge due to issues relating to obtaining care packages. | | |
| Transport issues for patients from the acute trust to the Inpatient Unit. | Transport issues need to be investigated with the providers locally (NSL and EMAS) to resolve any challenges. | **December 2015** | **General Manager, St Barnabas** |

## HEALTHWATCH LINCOLNSHIRE
## HOSPICE IN THE HOSPITAL UNIT - ACTION PLAN

| Issue | Action Required | Date | Responsible Person/s |
|---|---|---|---|
| Grantham Staff Movement across the Trust | This will be raised through the joint project team to address how the unit skill mix and staffing levels are properly and consistently resourced. | **November 2015** | **Joint Project Board** |
| Grantham Specialist Palliative Care CPD | St Barnabas Specialist Nurses review of the QELCA modules has been completed and they and will be rolling out and monitoring compliance with St Barnabas and Hospice in the Hospital staff. | **December 2015** | **Unit Sister Specialist Nurse Practitioner** |
| Community Mental Health and Out of Hours | Unit Sister is undertaking a course in Cognitive Behavioural Therapy in Palliative Care with St Barnabas Hospice and will be able to support staff to address some of the low level (Tier 1/ Tier 2) psychological care needs of patients, preventing undue referrals to Mental Health Services. | **December 2015** | **Unit Sister Specialist Nurse Practitioner** |
| Grantham | Although delivering the same kind of care did have a slightly different feel, will be addressed through joint clinical leadership at Partnership Board. Monitor actions above to measure impact on staff behaviours and unit culture. | **Ongoing Review January 2016** | **Joint Project Board DoPC, St Barnabas Head of Nursing, Grantham ULHT** |

***Healthwatch Lincolnshire welcomes the response and actions to this report and as a result will review the comments and recommendations in February 2016.***

***Following the report being finalised:***

- Healthwatch will submit the report to the Provider.
- Healthwatch will submit the report to CQC.
- Healthwatch will submit the report to LCC or NHS England
- Healthwatch will publish the report on its website and submit to Healthwatch England in the public interest.

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