



Healthwatch Lincolnshire Enter & View Visit to:
The Butterfly Hospice, Boston
Public & Provider Report
March 2016

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Summary

The following reports on Healthwatch Lincolnshire's visit to the Butterfly Hospice in Boston. The visit involved discussion with as many patients, carers and staff members as was appropriate.

The report identifies key themes which Healthwatch Lincolnshire (HWL) believe should be raised and addressed as areas of best practice, concern or for development.

HWL is mindful that some issues are outside the control of the individual departments and sometimes even beyond the control of the hospice, so we ask for a response to our report from wherever it is required.

We have included in this report some of the basic findings which may be of interest to users of the services and those which may impact on the delivery of the service for either the provider or commissioner.

In brief the following core findings have been highlighted within the report.

- A high level of patient satisfaction of care provided by the hospice, staff and volunteers.
- A high level of family engagement in the care and wellbeing of all those involved with the hospice.
- An under-utilised capacity within the hospice to provide care for more patients and families across the county.
- Acknowledgement of challenges within the community to provide timely packages of care that allow patients to have choice about the location of their care.

The environment provided a modern, spacious and comfortable setting for all those involved in providing or receiving the care.

Why do we carry out visits?

Visits are being carried out by HWL who have a statutory role to enter and view any publically-funded premises that provide health and social care services. These visits are carried out with the sole intention of collecting information relating to the quality of services provided. We do this by gathering the views of patients, relatives and carers accessing and receiving the services.

In addition, we have a duty to ensure any information gathered is shared with the relevant organisations which have a monitoring and commissioning responsibility and also to you as the public. We also have a duty to report any cause for concern relating to the safety and care of those in receipt of those services.

If you require any further information or wish to download a version of this document please go to <http://www.healthwatchlincolnshire.co.uk/download/>.

How we do the work.

HWL authorised representatives were appointed to undertake this visit. During the visit we talked with patients, relatives, carers and staff to support our observations.

In the interest of confidentiality we remove the names of those making specific comments although general comments themselves maybe included.

This feedback is from when we visited the Butterfly Hospice in March 2016.

The Provider

About the Butterfly Hospice. (This information is taken directly from the Butterfly Hospice website.)

The Butterfly Hospice is dedicated to improving the quality of life for patients and families facing a life limiting illness by providing choice, care and support in a Hospice setting.

When you or someone you care about is seriously ill, you want to know they're getting the best possible care and treatment. We do too. Our hospice provides 24-hour patient care to those who need it most.

Our services are for people aged 18 and over that are referred to us by a healthcare professional.

Our care teams include doctors, nurses, therapists and spiritual support. It is our aim to provide the best possible, personalised care 24 hours a day for the duration of someone's stay. Our average length of stay is 10 days. The unit is staffed by a clinical team with specialised skills in dealing with the physical and emotional effects of life-limiting illnesses including cancer, heart disease and neurological conditions.

We aim to enrich people's quality of life by relieving symptoms such as pain, breathlessness and other distressing problems through the skills of our experienced and caring teams. Our patients come to us for respite, symptom control and for care at the end of life.

Who did we speak with?

During the visit we spoke with a number of hospice staff along with Matron, the Complex Case Manager, Chair of the Trustee Board, Volunteer Co-ordinator and domestic support team. We also had a conducted tour of the premises.

Findings from the Visit

The following provides some highlights and key issues from the visit which may be useful to the general public using those services and those delivering or commissioning the service.

In this section we try to capture the main themes and trends of what was being shared. We acknowledge that not everyone's experience will be the same but, for that reason we make a point of saying within this report that the views gathered were in a period of time and might not be reflective of the service on another day.

The Voice of the Patient - The Butterfly Hospice, Boston

The voice of the patient is valuable in shaping services which reflect need. They are also useful so providers can gauge how well they communicate. By sharing their views these collective responses can change the way services are run.

The following highlights the key areas which either the patients found good, had concerns about or just wanted to make comment. Where we have had a response from the hospice we have included it so you can see what difference your views make.

- Patients said that this was their first visit and really hadn't known what to expect from this type of setting.
- The District Nurses are instrumental in ensuring patients and families can access this care.
- A patient and loved one told us how comfortable they were in the Hospice environment and for the first time they felt confident to leave for periods of respite.
- We were told staff are very attentive and watchful without being overbearing. This appeared to support the feeling of safety and confidence for both the patient and the family.
- We were told that when the family weren't present the staff spent one-to-one time with the patient as much or as little as they wanted.
- The family is always welcome and treated as individuals and felt their own needs were recognised.
- A patient said that the food was always excellent and we understood that the food menu had been selected by the Trustee Board. However, if a patients needs change, this could be accommodated.

- A patient and family felt it was fantastic that there were so many staff to support so few people and that nothing seemed to be an issue.
- The family felt assured they could leave the patient and home to rest.
- We heard that the GP visited the patient in the Hospice.
- A patient told us that medication and any symptom relief was available as and when needed and discussed as appropriate.
- A patient and family told us they felt fully involved and informed about their care, what treatment they received and next steps etc.
- One aspect of the Hospice which was really important to patients and families was the ability to be able to share meal times and this was accommodated.
- Also equally important was the freedom to spend as much time as necessary with family and friends.
- A patient and family could not praise highly enough the support from the District Nurse at the outset through to the ongoing care, support and individual pathway they had experienced.
- A patient said ‘they weren’t scared anymore’.

The Voice of the Staff

- The Butterfly Hospice Trust is commissioned by LCHS and has been developed over the last 16 years. The hospice has been receiving patients for 18 months.
- The care is nurse-led and has strong links with community teams.
- Referrals come from East GPs (30); those out of the area are also able to refer but only after they have first explored their own region.
- Patients have a number of conditions but are predominantly cancer patients. Other conditions include heart failure, COPD, Dementia, Neurological and Cardiac.
- The service is available to anyone over the age of 18 years although the general demographic is more elderly.

- The criteria for care is that a patient is entering the last year of life.
- The unit consists of 6 beds - 2 beds within a bay, which is mainly used for respite and 4 individual rooms, all of which have en-suites.
- The hospice currently allocates no beds for emergencies, however, if there was a need community referrals would take priority over hospital referrals. Nonetheless, the majority are currently planned admissions and there is no waiting list.
- The occupancy rate for the Butterfly Hospice has been around 60% occupancy but has more recently increased to 80%.
- Staff told us they were able to work flexibly when very busy at peak times and draft in more staff support as required. The hospice recruits additional staff for weekends. The hospice also had a student nurse at the time of the visit and Macmillan are also based on site. Macmillan and LCHS nurses are always present at the point of handover shifts.

Challenges and Areas for Development ...

- Managing appropriate staffing levels and accessing staff with a range of speciality skills which can support cover for staff sickness etc.
- Patient preparation in terms of making sure everything is ready and ensuring all other parties have completed their responsibilities could sometimes be time consuming. End of life circumstances can quickly become clinically unsafe and this stage of planning needs to be done as effectively as possible with multiple partnerships.
- An atrium is planned which will give further beds and is phased over 4 years. The hospice would like to expand into day services, be able to bring people in for IV diuretics and, therefore, better utilise the beds and staff and save hospital admissions. This would have a positive impact for patients and services.
- We heard some of the external challenges and understood that getting packages of care in place could effect patient length of stay.
- Public and professional awareness of the service, what was available and its current levels of capacity are all areas which require marketing and promotion to ensure the unit is used effectively and that patients and families benefit from the care.

Best Practice ...

- **Patient Bereavement Group (PBG).** The staff develop and manage this group. Three months after someone has died, the family and carers are invited to attend the PBG and they can attend for as long as they feel they need to, recognising everyone is individual in their grief. Cruse Bereavement is based on site and for more complex needs, professional support can be obtained.
- The Complex Case Manager has been invited to attend a conference in the Houses of Parliament to share and celebrate hospice care. It was an excellent recognition for both the hospice and Lincolnshire.
- **Volunteers.** Volunteers play a very important part of the hospice through 7 Trustees, hospitality volunteers and gardeners (the head gardeners recently received an award at The Pride in Lincolnshire Awards) totalling 170 volunteers. There are charity shops which raise funds to support the hospice - these could possibly grow to support future developments.

Observations ...

There is a large welcoming family room with books, puzzles, children's toys and free drinks. This room felt very much like a lounge "at home" with no timings for visits; family and friends are welcome to stay; comfortable reclining chairs, friends and family are able to share meal times with patients for a small charge.

All rooms face out into gardens with patio doors for easy access. Everyone is encouraged to visit the hospice and to have a better understanding of what the environment of 'hospice' really means in today's society.

General Overview of Observations and Conclusion

The main theme which emanated from the visit and perhaps the most powerful, was the overwhelming support and care the patient and family told us about during their period with The Butterfly Hospice. It was clear from these discussions and in these circumstances, The Butterfly Hospice was both patient and family focussed in delivering appropriate care in a safe and as comfortable a setting as possible.

The plans for the new development bring about opportunity to provide some excellent services for people across Lincolnshire requiring hospice and respite care. However, how effectively the services are utilised, will have an impact on what will be feasible in the future. It could be suggested that countywide usage and promotion becomes more normal with a good working protocol with other hospice providers to ensure waiting times for hospice care can be accommodated.

We heard the challenges relating to some difficulty in getting care packages in place which in turn could lead to an extended stay in the hospice. We heard about the relative short windows of opportunity where delays may mean it becomes clinically unsafe to transport a person and, therefore, the patient's choices of location can be affected and limited.

In general, the visiting team felt the hospice would benefit from wider promotion. The team would also like to see how all the hospices across the county work together to provide this high level of care, particularly after hearing the benefits and reassurance it brought the patient and the family whose messages were honest, sincere and powerful.

Final Recommendations.

In our view the following core observations and recommendations need to be considered by the commissioners and providers of care, not only of The Butterfly Hospice, but also the relevant commissioning Clinical Commissioning Groups (CCGs). The following table provides the outline of the recommendations and suggestions made and includes the responses in the public interest. *It is acknowledged that the items overleaf highlight the areas for development and comment and should in no way detract from the positive feedback and activity described within the findings.*

HWL Issue Raised	HWL Commentary/Recommendations Related to the Report	Feedback/Commentary/ Action in Response	Responsibility
Butterfly Hospice			
1. Alternative Symptom Relief and Therapies	We noted that the Trust was not currently able to offer patients massage/reflexology and other alternative therapies but hoped they could be introduced in the future. Does the Trust have a timeline for this facility to be made available?	No current provision within LCHS. To be explored with Charity representatives. There are long term plans to extend the facility and enable other day facilities to be available. Explore with Macmillan nurses any current opportunities currently provided by professional groups and if the hospice can benefit; consider information which can be shared with patients about alternative therapies.	Alison Morant CTL
2. Alternative Language Formats	It was queried that only one leaflet was available in an alternative language. The hospice told us they had access to a 'language line' and there was an information pack in a reception holder in Polish. We did not ascertain to what extent language line is effective in caring for those on this patient journey. We would be grateful if the hospice could comment and where improvements could be made, to make them.	To review current information leaflets regularly used within the Hospice and discuss with E&D and PPI Clinical Governance Manager about ways in which multi-language can be produced. Ascertain the required languages based on local population. Update staff at team meeting about language line and services.	Clare Credland Alison Morant
3. Community Care Packages	We heard that some of the external challenges were getting packages of care in place at the patient's home which could affect patient length of stay. HWL asks what actions are being taken to improve this situation and are they working?	As an organisation LCHS monitor on a monthly and escalate DTOC (Delayed Transfer of Care). We are contributing to DTOC workshops and working to improve our working relationships with providers alongside our transitional care colleagues. Unfortunately external packages of care are out of LCHS control but we will always look at	

		our local ICT capacity and combine provision if appropriate and possible.	
4. Occupancy Rates	The occupancy rate for The Butterfly Hospice has been around 60% occupancy but has more recently increased to 80%. The public and professional awareness of the service needs of what was available requires constant promotion to ensure the unit is used effectively and that patients and families benefit from the care. What actions can be taken to improve the rate of referral?	We continue to improve our relationships with local providers and GPs to ensure our stakeholders understand the provision available at the hospice. The staff are regularly contacting the acute provider , GPs, and community teams to advise on our bed state and capacity. This is ongoing work and with the 2 year birthday event coming up in the summer, we hope to improve both public and professional understand about the service we offer.	
5. Day Service Development	The hospice would like to expand into day services, be able to bring people in for IV diuretics and, therefore, better utilise the beds, staff and save hospital admissions. This would have a positive impact for patients and services. Is the hospice and LCHS supportive of developing these services?	Yes, as an organisation we are committed to exploring models and pathways of care which enable care to be provided closer to home and improve utilisation. We are currently reviewing our pathways within our Community Hospitals and provide single interventions within our other services so when agreed, these pathways can be used to explore expansion within the Hospice.	
6. Managing Expectations	Patient and family felt that it was fantastic that that there were so many staff to support so few people and that nothing seemed to be an issue. Does the hospice have plans to support the same level of care when capacity increases?	A positive patient, carer and family experience is vitally important to us, so any expansion or change to the service would need to be reviewed prior to agreement and this would include staffing and skill mix.	

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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