


Agenda Item 9

		THE HEALTH SCRUTINY COMMITTEE FOR LINCOLNSHIRE	
Boston Borough Council	East Lindsey District Council	City of Lincoln Council	Lincolnshire County Council
North Kesteven District Council	South Holland District Council	South Kesteven District Council	West Lindsey District Council

Open Report on behalf of St Barnabas Lincolnshire Hospice

Report to	Health Scrutiny Committee for Lincolnshire
Date:	20 April 2016
Subject:	St Barnabas Lincolnshire Hospice

Summary:

Palliative and end of life care seeks to improve the quality of life for patients with life limiting conditions. St Barnabas Hospice Trust was established in 1979 to improve end of life care for the people of Lincolnshire.

The Trust continues to be committed to improving and developing palliative and end of life care services for the people of Lincolnshire in partnership with other health and social care providers.

The Organisation is engaged in the Lincolnshire Health and Care development programme both on the ground through neighbourhood team working and at senior level through established partnerships.

Actions Required:

To consider and comment on the content of this update report for St Barnabas Hospice Trust.

Definition of Palliative Care

Palliative¹ care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, **(this includes both cancer and non cancer conditions)** through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

¹ World Health Organisation definition of palliative care (2014)

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement.
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Background

St Barnabas Hospice Trust was created in 1979 by a small group of people to provide a haven of comfort and care, with total funds amounting to £270. By 1989, the reputation of the hospice and demand for the service had grown and the hospice purchased a building on Nettleham Road. This building continues to provide inpatient facilities for eleven patients.

In 2008 the inpatient unit underwent an extensive refurbishment programme and was re-opened in December 2008. An official opening ceremony was performed by Professor Mike Richards, CBE, and National Director for Cancer and End of Life Care, in February 2009.

Over the next few years the Trust expanded further and by 1994 had five day centres operating around Lincolnshire, i.e. Gainsborough, Sutton-on-Sea, Lincoln, Boston and Spalding. Further services we developed to include hospice at home, welfare support, and family support and bereavement services.

The aim of all of the services is to support the patient psychologically, physically and emotionally to enable them to achieve, within the limits of their illness, what is important to them. This is achieved through a combination of activities including nursing care and medical care, physiotherapy and occupational therapy, arts and crafts, complementary therapies, counselling and spiritual care.

St Barnabas currently employs approximately 350 staff and has over 1000 volunteers who help to provide support to patients and their families at all sites throughout the county. The Trust Shops and Fundraising Teams are required to raise in excess of £4 million to fund services.

Introduction

Nationally, over the next 10 years, not only is the incidence of cancer projected to rise by 30% in men and 12% in women, but dementia and chronic illnesses linked to lifestyle will also increase. It is estimated that by 2021 over one million people in the UK will be living with dementia – with a further half a million likely to have undiagnosed dementia. This increase in people living with, and dying from, multiple chronic conditions will have a significant impact on the families and communities who support them.

St Barnabas Hospice is a county-wide organisation that recognises the differing demographic and health challenges faced by communities within Lincolnshire. The ageing population and long-term health needs of those on the east coast being a specific example. We acknowledge that our services need to reflect local needs.

Our services

St Barnabas Hospice has the needs of the patients at the centre of everything we do. We seek to ensure that patients with palliative and end of life care needs, irrespective of their diagnosis, have access to and receive high quality support and care that is centred around them. Whether we are delivering care in the patient's home, nursing home or hospital we seek to improve their experience and enhance their quality of life.

The services and expertise we offer for people from the age of 18 years and upwards have been developed in a variety of care settings to support a wide range of needs from controlling pain and other distressing symptoms to accessing welfare benefits advice.

Palliative Care Co-ordination Centre

The Palliative Care Co-ordination Centre, based in Lincoln, has a county-wide remit to co-ordinate care packages to support patients who have been diagnosed with any life-limiting illness, so that they can stay safely at home if that is their preferred place of care. The team consists of a number of co-ordination administrators and specialist palliative care nurses, who provide advice and support to patients, their families and clinical staff.

The co-ordination centre arranges care from a number of providers, including our own Hospice at Home teams, Marie Curie night care and Rapid Response services and, where healthcare or joint health and social funding has been allocated, private care agencies.

The choice of provider and the number of visits allocated depends on the patient's clinical needs and urgency of those needs. These needs are determined by regular assessment of the patient and their family circumstances, using a Responsive Needs Tool, developed by the Hospice and shared across all health and social care providers in Lincolnshire.

In order to achieve the patient's preferred place of care, the centre aims to provide the right level of care to the right patient at the right time. The PCCC is open 365 days per year, Monday to Friday 9am to 6pm, weekends and bank holidays 9am to 5pm.

During 2015/16 1,538 new referrals were received by the service. Over 225 of these patients lived alone, and required very complex packages of care to achieve their preferred place of care.

Hospice at Home



Hospice at Home is a service for people with an advanced, life limiting illness who choose to be cared for and to die in their own home.

Hospice at Home is a countywide service, operating 7 days a week. Care is provided by a team of experienced specialist registered nurses and healthcare support workers. All care is planned with the person and their relatives/carers working closely alongside community nursing teams to meet the needs of both the patient and the family.

As well as providing personal care for the patient a major part of our role is to manage physical and psychological symptoms, and provide advice and emotional, social and spiritual support to the patient, and those significant to them.

During 2015/16 1,715 patients have received care from Hospice at Home teams across Lincolnshire and 90% of patients were able to die in their preferred place of death.

Inpatient Unit

Our 11-bed specialist inpatient unit, located in Lincoln, is the only specialist palliative care inpatient unit in Lincolnshire.

The inpatient unit supports patients with complex physical or emotional care needs. The multi professional team work closely with patients, families and carers to manage complex symptoms.

Year to date 2015/16 there have been 145 admissions to the unit, the largest number of referrals are received from the community and the hospital specialist palliative care service.

Day Therapy



Our Day Therapy service welcomes anyone over the age of 18 years who has a life limiting illness, and aims to support people to live independently, through a model of palliative rehabilitation, advice and information and helps people to make informed choices about their future care.

Care is provided by a team of experienced specialist registered nurses, occupational therapists, physiotherapists, health and rehabilitation support workers, chaplains, complementary therapists and volunteers.

During 2015/16 780 referrals to the service were received.

Welfare Service



The Welfare Benefits Service is a team of experienced benefits advisors who provide confidential advice on all Personal Independent Payments (PIP), tax credits, grants and blue badges.

Many people do not receive payments to which they are entitled because they believe that their income or savings are too high. This is frequently not the case. Benefits advice can be given over the telephone, face to face by appointment at one of our sites across the County or, in exceptional circumstances we can visit you in your own home.

During 2015 the team received over 300 referrals per month and secured in excess of £7 million of benefits for patients and their carers.

Family Support Service

St Barnabas Family Support Service is a service providing emotional and psychological support to patients, their families and carers, together with support for those who have experienced bereavement.

The service consists of a small team of paid staff and approximately eighty volunteers who work throughout the county. Our volunteers all receive training and we have a team of fully qualified and some trainee counsellors.

The bereavement service facilitates several bereavement groups across the County. The purpose of these groups is to enable bereaved people to meet with each other in a safe and comfortable place with trained, experienced volunteer help at hand.

Support can also be offered according to need on an individual face to face or telephone basis from one of our trained listeners or by a member of our counselling team.

Groups are structured to enable support to be provided relevant to the individual and members are encouraged to move through from bereavement to friendship to companion groups at appropriate stages. Support is available through these groups for as short or as long a time as is required.

Currently there are 568 clients receiving support from the service.

Hospice in the Hospital – a partnership initiative



This Unit is a unique partnership between St Barnabas, United Lincolnshire Hospitals Trust and South-West Lincolnshire Clinical Commissioning Group. The unit provides six community hospice beds to serve South-West Lincolnshire community and is based within Grantham and District General District Hospital.

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

The unit directly benefits local people who require end of life care in an in-patient setting, assessment and treatment of symptoms or palliative rehabilitation. Clinical treatment provided within this unit particularly benefits those patients who have frequent hospital admissions for symptom management as they will receive timely interventions and will be able to return home to the care of community teams for on-going support.

Since opening in September 2014 the unit has cared for 165 patients.

Service Developments

St Barnabas Hospice continues to be ambitious in developing and improving services, to ensure services evolve to meet patient and carer needs and to widen access to palliative and end of life care for all.

The priorities the Trust has established for the forthcoming year reflect local need and national guidance. The following national documents describe some of the critical outcomes and success factors for palliative and end of life care.

Ambitions for palliative and end of life care

The national palliative and end of life care partnership² has identified the ambitions and local actions that will support people's wishes. We fully support and endorse these ambitions and they form the basis of our strategy:

- Each person is seen as an individual and care is goal orientated and person-centred.
- There is fair access to care, irrespective of diagnosis or place of residence.
- Comfort, wellbeing and control are maximised taking a rehabilitative palliative care approach to self-management and empowerment, enabling people to maintain their independence and to live until they die.
- The care provided is integrated and co-ordinated, staff work with other providers to ensure the patient receives the right care at the right time from the right person in a timely manner.
- Care is delivered by well-trained, skilled, supported and resilient multi-professional teams.

Every Moment Counts³

This narrative document informs us from the perspective of patients, carers and families what person centred care means from the viewpoint of someone approaching the end of life and what really matters to them:

² Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
<http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

³ Every Moment Counts (2015) <http://www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations>

- We work for my goals and the quality of my life and death and I am respected as a whole person, not treated as an illness.
- I have honest discussions and the chance to plan and I am confident that staff are able to have difficult conversations.
- The people who are important to me are at the centre of my support and I can decide the people most important to me.
- My physical, emotional, spiritual and practical needs are met and I am helped to feel safe, in control, comfortable and dignified with as little fear as possible.

Commitment to Carers⁴

This document describes the critical role of carers in supporting patients. Caregivers may be prone to depression, grief, fatigue and changes in social relationships. They may also experience personal physical health problems and fatigue. Perceived caregiver burden has been associated with an increase in the use of primary care services by carers, premature institutionalisation and patient reports of unmet needs.

St Barnabas also recognises the importance of carers and is committed to embedding the priorities outlined in the Commitment to Carers document by developing direct supportive interventions for carers including strategies and support for psychological, spiritual and emotional wellbeing.

Delivering Our Ambitions

The table below identifies the actions we are taking, or will take, to continue the improvement of palliative and end of life care services in Lincolnshire, taking into account the documents referenced above. To deliver our ambitions we plan to:

Our Ambitions	Making this a reality
Continue to develop our understanding of each locality within Lincolnshire, listening to local communities, and our partners, so that our plans reflect and are responsive to the needs of local populations.	<p>Develop local strategies for each locality – we are currently consulting on the first of these – East Lindsey.</p> <p>We have a programme of public engagement, including a '<i>listening volunteers</i>' project which supports the gathering of valuable patient and family feedback on their experience of end of life care in Lincolnshire.</p>

⁴ Commitment to Carers (2014) <https://www.england.nhs.uk/wp-content/uploads/2-14/05/commitment-to-carers-may.14.pdf>

Our Ambitions	Making this a reality
Support better access to palliative care services by providing care closer to people's homes, including care homes and to those who are in minority groups.	<p>Working with other providers to support End of Life care in care homes and a specific project '<i>Hospice in your Care Home</i>'.</p> <p>We are working with HMP North Sea Camp to deliver Advance Care Planning training for the prison population who are approaching end of life.</p>
Ensure that our staff and volunteers continue to receive education and training, using best practice evidence to support people's goals and, quality of life and death.	<p>We have recruited a clinical practice educator supporting continuing professional development of the workforce.</p> <p>We are developing a training package to support staff to care for people with learning disabilities at the end of life.</p> <p>We are supporting our specialist nurses to undertake Non-medical prescribing.</p>
Continue to work closely with families, GPs, community nurses, hospital teams and other agencies involved in the care and support of patients.	We have funded and recruited to a Matron in Palliative and End of Life Care who will work with the palliative care teams across the United Lincolnshire Hospitals Trust.
Work with partner organisation to actively explore new ways of working and opportunities to better co-ordinate care, including the use of technology.	<p>Introduce a patient flow system 'Cayder', alongside the Lincolnshire Community Health Services to improve discharge from hospitals, better identify capacity and resources and provide timely responses.</p> <p>We are in the final stages of deploying EPaCCS (Electronic Palliative Care Co-ordination System) which will share pertinent end of life information across health (and eventually social care) providers to support seamless care, patient choice and unnecessary admission to acute care.</p>
Offer specialist education and training opportunities for health and social care professionals.	We continue to provide a range of education and training – we have recently provided education to Lincolnshire County Council for both qualified Social Workers and Social Support Workers.
Share our estate and that of others to support partnership working and the local community caring for those with palliative and end of life care needs.	We are exploring opportunities to work differently and to share premises to benefit health professionals and patients locally.
Deliver rehabilitative palliative care through our day therapy services across local communities.	We are reviewing demand and capacity of our day therapy services and seeking opportunities to deliver day therapy services to the housebound and those in isolated communities.

Develop our services to better support the emotional, spiritual and psychological well-being of patients, their carers and families during the person's illness and into bereavement.	We are developing an integrated spiritual and wellbeing assessment to determine need and who is best placed to support the person, we are also training staff in Cognitive Behavioural Therapy and Mindfulness to support earlier, preventive psychological support and reduce the need to refer to mental health providers.
Encourage and develop the community's ability to discuss dying, death and bereavement in open, honest and more confident ways.	We are supporting Dying Matters week (May 16-22 nd) across the county with various activities including death cafes in Lincoln and Skegness including a family open day to acknowledge the needs of parents with young children who are bereaved and the specialist support they require. That week we will also be launching an App – ' <i>Good Goodbyes</i> ' that promotes conversations about death and dying. A priority is the development of a Dementia Strategy for the organisations that aligns with the Lincolnshire Strategy – specifically enabling people to make advance care plans whilst they have capacity to make informed choices.
Improve public awareness of the difficulties people face and create a better understanding of the help that is available and to identify new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.	We are working with local communities, third sector organisations and other social care providers to support the ownership of end of life care in local communities.

Conclusion

People, who face progressive life-limiting illness and those important to them, require different levels of health and social care at different times in their illness in order to live as well as possible, for as long as possible. Palliative and end of life care is important, our society is ageing with 10 million people in the UK over the age of 65.

As medical treatments continue to improve with many people surviving and living with continuing illness, including heart and respiratory disease, diabetes, and cancer. This has led to people experiencing a different set of health needs, frequently complex in nature. Today at least 15 million people in the UK have a chronic condition and the number of people with more than one chronic condition is growing rapidly.

St Barnabas Hospice prides itself in leading local, regional and national initiatives to improve end of life care outcomes locally. Despite the economic and demographic challenges we face we are confident that we can continue to achieve our ambitions for the maximum impact on patient care.

Consultation

This is not a consultation item.

Appendices

There are no appendices.

Background Papers

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020 (2015) <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

Every Moment Counts (2015) <http://www.nationalvoices.org.uk/every-moment-counts-new-vision-coordinated-care-people-near-end-life-calls-brave-conversations>

Commitment to Carers (2014) <https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may.14.pdf>

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