

Report to Brighton and Hove HWOSC

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Author: Simone Lane– CCG Commissioning Manager for Community Care

Purpose of the Report

The purpose of the report is to provide HWOSC with an update on developments in Palliative Care and End of Life services and pathways in Brighton and Hove.

End of Life Definition

End of life care: Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of patients, their carers and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. Source: National Council for Palliative Care 2006 from National End of Life Care Strategy, 2008.

Background

Just over 1% of people die each year and around 455,000 people died in England in 2010. There are changing trends in the age of death, with increasing numbers of deaths in people aged 85 and over and a decreasing trend in people aged 65 to 84. The older age group has a greater likelihood of frailty and multi-morbidities. The majority of deaths occur in an acute hospital and do so following a period of chronic illness such as heart failure, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Deaths in England and Wales are expected to rise by 17% from 2012 to 2030. A large proportion of deaths are foreseeable, and a recent estimate suggests that approximately 355,000 people need good palliative care services every year but around 92,000 people are not being reached. Although 63% of people surveyed stated that home is their preferred place of death, in 2010 most deaths occurred in hospitals (53%) and only 21% occurred in the home with an additional 18% in care homes. Traditionally, end of life care services have been orientated towards cancer care. In 2010 non-cancer related deaths accounted for over 70% of deaths. The percentage and number of people with non-cancer diagnoses accessing specialist palliative care services has increased overall in the past 12 years. However -The proportions of people with conditions other than cancer who access these services still remains very low. In Brighton and Hove we have seen an increase in deaths in usual place of residence, in Brighton and Hove in 2011/12 42.8% of people died in their usual place of residence, compared to 44.7% in 2012/13, (nationally the figure was 43.9% in 2012/13)

National Strategy

In July 2008, the Department of Health published a national strategy to improve provision of end of life care. The aim of this strategy is to bring about a step change in access to high quality care for all people approaching the end of life. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money.

Local Delivery of the National Strategy

In Brighton and Hove there is a joint palliative and care group (the Palliative Care and End of Life Steering Group), that has representative from primary, secondary, social and community care services as well as the voluntary sector. This group strives to promote and deliver high quality care for patients approaching the end of life. This group and is responsible for forming a joint action plan to deliver the national strategy on end of life care locally.

End of Life 2013-14 - Main Work streams

1. Sussex End of Life Care and Dementia Project

This project aims to improve end of life care for people with Dementia across Sussex, so that more people with dementia die in their preferred place of death, with dignity, without undue pain and with their advance wishes respected. The specific project objectives were:

- To increase advance care planning with/for people with dementia
- To develop a comprehensive integrated end of life and dementia care pathway
- To develop practitioners understanding, knowledge & skills enabling them to deliver safe, high quality end of life care to people with dementia.

Achievements to date are:

- Establishing a multi-agency stakeholder groups
- Development of the Sussex Integrated End of Life and Dementia Care Pathway.
- Increased co-operation between end of life care and dementia specialist practitioners
- Providing 'Conversations for Life' education and training events to promote Advance Care Planning.
- Providing two Namaste Care workshops to promote compassionate, sensory based end of life care.
- Distribution of 10,000 'This is Me' Bags across Sussex the dissemination and promotion of examples of good practice in end of life and dementia care.
- Providing organisations with support so they can 'dementia and end of life proof' their existing education and training opportunities and integrate these into their workforce development plans.

2. Palliative Care Partnership

In 12/13 after a pathway review and stakeholder consultation, a major redesign of End of Life and Palliative Care pathway was carried out. In April 2013 the Palliative Care Partnership (PCP) service was commissioned and is provided by Sussex Community Trust and the Martlets Hospice.

The Palliative Care Partnership provides expert support and advice for palliative and end of life care patients and their families, as well as the professionals caring for them. The service is working to improve patients' experiences of community palliative and end of life care health service. It is also contributing towards achieving reductions in unscheduled admissions into secondary care and A&E, and an increase in the number of patients dying in their preferred place of care.

3. Primary Care

The Gold Standard in Palliative Care supports primary health care teams in providing the highest standards of generalist palliative care, to enable patients in the last year of their life to achieve the best possible physical, spiritual, and social care in the place of their choice. The GSF was first introduced in Brighton & Hove in 2001 in 2013/14 there are 41 practices out of 47 signed up for the Palliative Care Local enhanced service

The key to improving access to services, is to identify all patients, regardless of diagnosis, in their last year of life (aiming for 1% of the practice population), add them to a GSF register and for their care to be discussed and reviewed monthly in a multi-disciplinary team meeting. Early identification allows time for Advance Care Planning. Patients, relatives, carers and health care professionals can discuss and ascertain the patient's choices and preferences whilst they still have capacity and anticipate their needs. The appropriate care and support can then be accessed for the patient and their carer in their preferred place of care.

There have been improvements year on year in the numbers of patients having their Preferred Place of Care documented and achieved. In 2011/12 90% of patients on practice GSF registers had their PPC documented. GP training about anticipatory medications has seen an improvement in practice.

In 2013/14 there has been a requirement for GPs to attend training on Dementia and end of life care. This included the importance of giving patients with Dementia the opportunity to discuss and document their wishes and preferences (whilst they still have capacity) by completing an Advance Care Plan and also making GPs aware of prognostic tools which will assist them in identifying when patients with dementia are in their last year of life.

4. The Liverpool Care Pathway (LCP)

The Liverpool Care Pathway for the Dying Patient (LCP) is a model of care which enables healthcare professionals to focus on care in the last hours or days of life when a death is expected.

The LCP is tailored to the person's individual needs and includes consideration of their physical, social, spiritual and psychological needs. It requires senior clinical decision making, communication, a management plan and regular reassessment. The LCP is not a treatment in itself but a framework for good practice – it aims to support, but does not replace, clinical judgement. The LCP guides and enables healthcare professionals to focus on care in the last hours or days of life, when a death is expected.

Good, comprehensive, clear communication is essential to the LCP and all decisions leading to a change in care delivery should be communicated to the patient where possible and deemed appropriate, but always to the relative or carer. This is in accordance with GMC best practice guidance (GMC 2010). The views of all concerned must be listened to, considered and documented.

Following a series of instances nationally of poor care, the Department of Health announced in January 2013 that an independent review into the use of the LCP would be undertaken, chaired by Baroness Julia Neuberger. In July 2013 the independent review of the Liverpool Care Pathway (LCP) published its report 'More Care Less Pathway'.

In the report Baroness Neuberger said: "There is no doubt that, in the right hands, the Liverpool Care Pathway supports people to experience high quality and compassionate care in the last hours and days of their life. But evidence given to the review has revealed too many serious cases of unacceptable care where the LCP has been incorrectly implemented."

This national document therefore makes a number of recommendations about how people at the end of their life should be cared for, and specifically recommends that 'the use of the Liverpool Care Pathway should be replaced within the next six to 12 months by an end of life care plan for each patient'.

The CCG, as part of the work of the Palliative Care and End of Life Steering Group, held a meeting with key stakeholders in primary, community and secondary care in September 2013, to ensure that interim arrangements were in place during this transition period. It was agreed that services would follow the NHS England interim guidance for Doctors and Nurses regarding how to care for the dying patient (NHS England July 2013), and will continue to follow this until further guidance is available. This interim guidance recommends that the principles of good palliative care, on which the LCP was originally based are continued to be upheld. These are regular assessment and management of symptom control and comfort measures, effective communication with patients and their families, provision of psychological, social and spiritual support. These principles hold true, whether or not the LCP or any integrated care pathway or plan for dying is used.

In response to the recommendations in the 'More Care Less Pathway report, the Leadership Alliance for the Care of Dying People (LACDP) was set up, to lead and provide a focus for improving the care for these people and their families in response to the recommendations made in the report. As part of this work, the alliance is now running an engagement process to hear the views of clinicians, patients, families and carers around the proposed advice to health and care professionals, about care in the last days to hours of life.

(<https://www.engage.england.nhs.uk/consultation/care-dying-ppl-engage>)

The CCG as part of the work of the Palliative Care and End of Life Steering Group is now leading an engagement process, to ensure that there is thorough local consultation on what a local end of life care plan to replace the LCP should look like. As a first step in this process a stakeholder event was held on December 17th 2013 to provide a collective response to the proposed advice to health and care professionals, about care in the last days to hours of life.

The event was attended by: Representatives from B&H CCG; three local service users: Age UK; The Trust for Developing Communities; staff from Brighton & Hove City Council, and Brighton Older Peoples Council; representatives from Brighton & Sussex University Hospitals including palliative care consultants, clinical nurse specialists and the trusts chaplain and rabbi; Brighton Carers Centre; two local GPs, three members of Healthwatch; a GP from the out of hour's service (IC24). Living Well/Dying Well a local charity with specialist interest in dying; the Martlets Hospice, including clinicians, nurses and chaplain; Macmillan Cancer; Sussex Community Trust staff, including clinicians, service director and chaplain; a clinician from Sussex Partnership Foundation Trust; the homeless co-ordinator for the St Johns Ambulance; a local Nursing Home Manager

This event will be followed by a further stakeholder consultation in April 2014 to discuss the content and implementation of a local end of life care plan, when the final advice from the Leadership Alliance for the Care of Dying People has been received.

Priorities for Palliative Care and End of Life 2014 -15

Priorities for 2014/15 will be agreed by the Palliative Care and End of Life Steering Group in March 2014 but will include:-

- Rolling out and embedding the work of the Sussex End of Life Care and Dementia Project and developing a training strategy and forum to develop this work.
- Developing a shared care plan as an alternative to the LCP agreed by all providers, and ensure this is disseminated and staff receive training across the whole pathway.
- Working to ensure an appropriate shared palliative care and end of life electronic record is developed.
- Ensuring Advanced Care Planning is incorporated to the new frailty model
- Ensuring all GP practices in Brighton and Hove are utilising the Gold Standards Framework (GSF) and appropriately trained, especially on an alternative to LCP.
- Increasing the number of identified palliative care patients with a non-malignant diagnosis, where the trajectory of their disease is more complex, who are added to the practices GSF register.