Background

End of life care is one of the core services of Western Sussex Hospitals NHS Foundation Trust catering for a population of around 450,000 people with approximately 950 beds across two sites. There are approximately 2000 deaths per year across the 2 hospital sites, and whilst there are concerted efforts taking place to reduce the number of deaths in hospital, approximately half of all deaths occur in acute care settings. It is therefore essential that we do everything we can to ensure and enable excellent quality of care for patients and their families at the end of life.

Western Sussex Hospitals NHS Foundation Trust aims with its partners to ensure that patients are able to say:

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”

‘Every Moment Counts’ National Voices, National Council for Palliative Care and NHS England.

Following withdrawal of the Liverpool Care Pathway for the dying patient (2014) the ‘One Chance to get it Right’ document (2014) described 5 priorities of care that must be in place to care for patients in the last days of life.

1. The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the persons needs and wishes and these are regularly reviewed.

2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent of the dying person’s wishes.

4. The needs of families and others identified as important to the dying person are explored, respected and met as far as possible.

5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

More recently the Ambitions for Palliative and End of Life Care A National Framework for local action 2015 – 2020 proposes 6 Ambitions. The Trust is committed to ensuring that as an organisation We make these ambitions a reality. Such success will not just occur, and requires leadership and commitment from all parts of the organisation. The organisation is fully supportive of the Six Ambitions described in the National Framework for local action 2015 -2020. To see fulfilment of the overarching vision.

• Each person is seen as an individual.
• Each person gets fair access to care.
• Maximising comfort and wellbeing.
• Care is co-ordinated
• All staff are prepared to care
• Each Community is prepared to help.

Each member of staff within the organisation has a part to play in making these ambitions reality speaking the words or writing them in a strategy will not make them a reality. The quotes below help us focus our thinking both organisationally and may help us as individuals.
Western Sussex Hospitals NHS Foundation Trust cannot achieve this vision on its own as the acute setting can only provide just one part of the patient’s care at end of life. A key part of this vision is the partnership working that is taking place between the Clinical Commissioning Group, other providers both statutory and Voluntary. “The will, determination and innovation of organisations working collaboratively to find new ways of delivering better care will, and must, make a difference”.

As patients require different levels of care throughout their illness as described in the Triangle below. Providers and commissioners alike are now committed to better co-ordination across the area to ensure that patients have access to the appropriate level of care at the appropriate time.

“The Foreword: Ambitions for Palliative and End of Life Care

By working together, the Health Economy is already signed up to a model of care that supports Specialist Palliative Care to those patients that need it.

Ambition is not what a man would do, but what a man does, for ambition without action is fantasy.”

Bryant McGill

“Let your action manifest your thought, your belief and your passion.”

Mohammed Ali Bapir

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**Public awareness**

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Workforce

- Ensure that strong specialist Leadership is in place across the organisation to instil the Trust Vision and Ambitions for End of Life care across the organisation at all levels and places.

- Collect and provide quantative and qualitative data to support the on-going resource requirement within the specialist palliative care team for end of life care, which is currently being provided by two local hospices and admission avoidance monies from the Clinical Commissioning Group (CCG).

- Review the ward allocated palliative care Clinical Nurse Specialist (CNS) to ascertain whether this delivers the envisaged improvements in ward level knowledge and skills to deliver end of life care.

- Increase the amount of Palliative Medicine Consultant time in accordance with National benchmarking.

- Further develop the ward palliative care link nurses to become champions for end of life care within their ward areas.

- Provide end of life training to all ward and clinical areas by 2016, including identification of patients and assessment of needs (including psychosocial and spiritual).

- Ensure all staff dealing with patients and families towards the end of life have the skills and knowledge to deal with their needs with compassion and understanding, and know when and how to refer to other teams, for example specialist palliative care team, chaplaincy or bereavement support.

- Provide and encourage uptake of Sage and Thyme courses (communication skills training for dealing with patients and families in distress). Target numbers in accordance with an agreed training plan working with the Training Department and Hospital Learning and Development Department.

- Identify and target specific staff groups that require more specialised or advanced skills and complete this training by 2017.

- Ensure the workforce is confident and proud of the care they provide for those approaching the end of their lives.

- Communications skills training.

- Ensure that medical staff at all levels and senior nursing staff feel confident to discuss resuscitation with patients and carers.
Personalised end of life care

- The identification of approaching End of Life is challenging for both patient and Health Care Professional. However, Western Sussex Hospitals NHS Foundation Trust is committed to working with partners to support patients to describe how they would like to manage the closing months of their life by completing an Advance Care Plan and agree that Cardio Pulmonary Resuscitation should not be undertaken where appropriate. Formally record any decision the patient may make in respect of DNACPR.
- We will work with the Area End of Life project team to provide quality End of Life Care across the health economy by being an integral part of the two year project, lead by the Clinical Commissioning group. This will include embracing the Area Guidance agreed by all providers and Commissioners.
- We will ensure that patients within the last days of life are identified and that they and their families have opportunity to discuss and create a personalised plan of care encompassing the five priorities of care as laid out in the 2014 document ‘One Chance to get it Right’.
- We will facilitate the development of processes to enable patients to leave hospital for end of life care if this is their wish. This will be achieved through further development of the Rapid Discharge Home to Die pathway and through collaboration with external agencies such as Hospice at Home teams, and Continuing Health Care.
- We aim to increase the awareness and use of Advance Care Planning tools such as the Planning Future Care document and PEACE tool, particularly for patients thought to be in the last year of life being discharged from hospital.
- Patients who die in hospital will do so with as much comfort and dignity as possible with those they choose around them, with the knowledge that staff will support them and their families as much as they possibly can.
- Complete an annual audit of 50 sets of notes of patient deaths, reviewing the use of the Individualised plan of care for the last days of life to ensure its safe and effective use.
- Complete an annual audit of the Rapid Discharge home for end of life care, looking to reduce any delays identified and checking for readmission rates.
- Develop seven day working of the nursing team with appropriate specialist medical support.
Environment

* Identify ways of offering patients and carers as much privacy and quiet as possible within a busy ward environment, according to patient preferences.
* Identify ward areas that are suitable for sensitive discussions with patients and family members.
* Ensure family members have information regarding meals, parking and open visiting access.
* Allow patients and relatives to express their spiritual needs in the way they want to without them feeling embarrassed, awkward or different to others.
* Ensure facilities appropriate to meet the needs of bereaved relatives (both on the ward, patient affairs and mortuary).

Communication/Information

* Embed the use of the Guidance and Individualised Plan of Care for Last Days of Life throughout the whole Trust through staff education and repeated clinical audit measures.
* Participate in the implementation of EPaCCS (Electronic Palliative Care Coordination System) when commissioned by the Clinical Commissioning Group.
* Provide written information for patients and carers regarding care at the end of life, rapid discharge and Advance Care planning, and the PEACE tool.
* Review the VOICES survey of bereaved relatives on a quarterly basis to ensure families feel supported and satisfied with care, and act on any issues identified.
* Support Medical Staff and patients to identify and record the decision that Cardiopulmonary Resuscitation would not be appropriate for particular patients and that this decision is communicated.
* Ease, whenever possible, the feelings of bewilderment and confusions for those facing bereavement by providing as much information and support as possible after death for relatives and carers working with other providers where appropriate.
Indicators of success

- Improved positive feedback from bereaved relatives.
- Reduction in complaints relating to end of life care.
- Increasing percentage of patients dying in the place of their choice.
- Increase in number of patients participating in Advance Care planning.
- Increase in numbers of patients having an individualised Care Plan in the last days of life.
- Take part both in local and national audit and research.
- Not only meet but exceed the target number of staff who have undertaken training in End of Life care in all staff groups across the Trust.
- Implementation of EPaCCS system across the Locality.
- Centralised Hub in place across the locality with sufficient care in place to provide seamless service for patients wishes to die at home.
Conclusion

Western Sussex Hospitals NHS Foundation Trust cares about the quality of care that it provides. It is keen to work in partnership with other providers to ensure that patients are able to die where they choose in comfort and in dignity.

To achieve this there must be the resources in place and the relationship with others to ensure that patients and relatives have the confidence in the services provided and that a timely response can be made. This means the organisation must adopt a continuous service improvement approach to the provision of well trained staff, quality environment, with efficient processes in place that are monitored in a simple but effective way.

Historically we have worked well with local partners and patients and this will remain a cornerstone to achieve our organisational aspirations.

The foundations of the National End of Life Care Framework will form the basis of reflection and benchmarking to the strategic actions described above.

- Personalised Care Planning
- Shared records
- Education and training
- Evidence and information
- Co-design
- 24/7 day week access
- Involving supporting and caring for those important to the dying person
- Leadership

References

- Area Guidance for EOL Care 2014.
- Leadership Alliance for the Care of Dying people (2014) One chance to get it right. UK. Leadership for care of Dying People.
- Trust Wide EOL Guidance Folder 2015 (found in each clinical area)

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