East Sussex Healthcare NHS
NHS Trust

End of Life Care Report – June 2017

1. Purpose

This is a briefing note to update HOSC on the progress East Sussex Healthcare NHS Trust (ESHT) is making to ensure that high quality end of life care is experienced by service users and their families/carers.

2. Introduction

We are committed to improving end of life care (EOLC) to ensure people and their families are able to access the care they need, as well being supported to die with dignity in their preferred setting of care.

Following the Care Quality Commission inspection in October 2016 we strengthened our existing EOLC programme to support us in delivering our aims of ensuring:

- Adults approaching end of life have access to consistent care that meets national best practice standards.
- Reduce unwarranted variation in care delivery across ESHT for people approaching end of life and/or requiring specialist palliative care.

The project will ensure changes and improvements in clinical practice, governance and operational management are well co-ordinated; progress is monitored and reported to provide maximum contribution to the achievement of our 'high quality end of life care aims'.

On closure of the project, all operational and support teams will have embedded the requisite governance requirements into their "business as usual" activities.

3. Definitions

The following definitions all contribute to the delivery of end of life care:

- **Last days of life care**: patient is identified as being within a very few days or hours of death, the patient and those important to the patient should be involved in decision making and individualised care planning.

- **Palliative Care:** Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual. (World Health Organisation (WHO) 2002)

- **General Palliative Care**: General palliative care is an integral part of the routine and essential care delivered by all health and social care professionals to those living with a progressive and incurable disease, whether at home, in a care home, or in hospital. (Scottish Partnership for Palliative care http://www.palliativecarescotland.org.uk/content/what_is_palliative_care/)

- **Specialist Palliative Care:** Specialist palliative care is based on the same principles of palliative care outlined above, but can help people with more complex palliative care needs. Specialist palliative care is provided by specially trained multi-professional specialist palliative care teams and can be accessed in any care setting. (Scottish Partnership for Palliative care http://www.palliativecarescotland.org.uk/content/what_is_palliative_care/)

4. National Developments

Over the last few years much work has been undertaken nationally in the area of EOLC, these include:

Author	Date	Title
National Palliative and End of Life Care Partnership	2015- 2020 (Sept 15)	Ambitions for Palliative and End of Life Care: A national framework for local action
NICE	Revised March 2017 March 17	End of life care standards QS13 Care of dying adults in the last days of life QS 144 End of life care for people with life-limiting conditions (clinical pathway)
National Resuscitation Council	April 2017	ReSPECT- documentation to replace DNACPR documents and to cover in part escalation planning
	2013	Transforming end of life NHS England (Revised December 2015)

Table 1 – Key National EOLC Documents

Best practice and recommendations from these documents has been reviewed and where appropriate integrated into our EOLC project.

5. Local developments – EOLC steering group

Following feedback from the CQC, ESHT has identified a number of organisational requirements and enablers to support improvement in the delivery of end of life care.

The EOLC steering group oversees progress of these improvements. The key priorities overseen by the steering group are:

a) Governance and Strategy
b) Access to service
c) Quality of Care in the last days of life
d) Care After Death
e) Workforce: Education and learning

Key enablers are:

- Communications and engagement plan
- Informatics and working with partner organisations to achieve shared records (EPACCS).

5.1. Governance and Strategy

A new EOLC senior leadership team has been formed and includes:

- The Senior Responsible Officer - Medical Director of the Trust
- EOLC project lead – Deputy Director of Nursing
- Clinical Lead for Palliative Care - Consultant in Specialist Palliative Care.
- A new senior nurse role who will coordinate and oversee the service (commenced in May 2017)

Oversight of the key deliverables is through the EOLC Steering Group. The Terms of Reference for the Steering Group are being reviewed to ensure that

- 'Task to finish' groups deliver key actions, as identified by the CQC, with accountable officers identified.
- The EOLC strategy is refined, and implemented.

A key part of the EOLC steering group is the monitoring of the effectiveness of the EOLC for the patients. This includes reviews of incidents, complaints and compliments, identifying themes and opportunities for improvement. EOLC performance indicators have been agreed and will be monitored through the Divisional Integrated Performance Report.

A new five-year strategy on a page has been created setting the vision and direction for EOLC services. Our current EOLC Strategy will be reviewed to integrate the latest guidance from national guidance, and the key themes from the five-year plan. It is imperative that the refreshed strategy involves users in its development and, with this in mind, we shall be consulting and asking for feedback at our next Patient and Public Engagement meeting.

Following its inspection in October 2016 the CQC rated End of Life Care Services as 'Good' for Safety and Care but 'Requires Improvement' in the Effective, Well Led and Responsive domains. Key concerns raised by the CQC and actions are addressed below.

5.2. Access to service – reduce variation in practice

The CQC identified that there was a variation in practice across the Trust. One of the early actions undertaken has been to draw the staff from Conquest Hospital and Eastbourne District Hospital, Specialist Palliative Care, Clinical Nurse Specialists and EOLC Practice Development Nurses into one team. The team have been rebranded as the Supportive and Palliative Care Team with a single set of standards and access criteria. In addition regular team meetings are held, covering management and governance.

A referral flow chart has been created for ward staff, which describes how Trust staff can access specialist palliative care support.

An options paper for expanding the current service is being developed to review how 24/7 access to specialist palliative care can be delivered. In addition, the EOLC steering group is exploring how to ensure rapid discharge planning and enhancing community services at home.

5.3. Quality of care in the last days of life

There is an increased focus on early identification of patients, to ensure early planning of care. Both formal and informal training supports this.

An individualised care plan has been rolled out to all inpatient wards. The EOLC Practice Development Facilitators are providing training directly with staff on the wards to support its implementation. Audits of the roll out and care plan content have already been reported. An in depth audit against NICE 144 (see table above) is planned for July 2017.

An audit schedule has been developed which captures National and Local audits. Results and improvement plans will be monitored via the EOLC steering group in tandem with the Divisional Integrated Performance Reviews.

In addition, the chaplaincy services are developing a Standardised Operating Procedure that will describe how to access the service, how to make referrals, and how spiritual needs of patients should be captured to ensure patients and carers are supported.

5.4. Care after death

It is important to support carers and families in their bereavement. Therefore a separate task and finish group is being developed to ensure that the needs of people who use the services are recognised.

We want to ensure that following the death of a patient any carer/friend/family member wishing to receive bereavement support is offered this in a timely fashion and receives appropriate counselling and support.

A bereavement survey, based on the national VOICES survey, is being consulted on with key stakeholders. It is anticipated that it will be used from July onwards. Feedback will inform future service improvements.

5.5. Workforce

We are reviewing the learning and development needs of our staff and will be developing a Learning and Development Plan for specialist and generalist workforce to ensure staff have the knowledge and skills to meet the requirements set out in the NICE guidance - recognise imminent death, conduct difficult conversations; manage symptom control enable staff to conduct difficult conversations about end of life wishes and assess the needs of individuals and their carers, in a holistic and timely way, taking account of spiritual and cultural needs.

Staff find death of a patient very distressing and we are looking for innovative ways to support them. This includes after death reviews (currently being trialled), counselling, and access to informal support from the "Speak up Guardian". The Trust also utilises Schwartz Rounds for all staff to attend which focus on the impact of day-to-day work on staff wellbeing.

5.6. Enablers

5.6.1. Communications Plan

A core principle is to engage with local people to discuss and shape their EOLC strategy and services. It is important that leaders and frontline staff understand what matters to local people, and how services might be improved. The first step is raising awareness with frontline staff, which begins with a raising awareness month in and a "raising awareness month" is planned for July 2017. An annual communication and engagement plan will be developed to ensure all key stakeholders are involved and engaged.

5.6.2. Informatics

Patients and carers only want to describe information related to their personal needs once, and expect health care professionals to be able to access a summary record of their assessment, care and plans in a timely way to ensure effective high quality care. Currently the informatics systems within the hospital, GPs and community services vary on how they communicate together. As part of the strategic system wide review this will be reviewed and a plan put in place. In the meantime we are considering how we can develop systems to minimise duplication of information requests and provide seamless information exchange between services.

The EOLC steering group has commissioned a task to finish sub group to review and develop systems to enable sharing information across providers to ensure timely and appropriate support for EOLC patients.

6. East Sussex Better Together (ESBT)

ESBT has established a Clinical Advisory group for end of life care and we are contributing to this. Key objectives have been identified including learning and development and Advance Care Planning. It is planned that under an Accountable Care System this cross organisational group would become the strategic system wide steering group for end of life care.

7. Conclusion

As outlined in this report there is a commitment to improving EOLC for patients and their carers and to address concerns raised by the CQC. We have reviewed existing practice and are developing and embedding robust systems, improving training and promoting best practice across the organisation. This will ensure that people at the end of life receive the high quality care and support they need in the place of their choice. We are making good progress, whilst recognising there is more to be done, and propose that we provide a further update to HOSC in 6-9 months time.