

Report to: **Adult Social Care and Community Safety Scrutiny Committee**

Date: **13 June 2013**

By: **Assistant Chief Executive**

Title of report: **End of life care – seminar report**

Purpose of report: **To summarise the outcomes of the Committee’s seminar on end of life care and to propose a way forward.**

RECOMMENDATIONS

The Committee is recommended to request that the Health Overview and Scrutiny Committee considers progress with improving end of life care in East Sussex in late 2013.

1. Financial Appraisal

1.1. There are no specific financial implications arising from this report.

2. Background

2.1 In November 2012 the Committee considered the annual report on safeguarding vulnerable adults. Following this discussion, Members requested a one-off seminar at which further information on the management of end of life care in East Sussex could be considered. Given the significant links between health and social care in this area, and the need to promote integrated care, it was agreed to invite a representative of the Health Overview and Scrutiny Committee (HOSC) to attend.

2.2 The Committee’s request coincided with significant national media coverage of concerns regarding the use of the Liverpool Care Pathway, a recognised approach to managing the care of people in the last few days of life.

2.3 In addition, end of life care had been identified as a priority within the draft Health and Wellbeing Strategy produced by the then shadow Health and Wellbeing Board.

3. Findings

3.1 The seminar, on 28 February 2013, was attended by Councillors Barnes, Pragnell (Chairman) and Mrs Tidy, together with Cllr Cartwright (Hastings Borough Council) as HOSC representative.

3.2 Representatives from Adult Social Care, NHS Sussex (NHS commissioners), East Sussex Healthcare NHS Trust and St Wilfrid’s Hospice also attended.

3.3 The key questions identified by Members for exploration at the seminar were:

- Is there enough support available to allow people to have a choice of whether they wish to die, e.g. at home or in a hospice?
- Is the Liverpool Care Pathway being used appropriately?
- To what extent are families and carers consulted during the end of life care of a patient, particularly if they are placed on the Liverpool Care Pathway?

3.4 A summary report outlining the key issues covered at the seminar is attached at appendix 1.

3.5 Members' key conclusions were as follows:

- There is still some way to go to achieve best practice end of life care for all East Sussex residents who require it, including maximising choice.
- There is a new momentum around improving end of life care, notably:
 - enhanced opportunities to engage GPs through Clinical Commissioning Groups, all of which have identified end of life care as a priority
 - Board level leadership and new end of life care facilitators at East Sussex Healthcare NHS Trust
 - inclusion as a priority in the East Sussex Health and Wellbeing Strategy
 - considerable enthusiasm amongst those leading the work.
- There may be a need to review local end of life care strategy in light of the above developments, ensuring that it reflects commissioners' goals and builds on the previous strategy.
- There is a good business case for delivering best practice end of life care, as well as the clear quality and patient/carer experience case.
- When used appropriately, the Liverpool Care Pathway is an effective way to manage end of life care. Further education is needed for staff and the public to address myths and misunderstanding.
- Involvement of carers/families at end of life is critical for wellbeing of both the patient and the carer themselves. Intentions in this respect are often good, but involvement and communication could be improved.

3.6 It was clear at the seminar that a number of new or reinvigorated initiatives had recently been put in place, or were about to be launched. Members were therefore of the view that these needed time to become established before their impact could be properly assessed. Members were also cognisant of structural changes due to take effect within the NHS in April 2013 and a national review of the Liverpool Care Pathway which had just been announced.

3.7 It was also clear that much of the ongoing work on developing and delivering end of life care would be NHS-led, albeit with significant social care involvement. In this context, Members recommended that it would be essential to scrutinise the impact of the new approaches being taken and that HOSC would be best placed to consider a report, with a suggested timeframe of late 2013.

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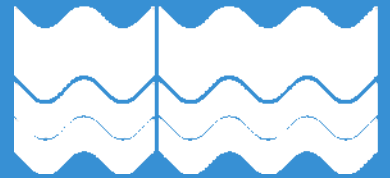
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Local member(s): ALL

Background Documents: NONE



End of Life Care in East Sussex

Seminar Report 28 February 2013

Adult Social Care and Community Safety Scrutiny Committee -
13 June 2013

1. This short report brings together key points from presentations, background papers and discussion at the end of life care scrutiny committee seminar on 28 February 2013.

End of life care – background information

2. The General Medical Council defines end of life as when a person is likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours of days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions
- existing conditions if they are at risk of dying from a sudden acute crisis
- life threatening acute conditions caused by sudden catastrophic events.

3. The national End of Life Care Strategy (2008) was one of the first of its kind in the world. It aims to bring about improvement in access to high quality care for all adults approaching the end of their life. The strategy has a whole systems approach, with a pathway involving the following steps:

- identification of people approaching the end of life and initiating discussions about preferences for end of life care;
- care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly;
- coordination of care;
- delivery of high quality services in all locations;
- management of the last days of life;
- care after death; and
- support for carers, both during a person's illness and after their death.

4. End of life care has been identified as a priority in the first mandate between the government and the NHS Commissioning Board that sets out the ambitions for the health service for the next two years. It falls under Domain 2 of the NHS Outcomes Framework, 'enhancing quality of life for people with long-term conditions', and also relates to Domain 4, 'ensuring people have a positive experience of care'.

5. It was noted that making improvements to care is inextricably bound up with societal issues about how we deal with end of life. For many people, death remains a taboo subject, making it more difficult to have discussions at individual, family or societal level which will help with the planning for people's last months, weeks and hours of life. In addition, media coverage tends to focus on life sustaining treatments rather than promoting quality of life. Professionals argued that there is a need to change wider attitudes towards death in order for end of life care experience to be at its most positive.

End of life care in East Sussex – where are we now?

6. Around 1% of the population of East Sussex would be expected to die each year – around 5,000-6,000 deaths. In 2011, 43% of all deaths occurred in hospital. 2011/12 saw a 5.5% reduction in deaths occurring in hospital. There has been a corresponding increasing trend in deaths occurring in a patient's usual place of residence (home or care home) with the figure now standing at approximately 47%.

7. Locally, health and social care commissioners have the shared aim to achieve high quality care to support individuals, their family and carers to have a 'good death' in their preferred place of care where possible. Commissioners are building on existing joint strategic work to develop an integrated approach to planning, contracting and monitoring of service delivery across health, social care and the voluntary sector. End of life care objectives are built into the existing joint health and social care Older People's and Improving Life Chances (long term conditions) Strategies.

8. End of life care has now also been included in the East Sussex Health and Wellbeing Strategy. It was selected as a priority due to the local demography and the opportunities for improvement through taking a whole systems approach. The specific objectives in the Health and Wellbeing Strategy are:

- More people identified as approaching end of life having an advance care plan
- People being supported to die in their preferred place of care, therefore reducing the number of people dying in acute hospitals
- Staff providing end of life care in community health and social care settings meeting the national end of life care core competencies and occupational standards.

9. There is an East Sussex End of Life Care Programme Board in place which has been overseeing the development of areas such as stakeholder engagement (particularly in promoting advance care planning), integration of systems and services, staff training and development of specialist palliative care.

10. In parallel with its inclusion in the Health and Wellbeing Strategy, end of life care has been given priority by the newly formed Clinical Commissioning Groups and within the local NHS Quality, Innovation, Productivity and Prevention (QIPP) programme. The development of Neighbourhood Support Teams, which will bring together health and social care teams in the community linked to GP practices, presents new opportunities to provide care and support to people at home 24/7 and to improve and embed end of life care in community services.

11. In addition, East Sussex Healthcare NHS Trust has acknowledged the need to improve end of life care within the Trust and has made it a priority. Board level leadership has been identified and specialist expertise is being accessed through a joint consultant appointment with St Wilfrid's Hospice. In October 2012 the Trust appointed two end of life care facilitators who are reinvigorating and supporting work with staff across the organisation. Work on end of life care has been linked into the Trust's Clinical and Patient Experience Strategies and significant progress is anticipated. In recognition of the need for ongoing improvement, end of life care was included as a priority in the Trust's 2011/12 Quality Account with specific aims to reduce the number of complaints related to this area and to manage 80% of expected deaths on the Liverpool Care Pathway.

12. Although finance is not the driver for improving end of life care, if the quality of care is right for patients there are also financial benefits to the system.

Choice in end of life care

13. One of the key precursors to providing increased choice is for people to plan for their future care at an earlier stage. Efforts are being made to encourage this, such as promotion of the 'Planning for your future care' guide and the 'Dying Matters' website and awareness week which provide frank information. Ultimately this needs to be a whole system approach, rather than a specialist end of life care issue. Training offered to care homes and home care providers by Adult Social Care is supporting this process.

14. A range of factors can influence people's choices, beyond what may seem obvious. For example, people may feel the 'right' place for their death is a hospice because they don't want to burden their family.

15. The eventual place of death can also be influenced by a range of factors. For example, there are differences between the Hastings and Rother area and the East Sussex Downs and Weald area which relate to the difference in hospice and nursing home provision. In addition, end of life care is provided in the community hospitals in the north of East Sussex. These differences are reflected in the proportions of deaths in different settings in the various parts of the county.

16. Professionals stressed that, even if a patient had stated a preference for another setting, it is still possible to provide a positive end of life experience for them and their family should unforeseen circumstances lead to them ultimately being admitted to hospital. This has been reflected in comments from some relatives.

17. In terms of advance care planning, there was discussion about the 'Do not attempt resuscitation' (DNAR) process which can enable patients to log their wishes regarding attempts at resuscitation in advance. The 'message in a bottle' scheme can also be used to record details of a person's condition and care plans for access by professionals such as the ambulance service. Health organisations are working towards electronic data sharing which will support the provision of appropriate care in line with plans and preferences.

18. In relation to DNAR status applied by clinicians, the national guidelines on this were outlined, including best practice guidelines for communicating with patients and families. Ultimately there are clinical judgements which have to be made regarding appropriate treatment which is in the patient's interests. The aim is to avoid putting patients through unnecessary procedures. ESHT has been auditing the use of DNAR to identify instances of poor communication and has taken these up with relevant staff. It was also noted that there can be instances where it is not possible to contact the family in time to discuss the treatment of the patient with them.

Involving carers and families

19. There were a number of points made in relation to communication and engagement with patients and their families/carers:

- There is a need to plan for different circumstances in advance, with the person and their family. Without this shared understanding and agreement it can be more difficult to know what care is needed/wanted when an acute episode arises, particularly if the patient is taken to hospital.
- People don't always take in information when distressed – there is a need for good conversations which ensure mutual understanding and agreement.
- There is a need to spread skills to all staff, not just specialists in palliative care, and staff need to accept good end of life care as a positive outcome, rather than viewing a death as a 'failure'.
- There are not many 'absolutes' – it can be difficult to tell what a patient's prognosis is. This makes communication and treatment decisions harder.

20. Giving people the opportunity to make plans needs to be seen as a positive outcome. Preparation time can be helpful for families on both an emotional and practical level. Local hospices have workers who are able to help with psychosocial and practical matters, plus access to counsellors and chaplains. There have also been instances of hospices supporting patients and families with reminiscence and sharing their legacy, contributing to a positive end of life experience. Other organisations such as Care for the Carers can also offer support to families.

21. Where carers are involved in directly providing care to support a patient's wish to remain at home, it is particularly important that they are prepared for the realities of end of life. It can be helpful for specialist palliative care staff to be able to discuss the process with the patient and their carer. This can prevent a crisis occurring where a carer feels vulnerable and calls an ambulance, which may result in admission to hospital.

22. Specialist palliative care assessments include an assessment of the carer's needs, based on conversations with both patient and carer. There is an aim to develop a 7 day a week specialist palliative care service (currently 5 days a week) which will provide better specialist support to patients and carers, particularly in crisis situations, potentially avoiding unnecessary or unwanted hospital admissions. A trial of a weekend service has demonstrated an impact in this respect. It was noted that effective communication to allay fears is as important as practical support.

23. Families/carers can have worries about practicalities after a death at home. It is important to explain the procedure for a clinician to verify death and for contacting undertakers, who are also engaged in supporting families. Training is being extended to district nurses so that they will be able to support families and carry out the verification.

24. Despite examples of good practice and appropriate guidelines being in place regarding communication with families, written evidence provided by Care for the Carers indicated there are still instances of carers not being adequately involved. They point out that assumptions should not be made about the level of care that relatives are able or willing to provide and that patients' choices may need to be tempered by the carer's feelings and capacity. Carers have also reported anxiety about whether the preferred place of death (e.g. a hospice bed) will be available when the time comes. Care for the Carers also recommend improved communication between health and social care services so that carers can be signposted to available support.

Liverpool Care Pathway

25. The Liverpool Care Pathway (LCP) is a core tool of the national End of Life Care Programme. It can be used in hospitals, care homes, hospices and in people's own homes.

26. The 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. It is tailored to the person's individual needs and includes consideration of their physical, social, spiritual and psychological needs.

27. It requires senior clinical decision making, communication, a management plan and regular reassessment. It is not a treatment in itself but a framework for good practice. It aims to support, but does not replace, clinical judgment. The LCP does not hasten or delay death, but ensures that the right type of care is available for people in the last days or hours of life when all of the possible reversible causes for their condition have been considered.

28. An audit undertaken by East Sussex Healthcare Trust before introduction of LCP showed a lack of documented good end of life care. The LCP is a proper pathway which prompts professionals to assess and document care. Professionals argued that there are a number of advantages to using the LCP as it ensures various supporting measures are put in place.

29. It was agreed that more could be done to raise staff awareness of what sort of care is appropriate, for example in terms of mouth care and hydration, which would address myths about what is 'allowed' under LCP. However, possibly the biggest issue is improving recognition of the dying patient which is a precursor to applying LCP appropriately. This has improved, but there is more to do.

30. Monitoring of LCP usage by the Trust is currently through 'spot' audits and it is recognised that this should be improved. Data collection is under review in conjunction with commissioners. It was agreed that reviewing specific cases, including the experiences of carers (and where possible patients), could be helpful as there are learning opportunities from both positive and negative experiences.

31. Following national media coverage and concerns regarding use of the LCP, which have impacted on public confidence, the view of the professionals was that it would be best to improve education and address concerns directly rather than attempt to 'rebrand' the LCP. Although LCP guidance clearly indicates that families/carers (as well as the patient where possible) should be involved in decisions about its use, Care for the Carers reported cases where families had been informed rather than consulted.

32. A written submission from St Michael's Hospice suggested that use of LCP in care and nursing homes is patchy and that there is a need for better engagement with GPs. The need for improved GP engagement in relation to LCP was supported by commissioners and East Sussex Healthcare Trust representatives.

33. It was noted that the LCP is not used for children and that there are specialist approaches to paediatric palliative care with different clinical leadership and input from specialist children's hospices.

Conclusions

34. Members agreed the following conclusions from the seminar discussion:

- There is still some way to go to achieve best practice end of life care for all East Sussex residents who require it, including maximising choice.
- There is a new momentum around improving end of life care, notably:
 - enhanced opportunities to engage GPs through Clinical Commissioning Groups, all of which have identified end of life care as a priority
 - Board level leadership and new end of life care facilitators at East Sussex Healthcare NHS Trust
 - inclusion as a priority in the East Sussex Health and Wellbeing Strategy
 - considerable enthusiasm amongst those leading the work.
- There may be a need to review local end of life care strategy in light of the above developments, ensuring that it reflects commissioners' goals and builds on the previous strategy.
- There is a good business case for delivering best practice end of life care, as well as the clear quality and patient/carer experience case.
- When used appropriately, the Liverpool Care Pathway is an effective way to manage end of life care. Further education is needed for staff and the public to address myths and misunderstanding.
- Involvement of carers/families at end of life is critical for wellbeing of both the patient and the carer themselves. Intentions in this respect are often good, but involvement and communication could be improved.

35. Members agreed that it would be important to scrutinise progress in improving end of life care locally. Given that much of the work will be led and delivered by NHS partners, albeit with significant social care input, it was recommended that the topic be referred to the Health Overview and Scrutiny Committee with a suggested timescale of late 2013 for a progress report.

Annex 1: Background information

The Seminar was established primarily to consider the following questions:

- a) Is there enough support available to allow people to have a choice of where they wish to die, e.g. at home or in a hospice
- b) Is the Liverpool Care Pathway being used appropriately?
- c) To what extent are families and carers consulted during the end of life care of a patient, particularly if they are placed on the Liverpool Care Pathway?

Attendees

Adult Social Care and Community Safety Scrutiny Committee

Councillor Peter Pragnell (Chairman)

Councillor John Barnes

Councillor Sylvia Tidy

Health Overview and Scrutiny Committee (HOSC)

Councillor Andrew Cartwright (Hastings Borough Council Member)

Adult Social Care

Barry Atkins, Head of Strategic Commissioning (Older People and Carers)

Caroline Moyes, Project Manager

Lisa Schrevel, Project Manager – Transformation and Service Redesign

NHS Sussex

Kay Muir, End of Life Care Programme Lead

East Sussex Healthcare NHS Trust (ESHT)

Dr David Hughes, Joint Medical Director

Dr Nick McNeillis, Deputy Medical Director

Sarah Stoddart

St Wilfrid's Hospice

Dr David Barclay, Consultant in Palliative Care (joint post with ESHT)

Karen Clarke, Patient Services Director

Scrutiny officers: Claire Lee, Scrutiny Lead Officer and Harvey Winder, Scrutiny Support Officer

Organisations which submitted written evidence:

Care for the Carers

St Peter and St James Hospice

St Michael's Hospice

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