

Report to: **East Sussex Health Overview and Scrutiny Committee (HOSC)**

Date: **21 November 2013**

By: **Assistant Chief Executive**

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

Purpose of report: **To report on progress and key developments in improving end of life care in East Sussex.**

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## **RECOMMENDATIONS**

**The Committee is recommended to consider and comment on progress with improving end of life care in East Sussex.**

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### **1. Background**

1.1 In November 2012 the County Council's Adult Social Care and Community Safety Scrutiny Committee considered an annual report on safeguarding vulnerable adults. During the discussion Members identified end of life care as a potential area of risk and 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.

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

1.3 The seminar, which took place on 28 February 2013, was attended by Councillors Barnes, Pragnell (Chair) and Mrs Tidy, together with Cllr Cartwright (Hastings Borough Council) as HOSC representative. Representatives from Adult Social Care, NHS Sussex (then NHS commissioners), East Sussex Healthcare NHS Trust and St Wilfrid's Hospice also attended.

1.4 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 (LCP) 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?

1.5 A summary report outlining the key issues covered at the seminar has previously been circulated to HOSC Members and is available on the County Council website here: <http://www.eastsussex.gov.uk/yourcouncil/about/committees/meetingpapers/scrutinysocial/2013/13june.htm>

1.6 In summary, Members' key conclusions in February 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.

1.7 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.

1.8 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 progress report in late 2013.

## 2. Progress

2.1 Since April 2013 Clinical Commissioning Groups (CCGs) have taken over NHS responsibility for commissioning end of life care. There remains a need to work closely with Adult Social Care.

2.2 The three East Sussex CCGs have provided a progress report on end of life care, in the **appendices** to this report, which focuses on developments over the past 6-9 months. It highlights the outcome of the national review of the Liverpool Care Pathway, which resulted in a government decision to phase out its use and to replace it with individualised care planning.

2.3 Kay Muir, Operational Delivery Manager for Eastbourne, Hailsham and Seaford (EHS) CCG, will present the report to HOSC, together with Sophie Clark, Strategic Commissioning Manager for Adult Social Care

2.4 HOSC is recommended to consider and comment on the progress made, the impact of key national developments – particularly around the use of the Liverpool Care Pathway – and the plans of CCGs and their partners for further development.

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# East Sussex CCGs' progress report on End of Life Care (EOLC)

## Introduction

This report is aimed at providing Health Overview and Scrutiny Committee (HOSC) with an update on key end of life care developments and progress made within the last 6-9 months:

1. Liverpool Care Pathway developments national and locally
2. Workforce development
3. Roll out of Advance Care Planning (ACP) and use of tools such as Preferred Priorities for Care (PPC)
4. Capturing, communicating and sharing of patient preferences and priorities for their care

## 1. Liverpool Care Pathway (LCP) update

1.1 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 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.

1.2 In July 2013 the independent review of the Liverpool Care Pathway (LCP) published its report 'More Care Less Pathway'. In response to its recommendations, 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. The alliance is chaired by Dr Bee Wee, National Clinical Director for End of Life Care at NHS England. Membership of review group and milestones in appendix 2.

1.3 The immediate objectives of the alliance are to:

- support all those involved in the care of people who are dying to respond to the findings of the review; and
- be the focal point for the system's response to the findings and recommendations of the LCP review.

1.4 How best inform professionals provision of care of the dying patient, the alliance is:

- developing advice for professionals on individual care plans and other arrangements in place of the Liverpool Care Pathway;
- considering how health and social care can best address the recommendations in the review about the accountability and responsibility of individual clinicians, out-of-hours decisions, nutrition and hydration and communication with the patient and their relatives or carers; and
- "mapping" existing guidance, training and development, as a prelude to considering how these impact on the care of dying people and the circumstances that might affect the adoption of good practice

1.5 Current proposal by the LACDP review group for comment through various engagement method and events in November 2013:

"Care of all patients must be set in line with a culture of professional care which is safe and effective, and which puts the person, his/her experience of care, and that of his/her family and carers, at the heart of everything we do. Setting the foundation for achieving good care in the last days to hours of life should start earlier in the process of care. It should begin

when the person's life expectancy is known, or expected, to be limited (or shortened) by his/her condition(s). Ideally these conversations should start well before the last days of life."

1.6 The principles of palliative care (see glossary – appendix 3) remain central to the care of people with progressive, life-limiting conditions until they die - and after they have died, for their families and carers.

### **What this means for people identified to be within the last 12 months of life their families and carers**

1.7 For the patient this would mean that they should be offered the opportunity to discuss their wishes and preferences about their care and treatment, and to put this in writing as a personal palliative care plan. It is entirely up to the individual whether or not they wish to do this – and they should not feel forced to do so. But such a plan can be shared amongst those caring for the patient, saving them the need to repeatedly explain their wishes. If they feel too unwell to actively participate in discussions about their care in the future, this plan would make it easier for those caring for them to take their views into account when decisions are being made. (This may need to be earlier than the last 12 months of life for people with dementia so their preferences and priorities for their care are known.)

1.8 Ideally patients should review the plan from time to time, so that it remains in line with their views if these change.

1.9 Patients can name individuals whom they would like their doctors, nurses and other professionals to consult if they are unable to make your own decisions. Unless they have appointed somebody to be your *Lasting Power of Attorney* for health and welfare, they cannot legally make decisions on their behalf. However, they can, and should, receive explanations and be involved in the discussions (unless they had previously stated otherwise). A specific treatment can be legally refused (at the time, or in advance by the patient) but specific treatments cannot be demanded.

1.10 If there are individuals with whom the patient would be happy for their doctors, nurses and other professionals to share information about their care and treatment, they can include their names in this plan.

1.11 If their condition changes, they should be promptly assessed. Treatment decisions require a balance to be struck between how likely the patient is to benefit from the treatment, the side effects that treatment might cause and how burdensome that treatment might be, given how they are at the time. For further information access: <http://www.england.nhs.uk/?s=LCP+engagement>

### **East Sussex participation with the national review process:**

1.12 During November 2013 a series of workshops are being held to share the alliance's thinking around providing consistent, high quality care for dying people in their last days and hours of life and to involve and engage clinicians and the public, in helping to determine what the best way forward is. The workshops will focus on the proposals for a set of desired outcomes for people who are dying which, supported by guiding principles for clinicians, should be the basis of care in different settings and circumstances.

1.13 Locally the East Sussex Healthcare NHS Trust (ESHT) End of Life Care Facilitators will be attending the 13<sup>th</sup> of November workshop reporting back to acute and community staff the outcomes and actions from that workshop.

## **What impact has the review has locally on use of LCP and response to support quality of patient care?**

1.14 Since the LCP review was announced, compliance in its use has reduced in East Sussex. To mitigate against the risk of compromised care, East Sussex Health Care Trust has developed a guide to good end of life care practice to assist staff with their documentation and care when the LCP is not utilised and to ensure patient/carer choice. An analysis of complaints and incidents showed that there are none in relation to the use or omission of the LCP.

### ***ESHT response to the Independent Review of the Liverpool Care Pathway published on Monday 15 July 2013- reference appendix 4***

*1.15 The Review Panel recognised that, when applied correctly, the Liverpool Care Pathway does help patients have a dignified and pain-free death and they support the principles underpinning it. Therefore staff of East Sussex Healthcare NHS Trust will continue using the Liverpool Care Pathway in our hospitals and community settings until NHS England publishes its response to this review. ESHT practice will continue to reflect the key recommendations from the review which state that:*

- As a general principle patients should only be placed on the Liverpool Care Pathway or a similar approach by a senior responsible clinician in consultation with the healthcare team.*
- Unless there is a very good reason, a decision to withdraw or not to start a life-prolonging treatment should not be taken during any 'out of hours' period.*

More information - [www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients](http://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients)

## **2. Workforce development**

2.1 Workforce development is key to ensuring professionals providing support are equipped with the right skills, competencies and confidence to support the patient needs along the different stages of the EOLC pathway. There are currently a range of Health and Social Care initiatives running to support this including;

- Working with local hospices to provide in reach support to care homes - key areas of focus include working with care homes to write Advance Care Plans using a national Preferred Priorities of Care (PPC) tool for residents of care home with high attending A&E attendances and admissions to hospitals. These care plans are to be shared with the patient's/resident's own GP practice.
- Support to access the National End of Life Care e-learning programme which has now worked with 76 organisations including: Care Homes, Personal Assistants, Carers, Home Care, Voluntary Organisations and Integrated teams. Over 500 modules have been completed and work is now in progress talks to sustain elements of the project through the ESCC Adult Social Care training department.
- Dementia training for Home Care providers which encompasses end of life issues ,

### ***ESHT Commissioning plans in place:***

2.2 ESHT Transforming End of Life Care in Acute Hospitals Programme (The Route to Success national guidance) being adopted:

- The trust has completed audits across its acute, community hospitals and wider community settings against the NICE EOLC quality standards. As part of the trust wide improvement programme, senior clinical leadership has now been identified to support the 3 work streams in their developments against the trust end of life care action plan.

- Completion of training of all ESHT community registered nurses in the verification of expected death for patients on their caseloads. This will result in more timely verification of death and lessen distress for family members and carers.
- Workforce development being developed and implemented across all ESHT clinical divisions and supported by identified EOLC clinical leaders.

### ***Patient and carer feedback***

2.3 The NHS Outcomes Framework asks for patient and carer experience feedback. To address this, ESHT has carried out a pilot questionnaire, feedback so far has been positive.

2.4 The appointment of 2 EOLC Facilitators at East Sussex Healthcare Trust (ESHT) to support workforce development planning for EOLC

2.5 Further work which supports a whole systems approach includes the development of an integrated EOLC and Dementia Pathway, focused on ensuring that people with dementia have the same choices and quality of care at end of life, has been agreed by Adult Social Care and all three Clinical Commissioning Groups in principle

### **3. Roll out of Advance Care Planning (ACP) and use of tools such as Preferred Priorities for Care (PPC)**

3.1 A whole-system approach is being taken to support discussion with patients, their family (where appropriate) and carers about knowing what their preferred priorities of care are as part of advance care planning. A copy of national guidance being applied locally in terms of the advance care planning discussion with the patient is shown in appendix 5.

3.2 The aim is to provide an opportunity for people identified as being within the last 12 months of life to discuss their preferences of care and place of death, have these recorded and with their permission share this with other providers of their care. For patients diagnosed with dementia this may take place earlier, when the person has mental capacity.

3.3 The national EOLC Preferred Priorities for Care (PPC) documentation embedded below, is a tool used to help facilitate end of life discussion to know what a person's preferences and priorities for their care is and with their permission share these with their family, carers and professionals involved with their care.

3.4 The PPC document is being used as across health and social care, to record in advance what individual preferences for care are. This is being introduced and rolled out across the Care Home setting, with District Nurses and Macmillan nurses employed by ESHT and Home Care providers commencing October 2013

3.5 The completion and sharing of this patient information is to support people to be cared for and die where possible in their place of choice. Sharing this information with all relevant services will provide information about what the patient preferences and priorities of care are to be taken into consideration when making care decisions. This is to support the patient and family to avoid unnecessary hospital admission/s and death in hospital if this is not what the person wants.

3.6 This is the beginning of a process to improve patient informed communication and sharing of information which will take time to implement across health and social care to improve the patient and family experience of end of life care.

#### **4. Capturing, communicating and sharing of patient preferences and priorities for their care**

4.1 Capturing feedback from patient experience takes place in a variety of ways including from events such as the CCGs event Shaping Health Stakeholder engagement in June and November 2013, direct clinical engagement, feedback from Care for the Carers staff, GP practice palliative care multi-disciplinary meetings and EOLC Programme Board members.

4.2 Through a combination of national evidence from what people want from their care and local feedback the Health and Wellbeing Board (HWB) Priority 7: high quality and choice of end of life care agreed a strategic outcome:

*“More people who are approaching the end of life being cared for are dying in their preferred place of care and death to receive the highest standards of end of life care in any setting”*

4.3 Three East Sussex CCGs have signed up to the Health and wellbeing priority for end of life care and continue to have end of life care as a commissioning and delivery priority.

4.4 As part of HWB delivery of the EOLC priority (7.1) More people identified as approaching end of life are cared for and die in their usual place of residence with the following objectives:

- More people identified as approaching end of life have an advanced care plan
- Fewer people identified as approaching end of life dying in hospital
- Staff providing end of life care in community, health and care settings meet the national end of life care core competencies and occupational standards

#### **Evidence to support greater numbers of people to die in their ‘home’**

4.5 The data from the Deaths in Usual Place of Residence (DiUPR) chart, appendix 6 shows that we have a steady increase in the percentage of people being supported to die in their usual place of residence, i.e. their own home or a care home. This retrospective data shows that all 3 CCGs have exceeded the HWB target of a 1% increase showing that more people in East Sussex are dying in their “home” setting than the previous year’s baseline. In comparison to all CCGs in England the East Sussex CCG are 5% above the English average which is encouraging.

4.6 With regard to the quality and place of care reflecting patient preferences and priorities for their care this is discussed as described in section 3. In addition all GP practices carry out multidisciplinary palliative care meetings during which any changes in health status of patient are reviewed, In addition after a patient’s death the care and family support is reviewed i.e. what went well, what didn’t, learning points and follow-up actions required.

4.7 With regard to specific measures to capture the experience of care for people at the end of their lives to be taken to the Health and Wellbeing sub-group for the Carers Partnership Board. This is to identify commissioning outcomes to support the collection of data.

4.8 When data is collected it can then be shared with integrated Soft Intelligence Group to compare and validate against other data sources.

#### **Wider communication and secure sharing of patient preferences of care**

4.9 All 3 East Sussex Clinical Commissioning Groups (CCGs) have agreed to use the national Summary Care Record (SCR) which is attached to the nationally secure NHS patient record system as the mechanism to host an enhanced electronic palliative care record.

4.10 The SCR is a GP patient held secure record uploaded to the NHS data spine that can be viewed by our in and out of hours providers.

4.11 GP practice pilots have commenced for the information collected through advance care planning discussion and use of the PPC will be uploaded to the GP practice system and shared with the electronic palliative care record attached to the SCR. When this system is fully implemented it will provide a simplified system of recording and sharing of up to date patient information with their preferences and priorities of care recorded and shared, with patient consent.



**Leadership Alliance for the Care of Dying People (LACDP) – time line of review process and review group members**

**LCP Review process timeline**

<b>Date</b>	<b>Activity</b>
2012	Various media reporting of concerns from use of the LCP
Jan2013	East Sussex EOLC Programme Board aware of national discussion about a LCP review, members waiting on guidance from NHS England as to whether to continue or not with LCP
Jan 2013	Need for a review of the LCP agreed and LCP to be phased out n next 6-12 months
July 2013	Review group Chair and members identified an commenced work on review process
July 2013	Discussion about LCP review process between commissioners and providers at the East Sussex EOLC Programme Board,
Nov 2013	Review group engagement with patients, families, carers and professionals
Jan 2014	Formal clinical advice to be issued
July 2014	LCP to be discontinued and new clinical advice and guidance in place

**Review Group Members:**

The alliance is chaired by Dr Bee Wee, National Clinical Director for End of Life Care at NHS England. Member organisations include:

Care Quality Commission (CQC)  
 NICE (National Institute for Health and Care Excellence)  
 College of Health Care Chaplains (CHCC)  
 NHS England  
 Department of Health (DH)  
 NHS Trust Development Authority (NTDA)  
 General Medical Council (GMC)  
 NHS Improving Quality (NHS IQ)  
 General Pharmaceutical Council Nursing and Midwifery Council (NMC)  
 Health and Care Professions Council (HCPC)  
 Public Health England (PHE)  
 Health Education England (HEE)  
 Royal College of GPs  
 Macmillan Cancer Support Royal College of Nursing (RCN)  
 Marie Curie Cancer Care Royal College of Physicians (RCP)  
 National Institute for Health Research (NIHR)  
 Sue Ryder Care

(Marie Curie is also representing Help the Hospices and the National Council for Palliative Care. Sue Ryder is also representing the National Care Forum (NCF) and the Voluntary Organisations Disability Group. Macmillan Cancer Support is also representing the Richmond Group of charities.)



### Glossary of terms

Advance Care Planning (ACP)	Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, to set on record: choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family and carers) in the event that they lose capacity to decide once their illness progresses.
Advance Decision to Refuse Treatment (ADRT)	This is a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act 2005 (England and Wales). Specific rules apply to advance decisions to refuse life-sustaining treatment.
Best interests	Any decisions made, or anything done for a person who lacks capacity to make specific decisions, must be in the person's best interests. The Mental Capacity Act 2005 (England and Wales) sets out standard minimum steps to follow when working out someone's best interests. Any staff involved in the care of a person who lacks capacity should make sure a record is kept of the process of working out the best interests of that person for each relevant decision, setting out: <ul style="list-style-type: none"> <li>• how the decision about the person's best interests was reached</li> <li>• what the reasons for reaching the decision were</li> <li>• who was consulted to help work out best interests, and</li> <li>• what particular factors were taken into account.</li> </ul>
Independent Mental Capacity Advocate (IMCA)	If a person who lacks capacity has no close family or friends and has not recorded any choices about their care and treatment or made an advance decision to refuse treatment in advance of losing capacity, then an <i>Independent Mental Capacity Advocate</i> (IMCA) should be instructed and consulted regarding decision making about serious medical treatment or about placement in hospital for longer than 28 days or a care home for longer than 8 weeks.
Lasting Power of Attorney (LPA)	An LPA is a statutory form of power of attorney created by the Mental Capacity Act 2005 (England and Wales). Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. There are two types of LPAs: (a) for health and welfare; (b) for property and affairs.
Mental capacity	Mental capacity is the ability to make a decision. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Under the Mental Capacity Act 2005 (England and Wales), anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity: <ul style="list-style-type: none"> <li>• does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.)</li> <li>• if so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?</li> </ul>

## Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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, psychosocial and spiritual. 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
- enhances 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, and includes those investigations needed to better understand and manage clinical complications

## Specialist palliative care

People who may benefit from specialist palliative care are those whose physical or psychological symptoms, emotional, social or spiritual needs are complex and cannot be adequately managed by professionals who have not had specialist training in palliative care. The goal of specialist palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of specialist palliative care are applicable earlier in the course of the illness (or condition) in conjunction with other treatments. It is provided by physicians, nurses, occupational therapists, physiotherapists and other therapists, social workers and chaplains who have been trained, and have specialist skills, in palliative care.



## East Sussex Healthcare NHS Trust Position Statement

### Following the Liverpool Care Pathway Review

Following the publication of the Liverpool Care Pathway (LCP) review it is important to direct staff as to the trust's position on the LCP and its use, in order that patient care is not compromised. NHS England guidance and the response from the LACDP have been distributed to all relevant staff. Neighbouring trusts have been consulted and show discrepancies in the paths taken to address the review. Some areas are continuing with the use of the LCP until a national replacement is developed, some are developing their own template to aid an individualised end of life plan of care approach. Following discussion at senior level, ESHT opted to continue to use the LCP. A trust statement was distributed:

#### ***ESHT response to the Independent Review of the Liverpool Care Pathway published on Monday 15 July 2013***

*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 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, the review findings were published on 15th July 2013.*

*The Review Panel recognised that, when applied correctly, the Liverpool Care Pathway does help patients have a dignified and pain-free death and they support the principles underpinning it. Therefore staff of East Sussex Healthcare NHS Trust will continue using the Liverpool Care Pathway in our hospitals and community settings until NHS England publishes its response to this review. Our practice will continue to reflect the key recommendations from the review which state that:*

- As a general principle patients should only be placed on the Liverpool Care Pathway or a similar approach by a senior responsible clinician in consultation with the healthcare team.*
- Unless there is a very good reason, a decision to withdraw or not to start a life-prolonging treatment should not be taken during any 'out of hours' period.*

*More information - [www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients](http://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients)*

Unfortunately since the LCP review, compliance in its use has reduced. To mitigate against the risk of compromised care a guide to good end of life care practice has been developed to assist staff with their documentation and care when the LCP is not utilised e.g. patient/carer choice. An analysis of complaints and incidents showed that there are none in relation to the use or omission of the LCP (source DatixWeb

May – September 2013). ESHT continues its commitment to the Transforming End of Life Care in Acute Hospitals Programme (The Route to Success) and is soon to attend a regional update day. The first step of this process is now complete following a trust wide audit against the NICE standards (data recorded on the End of Life Care Quality Assessment tool (ELCQuA). ESHT attendees will also be present at the LADCP update day in November. As part of the trust wide improvement programme, senior clinical leadership has now been identified to support the 3 work streams in their developments against the trust end of life care action plan. Other developments include the training of all ESHT community registered nurses in the verification of expected death for patients on their caseloads. This will result in more timely verification of death and lessen distress for family members and carers. It is important for ESHT that we receive family member and carer feedback. To address this, a pilot questionnaire has been undertaken. Feedback so far has been positive.

Future plans include:

- "Route to Success - Transforming End of Life Care in Acute Hospitals" events to be attended to share good practice.
- Development of a long term sustainable training programme.
- Development of methods to capture patients and carers views and narratives.
- Issue of the baseline audit report.
- PEACE plan development for all appropriate patients in East Sussex.
- Coding review in preparation for System One.
- Development of a trust End of Life Care Strategy.
- Development of a multiagency End of Life Care Policy.
- Working with partners in the development of access to the Summary Care Records.
- Raising awareness of the Preferred Priorities of Care document.
- Improving access for carers to assessment of their own needs.

To conclude ESHT remain committed to the delivery of high quality end of life care for the people of East Sussex through partnership working and continuing developments.



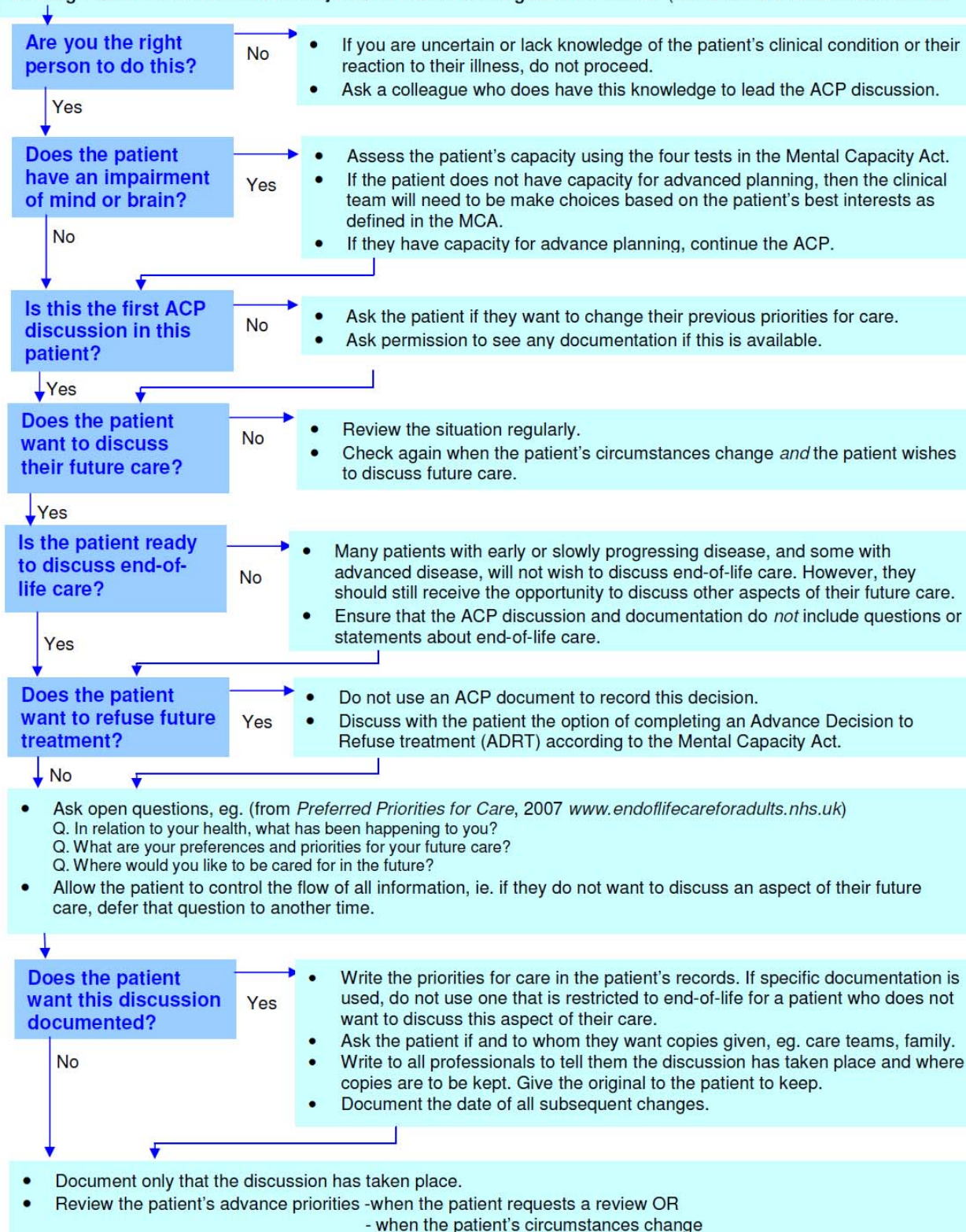


## Advance Care Planning process for discussion with the patient

## Advance Care Planning (ACP) v7 (Regnard C, Randall F. 25 Feb 2008)

ACP is a process of discussion between an individual and their care providers irrespective of discipline. If the individual wishes, their family and friends may be included. With the individual's agreement, discussions should be documented, regularly reviewed and communicated to key persons involved in their care (*Advance Care Planning: a Guide for Health and Social Care Staff*).

This algorithm should be used in conjunction with national guidance on ACP ([www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk))





### Sussex Clinical Commissioning Groups Deaths in Usual Place of Residence (DiUPR) comparison against the average or England CCGs

(Usual place of residence is a person's own home or current place of residence such as a care or nursing home)

