

TRUST BOARD
25th July 2013

TITLE	Responding to the Liverpool Care Pathway Review 2013
EXECUTIVE SUMMARY	This paper provides a summary of the 'More Care Less Pathway- A Review of the Liverpool Care Pathway,' the panels initial recommendations and the ASPH approach to these findings with actions.
BOARD (RISK)/ IMPLICATIONS	ASSURANCE Board assurance is provided within the paper with regards to the key recommendation and the current recommendations for ASPH regarding the End of Life Care
LINK TO STRATEGIC OBJECTIVE	SO1: To achieve the highest possible quality of care and treatment for our patients, in terms of outcome, safety and experience.
STAKEHOLDER/ PATIENT IMPACT AND VIEWS	Internal stakeholders only involved at this stage of the response to the LCP review paper 2013
EQUALITY AND DIVERSITY ISSUES	None Known
LEGAL ISSUES	None Known
The Trust Board is asked to:	Discuss the paper, note any recommendations that may arise and obtain assurance of ASPH's approach since the review.
Submitted by:	Dr David Fluck, Medical Director and Ms Suzanne Rankin, Chief Nurse
Date:	July 2013
Decision:	For Assurance

Responding to the review of the Liverpool Care Pathway

Introduction

Developed from a model of care successfully used in hospices, the Liverpool Care Pathway for the Dying Patient (LCP) is a generic approach to care for the dying, intended to ensure that uniformly good care is given to everyone thought to be dying within hours or within two or three days, whether they are in hospitals, nursing homes, or in their own homes. Because of substantial criticism of the LCP in the media and elsewhere, Norman Lamb MP, Minister of State for Care Support, asked Baroness Julia Neuberger to chair a panel to review of the use and experience of the LCP in England, to be kept independent of Government and the NHS. The Review considered evidence from many quarters: written submissions from members of the public and health professionals with experience of the LCP, as well as professional bodies and other organisations; a review of academic literature; a review of relevant hospital complaints; and surveys of health professionals. The panel also met members of the public at four sessions, to hear directly from them their experiences of the LCP. The review can be viewed by the following link <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

The report looked at the following:

- Use and experience of the Liverpool care pathway
- End of Life Care
- The Place of the LCP in the dying Process
- The LCP an integrated care pathway
- Evidence Base of the LCP
- LCP documentation
- Diagnosis of Dying
- Hydration and Nutrition
- Sedation and pain Relief
- Attempts of cardiopulmonary Resuscitation
- Financial Incentives

There are 44 recommendations which span across the wider NHS but will need to be actioned by acute Trusts.

Norman Lamb MP, Minister of State for Care and Support, raised serious concerns on the potential implications for the current quality of patient care. He asked for Trusts to put into effect the following Actions immediately:

- Undertake a clinical review, led by a senior clinician, of each patient who is currently being cared for using the LCP or a similar pathway for the final days and hours of life, to ensure that the care they are receiving is appropriate and that the patient, where possible, and their family is involved in decisions about end of life care; and
- Assure themselves that a senior clinician is assigned as the responsible clinician to be accountable for the care of every patient in the dying phase, now and in the future.

Actions can be found in appendix 1

ASPH End of Life Care

Initial ASPH Response

The detail of the ASPH response is important and will be articulated more fully when the Board has had sufficient time to review the Trust's current position, key challenges and priorities for action.

ASPH Position

An analysis of the ASPH position against two immediate actions can be found in appendix 1. A full list of recommendations can be found in appendix 2.

Current practice in delivery of the Liverpool Care Pathway

ASPH has been using the LCP to help support care in the final days and hours of life for many years. The Trust has received no specific complaints about the use of the LCP. Recent audits as mandated nationally and locally have been carried out by members of the Specialist Palliative Care Team on the use of the LCP, the audit results demonstrated that staff were using the LCP in an appropriate manner. This included, regular reviews, patient and family involvement in decision making and staff were delivering care in accordance to best practice. However, in the light of the recent report 'More Care, Less Pathway', and in discussion with other local Trusts and hospices, the Trust has decided to cease using the LCP with immediate effect. The Trust will continue to focus on individualised end of life care based on the patient and families' wishes and guided by the Trust's 5 key principles of good end of life care. Each care plan will continue to be led by a named consultant and named nurse and supported by specialist palliative care as required.

Following review the wider implications for removing the LCP are to:

- Ensure staff continue to identify when a patient is moving towards the final days/hours of life
- Ensure that each patient and family are involved in all decision making and that their individual preferences and wishes are addressed.
- Ensure that each patient has a individualised care plan addressing physical, emotional social and spiritual needs
- Prepare a press release outlining ASPH action plan
- Set up a contact number for concerned relatives
- Set up teaching package for staff based on 5 key principles
- Set up support for all clinical areas led by specialist palliative care team
- Appoint a board member(lay member) to lead on care of the dying

Future ASPH position

The EoLC Steering Group at ASPH will work with the Specialist Palliative Care Team and local partners to address each of the recommendations made by the report and to incorporate the necessary changes into the Trust EoLC Strategy. The steering group will continue to ensure that all staff are trained appropriately and supported to deliver EoLC at all times.

A more detailed response to the formal recommendations, complete with timescales, leads and progress (text in red within appendix 2) will be presented to the board in September once the initial steering group have had time to reflect and devise stakeholder opinions.

Appendix 1

Action Plan for Immediate Trust Actions in response to Norman Lamb’s recommendations.

	Trust Response- including systems in place to monitor	Lead
<p>Undertake a clinical review, led by a senior clinician, of each patient who is currently being cared for using the LCP or a similar pathway for the final days and hours of life, to ensure that the care they are receiving is appropriate and that the patient, where possible, and their family is involved in decisions about end of life care</p>	<p>Under the advice from the End of Life Care Lead (Dr Barry Quinn RN) and the Specialist Palliative Care Team, the Trust will cease using the LCP with immediate effect.</p> <p>The Trust’s commitment to providing best practice in end of life care as guided by the end of life care strategy will continue. This includes:</p> <p>Ensuring that every patient and their family members are included in end of life care decisions and care planning. Evidence of all discussions will be recorded in the patient’s notes.</p> <p>Each patient who is in the final days and hours of life will continue to be clinically reviewed regularly by a named consultant. Evidence of review will be recorded in the patient’s notes</p> <p>The named consultant will continue to have overall responsibility of care for each of these patients. Evidence of review will be recorded in the patient’s notes</p> <p>The five key principles of good end of life care based on – dignity at all times, early identification, assessment of patient and family wishes, co-ordination of care and good symptom control will continue to guide practice. These key principles need to be reflected in the patient’s individualised care plan</p> <p>Review and assessment relating to end of life care symptoms and decision making will be carried out by the team. All patients with complex needs (physical, emotional social and spiritual) should be referred to the specialist palliative care team for support and guidance. This needs to be clearly documented in the patients notes and referral made through PAS.</p> <p>The end of life care steering group will continue to support staff through EoLC</p>	<p>David Fluck, Suzanne Rankin, Barry Quinn, Susan Dargan</p>

	<p>teaching and update changes to current practice including the rationale for withdrawing the LCP.</p> <p>Each ward manager as the end of life care lead for their clinical area will work with the Consultant team to ensure best practice in end of life care for each patient and their family.</p>	
<p>Assure themselves that a senior clinician is assigned as the responsible clinician to be accountable for the care of every patient in the dying phase, now and in the future.</p>	<p>Each patient who is in the final days and hours of life will continue to be clinically reviewed regularly by a named consultant. Evidence of review will be recorded in the patient's notes</p> <p>The named consultant will continue to have overall responsibility of care for each of these patients. Evidence of review will be recorded in the patient's notes.</p> <p>Each ward manager as the end of life care lead for their clinical area will work with the Consultant team to ensure best practice in end of life care for each patient and their family.</p>	<p>David Fluck, Suzanne Rankin, Barry Quinn, Susan Dargan</p>

Appendix 2 Reviews recommendations

1	Terminology	NHS England should work speedily to issue clear definitions of time frames relating to end of life decision-making, and these definitions should be embedded firmly into the context of existing policies and programmes so that there is no room for doubt.
2		NHS England and the National Institute for Health and Care Excellence should review urgently the terms they are using to define clinical 'pathways', as opposed to protocols, standard operating procedures, guidelines, guidance, and best practice models.
3		The name 'Liverpool Care Pathway' should be abandoned, and within the area of end of life care, the term 'pathway' should be avoided. An 'end of life care plan' should be sufficient for both professionals and lay people.
4	Evidence base	The CQC and the Health Quality Improvement Partnership, should conduct fully independent assessments of the role of healthcare professionals in end of life care in England, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying.
5		The National Institute for Health Research fund should fund research into the biology of dying.
6		The National Institute for Health Research fund should fund research into the experience of dying. Research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience.
7	Falsification of documentation	Clinicians should be reminded by their registration bodies that the deliberate falsification of any document or clinical record, in order to deflect future criticism of a failure of care, is contrary to GMC and NMC guidelines, and therefore a disciplinary matter.
8	Diagnosis of dying – prognostic tools	NHS England and Health Education England should collaborate to promote:

		<p>the use of evidence-based prognostic tools, including awareness of their limitations; and</p> <p>Evidence-based education and competency based training, with regular refresher modules, for all professionals working with people approaching the end of their lives, both in the use of prognostic tools and in explanation to patients and relatives or carers of how they are used and the unavoidable uncertainties that accompany an individual's dying.</p>
9		<p>The National Institute for Health Research should fund research on improving, where possible, the accuracy of prognostic tools for the last weeks to days of life. This would cover, for example, the accuracy of prognostication where that is possible, suitably configured, mixed method trials of different forms of care during dying, specific interventions, such as hydration and nutrition, and symptom control measures.</p>
10	Diagnosis of dying – communicating uncertainty	<p>The National Institute for Health Research should as a matter of priority fund research into the development and evaluation of education and training methods and programmes addressing uncertainty and communication when caring for the dying.</p>
11		<p>The General Medical Council should review whether adequate education and training is currently provided at undergraduate and postgraduate levels to ensure competence. It should also consider how, given its recently increased responsibilities for specialist training and enhanced role in continuing professional development, it can ensure that practising doctors maintain and improve their knowledge and skills in these areas.</p>
12	Guidance on diagnosis of dying	<p>Clear guidance should be issued by the National Institute of Health and Care Excellence on:</p> <p>diagnosis and who should ultimately be responsible for diagnosing that someone is beginning to die</p>

		<p>the necessity for multidisciplinary decision-making</p> <p>the usefulness or otherwise of laboratory and other biological evidence</p> <p>the importance of case notes review for diagnosis</p> <p>how any uncertainty about whether a patient is in the active process of dying should be taken into account in the clinical management of the patient, in different healthcare settings.</p>
13	Good practice guidance for nurses on decision-making	As a matter of urgency the Nursing and Midwifery Council should issue for nurses guidance on good practice in decision-making in end of life care, equivalent to that issued by the General Medical Council for doctors.
14	Decisions to initiate an end of life care plan out of hours	Every patient diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any 'out of hours' period. Unless it is unavoidable, urgent, and is clearly in the patient's best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician in consultation with the healthcare team. The practice of making such decisions in the middle of the night, at weekends or on Bank Holidays, by staff that do not have the requisite training and competence, should cease forthwith.
15		The General Medical Council, the Health and Care Professions Council and the Nursing and Midwifery Council should ensure their professional standards clearly place the responsibility for such decisions on the senior responsible clinician, and they should take steps to emphasise how clinicians will be held to account against these standards. Furthermore, NHS England must ensure that appropriate systems are in place, with adequate levels of staffing to deliver these arrangements in practice. And CQC and Monitor should ensure their inspection regimes focus on this important aspect of the patient experience.
16	Training in shared decision-making	The Review panel is deeply concerned that the GMC guidance is clearly not always being followed in the care of the dying, and recommends that the Royal Colleges review the effectiveness of any

		training in shared decision-making that they provide, examining the extent to which it closely reflects the professional standards in GMC and NMC guidance and required competencies in this area, with a view to ensuring continued competence is maintained across the education and training spectrum from undergraduate teaching and learning through to continued professional development.
17	Nutrition and hydration	The General Medical Council should review its guidance on supporting oral nutrition and hydration to consider whether stronger emphasis could be given to this issue.
18		The Nursing and Midwifery Council should urgently produce guidance for nurses on supporting oral nutrition and hydration.
19		All staff in contact with patients should be trained in the appropriate use of hydration and nutrition at the end of life and how to discuss this with patients, their relatives and carers.
20		There should be duty on all staff to ensure that patients who are able to eat and drink should be supported to do so.
21		Failure to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct.
22	.	Specialist services, professional associations and the Royal Colleges should run and evaluate programmes of education, training and audit about how to discuss and decide with patients and relatives or carers how to manage hydration at the end of life
23	Sedation and pain relief	Before a syringe driver is commenced, this must be discussed as far as possible with the patient, their relatives or carers, and the reasoning documented.
24		New research is needed on the use of drugs at end of life, and in particular on the extent to which sedative and analgesic drugs themselves contribute to reduced consciousness, and perceived reduction of appetite and thirst.

25	Financial incentives	Payments 'per patient implemented on the LCP, or equivalent approach' should cease.
26	Accountability	A named consultant or GP, respectively, should take overall responsibility for the care of patients who are dying in hospital or the community.
27		The name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed.
28		The boards of healthcare providers providing care for the dying should give responsibility for this to one of its members – preferably a lay member whose focus will be on the dying patient, their relatives and carers – as a matter of urgency. This is particularly important for acute hospitals.
29	Documenting an end of life care plan	<p>Guidance should specify that the senior clinician writes in the patient's notes a record of the face to face conversation in which the end of life care plan was first discussed with the patient's relatives or carers. The record of that conversation must include the following:</p> <p>That the clinician explained that the patient is now dying and when and how death might be expected to occur.</p> <p>If the family or carers do not accept that the patient is dying, the clinician has explained the basis for that judgement.</p> <p>That the relatives or carers had the opportunity to ask questions.</p>
30		A shared care folder, kept at the hospital bedside and designed for communication between patients, relatives and the staff, should be introduced, supported by training for staff on how to use it.
31		There should be better integration in the community between LCP or other similar documentation and the existing system of shared care

		folders, so that the care provided by relatives and carers (professional or otherwise) is noted, and their contribution is incorporated into documentation.
32	Independent advocacy	For each patient on an end of life care plan that has no means of expressing preferences and no representation by a relative or carer, views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This applies to people of whatever age who lack capacity.
33	Availability of palliative care support	Funding should be made available to enable palliative care teams to be accessible at any time of the day or night, both in hospitals and in community settings, seven days a week.
34	Guidance for nurses in end of life care	As part of its work to review the Nursing and Midwifery Code in preparation for revalidation, and as a matter of priority the Nursing and Midwifery Council should provide guidance for nurses caring for people at end of life. This should encompass the good practice guidance on decision-making recommended in paragraph 1.42 (see recommendation 13).
35	Education in care for the dying	Health Education England should pay particular attention to the pressing need for more evidence based education in all settings that care for the dying in its work to improve workforce planning to ensure sufficient staff are trained with the right skills in the right locations to enable healthcare providers to deliver their commissioning plans.
36	Guidance	A series of guides and alerts should be developed that reflect the common principles of good palliative care and link directly to the General Medical Council's and Nursing and Midwifery Council's guidance (when the latter is developed). Implementation of this guidance should be the personal responsibility of clinicians.
37		In addition to the core driving palliative care philosophy common to all the guidance, there would be elements of technical guidance specific to certain disease groups. They should be designed to be readily adapted

		for local use to meet the needs of individuals.
38	End of life care plan	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, backed up by condition-specific good practice guidance.
39	A system-wide, strategic approach to improving care for the dying	<p>The system needs a coalition of regulatory and professional bodies with NHS England, along with patient groups, setting clear expectations for a high standard of care for dying patients – care that will also meet the important and sometimes neglected needs of their relatives and carers. Working together strategically, such a coalition should lead the way in creating and delivering the knowledge base, the education training and skills and the long term commitment needed to make high quality care for dying patients a reality, not just an ambition. As a minimum, this would entail close co-operation between the GMC, NMC, the Royal Colleges, the CQC, NHS England and NICE.</p> <p>Under this approach, the GMC and NMC would take the lead with the Royal Colleges, Health Education England and NHS England in:</p> <p>Providing any additional good practice guidance, building on the standards set out in the GMC guidance on treatment and care towards the end of life</p> <p>Reviewing whether current education and training standards adequately address care of the dying; setting requirements based on agreed levels of competence in the care of dying patients; and quality assuring the outcomes and effectiveness of teaching and learning.</p> <p>Setting relevant standards for continuing professional development, for all clinicians (generalist and specialists) who have a role in caring for dying patients and their relatives or carers. And, where appropriate, encouraging or facilitating the development of relevant resources or programmes for continuing professional development.</p> <p>As part of this coalition, the CQC would collaborate with patient groups in defining what good quality end of life care services should look like</p>

		and then inspect against those standards.
40	Hospital inspections	End of life care should be incorporated urgently into the hospital inspection programme of the newly announced Chief Inspector of Hospitals.
41	Thematic review of end of life care	The Care Quality Commission should carry out a thematic review within the next 12 months, of how dying patients are treated across the various settings, from acute hospitals to nursing and care homes, as well as hospice and the community.
42	Commissioning	Using its full powers and mindful of its general duties, NHS England should work with clinical commissioning groups to address what are clearly considerable inconsistencies in the quality of care for the dying, to drive up quality by means of considerably better commissioning practices than persist at present.
43	Mandate to NHS England	The Government should set improved quality of care for the dying as a priority for NHS England in the next Mandate.
44	Given the very strong links between the vulnerability of older people and the quality of care for the dying, the Vulnerable Older People's Plan should include a strand on care for the dying, and that NHS England's contribution to it should be specified also as a priority in the NHS Mandate.	