12 April 2013

Review of the Liverpool Care Pathway – call for evidence

1. The Royal College of General Practitioners (RCGP) welcomes the opportunity to submit evidence to the review of the Liverpool Care Pathway (LCP).

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. Founded in 1952, it has over 46,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline. We are an independent professional body with enormous expertise in patient–centred generalist clinical care. Through our General Practice Foundation, established by the RCGP in 2009, we maintain close links with other professionals working in General Practice, such as practice managers, nurses and physician assistants.

Introduction

3. The RCGP believes that the LCP provides a useful, evidence-based framework for good practice for care in the last hours or days of life. We share the view set out in the review’s terms of reference that the issue is not about the merits of the LCP itself, but about how it is being used in practice.

4. In September 2012, the RCGP joined with 19 other organisations in signing a consensus statement supporting the appropriate use of the LCP and seeking to dispel
misconceptions. This made clear that the LCP is not in any way about ending life, but rather about supporting the delivery of excellent end of life care.

5. The RCGP understands that the focus of this review is on the use of the LCP model, rather than on re-evaluating the model itself. We have therefore structured our response around three questions relating to the use and experience of the LCP in general practice.

6. In formulating our response we have solicited input both from our members and our clinical advisors on end of life care (EOLC). Please note that, although our call for evidence on the LCP was distributed widely amongst our membership, it is not a representative survey.

7. Please also note that the RCGP’s Clinical Expert on EOLC, Prof Keri Thomas - in collaboration with the Association for Palliative Medicine, the NHS National End Of Life Care Programme and other partners - helped to develop a separate survey for doctors and registered nurses who have used integrated care pathways for the dying, including the LCP. This survey was distributed to RCGP members on 22 March 2013, and it is likely that a number of our members will have responded directly.

Q1) How is the LCP used by GPs? How widely is it used?

8. The LCP is used by GPs both in the home and in care home settings. One of our members told us: “There are clear criteria for when it should be used and in my experience this has always been stuck to by GPs.”

9. Its frequency of use varies according to the individual GP or practice, with some GPs expressing greater familiarity with the LCP than others.

10. Often GPs using the LCP work in collaboration with nursing teams – such as community nurses, district nurses and specialist palliative care nurses – and, in some cases, the use of the LCP may be prompted by the nursing team. Several GPs that we spoke to mentioned the positive nature of this relationship (please see also our response to question 2 below).

11. We received variable feedback on the use of the LCP in care homes. Some felt that it worked well, while one GP told us: “I see it used less frequently in care homes but will often see inappropriate and more frequent hospital admissions from many of these homes, when the individual would have been better cared for at the care home and possibly on the LCP.”
12. Often GPs will attend to a patient who was first placed on the LCP while in hospital. Concern was expressed by some of our members regarding the implementation of the LCP in secondary care. One GP said: “I have had experience of one of my patients discharged from hospital on the LCP who I felt…should not have been placed on it. There was no communication from the hospital regarding this and the first I knew about it was when the community nursing staff requested a visit for re-assessment. The individual was elderly and frail and certainly advance care planning was appropriate but he was not suitable for the LCP. The LCP was discontinued and I did raise my concerns, with the permission of the family, with the hospital medical team.” (Please see further discussion of communication between primary and secondary care in question 3 below).

13. Often the use of the LCP in general practice is associated with cancer patients, but there are many other clinical situations where it has been used successfully and, according to some of our members, could be used more often - for example, heart failure and COPD.

14. As regards how the pathway is used, one of our members told us: “We deal with patients in the way that the pathway suggests: stopping unnecessary treatments/distressing interventions. We use it to help us recognise when patients are dying so that we can inform and support relatives. We focus on symptom relief in the last few days, and we review more frequently and intensively during this time…We do not use it to stop feeding or fluids. The point about the pathway is that the diagnosis of dying includes the parameter that the patient is no longer able to take more than sips of fluids, and this is part of the natural process of dying, not the result of the pathway.”

15. Some GPs said that they used the principles of the LCP - and found these helpful - but did not use the pathway itself. Respondents mentioned both the volume of paperwork associated with the LCP, and the recent adverse publicity surrounding the pathway as reasons for not using the LCP itself.

16. Other GPs felt that, by providing a framework for health professionals to follow, the LCP gives nursing teams and GPs confidence to deliver better care at home and in care homes, and ensures that all aspects of palliative care are covered. One respondent commented: “[The LCP] is particularly helpful as guidance for prescribing.” The LCP can also be useful for newly qualified GPs, who may need more guidance on how to deliver on all aspects of care.

Q2) Does the LCP work well in community settings and the home?
17. Generally the feedback that we received from our members on this question was positive. It was felt that the LCP works well in community settings and the home and, when implemented in this context, is generally used appropriately.

18. Comments from our members included:

“I think the LCP facilitates individualised, holistic care that can be planned according to the situation at any one time. It is particularly important when providing care for individuals outside ‘working hours’. Communication and education are the key determinants of this.”

“It is a very helpful framework to work from and is a good way of bringing some standardisation to care, as well as raising the standards of care.”

“The LCP works well in all community settings, including and especially care homes, where it gives a framework for care.”

19. As mentioned above, the LCP is frequently used by GPs in collaboration with nursing teams, with nurses playing an essential linking role with the GP. Several of our members highlighted the benefits of this team approach, as it facilitates effective communication between all involved, including patients and family members.

20. A problem with implementation of the LCP flagged by some GPs focused on the negative publicity that the LCP has received recently. Respondents felt that use of the LCP can cause additional concern amongst relatives, who may feel that their loved ones are being condemned to a standardised ‘model of dying’. One GP said: “More recently [the LCP] can be a barrier, rather than a tool to aid communication and planning for a dignified death.” (Please see also our comments on the use of the word ‘pathway’ in question 3 below).

21. Another GP felt that guidance around the provision of IV fluids within the LCP needs to be updated, particularly as this is a common source of concern for patients and families. The respondent stated: “strong and simple guidance is required in this area”. 

Q3) How could use of the LCP by health professionals be improved, if necessary?

22. The overwhelming message from our members was that improving communication between all those involved - including with patients and their families, and between primary and secondary care - will be key to improving use of the LCP.
23. It is worth noting that it was felt that communication with patients and relatives is generally done far better in the community setting than in the hospital at the present time.

24. Nevertheless, this process could be improved by making clear the rationale, processes, goals and criteria for the LCP to patients and families. The importance of including (subject to considerations of patient confidentiality) families from the outset in conversations about EOLC, including the use of the LCP, was emphasised by respondents - so that families and, where possible, patients are consulted about the LCP’s use and understand what being ‘on’ the LCP means (and does not mean). “Without this, the LCP is frightening and appears to be to do with withdrawing support and treatment, rather than caring.”

25. Some GPs also suggested that there should be better communication by healthcare professionals about how patients can come off the pathway if necessary.

26. Another point raised by our members was the use of the word ‘pathway’. Some felt that this does not aid communication with relatives and patients, as ‘pathway’ suggests a standardised approach to one-way care. One GP proposed re-naming the document as 'best practice' or 'guidelines', while another suggested that ‘pathways for the end of our lives’ is more reflective of the ethos behind the LCP.

27. Another important theme was improving communication between hospital and primary care. As discussed above, some GPs attend to patients who were placed on the LCP while in hospital. These GPs need information about when the individual was placed on the LCP, why and who has been involved in this decision. It was suggested that if individuals are placed on the LCP whilst in hospital, their GP should be informed as a matter of course.

28. Underpinning effective communication about EOLC and the LCP, particularly between healthcare professional and families and patients, is the need to ensure that all those who use the LCP, including nursing and care home staff, have undergone sufficient education and training in its use. It was suggested that teaching of undergraduates - both nursing and medical - should have EOLC embedded within their programmes.

One respondent said: “Training on having those ‘difficult conversations’, not only about dying but also about being placed on the LCP is vital.” Another said: “Training for all staff caring for patients at the end of their lives and how to care effectively should be
mandatory. There is a great deal of enthusiasm and passion to get this right for patients and we have to help facilitate this.”

The RCGP’s work on end of life care

29. End of life care has long been a priority for the RCGP. In 2009 we published our end of life care strategy which reflects the crucial role that GPs play in end of life care, and offers leadership in defining, enabling and pioneering good practice for the future. End of life care is also a key component of the GP curriculum, the foundation for GP training and assessment, that is developed by the RCGP.

30. In 2011, the RCGP published an end of life care patient charter, a collaboration between our End of Life Care English Working Group (chaired by Prof Keri Thomas), our Patient Partnership Group and the Royal College of Nursing. This charter represents an ideal of best practice that we think all patients should be able to seek from their primary healthcare team. It is supplemented by ‘Matters of Life and Death’, practical guidance for GP practices implementing the Patient Charter (pub. 2012).

31. In March 2013, we launched our RCGP Commissioning Guidance in End of Life Care, a six-step framework to support commissioners working across the health, social care and voluntary/independent sectors. The guidance brings together existing good practice and provides useful case histories, demonstrating how good end of life care can be achieved. (Available to download from www.rcgp.org.uk/commissioning from w/c 15 April).

32. Our Clinical Expert in End of Life Care, Prof Keri Thomas, a GP with a special interest in Palliative Care, is the originator of and National Clinical Lead for the National GSF Centre, which runs several training programmes, including the Gold Standards Framework (GSF) for Primary Care. This is a systematic approach to improving the quality and organisation of care for all people nearing the end of life, and is supported and endorsed by the RCGP. A key goal of this work is to enable more people to die where they choose, usually at home, or in a care home or hospice, and reduce hospitalisations.

33. Foundation Level GSF is used by over 95% of GP practices in the UK, and has been mainstreamed through QOF GP payments since 2005. The GSF Centre, with the support and endorsement of the RCGP, has also developed practice accreditation and quality recognition awards, as well as Prognostic Indicator Guidance, which helps early identification of adult patients nearing the end of their lives.
We thank you again for the opportunity to submit evidence to the review panel on this important issue. We gratefully acknowledge the contributions of our members and clinical advisers in formulating this response.

Yours faithfully,

Professor Amanda Howe MA Med MD FRCGP

Honorary Secretary of Council