

Jeff Stephenson addresses issues about care at the final stages of life



THE LIVERPOOL CARE PATHWAY

key points

LCP is widely used and probably the best known of such pathways. The onus is still on clinical teams to assess and review patients.

Misconceptions about LCP risk scaremongering and detracting from the real benefits.

The LCP encourages professionals to consider the needs of patients and families, current and anticipated.

Exemplary palliative care for dying patients and their families was pioneered in hospices, and end of life (EOL) care pathways were developed as a means to extend such care into other settings. The Liverpool Care Pathway for the Dying Patient (LCP) is widely used and probably the most well known of such pathways. However, it has been the subject of controversy. Concerns have been expressed over its inappropriate use and association with practices akin to euthanasia. This article looks at its background, addresses these concerns, and suggests some biblical perspectives.

Developed by the Marie Curie Palliative Care Institute Liverpool in the late 1990s, the LCP is recognised as a model of best practice,¹ was recommended in the End of Life Care Strategy (2008)², and is now identified as a quality marker for EOL care.³ The current Version 12 emerged in 2009 after two years of consultation and evidence from two rounds of auditing of its use in hospitals.⁴ Latest figures suggest that around 150,000 people a year are dying on the LCP, amounting to about a third of annual deaths in the UK.⁵

The LCP encourages professionals to consider the needs of patients and families, both current and anticipated, and guides them through the key areas of assessment and provision of care. As well as an initial assessment and after-death care covering twelve goals, it entails daily assessments in which patients are checked every four hours to ensure comfort.

There is a diverse range of evidence to suggest that EOL care pathways can improve care in a number of ways, including symptom control and bereavement experience of relatives.^{6,7} The second national audit of the LCP concluded that where it is used people are receiving high quality clinical care for the last days and hours of life.⁸

Periodically there has been adverse press about the LCP, including headlines in national newspapers suggesting it is being used to hasten death.^{9,10,11} Criticisms usually focus on: inappropriate use in those who are not dying; excessive use of sedation, encouraged by the prescribing of anticipatory medication and the use of syringe drivers; withholding of food and fluids; and the perception that it is a 'one-way street' to death.

Inappropriate use

The LCP is intended for use in people who are in the last days or hours of life. Diagnosing dying can be difficult and more so in some conditions than others. While in cancer patients it is usually evident when someone is entering the last few days, it is often more difficult to discern in patients with dementia and other non-malignant conditions. If there is any doubt about whether a patient is imminently dying, and these decisions should ideally be arrived at within a multidisciplinary team, then the LCP should not be initiated.

Excessive sedation

The LCP aims to prevent situations where a patient

is dying with uncontrolled symptoms, and without easy access to medication to relieve those symptoms. Hence there is guidance on the anticipatory prescribing of injectable medication, and the use of a syringe driver if necessary medication needs to be continued up to the point of death. If doses need to be increased, practice in the UK is that of incremental titration to match symptoms, with the primary intention being not to induce sleep but to achieve symptom control with the minimum necessary dose. When medication is used in this way there is no evidence that such practice shortens life.

This is to be contrasted with the practice of 'terminal sedation' where the intention is to reduce consciousness as a last resort in a dying patient with refractory symptoms.¹² In my experience the need to resort to the latter is rare. Unfortunately, misunderstanding about the use of morphine and sedatives at the end of life has led some to equate practice in the UK with that of 'continuous deep sedation' as practiced in the Netherlands, where there has been a progressive rise in the number of patients dying by this route, as well as a progressive increase in deaths by euthanasia.¹³ Indeed, one study suggests that a greater proportion of deaths in the UK involve continuous deep sedation than those reported most recently in the Netherlands (18.7%¹⁴ vs 12.3%¹⁵), but I believe this is due to misunderstanding around definitions.

The LCP has been described as 'the UK's main clinical pathway of continuous deep sedation'¹⁶ but this is simply not something that the LCP promotes. The second national audit of its use found that drugs prescribed for agitation and restlessness were given in only 37% of cases, and the median dose of midazolam, the most frequently used drug for this indication, was 10mg/24hrs.¹⁷ This contrasts markedly with guidance on continuous deep sedation from the Royal Dutch Medical Association¹⁸ which recommends a starting dose of 1.5 – 2.5 mg *per hour*, with progressive escalation until unconsciousness is achieved, up to a maximum of 20mg *per hour*. Interestingly, the use of the LCP in the Netherlands has been reported to reduce the extent to which physicians use medication that might hasten death.¹⁹

Food and fluids

The LCP encourages the offering of food and fluid for as long as the patient is able to take them. When patients are dying there usually comes a point when they stop eating and drinking, and for most patients initiating clinically assisted hydration (CAH) or nutrition is not appropriate and may be detrimental to their quality of dying. The LCP explicitly encourages consideration about whether or not CAH should be initiated or continued. There is no blanket discouragement from continuing treatments in those patients for whom it might be appropriate, and particularly so if there is some uncertainty about the diagnosis of dying. The most recent

national audit of the LCP found that for those patients receiving it CAH was continued in 16% after initial assessment.²⁰

A one-way street?

While the LCP is a useful tool, the onus is still on clinical teams to assess and review patients, and if there is any suggestion that they may be improving, the decision to continue the LCP must be reviewed. The LCP recommends an assessment whenever the patient's condition changes, and at least every three days. In my own practice there is a proportion of patients who come off the LCP, albeit usually only for a short while before they deteriorate again.

Biblical perspectives

Fundamental to a Christian approach to any ethical challenge is the principle that human beings are made in the image of God.²¹ Their lives are to be valued in and of themselves, and they are to be protected from harm. There is a particular expectation to protect the vulnerable, and the cry for justice resonates throughout Scripture.²² The law of love²³ constrains us to act with compassion towards those who are suffering, just as Jesus was moved with compassion repeatedly throughout the Gospel accounts of his ministry.²⁴ Death is a reality²⁵ but it is not the end.²⁶ High quality EOL care should not be restricted to a select few, and a tool that facilitates better care for those who are suffering should be welcomed and championed.

We have a responsibility to seek justice and speak out against injustice.²⁷ The biblical injunction against the killing of the innocent upholds the law of love and the inherent value of lives made in the image of God.²⁸ Where the LCP is being misused or abused, then we need to confront that, and we need to be vigilant in the years ahead as demographic changes may increase pressure for moral drift and economic expediency in healthcare. Sensational published misconceptions about the LCP risk scaremongering and detracting from the real benefits it can bring.

Conclusion

The LCP represents a pragmatic and effective response to some of the suffering experienced by many in the last days of life. It remains, however, a tool and it is only as good as those who use it. There is always potential for misuse and abuse and there are undoubtedly instances where this occurs. Where these arise by intention then those involved should be held to account, but more often they occur through poor understanding and inadequate training. Successful roll out of the LCP needs much education, both initial and ongoing, and this may sometimes be underestimated or under-resourced. We owe it to patients to not only furnish the means to better care, but also to equip adequately those who provide it.

Jeff Stephenson is a Consultant in Palliative Medicine based in Devon



references

1. NHS Beacon Programme (2001)
2. End of Life Strategy Care Strategy: promoting high quality care for all adults at the end of life. DOH 2008
3. End of life care strategy: quality markers and measures for end of life care. DOH 2009
4. National Care of the Dying Audit - Hospitals. Rounds 1 (2006-7), 2 (2008-9) and 3 (2011-12). Marie Curie Palliative Care Institute Liverpool-Royal College of Physicians
5. *Ibid*
6. Chan R, Webster J. End-of-life care pathways for improving outcomes in care of the dying. *Cochrane Review* 2009
7. Watts T. End-of-life care pathways as tools to promote and support a good death: a critical commentary. *European Journal of Cancer Care* 2012; 21: 20-30
8. National Care of the Dying Audit, *op cit*
9. Sentenced to death on the NHS. *Telegraph* 2009; 2 September
10. Top doctor's chilling claim: The NHS kills off 130,000 elderly patients every year. *Mail Online* 2012; 20 June
11. Hospitals 'letting patients die to save money.' *Telegraph* 2012; 8 July
12. Sales JP. Sedation and terminal care. *European Journal of Palliative Care* 2001; 8: 97-100
13. Onwuteaka-Philipsen BD *et al*. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* 2012; 380: 908-15
14. Seale C. Continuous deep sedation in medical practice: a descriptive study. *Journal of Pain and Symptom Management* 2010; 39: 44-53
15. Onwuteaka-Philipsen. *loc cit*
16. Treloar A. Dutch research reflects problems with the Liverpool Care Pathway. *BMJ* 2008; 336: 905
17. National Care of the Dying Audit, *loc cit*
18. Guideline for Palliative Sedation. Royal Dutch Medical Association (KNMG), 2009
19. Van der Heide A *et al*. End-of-life decision making for cancer patients in different clinical settings and the impact of the LCP. *Journal of Pain and Symptom Management* 2010; 39: 33-43
20. National Care of the Dying Audit, *loc cit*
21. Genesis 1:27
22. Amos 5:24; Zechariah 7:9-10
23. Matthew 7:12, 22:39
24. Matthew 9:36, 14:14, 15:32, 20:34; Mark 1:41, 6:34, 8:2; Luke 7:13
25. Ecclesiastes 3:2
26. Hebrews 9:27 and John 14:2-3
27. Isaiah 1:17
28. Genesis 9:6; Exodus 20:13