

Anscombe Bioethics Centre Response to The Independent Review of The Liverpool Care Pathway (LCP)



Summary

1. The Anscombe Bioethics Centre welcomes the publishing of *More Care, Less Pathway: A Review of the Liverpool Care Pathway*, and notes the clarity of its key findings that **‘plenty of evidence received by the Review shows that, when the LCP is used properly, patients die a peaceful and dignified death. But the Review panel is also convinced, from what it has both heard and read, that implementation of the LCP is not infrequently associated with poor care.’**¹
2. The Review panel thus affirms the principles of good treatment and care towards the end of life, which it sees reflected in the LCP when used well, while vigorously challenging examples of poor care of patients ostensibly supported by the LCP highlighting many of these examples and identifying some of the common patterns and underlying causes that need to be addressed.
3. **The Anscombe Bioethics Centre endorses all 44 recommendations of the Independent Review of the Liverpool Care Pathway, including the recommendation that the LCP should be replaced by an ‘an end of life care plan for each patient, backed up by condition-specific good practice guidance’**,² subject to all the recommendations being re-evaluated in the light of future evidence. For ease of reference a list of the 44 recommendations is included as an appendix to the present document.
4. The Review panel rightly seeks a ‘sea change that is urgently needed to raise the quality of care for the dying’.³ It remains essential that whatever plans or frameworks are adopted as part of this change ‘must be implemented ethically, with care for the patient always as the first priority’.⁴ The Centre has set out some key ethical principles in *Ethics of Care of the Dying Person*. That document begins with the governing principle: ‘The life of every human being, as made in the image of God, possesses an intrinsic worth or dignity which must be given strict respect in accordance with the fundamental requirements of justice.’⁵

¹ *More Care, Less Pathway*, page 13 bold in original.

² *More Care, Less Pathway*, page 58, recommendation 38; page 47, 3.3; See also page 10; page 17, 1.21; page 38-39, 2.17-2.20.

³ *More Care, Less Pathway*, page 47, 3.4.

⁴ Archbishop P. Smith ‘Archbishop’s Response to the Review of the Liverpool Care Pathway’ (17 July 2013) <http://www.catholicnews.org.uk/LCP-review-response-160713>

⁵ Anscombe Bioethics Centre ‘Ethics of Care of the Dying Person’ (12 July 2013), paragraph 3 <http://www.bioethics.org.uk/images/user/TheEthicsofCareoftheDyingPersonwebsite.pdf>

The call for an inquiry

5. The Liverpool Care Pathway for the Dying Patient (LCP), now in its twelfth edition,⁶ was devised to transfer to other settings, notably hospitals, the expertise in caring for the dying that had been developed in the hospice movement.⁷ It has been well documented that pain and other symptoms frequently attendant on dying had often been poorly controlled outside the hospice sector, and dying patients were sometimes being subjected to treatments and procedures which had become futile.
6. The LCP was designed with the good intention of improving the quality of care of the dying, and with no intention to hasten death or otherwise to harm patients. Nevertheless, it became the subject of persistent public and private criticism on the grounds that not all patients on the pathway have experienced good care, and some have been said to have come to serious harm and a precipitated or unsatisfactory death.
7. In response to concerns raised about the LCP's implementation, Peter Smith, Archbishop of Southwark, called on the Health Secretary to set up an inquiry.⁸ Heeding this and other such calls, the government established an Independent Review, chaired by Baroness Julia Neuberger.
8. The terms of reference of the Review were to:
 - examine systematically the experience of patients and families of the use of the Liverpool Care Pathway
 - examine the experience and opinions of health professionals about the use of the Liverpool Care Pathway
 - examine hospital complaints about end of life care and in particular those about the Liverpool Care Pathway
 - review the literature about the Liverpool Care Pathway in practice;
 - consider the role of financial incentives in this area
 - make recommendations about what steps can be taken to:
 - improve care
 - ensure that patients are always treated with dignity and are involved in decisions about their care wherever possible
 - ensure that carers and families are always properly involved in the decision-making process
 - restore public confidence.⁹
9. The Review panel took evidence from healthcare professionals and from patients and relatives and held several public meetings to gather evidence. The

⁶ Marie Curie Palliative Care Institute Liverpool, LCP Model Pathway – UK. Core Documentation (October 2012), p. 3 www.sii-mcpil.org.uk/media/10843/LCP%20Core%20Documentation.pdf

⁷ John Ellershaw and Susie Wilkinson (eds) *Care of the Dying. A Pathway to Excellence*. Second Edition (Oxford: Oxford University Press, 2011)

⁸ Archbishop Peter Smith, Letter to the Health Secretary Jeremy Hunt (27 September 2012).

⁹ J. Neuberger et al. *More Care, Less pathway: A review of the Liverpool Care*, Independent Review Of the Liverpool Care Pathway, July 2013, page 50, available at:

<https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients>

report, *More Care, Less Pathway: A Review of the Liverpool Care Pathway*, was published on 15 July 2013.

The Findings of the Review

Use and experience of the LCP

10. Having considered evidence from patients and families as well as from healthcare professionals and from a review of the scientific literature, the overall findings of the Review panel are that **‘plenty of evidence received by the Review shows that, when the LCP is used properly, patients die a peaceful and dignified death. But the Review panel is also convinced, from what it has both heard and read, that implementation of the LCP is not infrequently associated with poor care.’**¹⁰
11. This finding represents a *via media* between rejection of the LCP in principle and acceptance of the status quo. On the basis of the evidence it examined, the panel concluded that the LCP *could* work well when implemented ‘by well trained, well-resourced and sensitive clinical teams’.¹¹ The Review panel thus did not accept that the LCP was flawed in principle in such a way that it could not be implemented ethically. At the same time, the Review found credible evidence of examples of *very poor implementation* amounting to little more than ‘**a tick box exercise**’¹² leading to care that was ‘**clinically indefensible**’.¹³ For example, the panel heard ‘**far too many examples of sloppy and unmonitored clinical decision-making for the status quo to go unchallenged**’.¹⁴
12. The findings of the Review will be examined in more detail in relation to issues such as diagnosis of dying, consent, hydration and nutrition, sedation and pain relief, and hastening of death. The Review panel affirms the principles of good treatment and care towards the end of life – principles which it sees reflected in the LCP when used well – while vigorously condemning examples of poor care of patients on the LCP, usefully highlighting such examples and identifying some of the common patterns and underlying causes that need to be addressed.

Terminology

13. The Review pointed to some terminological confusion, both among patients and families and among healthcare professionals. The term ‘end of life’ was being used to cover very different time frames in a way that might lead to the LCP being ‘initiated inappropriately’ especially ‘where there is little or no input from a specialist palliative team’.¹⁵

¹⁰ *More Care, Less Pathway*, page 13 bold in original.

¹¹ *More Care, Less Pathway*, page 3.

¹² *More Care, Less Pathway*, page 29 bold in original.

¹³ *More Care, Less Pathway*, page 30, 1.72 bold added.

¹⁴ *More Care, Less Pathway*, page 21 bold in original.

¹⁵ *More Care, Less Pathway*, page 14, 1.10.

14. The Review was also highly critical of the use of the term ‘pathway’ which it found was not only ‘misunderstood by people at the bedside’¹⁶ but also suffered from a lack of clarity due to being described variously as ‘a stand-alone document’,¹⁷ as including ‘all relevant... clinical guidelines’,¹⁸ and as ‘a complex intervention’.¹⁹ In the view of the panel, ‘due to this lack of clarity, the LCP is being perceived by some of its users – doctors and nurses – not as a document, nor as a guideline, but most frequently as a set of instructions and prescriptions, that is to say a protocol’.²⁰
15. We would add that the misuse of LCP as a ‘tick box exercise’, a misuse referred to repeatedly by the Review,²¹ cannot be traced primarily to the regrettable lack of clarity in terminology. Even if misconstrued as ‘a protocol’, the LCP should be more than a tick-box exercise, for protocols also have to be applied intelligently and with attention to the patient’s needs. The misuse highlighted by the Review is related to a wider issue concerning the ethos of care, and *virtue*²² – the virtue of (to say the least) attentiveness.

Evidence

16. Though the LCP is put forward as ‘an evidence-based framework for the delivery of care in the last days or hours of life’,²³ the Review panel finds ‘significant gaps in evidence about the LCP’²⁴. These are basically of two kinds:
17. In the first place there is a lack of robust evidence for the effectiveness of the LCP in comparison with other forms of support for managing the dying phase. Related to this lacuna is the lack of evidence of which factors, ‘such as training, on-going expert support, or the environment’,²⁵ result in good or poor implementation of the LCP.
18. A second gap, not specific to the LCP, relates to part of the evidence base for the care of the dying, namely, ‘the biology and experience of dying’²⁶ and the effects of various interventions on dying patients. There is some robust evidence in this area,²⁷ but much is related specifically to cancer and/or

¹⁶ *More Care, Less Pathway*, page 16, 1.14.

¹⁷ *More Care, Less Pathway*, page 16, 1.15.

¹⁸ *More Care, Less Pathway*, page 16, 1.16.

¹⁹ *More Care, Less Pathway*, page 16, 1.17.

²⁰ *More Care, Less Pathway*, page 16, 1.18.

²¹ *More Care, Less Pathway*, page 3; page 11; page 29; page 34, 1.90; page 49, 3.13.

²² Atkins, M. 2012. ‘Care or Neglect? Underneath the LCP’ *Catholic Medical Quarterly* 62(3): 23-26.

²³ *More Care, Less Pathway*, page 16, 1.15 quoting *End of life care strategy. Fourth Annual Report*. Department of Health, October 2012 (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf).

²⁴ *More Care, Less Pathway*, page 17, 1.22.

²⁵ *Ibid.*

²⁶ *More Care, Less Pathway*, page 5; page 18, 1.25-6.

²⁷ For example, *More Care, Less Pathway*, page 26, 1.54; page 28, 1.68.

specifically to a hospice setting.²⁸ There is a significant gap in robust evidence for some areas of care of dying people. The report panel note that ‘well below one per cent of research funding is devoted to end of life care’²⁹ and highlights a number of areas which would benefit from more research.³⁰

Diagnosis of imminent dying and initiation of the LCP

19. A key concern raised by the Review is that the LCP is designed specifically to support care ‘in the last days or hours of life’,³¹ whereas the existing tools for improving the accuracy of prognosis of death are not yet (and indeed may never be) ‘sensitive enough to identify reliably those who will die within hours or days’.³²
20. The Review panel paid particular attention to the question of prognosis of death. A number of recommendations call for greater research into the biology³³ and prognosis³⁴ of dying, and better guidance³⁵ and training³⁶ in the use of evidence-based prognostic tools, better communication³⁷ of the uncertainties, and better guidance on ‘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’.³⁸
21. With these important caveats, the Review panel nevertheless affirms the principle that there can be appropriate and good care that is specifically ‘care for the dying’,³⁹ with the implication that prognosis of dying (including of imminent dying) is relevant to good patient care. The Review panel did not accept the argument of some clinicians that because prognosis is uncertain it should never inform the pattern of care or conversations with patients or relatives. Indeed the Review states that it **‘fully recognises the valuable contribution that approaches like the LCP have made in improving the timeliness and quality of clinical decisions in the care of dying patients. It is therefore vital that the comments which follow below do not result in clinicians defaulting back to treating dying patients as though they are always curable, for fear of censure.’**⁴⁰

²⁸ *More Care, Less Pathway*, page 30, 1.76.

²⁹ *More Care, Less Pathway*, page 18, 1.25.

³⁰ *More Care, Less Pathway*, page 5; page 6; page 18, 1.25-6; page 20, 1.36; page 30, 1.76; Recommendations 5, 6, 9, 10, 24.

³¹ *More Care, Less Pathway*, page 16, 1.15 quoting *End of life care strategy. Fourth Annual Report*. Department of Health, October 2012 (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf).

³² *More Care, Less Pathway*, page 20, 1.32.

³³ *More Care, Less Pathway*, page 18; 1.25.

³⁴ *More Care, Less Pathway*, page 20, 1.36.

³⁵ *More Care, Less Pathway*, page 20, 1.35.

³⁶ *More Care, Less Pathway*, page 22, 1.38.

³⁷ *More Care, Less Pathway*, page 6.

³⁸ *More Care, Less Pathway*, page 22, 1.38; page 54, rec. 12.

³⁹ *More Care, Less Pathway*, page 3; page 7; page 8 (three times); page 9 (twice); page 10 (twice) and throughout the document.

⁴⁰ *More Care, Less Pathway*, page 21 bold in original.

22. On the other hand, in relation to the decision to initiate the LCP, the Review panel ‘heard stories of relatives or carers visiting a patient, only to discover that without any forewarning there had been a dramatic change in treatment... They were told that, following an overnight decision by a relatively junior clinician, this patient had been “placed on the pathway”’.⁴¹ The Review recognises that this practice is utterly unacceptable, and that ‘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’.⁴²
23. In relation to diagnosis of imminent dying, and the decision to initiate a plan of care appropriate to the last hours or days of life, the Review again sets out a sound *via media*. The Review recognises the uncertainty of such diagnoses, and makes recommendations aimed both at improving their accuracy and at acknowledging their uncertainty (in relation to decision-making and in relation to communication). However, it rightly does not regard this uncertainty as reason to abandon the very idea of care specifically directed to patients who are dying. Care for the dying requires the virtue of good sense (*prudentia*, principled but with an element that is experience-, circumstance-, and case-relative) if it is to work well in practice. Acknowledging the need for virtue here is ethically sounder, we think, than implicitly adopting the vitalist⁴³ rule: ‘treat dying patients as though they are always curable’.⁴⁴

Consent, explanation and involvement

24. Another issue of law and medical ethics that has been troublesome is whether consent of the patient is needed in order to initiate the LCP. The Review states that ‘the LCP is not a single, simple medical procedure, and there is no legal requirement for consent to be sought before it is commenced.’⁴⁵ Still, ‘for aspects of the LCP that do involve medical treatment – for example, starting, continuing or stopping the use of strong analgesia or sedation, artificial nutrition or hydration – discussion and consent will be appropriate’,⁴⁶ and ‘if a patient lacks capacity, the Mental Capacity Act 2005 (MCA) applies to any medical decision that is taken on their behalf’.⁴⁷
25. The Review found that there was considerable misunderstanding and uncertainty both among relatives and among healthcare professionals about which aspects of the LCP required consent and how decisions about these were to be made where the person lacked capacity. **‘In some cases, relatives**

⁴¹ *More Care, Less Pathway*, page 22, 1.41.

⁴² *More Care, Less Pathway*, page 22, 1.4.

⁴³ On ‘vitalism’ as a term referring to an ethical stance see John Keown *Euthanasia, Ethics, and Public Policy: An argument against legalisation* (Cambridge: Cambridge University Press, 2002), Part II.

⁴⁴ *More Care, Less Pathway*, page 21 bold in original.

⁴⁵ *More Care, Less Pathway*, page 23, 1.45.

⁴⁶ *More Care, Less Pathway*, page 23, 1.46.

⁴⁷ *More Care, Less Pathway*, page 22, 1.44.

and carers incorrectly consider they are entitled to decide what treatment their relatives receive, and in others clinicians fail to seek consent or consult the relatives and carers in a “best interests” assessment when they should.’⁴⁸

26. The Review was also ‘deeply concerned’⁴⁹ that the GMC’s guidance *On Treatment and Care towards the end of life* (May 2010), which sets out a ‘proper process of joint decision-making’, is not always being followed. ‘Failure to discuss the prognosis and the care plan with patients and their relatives or carers is unacceptable practice, leading to untold levels of distress that severely impact relatives’ and carers’ experiences of the dying process and subsequently their bereavement.’⁵⁰
27. The Review has set out well the legal and ethical requirement for consultation and consent in the treatment of patients who are dying (irrespective of whether these patients are supported by the LCP or a similar framework). It might helpfully have gone on to distinguish plainly between using a ‘pathway’ in the sense of a framework or piece of guidance (which does not generally require consent) and implementing an individual ‘care plan’ of the kind which it recommends in place of pathways and which on any reading of the relevant law and GMC guidance surely not only requires consultation with the patient but also, as to certain of its aspects, will clearly require consent or at least, if the person lacks capacity, a best interest decision informed by consultation with those who know that person.

Hydration and nutrition

28. Another important finding is that there have been recurrent failures to give adequate support for nutrition and hydration, including oral nutrition and hydration. The Review notes, with approval, that it is a goal of the LCP that the patient be ‘supported to take oral fluids/thickened fluids for as long as is tolerated’.⁵¹ However, most of the submissions from relatives or carers which were critical of the LCP made reference to nutrition and hydration, from which the Review concludes that, ‘far too often the LCP advice is not being followed’,⁵² and presumably also that the GMC’s ‘good advice to doctors on clinically assisted nutrition and hydration’⁵³ is likewise too often neglected.
29. In relation to nutrition and hydration generally, the Review emphasises the obligation that these should be provided: ‘The Review panel considers that the current version of the LCP, version 12, does not go far enough to adjust the language of the previous version, to advise that the default course of action should be that patients be supported with hydration and nutrition unless there

⁴⁸ *More Care, Less Pathway*, page 23 bold in original.

⁴⁹ *More Care, Less Pathway*, page 25, 1.50.

⁵⁰ *Ibid.*

⁵¹ Goal k in section 2 of the LCP document, cited at *More Care, Less pathway*, page 26, 1.53.

⁵² *More Care, Less Pathway*, page 26, 1.53.

⁵³ *More Care, Less Pathway*, page 27, 1.56, citing *Treatment and Care towards the end of life: good practice in decision making*, General Medical Council, May 2010, pp.54-59 (http://www.gmc.uk.org/Treatment_and_care_towards_the_end_of_life___English_0513.pdf_48902105.pdf)

is a strong reason not to do so'.⁵⁴ It may be that the desire for food and drink diminishes as a patient approaches the end of life. However, the panel is clear that 'refusing food and drink is a decision for the patient to make, not clinical staff'.⁵⁵ Still, 'at the end of life, a person may become overhydrated, and there is no moral or legal obligation to continue to administer clinically assisted hydration or nutrition if they are having no beneficial effect'.⁵⁶ Here, as on other questions, the Review adopts a nuanced *via media* that appears to us sound.

30. In relation to *clinically assisted* nutrition and hydration, the Review should, we think, have called attention to the requirement that doctors make an assessment of need, a requirement not emphasised with sufficient clarity in the LCP documentation. The GMC guidance is unequivocal on this point: 'If you are concerned that a patient is not receiving adequate nutrition and hydration by mouth, even with support, you *must* carry out an assessment of their condition and their individual requirements. You *must* assess their needs for nutrition and hydration separately and consider what forms of clinically assisted nutrition and hydration may be required to meet their needs.'⁵⁷
31. The Review's recommendation that 'Failure to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct'⁵⁸ should thus be augmented: **Failure to assess a patient's need for nutrition and hydration, or to consider what forms of clinically assisted nutrition and hydration may be required, should be regarded as professional misconduct.**
32. In general the Review expresses well the clinician's obligations in relation to nutrition and hydration. However, the observation that 'refusing food and drink is a decision for the patient to make',⁵⁹ while helpful for what it excludes, is insufficient in so far as it leaves unexamined the reasons or motives different patients may have for making such a refusal. Healthcare professionals have an obligation to assess and address any underlying physical or psychological causes that could inhibit someone from eating or drinking; 'for example, some patients stop eating because of depression, or pain caused by mouth ulcers or dentures, or for other reasons that can be addressed'.⁶⁰
33. Furthermore, considering the ethical obligations on all concerned, it may well be the case that, even though healthcare professionals should respect a competent refusal of food or fluid, the patient nonetheless has a duty not to

⁵⁴ *More Care, Less Pathway*, page 25, 1.53; page 7.

⁵⁵ *More Care, Less Pathway*, page 27, 1.58.

⁵⁶ *More Care, Less Pathway*, page 7; 1.54.

⁵⁷ *Treatment and Care towards the end of life*, page 53, paragraph 111, emphasis added. Note that the where GMC guidance uses the word 'must' this represents 'an overriding duty or principle' (*Treatment and Care towards the end of life*, page 7).

⁵⁸ *More Care, Less Pathway*, page 57, recommendation 21; page 28, 1.64.

⁵⁹ *More Care, Less Pathway*, page 27, 1.58

⁶⁰ *Treatment and Care towards the end of life: good practice in decision making*, General Medical Council, May 2010, page 52, para 110 (http://www.gmc.uk.org/Treatment_and_care_towards_the_end_of_life___English_0513.pdf_48902105.pdf)

refuse them. Due respect for my life generally obliges me to accept food and fluids and ‘ordinary’ treatment and care which is not futile or burdensome. This is not an issue that the Review addresses.

Sedation and pain management

34. The Review panel heard many accounts about dying people who ‘were started on strong pain killers, such as morphine, and/or sedatives by a continuous subcutaneous infusion, as a matter of course, not because of a need for symptom control.’⁶¹ At best this was an impression given to bystanders as a result of a failure of communication; at worst it was an accurate picture, reflecting ‘**a “tick-box” exercise, through which the next step was to stop food and fluids and give continuous infusions of strong opioids and sedatives without justification or explanation.**’⁶² Such a step, the Review is clear, would be ‘clinically indefensible’.⁶³
35. The seemingly routine use of a syringe driver with morphine is not only clinically indefensible, it also, as the Review recognises, threatens the wellbeing of those patients ‘for whom remaining lucid is their overwhelming priority; this is a position adopted by some religious traditions and by some individuals, irrespective of any religious belief.’⁶⁴ This is an important ethical principle, affirmed within Catholic tradition. It is quite common that people slip into unconsciousness naturally as part of the process of dying,⁶⁵ but ‘it is not right to deprive the dying person of consciousness without a serious reason.’⁶⁶
36. The Review did not think it appropriate for them to ‘make a judgement on the correct usage of morphine and other painkilling drugs’.⁶⁷ Nor did it address the question of whether the use of sedatives on the LCP has, in cases of the kind considered in paragraphs 34 and 35 above, been analogous to the practice of *continuous deep sedation* as used in the Netherlands. The panel was wise not to address these questions. Audit evidence suggests that the doses of sedative typically used on the LCP are considerably lower than the doses

⁶¹ *More Care, Less Pathway*, page 29, 1.67.

⁶² *More Care, Less Pathway*, page 29 bold in original.

⁶³ Page 30, 1.72.

⁶⁴ *More Care, Less Pathway*, page 30, 1.72. See also MY Rady and JL Verheijde, ‘Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death?’ *American Journal of Hospice & Palliative Medicine* 27(3) (2010): 205-214: ‘The irony of incorporating continuous deep sedation into the practice of palliation is that 96% of terminally ill patients and 65% of treating physicians in the United States consider mental alertness an important attribute at the end of life’.

⁶⁵ For example, in a study of nursing home patients in The Netherlands, 25% of patients had slipped into unconsciousness by 24 hours prior to death and a further 19% slipped into unconsciousness in the last 24 hours, Hella E. Brandt et al., ‘The last two days of life of nursing home patients - a nationwide study on causes of death and burdensome symptoms in the Netherlands’. *Palliative Medicine* 20 (2006): 537.

⁶⁶ Pope John Paul II *Evangelium Vitae* para 65 quoting Pius XII, ‘Address to an International Group of Physicians’ (24 February 1957), III: AAS 49 (1957), 145.

⁶⁷ *More Care, Less Pathway*, page 30, 1.71.

recommended in the Netherlands,⁶⁸ but this is beside the point. The key ethical questions are not whether prescribing practice is like the Netherlands, or what the precise figures for the typical doses are. The key ethical questions are whether patients are being assessed adequately for pain and agitation, and whether decisions to prescribe analgesics and sedatives are justified, are free from any intent to euthanise or to assist suicide, and are properly communicated. It bears repeating that the Review found credible evidence that ‘too often it appears that a syringe driver is put in place as the “next step” on the LCP, *overlooking the needs and wishes of the patient*’,⁶⁹ and that at least some of the decisions to do so have been ‘clinically indefensible’.⁷⁰

Good care of the dying is not assisted dying

37. While the Review panel recommends the replacement of the LCP, it does not consider that the problem lies with the ethical principles embodied by the LCP: ‘The Review panel is content, however, that the LCP entirely reflects the ethical principles that should provide the basis of good quality care in the last days and hours of a person’s life’.⁷¹
38. According to the Review, ‘The present religious and secular consensus is that any attempt deliberately to shorten a person’s life is morally wrong as well as illegal, but that there is no obligation, moral or legal, to preserve life at all costs. If a treatment is burdensome and futile, it is right to refuse or stop it. It should be noted, however, that some patients might prioritise consciousness over pain relief and sedation’.⁷²
39. The Review overstates the case in saying that there is a secular consensus that ‘any attempt deliberately to shorten a person’s life is morally wrong’.⁷³ Those who wish – and those who regularly press Parliament and the courts – to legalise euthanasia and assisting suicide quite evidently regard some deliberate shortening of life as morally acceptable. Nor is the deliberate shortening of life always ‘illegal’. In the case of patients diagnosed as being in a persistent vegetative state (PVS) the law permits withdrawal of clinically assisted nutrition and hydration notwithstanding that the decision to do so may deliberately aim to shorten life. Nevertheless, setting aside the question how far secular opinion supports it or the law adequately expresses it, the principle itself (that any attempt deliberately to shorten a person’s life is morally wrong) is morally sound and important.
40. The Review panel addresses the question of whether the LCP, used properly, reflects the ethical principles of good quality treatment and care towards the end of life and concludes that it does. Nothing in the formulation of the LCP

⁶⁸ J. Stephenson, ‘The Liverpool Care Pathway’, *Triple Helix* (Winter 2012): 14-15, though it should be noted that this evidence only addresses the *typical* use of the Pathway, not its misuse in individual cases.

⁶⁹ *More Care, Less Pathway*, page 30, 1.72 emphasis added.

⁷⁰ Page 30, 1.72.

⁷¹ *More Care, Less Pathway*, page 8; page 33, 1.86.

⁷² *More Care, Less Pathway*, page 33, 1.87.

⁷³ *Ibid.*

either mandates or warrants the intentional hastening of death or any other intrinsically evil choice. The LCP can be used well by a conscientious multidisciplinary team.

41. The Review has highlighted cases where the LCP was not used well. The panel do not directly address the question of whether on some occasions the LCP may have been used deliberately to shorten life. Nevertheless, based on the evidence it received of ‘premature, or over-prescription of strong pain killing drugs... [and] apparently unnecessary withholding or prohibition of oral fluids’,⁷⁴ and of ‘poor communication between clinicians and patients, their relatives and carers about what was happening during the dying process’⁷⁵ the panel ‘understands only too well how this fear has arisen’.⁷⁶

Wider issues

42. In general, the Review considered that many of these failures of care were due to failures of communication: ‘**Perfectly preventable problems of communication between clinicians, relatives and carers appear to account for a substantial part of the recent controversy and unhappiness surrounding the LCP.**’⁷⁷ As we have noted, the Review also expresses concern that the advice available in the LCP and guidance provided by the GMC⁷⁸ are not being followed in practice.⁷⁹
43. Other general issues identified include: problems of accountability (and clarity about who had overall responsibility for the care of a patient); failures of compassion and failure to respect the dignity of older patients; and problems of availability of staff and equipment (an aspect of the issue of fair allocation of healthcare resources). To these the Review implicitly adds the ‘tick box’ mentality it mentions so often in its report. This, in essence, is a preference for defaulting to easy automatic processes which do not require thought or attention.
44. These wider issues are not easily addressed. They require a culture shift (to a culture more supportive of virtuous practice, what Pope John Paul II called a ‘culture of life’⁸⁰). Their identification is to be welcomed as the necessary pre-requisite to the task of addressing them.

Some reflections on the Review’s recommendations

45. The failures of care identified by the Neuberger Review panel do not show that care was better prior to the implementation of the LCP or would be better

⁷⁴ *More Care, Less Pathway*, page 8

⁷⁵ *More Care, Less Pathway*, page 3-4

⁷⁶ *More Care, Less Pathway*, page 33, 1.86.

⁷⁷ *More Care, Less Pathway*, page 24 bold in original.

⁷⁸ General Medical Council, *Treatment and care towards the end of life*. (London: GMC, 2010): paragraphs 112-127.

⁷⁹ *More Care, Less Pathway*, page 7 (twice); page 25, 1.50; page 26, 1.53.

⁸⁰ *Evangelium Vitae* paragraphs 78-101

if the LCP were abandoned without giving sufficient thought to its replacement. The Review itself notes that ‘before the widespread introduction of the LCP into hospitals, the care that patients received was variable and there were many examples of poor care.’⁸¹ Nevertheless, the failures considered by the Review associated with the LCP’s use in England represent an unacceptable level of care. It seems unlikely that the causes of these failures would be addressed adequately if the status quo were maintained.

46. It is for this reason that the Review urges a ‘sea change that is urgently needed to raise the quality of care for the dying’.⁸² To signal and facilitate this sea change the panel recommends that the LCP should be replaced by ‘an end of life care plan for each patient, backed up by condition-specific good practice guidance’.⁸³ This would involve, among other things, a senior clinician having a face to face conversation which would include explaining ‘that the patient is now dying and when and how death might be expected to occur, using language which is clear, direct and unambiguous’.⁸⁴
47. The proposal to replace the LCP is only one of 44 recommendations of the panel. Some of these are entirely unproblematic: all of the recommendations for further research fall into this category. In some other cases, however, it remains unclear how the recommendation will be specified and made operational in detail (for example, the design, format and content of the ‘end of life care plan’). It is noteworthy that both the recommendation to create condition-specific guidance on treatment and care towards the end of life, and the recommendation to replace the LCP, are phrased in the passive voice: ‘A series of guides and alerts *should be developed*’, ‘Use of the Liverpool Care Pathway *should be replaced*’. The panel does not specify who should create this guidance, who should oversee this process of replacement, and what precisely the replacement arrangements will be.
48. The Review makes a good argument for better coordination between the many organisations and agencies involved in regulating end of life care. It does not, however, identify who would have overall responsibility for certain key elements of this project of coordination. Some of its recommendations implicitly depend on this problem being addressed adequately. One example: the recommendation that the task of audit and inspection of care of the dying should be undertaken by the already overstretched Care Quality Commission seems to overlook recent criticism of that body.
49. In some cases the recommended changes may even bring new risks and bad outcomes. For example, a problem identified by the Review is the tendency to treat the LCP not as a framework for decision-making but as a protocol – a kind of formula for decision, or a formulaic decision making.⁸⁵ If the root causes of this attitude are not addressed, there is a significant risk that any new

⁸¹ *More Care, Less Pathway*, page 47, 3.1.

⁸² *More Care, Less Pathway*, page 47, 3.4.

⁸³ *More Care, Less Pathway*, page 10; page 17, 1.21; page 38-39, 2.17-2.20.

⁸⁴ *More Care, Less Pathway*, page 39, 3.18.

⁸⁵ *More Care, Less Pathway*, page 16, 1.18.

‘condition-specific good practice guidance’⁸⁶ will similarly be regarded as a set of protocols, albeit ‘condition-specific’. Indeed, the more specific the guidance tool, the greater the danger that some will use it not as a prompt to clinical judgment but as a substitute for clinical judgment. It is not easy to know how to support attentiveness to patient needs in a context of intense time and resource pressures, but if such attentiveness is not present then whatever replaces the LCP will be sure to suffer from analogous problems.

50. The recommendation that the LCP be replaced within 12 months is another challenge. The rationale for replacing the LCP can only be that it should be replaced by something that is better, that incorporates all ‘the positive aspects of the LCP’⁸⁷ while (further) enhancing individualised care. Any replacement must be *at least* as well-designed as, and if anything better supported by training, research, audit and governance than the LCP is currently, and this will not be easy to do quickly (the current version of the LCP is, as we have noted, the 12th iteration of it).
51. The Review noted a remarkable evidence gap in relation to the LCP: ‘**No research has yet produced evidence by robustly comparing these pathways with other forms of care**’.⁸⁸ It is also important therefore that, if new ‘end of life care plans’ linked to ‘condition-specific guidance’ are introduced, this be done in such a way as to include assessment of their effectiveness in a robust manner (both in comparison to the LCP and analogous pathways, and in comparison to deaths managed without the support of any care plan or pathway).
52. In general, the Review’s recommendations might conceivably have been even stronger and clearer had it given more express attention to examples of *good* practice, whether using the LCP or other approaches to managing end of life care. In general in ethics and moral life, the identification and correction of vices, while important, is no substitute for the characterisation and pursuit of virtue. In the context of care of the dying, there is still work to be done to establish agreement (among clinicians and patients and their families) about what excellence of care looks like across different settings.
53. There is therefore reason to be cautious or conditional in accepting some of these recommendations, and it remains unclear how the diverse recommendations will be integrated in a single programme of change. On the other hand, the recommendations clearly need to be taken together rather than just one by one. The greatest danger at this juncture is probably that the most high profile recommendation might be implemented (the replacement of the LCP) without the implementation of other recommendations that is needed to ensure that care actually improves.

⁸⁶ *More Care, Less Pathway*, page 47, 3.3; page 57, rec. 38.

⁸⁷ Bishop P. ‘Egan Message from Bishop Philip about the Liverpool Care Pathway’ (13th July 2013) http://www.portsmouthdiocese.org.uk/bishop/talks_and_addresses/20130713-BoP-Message-about-the-LCP.php;

⁸⁸ *More Care, Less Pathway*, page 17.

54. Bearing in mind the need to take all the recommendations together as a programme for positive change, the **Anscombe Bioethics Centre endorses the recommendations of the Independent Review of the Liverpool Care Pathway, including the recommendation that the LCP should be replaced by ‘an end of life care plan for each patient, backed up by condition-specific good practice guidance’**, subject to all the recommendations being re-evaluated in the light of future evidence. For ease of reference, we append the full list of 44 recommendations.
55. The Review has highlighted problems in care of the dying and has initiated a process of positive change. It remains essential that ‘whatever pathway, plan or framework is adopted, it must be implemented ethically, with care for the patient always as the first priority’.⁸⁹
56. The Anscombe Bioethics Centre has set out some of the key ethical principles which must inform the design and implementation of any plan or framework to support treatment and care of dying patients.⁹⁰ The governing principle is: ‘The life of every human being, as made in the image of God, possesses an intrinsic worth or dignity which must be given strict respect in accordance with the fundamental requirements of justice.’⁹¹

Agreed on 9 September 2013 by the Director and the Governing Board of the Anscombe Bioethics Centre.

Professor David Albert Jones MA MA MSt DPhil FHEA (Director)
Rev Dr Michael Jarmulowicz KSG FRCPath MB BS BSc (Chairman)
Most Rev Mario Conti KCHS PhL STL DD FRSE
Most Rev Donal Murray DD
Most Rev Peter Smith LLB JCD
The Rt Rev John Cunningham
Mrs Elizabeth Bano MA
Rev Adrian Cullen BSc MBA
Dr John Curran MB PhD FRCA
Professor John Finnis LLB MA DPhil FBA
Mrs Clarissa Fleischer BSc MSc
Professor Luke Gormally KSG Lic Phil
Dr Andrew Hegarty MA DPhil
Dr Luke Howard MA MB BChir DPhil FRCP
Mr James McManus FFPH CPsychol CSci AFBPsS
Dr Joseph Shaw BA DPhil (Oxon)

⁸⁹ Archbishop P. Smith ‘Archbishop’s Response to the Review of the Liverpool Care Pathway’ (17 July 2013) <http://www.catholicnews.org.uk/LCP-review-response-160713>

⁹⁰ Anscombe Bioethics Centre ‘Ethics of Care of the Dying Person’ (12 July 2013)

<http://www.bioethics.org.uk/images/user/TheEthicsofCareoftheDyingPersonwebsite.pdf>

⁹¹ ‘Ethics of Care of the Dying Person’, paragraph 3.

Appendix: The 44 recommendations of the Independent Review of the Liverpool Care Pathway

Terminology

1. 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.

Evidence base

4. 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.

Falsification of documentation

7. 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.

Diagnosis of dying – prognostic tools

8. NHS England and Health Education England should collaborate to promote: the use of evidence-based prognostic tools, including awareness of their limitations; and 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.

9. 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.

Diagnosis of dying – communicating uncertainty

10. 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.
11. 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.

Guidance on diagnosis of dying

12. Clear guidance should be issued by the National Institute of Health and Care Excellence on: diagnosis and who should ultimately be responsible for diagnosing that someone is beginning to die; the necessity for multidisciplinary decision-making; the usefulness or otherwise of laboratory and other biological evidence; the importance of case notes review for diagnosis; 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.

Good practice guidance for nurses on decision-making

13. 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.

Decisions to initiate an end of life care plan out of hours

14. 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.

Training in shared decision-making

16. 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.

Nutrition and Hydration

17. 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.

Sedation and pain relief

23. 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.

Financial incentives

25. Payments ‘per patient implemented on the LCP, or equivalent approach’ should cease.

Accountability

26. 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.

Documenting an end of life care plan

29. 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: That the clinician explained that the patient is now dying and when and how death might be expected to occur. If the family or carers do not accept that the patient is dying, the clinician has explained the basis for that judgement; That the relatives or carers had the opportunity to ask questions.
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.

Independent advocacy

32. 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.

Availability of palliative care support

33. 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.

Guidance for nurses in end of life care

34. 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 (see recommendation 13).

Education in care for the dying

35. 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.

Guidance

36. 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.

End of life care plan

38. 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.

A system-wide, strategic approach to improving care for the dying

39. 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.

Under this approach, the GMC and NMC would take the lead with the Royal Colleges, Health Education England and NHS England in:

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.

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.

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.

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 and then inspect against those standards.

Hospital inspections

40. End of life care should be incorporated urgently into the hospital inspection programme of the newly announced Chief Inspector of Hospitals.

Thematic review of end of life care

41. 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.

Mandate to NHS England

43. 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.