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Liverpool Care Pathway Review  
*Department of Health*  
Richmond House  
79 Whitehall  
London  
SW1A 2NS

4 April 2013

Dear Baroness Neuberger,

Please accept the following as the submission on behalf of the Care Not Killing Alliance to the Liverpool Care Pathway Review.

Care Not Killing is an alliance of some 40 organisations including medical professionals, disability rights campaigners and faith groups who support our threefold mission to promote good palliative and end-of-life care, to oppose the legalisation of euthanasia and assisted suicide, and to influence public debate on these issues.

We have been constantly engaged with the issues surrounding the LCP in the media, and were also represented at Minister Lamb's roundtable talks in Whitehall last year. I hope you find the following of value.

Let me begin by thanking you for your statement that *'the issue is... not about the merits of the LCP itself, but about how it is being used'*. We agree that the LCP is a valuable tool which has helped many thousands of patients to experience reduced pain and distress at the end of life, and it is essential that misapplication should not mean the loss of a protocol which continues to benefit people right round the country.

A key question relates to the **comprehensive failure to explain and defend the protocol** by the Department of Health and health authorities. This doubtless stems from the fact that very few treatment protocols are named and critiqued in this public fashion, but the current controversy presents an unmissable opportunity to ensure that the Department, health authorities and frontline medical professionals are in a position to explain why certain protocols are being implemented and what they entail. For example, many stories emphasised the role of dehydration in LCP deaths, but the fact that most patients are dying within 33 hours of being placed upon it tells us that they are dying not from dehydration but from their underlying conditions. Why are the public not hearing the messages that the LCP in no way requires the withdrawal of hydration, that patients in the last hours or days of life often do not utilise fluids



well and have no desire to drink or that, in any case, people usually take 10-20 days to die from dehydration? Why are the public and some clinical staff not getting the message that the LCP encourages only treatments that are appropriate to a patient's specific symptoms: anxiolytics should only be given for anxiety, pain relief only for pain, antiemetics only for nausea etc. Care must not be given in a blanket fashion but carefully individualised for each patient. It also needs to be made clear that morphine given appropriately to relieve pain does not shorten life and that the doses of anxiolytics and sedatives recommended in the LCP do not produce 'deep sedation'.

The Independent Review's terms of reference mention accusations laid against the pathway, including that 'doctors select people to be killed on the LCP without telling them or their relatives [and that] it is used to clear beds and save money'. Appropriate bodies should be able to clarify such matters swiftly for the good of patient care, and the inability to do so demonstrates an urgent need for a health service that can be communicative and responsive.

Regarding the Review's specific terms of reference:

- ***Examine systematically the experience of patients and families of the use of the Liverpool Care Pathway*** – successive audits have demonstrated overwhelming support for the LCP from families, and too little has been done to reassure a general public confronted with unrepresentative horror stories in the press. These ought to have been more strongly challenged to maintain trust in clinical judgement and in protocols with strong track records.
- ***Examine the experience and opinions of health professionals about the use of the Liverpool Care Pathway*** – our extensive contact with doctors and nursing staff through our member organisations has shown that the LCP is an incredibly useful tool to help frame end-of-life care decisions, but a significant number have remarked that their implementation is impacted or influenced by insufficient training, inadequate supervision by senior staff and pressure from clinical management. We have also been made aware of concerns relating to continuity of care: this was demonstrated by Professor Patrick Pullicino in Channel 4's *Dispatches* programme, in which he described one of his patients being placed on the Pathway by weekend junior medical staff in his absence.

In light of the many issues that have been raised with regard to the LCP, we commend to you the following ten proposals which we believe will help eliminate abuses and ensure a return to effective and appropriate implementation of a framework whose principles are fundamental to care of the dying.

1. It should be made absolutely clear that only patients at risk of dying within two or three days, should be placed on the LCP. Regular reassessments must take place and patients who show improvement should be taken off it. These assessments should be made by senior clinicians.





2. No one should be placed on the LCP without it being discussed with the relative or carer (although the latter are not required to give consent under present legislation)
3. Every patient placed on the LCP must be regularly monitored and reassessed by a multidisciplinary team as stipulated in the existing pathway.
4. The present documentation for clinical staff is far too complex and needs to be simplified and standardised so that those implementing it can easily follow the guidelines and supervisors can easily tell what is going on with each patient.
5. Training and supervision of those using the pathway needs to be standardised and improved and formal training should be required before any healthcare professional is able to use it.
6. Participation in a national annual audit programme should be mandatory for all organisations using the LCP and all suboptimal use identified promptly acted upon.
7. Non-clinical priorities in the use of the pathway, especially financial priorities, must be eradicated and every patient treated solely according to their need. In this connection it would be far better to link CQUIN payments to staff training in the use of the pathway rather than numbers of patients placed on the pathway.
8. Communication with relatives by both health professionals and organisations involved in LCP implementation needs to be substantially improved.
9. Those misusing the LCP should be quickly identified and in the case of abuse reported to the appropriate authorities (e.g. General Medical Council or Nurses and Midwifery Council).
10. In order to restore public confidence, the framework will almost certainly, in addition to the above nine modifications, need repackaging and rebranding. We expect that a new name avoiding the words 'Liverpool' and 'Pathway' will be necessary. 'Liverpool' is not appropriate for a national guideline and 'pathway' implies a one-way street and unthinking blanket approach rather than a clinical framework encouraging staff to respond to each patient as an individual using a tailored, personalised approach to care in the very last days of life.

These proposals we commend to you with a wish to maintain, enhance and ensure proper use of a valuable tool which has been of great help and comfort to any thousands of patients. We wish you well in your deliberations, and await your review's outcome with great interest.

Yours sincerely,

**Dr Peter Saunders**  
Campaign Director