



Response of Care Not Killing Alliance to the consultation document,  
***‘Leadership Alliance for the Care of Dying People: Engagement with patients,  
families, carers and professionals’***

Submitted 28 January 2014

The content of this submission should be read alongside the consultation document,  
as answers are broken down according to ‘outcomes’ listed in said document.

***1. Do you agree with the proposed outcomes? If not, how can they be improved?***

We agree with all outcomes. We comment specifically on the following:

- B. The prominence given to the ‘emotional, psychological, social and spiritual needs’ is welcome, as is their continued reference throughout. We welcome the move to re-assessment at least daily.
- C. Communication is key.
- D. Multi-disciplinary discussion and decision-making are key.
- F. However, generalist medical, nursing and social work staff are going to have to cope after adequate training with the majority of end of life care. There will never be enough specialists for every patient.
- J. Recommend that this outcome should receive higher priority.

***2. Are the guiding principles right and sufficient to achieve the particular outcomes? If not, how can they be improved?***

We agree in general but make the following specific comments:

- A. Use of ‘regularly’ and ‘time to time’ is unhelpful; although guidance on these themes is given later, ‘regularity’ should be more clearly defined.

While healthcare professionals should have an understanding of how legal devices such as Lasting Powers of Attorney affect their work, they are not legal experts and should not be expected to advise on these.

It is crucial that the principle that ‘*treatment can be legally refused... but specific treatments cannot be demanded*’ be made explicitly clear to patients and families.

- B. The focus on re-evaluation, multi-disciplinary decision making and proper training is very welcome, but the LACDP must devise guidance emphasising the shift from ‘*maintain life and wellbeing... towards palliation and preserving the individual’s*

*comfort and dignity*'. Many palliative care practitioners have recently found the negative image portrayed of their work following LCP coverage has damaged their ability to do their best for their patients.

Point 6 should more explicitly note that an inability to swallow does not necessarily preclude capacity to communicate, as suggested by the immediate link with 'best interests'. Withdrawal of fluids was one of the most contentious issues concerning use of the LCP, and this issue must be dealt with much more carefully.

Points 7 & 8 are excellent on decisions concerning medications. Point 9 confirms the dual importance of consultation and explanation, and also in putting the patient's needs first.

- C. Point 1 needs to strike a balance between recording necessary information adequately without the process becoming so laborious that it engenders a 'tick box' mentality.

Point 3 should be given top priority.

Point 4 is welcome but should be read with E1 – individual care plans do not make up for fractured decision-making.

- D. As at C1, we reaffirm regarding point 2 the importance of avoiding excessive bureaucracy.

Point 5 is very welcome.

- E. These are amongst the most necessary of the guiding principles, with point 1 especially clear.
- F. It should be clearer to patients that palliative care is a multi-disciplinary concept, but only some cases require specialist palliative intervention.
- G. While we embrace an approach which supports families, is point 1 about primary care, secondary care, or both?
- I. Point 2 should make clear that much bereavement care will be long-term and carried out in the community.

- 3. ***Do you agree that anyone who has a progressive life-limiting condition should be offered opportunity to develop, document, review and update a personalised palliative care plan, rather than a plan that focuses only on the last days of life?***

No - this is a sensitive and potentially controversial area. Medical prognosis is notoriously difficult and it would be inappropriate and an impossible burden on resources to carry out this generally worthy principle in every potentially possible case.

- 4. ***If you agree with the proposal to offer a personalised palliative care plan, do you agree with calling it a 'Personal Palliative Care Plan'? If not, what should it be called?***

No - if any eventual document is to be used by patients and their families and carers, we think the language of 'Personal Palliative Care Plan' is too cold and professional; it explains the document's purpose but does not give a sense of ownership to the patient. We suggest using

this as a subtitle, with a warmer and more personal headline description such as ‘How I would like you to care for me as I approach the end of my life.’

5. *If personalised palliative care plans are to be introduced, it raises a question of how and where this should be kept. If it is kept in the person’s home, he/she would be able to look after it more easily. However, it may delay the ability of health and social care professionals (such as a doctor, nurse or ambulance staff) to take appropriate action on behalf of the person if the professional is not able to easily get hold of the information when needed. Do you have any ideas for how to find an answer to this practical question?*

If the NHS IT infrastructure permits, the plan should be kept securely online so that all with need and permission can access it. Where this is not possible, concepts like Lions International’s ‘Message in a Bottle’ may be worth investigating (<http://bit.ly/1mREN43>).

6. *Do you have any other ideas or suggestions for how we can improve care for people in the last days of life?*

The LACDP must recognise that the LCP provided a framework within which individual patients could be assessed and certain, suitable tools then used better to serve a patient. The personal care plans should be viewed as a progression in that clinicians, patients and families are committed to a dialogue which ensures that all understand what is happening, and why. Families must be heard and advised, but experienced clinicians must not be impeded in acting for the good of their patients.

We welcome a rededication to re-evaluation of patients, but consider that there has been no explanation of how this will be better ensured than under the LCP. There is no mention of how the new system will guard against suggestions of budgetary considerations coming into play, as with the CQUIN payments, nor is there sufficient attention paid to how failings on the part of clinicians should be dealt with.

We are, however, heartened by the renewed emphasis on communication, re-evaluation, mutual goal development, and a holistic understanding of the patient’s needs. We consider these proposals to be broadly in line with our own recommendations to Lady Neuberger’s Review, which for convenience we reproduce here:

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 Nursing 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.