

# **UNHEARD VOICES**

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## **THE LIVERPOOL CARE PATHWAY**



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# **CONTENTS**

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<b>EXECUTIVE SUMMARY</b>	<b>1</b>
<b>INTRODUCTION</b>	<b>2</b>
<b>TRANSPARENCY AND ACCOUNTABILITY</b>	<b>3</b>
<b>ADVOCACY</b>	<b>5</b>
<b>CONSENT</b>	<b>7</b>
<b>CONCLUSION</b>	<b>8</b>
<b>FEEDBACK</b>	<b>9</b>

## EXECUTIVE SUMMARY

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The Liverpool Care Pathway (LCP) is a type of care used in hospitals when patients are at the end of their lives, typically replacing treatment with palliative care to make patients feel as comfortable and dignified as possible. In 2011 the LCP affected an estimated 81,000 hospital patients. However, the LCP has recently been subject to controversy, with high profile concerns about how patients and families are treated by those who operate the pathway in hospitals.

This report examines the LCP from the point of view of the average patient in London. We have found a number of ways in which the LCP can become more accountable and responsive to patients, their families and the wider public, and how public trust and confidence can be restored. The issues we have found are as follows:

- A lack of clear, reliable and publicly accessible information as to how the LCP is applied in hospitals.
- Recording of the checks and reassessments that are made on LCP patients does not always take place.
- There needs to be better support for people with no family or friends to look after their interests.
- Improvements should be made to the system of consent.

Our key recommendations are as follows.

1. To improve transparency and accountability, hospitals should record and publish key information relating to the Liverpool Care Pathway on a regular basis and make this publicly available. This should include the number of deaths of patients on the LCP by age range, the length of time that patients are treated on it and the number of patients removed from the pathway.
2. There should always be proper recording of the regular checks and assessments of LCP patients and this should be made mandatory.
3. Clinical Commissioning Groups in London, assisted by Healthwatch, should regularly monitor the performance of hospitals on the LCP on behalf of their patients. This should include the level of transparency and the proper recording of regular checks and assessments.
4. Independent End of Life Care Advisers should be made available in all hospitals to help represent individual patients on the LCP, where necessary, in their relations with the hospital. This should especially be targeted at patients without family, friends, carers or a mental capacity advocate to represent them. Pilot projects should be set up in London hospitals as soon as possible.
5. There should be an element of formal written acknowledgement by either the patient, their family or other representatives that the LCP is to be used.

Our recommendations will make the LCP work better for patients, as well as improving perceptions of it in the eyes of the public, and we very much hope they will be taken up.

## INTRODUCTION

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The Liverpool Care Pathway for the Dying Patient (LCP) is a type of care used by hospitals during the last days or hours of a patient's life. When treatment is judged to no longer be effective, the LCP aims to make patients feel as comfortable and dignified as possible through palliative care.

The LCP has been in use within the National Health Service (NHS) for over a decade, and was developed in the late 1990s by specialists from the Royal Liverpool University Hospital and the Marie Curie Palliative Care Institute Liverpool (MCPCIL).

Based on the latest figures from the National Care of the Dying Audit, there were an estimated 81,000 hospital deaths on the LCP in 2011 in England and Wales<sup>1</sup>. In addition, there are patients who are treated on the LCP in hospices, care homes and nursing homes.

The LCP is designed to provide a structure for the treatment of the dying<sup>2</sup>. According to the LCP's key messages<sup>3</sup>:

- It neither hastens nor postpones death
- It does not preclude the use of artificial hydration
- It does not recommend the use of continuous deep sedation
- Diagnosis of the dying should be made by the multidisciplinary team (MDT)
- It should not be used without the support of education & training
- It supports continual reassessment
- Good communication is pivotal to success

The LCP has been endorsed by a number of organisations, including Age UK, the Alzheimer's Society, the British Geriatrics Society, the Motor Neurone Disease Association, the Royal College of Nursing, the Royal College of Physicians and Sue Ryder. These organisations recently said in a joint statement that "we support the appropriate use of the Liverpool Care Pathway and make it clear that it is not in any way about ending life, but rather about supporting the delivery of excellent end of life care."<sup>4</sup>

However, in recent years the LCP has been subject to controversy. This has included allegations that patients had been placed on the LCP without consent or the knowledge of their next of kin<sup>5</sup>, that some patients should not have been placed on the LCP because they were not dying<sup>6</sup>, or that use of the LCP has been motivated by financial targets.<sup>7</sup> As a result, at the end of 2012 the Government established a series of reviews into how the LCP is working.

Our report examines this issue from the point of view of the average patient in London, rather than a medical expert. We do not set out to criticise the LCP in principle or to determine whether or not specific allegations against it are valid. However, it is clear to us that there are a number of ways in which the application of the LCP can be improved in order to improve public trust and confidence in the system, and

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1. According to the ONS ([http://www.ons.gov.uk/ons/dcp171778\\_270569.pdf](http://www.ons.gov.uk/ons/dcp171778_270569.pdf) page 4) there were 484,367 total deaths in 2011 in England and Wales. The National Care of the Dying Audit 2011/12 states on p4 that 58% of total deaths took place in hospitals, and on p28 that 29% of hospital deaths were on the LCP.

2. <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>

3. [http://www.liv.ac.uk/media/livacuk/mcpcil/migrated-files/liverpool-care-pathway/updatedlcpdfs/What\\_is\\_the\\_LCP\\_-\\_Health\\_care\\_Professionals\\_-\\_April\\_2010.pdf](http://www.liv.ac.uk/media/livacuk/mcpcil/migrated-files/liverpool-care-pathway/updatedlcpdfs/What_is_the_LCP_-_Health_care_Professionals_-_April_2010.pdf) page 4

4. [http://www.rcn.org.uk/\\_data/assets/pdf\\_file/0011/477677/Liverpool\\_Care\\_Pathway\\_consensus\\_statement.pdf](http://www.rcn.org.uk/_data/assets/pdf_file/0011/477677/Liverpool_Care_Pathway_consensus_statement.pdf)

5. <http://www.telegraph.co.uk/health/9635842/Families-left-grieving-and-angry-by-the-Liverpool-Care-Pathway.html>

6. <http://www.dailymail.co.uk/news/article-2224556/Still-enjoying-life-grandmother-death-pathway-years-ago.html>

7. <http://www.dailymail.co.uk/news/article-2223286/Hospitals-bribed-patients-pathway-death-Cash-incentive-NHS-trusts-meet-targets-Liverpool-Care-Pathway.html?ito=feeds-newsxml>

to become more accountable and responsive to patients, their families and the wider public.

It is important that clear, reliable and publicly accessible information is provided as to how the LCP is applied in hospitals. Many London hospital trusts were unable to tell us basic facts and figures on the LCP for their own hospitals, as we will see later.

There should also be mandatory recording of the checks and reassessments that are made on LCP patients, and the performance of hospitals on the LCP should be monitored by local health professionals in the new Clinical Commissioning Groups.

In addition, there may be a lack of support for patients without close family or friends and who find themselves alone in hospital facing momentous decisions about their care. If they are mentally incapacitated they qualify for a special advocate, but otherwise they do not have anyone to support them and look after their interests. All patients in this position should therefore be offered independent End of Life Care advisers as standard.

Finally, there should be improvements to the system of consent so that patients' wishes are much clearer or better known.

## TRANSPARENCY AND ACCOUNTABILITY

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At the heart of many of the concerns and allegations that have been expressed about the LCP is a lack of clear and publicly accessible information about the way that it is applied. Such a lack of information can often breed suspicion and makes it more difficult to refute claims that are made, especially on such a sensitive issue.

Although comprehensive reports are produced regularly as part of the National Care of the Dying Audit (NCDA), it is very difficult for the layman to understand the statistical information in these reports. In addition, this information is not broken down to the level of individual hospitals, so that people can see how their local hospital is performing, and is only based on a specific three months of data in a particular year.

Indeed, our own research highlights concerns about the level and quality of information that is recorded by individual hospitals. Given the particular issues around the experiences of the elderly on the LCP, we made Freedom of Information requests to 21 hospital trusts in and around London, with a set of standard questions relating to patients over 65 years of age. We asked for information on the number of patients over 65 who died whilst on the LCP, the longest and shortest period that these patients were on the LCP, and the number that were removed from the LCP and/or survived.

There was a wide variation in the level and quality of the information that the different hospital trusts were able to provide to us. Only one hospital trust was able to provide all the information that we requested and in the format that we requested. Eight trusts, around 38%, could not provide any information that we asked for on the LCP.<sup>8</sup>

13 hospital trusts, around 62%, were able to provide some information on the number of patients on the LCP, although in a wide variety of different formats. Eight of these trusts were able to provide annual data for some or all of the years requested, either by calendar year or financial year. Others provided data for part of a year, either a one or three month period.<sup>9</sup>

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8. Freedom of Information responses from hospital trusts to the office of Andrew Boff AM.

9. Ibid

Four hospital trusts were able to give some information on the longest and shortest periods of patients being on the LCP, and four trusts were able to tell us how many patients that were removed from the LCP and/or survived.<sup>10</sup>

The aim of this exercise was not to single out or attach blame to individual trusts, but to point out overall weaknesses in the system. As several trusts pointed out in their responses, they are not required to routinely collect information on the Liverpool Care Pathway. In our view this has to change, and hospitals should be required to routinely record and publish this information in a standardised and easily accessible format.

Where we did receive responses, the longest period of treatment on the LCP contained in those responses was 34 days.<sup>11</sup> This is of particular concern, since there is often the perception that, once a patient is on the LCP, mortality could become a self-fulfilling prophecy since, presumably, the withdrawal of all treatment for a condition except palliative care would eventually lead to death.

During a debate on the LCP in Westminster Hall on 8 January this year, Andrew Bridgen MP raised this point, "I am particularly concerned that patients may have no opportunity to be taken off it if they improve. There are no figures on the number of patients for whom care has been reintroduced after being placed on the pathway."<sup>12</sup>

### **Recommendation 1:**

**To improve transparency and accountability, hospitals should record and publish key information relating to the Liverpool Care Pathway on a regular basis and make this publicly available. This should include the number of deaths of patients on the LCP by age range, the length of time that patients are treated on it and the number of patients removed from the pathway.**

The LCP provides that the patient's condition be checked at least every four hours<sup>13</sup> and that a full multidisciplinary team reassessment take place every three days.<sup>14</sup> According to the National Care of the Dying Audit 2011/2012 there is wide variation between different hospitals as to how often they document these reassessments. Whilst "some hospitals are achieving this on 100% of occasions"<sup>15</sup>, the clear implication is that many are not. While patients who have relatives are in a position where the treatment can be challenged and reviews requested, those who are alone do not.

### **Recommendation 2:**

**There should always be proper recording of the regular checks and assessments of LCP patients and this should be made mandatory.**

Tom Gentry, Age UK's Policy Adviser, Health Services, has suggested that the new clinical commissioning groups (CCGs) actively monitor the performance of hospitals from which they commission services, in relation to the LCP, and to ask to see their records<sup>16</sup>. It would be perfectly reasonable for the CCG, as a consumer, to expect to see the performance data of hospitals that they work with, and this could act as an additional safeguard to ensure that the LCP was working properly.

In addition, Healthwatch, which came into being in April 2013, could be a useful tool in helping CCGs to

10. Ibid

11. Freedom of Information response from Guy's and St Thomas' NHS Foundation Trust, 12 December 2012

12. <http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130108/halltext/130108h0001.htm> column 38WH

13. [http://www.liv.ac.uk/media/livacuk/mcpcl/migrated-files/liverpool-care-pathway/updatedlcppdfs/What\\_is\\_the\\_LCP\\_-\\_Health\\_care\\_Professionals\\_-\\_April\\_2010.pdf](http://www.liv.ac.uk/media/livacuk/mcpcl/migrated-files/liverpool-care-pathway/updatedlcppdfs/What_is_the_LCP_-_Health_care_Professionals_-_April_2010.pdf) page 8

14. [http://www.liv.ac.uk/media/livacuk/mcpcl/migrated-files/liverpool-care-pathway/updatedlcppdfs/What\\_is\\_the\\_LCP\\_-\\_Health\\_care\\_Professionals\\_-\\_April\\_2010.pdf](http://www.liv.ac.uk/media/livacuk/mcpcl/migrated-files/liverpool-care-pathway/updatedlcppdfs/What_is_the_LCP_-_Health_care_Professionals_-_April_2010.pdf) page 5

15. National Care of the Dying Audit 2011/2012 page 83

16. Meeting on 15 February 2013

monitor performance of the LCP. Healthwatch will be able to “help and support Clinical Commissioning Groups to make sure that services really are designed to meet citizens’ needs.”<sup>17</sup> Its aim is “to give citizens and communities a stronger voice to influence and challenge how health and social care services are provided within their locality.”<sup>18</sup> It will “provide authoritative, evidence-based feedback to organisations responsible for commissioning or delivering local health and social care services.”<sup>19</sup>

### **Recommendation 3:**

**Clinical Commissioning Groups in London, assisted by Healthwatch, should regularly monitor the performance of hospitals on the LCP on behalf of their patients. This should include the level of transparency and the proper recording of regular checks and assessments.**

## **ADVOCACY**

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Of particular concern is the situation of those elderly people who have no close relatives and those who have had no contact with their relatives for a considerable time, nor received care from them. Patients with relatives will have their interests safeguarded by their families. Those who lack capacity and have no close family will have their interests safeguarded by the intervention of an Independent Mental Capacity Advocate (IMCA) under the Mental Capacity Act. However, those who are mentally capable but ill and alone in the world have nobody to fight their corner.

In the event of relatives or carers disagreeing with the use of the LCP, the Liverpool Care Pathway FAQs state the following:

*If disagreements occur between the members of the healthcare team or between the healthcare team and those close to the patient, then the clinical team should involve an independent advocate, and/or should seek advice from another senior colleague, and should also seek a second opinion and/or use local mediation services. (GMC 2010)*

*Good, comprehensive, clear communication is crucial and all decisions leading to a change in care delivery should be communicated to the patient where possible and deemed appropriate but always to the relative or carer. The views of all concerned must be listened to, considered and documented.<sup>20</sup>*

The Mental Capacity Act safeguards the interests of those who lack capacity to take decisions for themselves and defines people who lack capacity. It says:

*(1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of the mind or brain.<sup>21</sup>*

The Act requires the intervention of an Independent Mental Capacity Advocate (IMCA)

*If an NHS body –*

- (a) is proposing to provide or secure the provision of, serious medical treatment for a person (“P”) who lacks capacity to consent to the treatment, and*
- (b) is satisfied that there is no person, other than those engaged in providing care or treatment for P in a*

17. <http://healthandcare.dh.gov.uk/what-is-healthwatch/>

18. <http://healthandcare.dh.gov.uk/what-is-healthwatch/>

19. <http://healthandcare.dh.gov.uk/what-is-healthwatch/>

20. <http://www.liv.ac.uk/media/livacuk/mcpil/documents/LCP%20FAQ%20August%202012.pdf> page 2

21. Mental Capacity Act 2005, Part 1, Section 2, (1) page 2

*professional capacity or for remuneration, whom it would be appropriate to consult in determining what would be in P's best interests.*<sup>22</sup>

It defines serious treatment as “treatment which involves providing, withholding or withdrawing treatment of a kind prescribed by regulations made by the appropriate authority”<sup>23</sup>.

The Act further states that “before the treatment is provided that NHS body must instruct an independent mental capacity advocate to represent P.”<sup>24</sup> The IMCA may even obtain, “a further medical opinion where treatment is proposed and the advocate thinks that one should be obtained.”<sup>25</sup>

However, it appears that a person with no near relatives, or uninterested relatives, is left at a disadvantage if they feel that they should not be on the Pathway providing they are conscious and not lacking mental capacity. Those who are elderly now are members of generations that learned deference from an early age, including submission to the concept of ‘doctor knows best’. Because of this, they may not be as prepared to contest decisions taken by confident medical professionals regarding their treatment, particularly if they are feeling extremely ill, though perfectly able to understand matters.

Patients like these are particularly vulnerable, especially if there is nobody available to represent them at a time when they most need a friend. This is particularly pertinent in view of the fact that the latest National Care of the Dying Audit states “There is wide variation in hospital performance (coded achieved) for goals relating to conversations with the patient regarding awareness of dying”<sup>26</sup>.

In this context, it is interesting to recall that the Mental Capacity Act specifies that an IMCA should be involved in cases where “there is no person, other than those engaged in providing care or treatment for P in a professional capacity or for remuneration, whom it would be appropriate to consult in determining what would be in P's best interests.”<sup>27</sup> Surely, there should be a similar safeguard for those fragile patients who, whilst having capacity, will be sorely in need of the advocacy of a knowledgeable and well-informed friend.

Deborah Hayes, Age UK East London's Director of Individual Services, has obtained funding for a scheme for a Last Years of Life Service. The scheme, which started in April 2013 in Tower Hamlets, supports people who are reaching the end of their lives in their own homes. A support worker will be allocated to each person for up to 14 hours per week.<sup>28</sup> “Staff specifically trained in end of life care will support isolated, elder people (50+) who have little or no informal care network (family/friends).”<sup>29</sup> The service includes::

- Befriending
- Practical Support (dealing with correspondence, booking appointments, etc.
- Accompanying to places of interest/appointments
- Signposting to appropriate services, following up referrals, etc.<sup>30</sup>

The service will also include advocacy, domestic help, shopping, information and advice, practical support, gardening and holistic wellbeing therapies. Support workers will also be able to assist with funeral planning,

22. Mental Capacity Act 2005, Part I, Section 37, (1), Page 22

23. Mental Capacity Act 2005, Part I, Section 37 (6) page 22

24. Mental Capacity Act 2005, Part I, Section 37 (3)

25. Mental Capacity Act 2005, Part I, Section 36, (2) €, page 22.

26. National Care of the Dying Audit 2011/2012 page 5

27. Mental Capacity Act 2005, Part I, Section 37, (1), Page 22

28. Meeting on 1 March 2013

29. <http://www.ageuk.org.uk/towerhamlets/our-services/end-of-life-support/>

30. <http://www.ageuk.org.uk/towerhamlets/our-services/end-of-life-support/>

assistance in documenting a person's wishes and supporting family and loved ones. Support workers will work closely with palliative care teams not instead of them. Age UK has received £92,000 to fund the project's first year from Tower Hamlets Clinical Commissioning Group.<sup>31</sup>

Deborah Hayes has proposed the extension of this project, continuing to support people the scheme is already assisting if they are hospitalised. She is also suggesting that the scheme support people in hospital in end of life situations who are not previous users of the scheme and who, whilst not lacking capacity to consent to treatment, need support from somebody able to voice their wishes and concerns.<sup>32</sup>

#### **Recommendation 4:**

Independent End of Life Care Advisers should be made available in all hospitals to help represent individual patients on the LCP, where necessary, in their relations with the hospital. This should especially be targeted at patients without family, friends, carers or a mental capacity advocate to represent them. Pilot projects should be set up in London hospitals as soon as possible.

## CONSENT

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In launching the Government's review, Norman Lamb MP, Minister of State at the Department of Health stated that "there have been too many cases where patients or their families were ignored or not properly involved in decisions"<sup>33</sup>.

The decision to place a patient on the LCP does not require written consent from either the patient or their family or carers because it is "not a treatment but a framework for good practice"<sup>34</sup>. The decision is taken by a "multi-disciplinary team" who use a detailed form to record their regular assessments and treatment of the patient and which contains an algorithm to guide decisions on care.<sup>35</sup> The Marie Curie Palliative Care Institute Liverpool (MCPIL) produces examples of documentation to be given to relatives and carers<sup>36</sup>. In the position statement mentioned above the MCPIL states that "identifying that someone is in the last hours or days of life should be discussed with the patient where possible and deemed appropriate and always with the relative or carer".<sup>37</sup> However, the National Care of the Dying Audit states "There is wide variation in hospital performance (coded achieved) for goals relating to conversations with the patient regarding awareness of dying"<sup>38</sup>.

#### **Recommendation 5:**

There should be an element of formal written acknowledgement by either the patient, their family or other representatives that the LCP is to be used.

31. Meeting on 1 March 2013

32. Meeting on 1 March 2013

33. <http://mediacentre.dh.gov.uk/2013/01/15/independent-review-of-liverpool-care-pathway-to-be-chaired-by-baroness-neuberger/>

34. <http://www.liv.ac.uk/media/livacuk/mcpil/documents/LCPFAQ,August,2012.pdf> page 2

35. [http://www.liv.ac.uk/media/livacuk/mcpil/migrated-files/liverpool-care-pathway/updatedlcpdfs/LCP\\_V12\\_Core\\_Documentation\\_FINAL\\_\(Example\).pdf](http://www.liv.ac.uk/media/livacuk/mcpil/migrated-files/liverpool-care-pathway/updatedlcpdfs/LCP_V12_Core_Documentation_FINAL_(Example).pdf)

36. [http://www.liv.ac.uk/media/livacuk/mcpil/migrated-files/pdfs/lcpv12newdocuments/LCPRelative\\_CarerInformationLeaflet\\_-\\_Nov.09.pdf](http://www.liv.ac.uk/media/livacuk/mcpil/migrated-files/pdfs/lcpv12newdocuments/LCPRelative_CarerInformationLeaflet_-_Nov.09.pdf)

37. <http://www.liv.ac.uk/media/livacuk/mcpil/documents/POSITION.STATEMENT,-Marie,Curie,Palliative,Care,Institute,Liverpool.pdf> page 4

38. National Care of the Dying Audit 2011/2012 page 5

## CONCLUSION

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As stated earlier, the purpose of this report is to examine the Liverpool Care Pathway from the point of view of the patient and the public in London, and to seek ways of making it more transparent, accountable and responsive.

In the Westminster Hall debate on the LCP mentioned, an important point was made by Rosie Cooper MP that “the huge problem lies in the human application of the rules, not necessarily in the rules themselves.”<sup>39</sup> To that end, we very much hope that our recommendations will be taken in the spirit that they were intended, as practical measures to help improve and strengthen the LCP in the eyes of patients and the public.

### Summary of Recommendations

1. To improve transparency and accountability, hospitals should record and publish key information relating to the Liverpool Care Pathway on a regular basis and make this publicly available. This should include the number of deaths of patients on the LCP by age range, the length of time that patients are treated on it and the number of patients removed from the pathway.
2. There should always be proper recording of the regular checks and assessments of LCP patients and this should be made mandatory.
3. Clinical Commissioning Groups in London, assisted by Healthwatch, should regularly monitor the performance of hospitals on the LCP on behalf of their patients. This should include the level of transparency and the proper recording of regular checks and assessments.
4. Independent End of Life Care Advisers should be made available in all hospitals to help represent individual patients on the LCP, where necessary, in their relations with the hospital. This should especially be targeted at patients without family, friends, carers or a mental capacity advocate to represent them. Pilot projects should be set up in London hospitals as soon as possible.
5. There should be an element of formal written acknowledgement by either the patient, their family or other representatives that the LCP is to be used.

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39. <http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm130108/halltext/130108h0001.htm> column 40WH



## FEEDBACK

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