A recent article in the Daily Telegraph has again highlighted the topic of palliative care. The issues surrounding the palliative care of the dying are complex. In this article we explore some of the concerns which have been raised since the Liverpool Care Pathway was introduced.

The Liverpool Care Pathway was developed by Marie Curie, the cancer charity, in a Liverpool hospice. It was initially developed for cancer patients but now includes other life threatening conditions. It aims “to transfer the best quality for care of the dying from the hospice movement into other clinical areas.” It has been gradually adopted nationwide in hospitals, hospices and care homes.

Thousands of patients in the NHS are put onto the LCP each year in their last days and hours. It claims to give patients a “good death” by avoiding unnecessary and burdensome medical intervention. According to its guidelines, “The LCP neither hastens nor postpones death,” and, “Good communication is pivotal to success.”

A recent report into palliative care in the NHS by the Royal College of Physicians has said that many doctors were not following guidelines recommending that physicians discuss with relatives whether or not their loved one is placed onto the controversial Liverpool Care Pathway (LCP). The LCP has been dubbed the “death pathway” in an article which appeared in the Daily Telegraph on 2nd December.

It is on the issue of communication that the report expressed concern. Health service guidance states that doctors should discuss with relations whether or not their loved one is placed on the scheme but, according to the audit, in many cases this has not been happening. In one hospital trust, doctors had conversations with fewer than half of families about the care of their loved one. In a quarter of hospital trusts, discussions were not held with one in three families.

The article in the Telegraph also raised other concerns such as the fact that, “Tens of thousands of patients with terminal illnesses are being placed on a ‘death pathway’, almost double the number just two years ago, the Royal College of Physicians has found.” The newspaper quotes Dr Patrick Pullicino, a consultant neurologist at East Kent University Hospitals. He said that it was vital that more information was made available about the use of the Liverpool Care Pathway in the NHS.

He said: "We need to know how frequently it is being used. Data should be released showing the proportion of patients who die in hospital who were on the Liverpool Care Pathway and how many were on it against their will or that of their family."

Questions concerning the LCP have been raised before. In 2009 the Telegraph had published a letter. In it, a group of experts who care for the terminally ill claimed that some patients were being wrongly judged as close to death and being wrongly placed on the LCP. “Forecasting death is an inexact science,” they said. “If you tick all the right boxes in the Liverpool Care Pathway, the inevitable outcome of the consequent treatment is death. As a
result, a nationwide wave of discontent is building up, as family and friends witness the
denial of fluids and food to patients. Syringe drivers are being used to give continuous
terminal sedation, without regard to the fact that the diagnosis could be wrong.”

It was signed by: P. H. Millard, Emeritus Professor of Geriatrics University of London; Dr
Anthony Cole, Chairman, Medical Ethics Alliance; Dr Peter Hargreaves, Consultant in
Palliative Medicine; Dr David Hill, Fellow of the Faculty of Anaesthetists of the Royal College
of Surgeons; Dr Elizabeth Negus, Lecturer, Barking University; Dowager Lady Salisbury,
Chairman, Choose Life.

This was followed by an article in the Telegraph, “Sentenced to death on the NHS”. 5

In reply to the first letter, Katherine Guellard, a retired palliative care nurse specialist, then
working as a community nurse specialist, defended the pathway. She wrote, “The LCP has
enabled thousands to be cared for more appropriately in hospital, to be discharged with a full
range of services and, above all, to die comfortably in their homes, as most would wish.” 6

Soon after this correspondence in the Telegraph a national audit concluded that the use of
the LCP was resulting in high quality care for those who are in the very last hours and days
of life. The LCP was also endorsed by the organisation Care Not Killing. 7

The December 2011 article in the Telegraph drew a large number of comments, some of
which can still be viewed from the website. 3

Some of the comments are strongly supportive of the LPC. For example,
“The idea of the pathway is that it stops people being subjected to unpleasant, undignified
and futile medical intervention, gives the opportunity for unpleasant symptoms that occur
around the time of death to be managed properly, and allows patients' psychological and
spiritual needs to be taken account of (this includes speaking to relatives). I'm proud to have
managed patients using it.”
(Comment from princeheathen).

Others express concern that relatives have died prematurely or have only survived because
they have been “rescued” from the LPC.
For example,
“My mother was admitted to the Conquest hospital in Hastings in January 2009 with a chest
infection, after five days I was told in front of my mum that she was going to die and would
be put on the LCP; I was told, not asked. Her IV antibiotics were immediately taken off but I
refused to allow her fluid drip to be taken away …….. Over the next few days mum kept
saying I don't want to die and was much brighter, she had not been given ANY nutrition in
any form since her admission and the medical staff just kept saying she was dying. After a
long battle with the hospital, mum was taken off the LCP and is still alive today. Undoubtedly
if I had not been able to fight my mother's case she would have been starved to death
courtesy of the NHS. The LCP in many geriatric cases is just a subterfuge for murder on the
NHS.” (Comment from Christine Ball).

Another contributor was Dr Rita Pal who has been expressing concern over these issues for
11 years, including an article the Sunday Mercury in 2006. 8

A few years ago Look East interviewed a daughter who was shocked to be asked, within the
first 48 hours of her mother entering hospital, if she would be prepared to “let her mum go"
by gradually withdrawing foods and nourishment until she passed away. She had refused and says that “My mum lived for 5 more years and she saw happiness.”

One area of concern is the withdrawal of nutrition and fluids. The LCP website states, “When a patient is dying they generally eat and drink less – this is part of the normal physiological process of dying. Food and fluid is provided to dying patients at their request, and is not withdrawn within the LCP Framework. Fluids via a drip (artificial hydration) are given when the doctor / clinical team makes a clinical decision that this will be beneficial and not cause undue distress to the patient”

The LCP does not preclude the use of artificial hydration but those who are involved in palliative care are aware that, if a patient is imminently dying, hydration will not improve survival and may cause distress to the patient. In these circumstances, most people would agree that artificial hydration should be removed. However, one concern is that I/V fluids may be withdrawn when death is not imminent and dehydration may become a contributory factor to death.

**Questions to be asked**

When implemented correctly, there can be little doubt that the LCP is beneficial to the enhancement of palliative care of the dying.

There are, however questions which need to be asked:

The first two Key Messages from LCP are, “The LCP is only as good as the people who are using it.” and, “The LCP should not be used without the support of education & training.”

As the pathway has been extensively rolled out over the last few years, have there been sufficient numbers of well-trained staff to implement it correctly?

It also says, “The LCP supports continual reassessment; Reflect, Audit, Measure & Learn; Stop, Think, Assess & Change.”

Is there adequate staffing to allow the state of health of a patient to be closely monitored?

One might also question the attitude of some carers towards the elderly. Louise Smith comments on the Daily Telegraph website, “Old Age is NOT a terminal illness, but in applying the LCP it is being treated as one, and families are being left devastated as a result of this.”

Do all involved in implementing the LCP have respect for the sanctity of human life – including the lives of those with dementia?

This is a question that must be asked, given the comments of high-profile public figures such as Baroness Warnock, adviser on ethics to successive governments. She has said that elderly people suffering from dementia are “wasting people’s lives” and “wasting the resources of the National Health Service” and should be allowed to die. “If you’re demented,
you’re wasting people’s lives – your family’s lives – and you’re wasting the resources of the National Health Service.”

This leads to another question; **Are decisions made purely on medical, rather than financial, considerations?**

In their letter to the Daily Telegraph Professor Millward et al said, “forecasting death is an inexact science.”

**Can we be sure that the diagnosis of approaching death is a correct one?**

LesDoe comments on the Telegraph website, “CQUIN is the DOH funding policy. CQUIN has set targets for 2011/2012 with regard to the End of Life LCP program. The forward plan is to increase the number of patients identified to be on the end of life care pathway from a baseline of 0% to 20%; it is further planned to have 30% of all patients who die in hospital dying on the Liverpool Care Pathway. To ensure they receive their provider income in full, Trusts have to comply with or exceed these goals.”

**Is a target-driven financial incentive to hospital Trusts the best way of ensuring that the Pathway is adopted in a considered way or is the DoH steam rollering out its end-of-life care policy?**

In her letter to the Daily Telegraph, Katherine Guellard defended the LCP but she also said, “I do agree with Professor Millard that we should be concerned about the enthusiasm with which the Department of Health appears to be steam-rollering out its end-of-life care strategy.

I fear it may be another case of fools rushing in. Implementation of the LCP has required long, dedicated educational work by palliative care specialists. Continuing audit, evaluation and review should remain paramount.”

LCP Key messages:

1. The LCP is only as good as the people who are using it
2. The LCP should not be used without the support of education & training
3. Good communication is pivotal to success
4. The LCP neither hastens nor postpones death
5. Diagnosis of dying should be made by the multidisciplinary team (MDT)
6. The LCP does not recommend the use of continuous deep sedation
7. The LCP does not preclude the use of artificial hydration
8. The LCP supports continual reassessment
9. Reflect, Audit, Measure & Learn
10. Stop, Think, Assess & Change

**The responsibility for the use of the LCP generic version 12 - UK document as part of a continuous quality improvement programme sits within the governance of an organisation and must be underpinned by a robust education and training programme**
LCP - references to source materials