

End-of-life care remains lethal

One of the most trenchant critics of the Liverpool Care Pathway says that new guidelines on the care of dying patients are, if anything, even worse

PATRICK PULLICINO

The controversial Liverpool Care Pathway for dying patients was phased out after an independent review by Baroness Neuberger, which concluded that it had been “misused and misunderstood” by hospital staff.

But although the LCP has gone (in name, at least), it represented “the best quality of care possible” for the dying as defined by palliative medicine physicians. It is therefore not surprising that new guidelines replacing the LCP, recently issued by the National Institute for Health and Care Excellence (Nice), are very similar. Indeed, they perpetuate the features that made the LCP so dangerous.

The Nice guidelines are, if anything, even worse than the LCP as a result of certain additions. The writers had the Neuberger report to draw on, but they have not taken on board some of its main recommendations. Although the guidelines say they respond “to a need for an evidence-based guideline for the clinical care of the dying”, references to a solid base of scientific evidence are almost totally lacking.

Diagnosis of those imminently dying was the core problem of the LCP. This problem remains in the Nice guidelines. They include a list of features that may suggest someone is dying. But they are inadequate as the basis for a diagnosis and are not evidence-based. So we are back to where we were with the LCP in terms of the risk of putting patients who are not dying on to inappropriate and potentially lethal treatment.

This issue is so crucial that no new attempts to set up this sort of pathway should be made until research shows that it is possible to accurately diagnose impending death. Until then, as Baroness Neuberger said, good quality compassionate care is what should be given, without the need for any pathway.

The most forceful section of the Neuberger report was on nutrition and hydration. It left no doubt that the practice under the LCP was inhumane in some cases. It said that “the default course of action should be that patients be supported with hydration and nutrition unless there is a strong reason not to do so”.

Yet the section on hydration in the Nice document is a disaster of misinformation, distortion and ambiguity. There is at least one serious major error: it says that “death is unlikely to be hastened by not having clinically assisted hydration”. This is completely untrue. Not giving hydration is certain to



The Liverpool Care Pathway was developed by Royal Liverpool University Hospital

kill someone if they can't take hydration by mouth. And there is no mention whatsoever of nutrition in the document.

The Neuberger report was clear that providing hydration and nutrition is a serious duty. Yet the Nice document has actually reduced the meagre provisions of the LCP.

The Neuberger report said that the failure to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct. Dehydration was a central mechanism of the deaths on the LCP. But despite the removal of the LCP, I still frequently witness severely dehydrated

The section on hydration is a disaster of misinformation, distortion and major errors

elderly patients on hospital wards. Unless it becomes standard practice, monitored by the Care Quality Commission, that hospitals are obliged to give adequate nutrition and hydration for patients' physiological needs at all times and regardless of prognosis, end-of-life care is going to remain lethal.

One of the most deadly aspects of the LCP was “anticipatory prescribing”, where the physician wrote up sedatives and narcotic medication ahead of time,

The nurses were empowered to use pre-set LCP criteria (eg pain, agitation) as justification for increasing the dose, often too rapidly. This was a major factor in patients' very short average time from adopting LCP to death of 33 hours.

Anticipatory prescribing has been used in hospices to allow a patient to remain pain-free. It has never been allowed in general hospitals, as the rule has been that the patient must be reassessed by the physician before any change in medication. This not only helps to avoid unintended overdosing, but also makes the physician fully responsible for any overdosing. The standard of care in hospitals should be that anticipatory prescribing is not allowed, particularly with elderly fragile patients where small dose increases can be fatal.

The Neuberger report said it was essential to have a senior responsible clinician accountable for all decisions in end-of-life care. The LCP's decision-making process was based on the Mental Capacity Act 2005, which called for someone to be designated as a “decision-maker” and for a “best interest” meeting to be held.

The decision-maker who takes end-of-life decisions does not have to be the senior responsible clinician, but can be a nurse or other member of the support team. The decision-maker is helped by a meeting of all staff and relatives (including the spouse or parents

of the patient) at the “best interest” meeting. But the relatives do not have privileged input into the decision over other members of the team.

These Mental Capacity Act 2005 provisions effectively usurped the role of the responsible senior clinician and undermined well-established, evidence-based medical care in hospitals. The new Nice guidelines continue to use these provisions, and thereby sidestep the Neuberger recommendation for control to lie with the senior responsible clinician.

A recent article about the “best interest” concept by Søren Holm and Andrew Robert Edgar concludes that it is a legal fiction. “Best interest” decision-makers actually make the decision that maximises their expected personal utility.

The idea that a group can actually determine the single “best interest” of the patient is also fallacious. Yet this is the process by which life and death decisions will be made under the Nice guidelines. This is wrong. Consultants must be restored to full care and responsibility of their patients at all times.

In reality, the LCP has been in operation for so long that it has changed accepted practice in the NHS. Even after the LCP was removed, similar practices continued under different names. I regularly receive reports from desperate relatives of individuals being treated in an LCP-like fashion. They want their relatives who have been determined to be “dying” to receive active care. I have also attended “best interest” meetings and found that often the relatives are not medically knowledgeable enough to question the medical staff, and they need support.

Evidence-based medicine is the gold standard for 21st-century medicine. The LCP abandoned evidence-based medicine. This has been disastrous not only for the patients who are put on the pathway, but also because it has undermined the practice of medicine in other areas.

The Care Quality Commission should require all physicians practising in general



Doctors are required to attend ‘best interest’ meetings with staff and relatives

hospitals to use only evidence-based treatments and pathways. Nice should ensure that all pathways are held to this standard. Its current guidelines certainly do not do this. But how else will patients know that the treatments they are given are based on science and not being biased by NHS requirements or financial incentives?

In order to ensure that patients are not dehydrated in hospitals or left without nutrition, the commission has to set standards for obligatory reporting. Hospitals should be required to report to the commission immediately if any patient is left without fluid for 48 hours, or nutrition for more than four days, as that is a serious error. This would be a step in the right direction.

Patrick Pullicino is professor of clinical neuroscience at the University of Kent, Canterbury