

Nursing Comments to the Neuberger Review of the Liverpool Care Pathway, 2013.

Having worked as a senior nurse in Palliative Care for many years I do not ever recall the need for a blanket approach to treatment produced by the Liverpool Care Pathway. Firstly, care is the province of nurses while treatment is ordered by clinicians. Effective nursing care should be a prerequisite of a patient's experience whether the patient is dying or not. A treatment pathway needs to be correctly described as such.

The term 'treatment' is not addressed either within the LCP title or content, with all the implications for consent this word entails.

The LCP has been endorsed by the past and present Government as a Gold Standard Framework for palliative care in hospitals and community care settings. However, this Framework which underpins the LCP fails to provide accurate predictors of imminent death across a wide range of malignant and non-malignant conditions.

Entry onto the LCP is predicated on the view that death is imminent within a time frame in which death has never been accurately and reliably predicted.

The government's End of Life Care Strategy (2008) suggests that "the definition of the beginning of 'end of life' care is variable, and according to the individual person and professional perspectives. For some, the start may be at the time of diagnosis of a condition which usually carries a poor prognosis...For others it will be at a point when there is deterioration in a chronic illness and it becomes apparent that the likely prognosis is measured in months or possibly a year or two... Alternatively, it could be an elderly person who is becoming increasingly frail" 1.

But patients with increasing frailty or with a stable chronic illness, should not automatically be considered to be at the end of life, in the 'dying' phase, which puts them at risk of being eligible for a care pathway for dying patients. Point of entry to the Pathway is "a decision by the multidisciplinary/multi professional team that the patient is in the last few hours or days of life". The decision by the multidisciplinary team that the patient has entered the last few hours or days of life (the 'dying' phase) may well be a self-fulfilling prophesy.

- The LCP does not attempt to use any prognostic index to determine who is placed on the pathway.

- There is also the danger that The personal views of the physician and other medical team members of perceived quality of life or low likelihood of a good outcome are probably central in the decision to put a patient on the LCP.

The difficulty in predicting death within the next few hours or days.

The LCP is regarded as providing evidence-based guidelines for the management of the terminally ill based upon a prognosis of imminent death. This is simply not the

case – there is no such evidence base in the medical literature. In the 2007 Audit conducted by the Marie Curie Palliative Care Institute, 2672 patients were included and 2664 patients

died within a median time of 33 hours. This means that 99.7% of enrolled patients died on the LCP. 2.

The fact is that entry onto the LCP is purportedly decided by the multidisciplinary/multi professional team, but according to the last audit of the LCP its commencement was not endorsed by the senior healthcare professional in 28% of cases. This gives rise to on-going senior medical concern with the LCP. 3. Entry onto the LCP may be interpreted as a management decision that the patient's life should end within days - on the LCP.

Once on the LCP, very few patients come off.

The identification of one third of deaths in hospital with deaths occurring within days involving the LCP, cannot exclude a direct euthanasia intention, especially when fluids are deliberately and permanently withdrawn as is more often the case according to what reviews of the LCP are conducted. The latest Audit reveals that for patients on the LCP, assisted fluids were continued in only 16% of cases and were virtually never started. 3

An obvious conclusion is that this figure, rather than decline, will increase, should the LCP system become an embedded, familiar part of uncritical healthcare culture.

However, adoption of the LCP, is considered to be an indirect indicator of the quality of care received by dying patients. Trusts are commissioned to performance manage staff to assure that the Pathway is implemented and at least in some regions forfeit income (under the CQUIN scheme) if they do not.

In the Netherlands, since legalisation of Euthanasia in 2002, the numbers dying after continuous deep sedation (CDS) had risen from 5.6 per cent in 2001 to 12.3 per cent in 2010. 4. However, one UK study, by Bart's and the London School of Medicine and Dentistry, (2009), found CDS is used more frequently in Britain - in 16.5 per cent of cases. Professor Clive Seale, the author, suggested that could be because euthanasia was not a legal option here in the UK. 5.

Code of Professional Conduct

The often, uncritical acceptance by NHS Trusts, and the financial incentives appear to provide a degree of credibility and apparent protection for practitioners in LCP implementation. The subliminal message through silence and the acceptance by the Royal College of Physicians and others is that this is a good care development. Practitioners, despite their conscience and misgivings may be forced into what they believe to be unethical practice.

The professional code of conduct of the Nursing and Midwifery Council can be used by nurses acting in good faith to: protect both patients and the practitioners:

"You have a duty of care at all times and people must be able to trust you with their lives and health. To justify that trust, you must:

- make the care of people your first concern, treating them as individuals and respecting their dignity”
- work with others to protect and promote the health and wellbeing of those in your care, their families and carers, and the wider community.

The historical expectation of the professional bodies is to remind nurses that they will be at risk of disciplinary action if they do not follow their professional code of conduct, which insists on care (which includes required nutrition and fluids, where appropriate and practicable) and not to administer unnecessary drugs. The need for evidence-based nursing is a requirement of the nursing code of conduct. The code further states:

“As a professional, you are personally accountable for actions and omissions in your practice, and must always be able to justify your decisions” 6.

A nurse has summarised her experience of trying to reconcile this pathway with ethical nursing practice and the concept of doing no harm:

“I think this is best summed up as a feeling of complete ‘moral distress, due to not being able to give children fluids and watching children suffer effects of dehydration and potentially dying from dehydration before the natural disease process, feeling powerless to help with this, despite raising concerns. Overwhelming concern that your patient is being over sedated and dying too soon as a result and with no way back for patients should things turn around, (as can sometimes happen). Alongside over-sedation, further distress results for nurses with a system where there are no upper limits on morphine doses. The nurse suffers the effect of giving extremely high doses of morphine/sedatives not knowing whether the dose they give will potentially end the life of the patient. As a nurse, I wanted to care for the dying child, giving them a drink when they needed it, relieving their suffering with pain relief without the terrible burden of whether we are crossing the fine line between where palliative care end and euthanasia begins. I also had to endure being treated very badly for raising concerns about the LCP in the workplace”.

The conclusion of the Francis Inquiry into Mid Stafford NHS Foundation Trust found that a chronic shortage of staff, particularly nursing staff, was largely responsible for the substandard care. Morale at the Trust was low, and while many staff did their best in difficult circumstances, others showed a disturbing lack of compassion towards their patients. Staff who spoke out felt ignored and there is strong evidence that many were deterred from doing so through fear and bullying.⁷

There remain obvious problems with the current pathway:

1. The LCP is clearly a treatment rather than a care pathway. The word 'treatment' is conspicuously absent from LCP descriptors. Consent to treatment is significantly under discussed
2. Medical practitioners are responsible for medication prescriptions inherent to the pathway. The patient /family members/ patient advocate need to be aware of and formally

consent to the powerful cocktail of drugs involved and general lack of fluid provision or its continuation (in line with last audit findings).

3. The concepts of holistic care and 'unfinished business', are very important issues for patients reaching the end of life and for their families. The onus of meeting these needs, wherever possible, is on those health care professionals who are responsible for patient treatment and care.

Sedation

Misuse of terminal sedation involves the sedating of patients who are not terminally agitated, delusional or psychotic and have no clinical need to be sedated. Families have reported that patients often were eating, drinking, talking, even walking immediately before being sedated and all of a sudden, became comatose.

In chapter VII of his internet published book about palliative sedation in America, Dr Panzer Dr Ron Panzer President of the American Hospice Patients Alliance, believes that "terminal sedation" or "palliative sedation", was never mainly used as a pain control method. It was properly applied for certain clinical conditions: the sedating of a patient with extreme agitation (called "terminal agitation at the end-of-life"), delusional or psychotic states, or extreme pain that could not be managed any other way. Dr Panzer argues that there is also nothing in the original use of "terminal sedation" that required the patient to be denied assisted fluid and nutrition through a feeding tube, IV or sub cutaneous route. He further states:

"If every patient, no matter what their disease process, is given the same treatment, then the clinically-precise, wonderful interventions that can alleviate suffering at the end-stages of many diseases ... are all "thrown to the wind," and hospice is reduced to a death mill" (Panzer 2011). 8

Social commentator Yuval Levin, has described an emerging societal culture, in his book: *Imagining the Future: Science and American Democracy* as no longer being concerned primarily with helping citizens to lead "the virtuous life. He argues that preventing suffering and virtually all difficulty is now paramount. In such a cultural milieu, eliminating suffering easily mutates into eliminating the sufferer (Levin 2008).9

It is noteworthy that the LCP is endorsed by "Compassion in Dying" which has strong affiliation to "Dignity in Dying" and the former "Voluntary Euthanasia society.

References

1. Department of Health (2008) End of Life Care Strategy - promoting high quality care for all adults at the end of life. July.
2. MCPCIL (2007) National Care of the Dying Audit Hospital Generic Report Round1
<http://www.mcpcil.org.uk/liverpool-care-pathway/pdfs/NCDAHGENERICREPORTFINAL-Auglockepdf.pdf>
3. MCPCIL (2011) National Care of the Dying Audit Hospital Generic Report Round
3.<http://www.liv.ac.uk/media/livacuk/mcpcil/documents/NCDAH-GENERIC-REPORT-2011-2012-FINAL.doc-17.11.11.pdf>
4. Onwuteaka-Philipsen BD et al (2012) Trends.
<http://www.thelancet.com/search/results?fieldName=Authors&searchTerm=Bregje D+>
(Last accessed 22/09/12).
5. Seale C. (2009) Continuous Deep Sedation in Medical Practice: A Descriptive Study. Centre for Health Sciences, Barts and the London School of Medicine and Dentistry, Queen Mary University of London, London, United Kingdom. Journal of Pain and Symptom Management. Volume 39, Issue 1, Pages 44-53, January 2010. Accepted 22 June 2009. Published online 26 October 2009. (Last accessed 07/10/12).
6. Nursing and Midwifery Council (2008) The code: Standards of conduct, performance and ethics for nurses and midwives. NMC: London. May.
7. Francis R (2013) Final Report Of The Independent Inquiry Into Care Provided By Mid Staffordshire NHS Foundation Trust. March.
8. Panzer R. (2011) Stealth Euthanasia: Health Care Tyranny in America (Hospice, Palliative Care and Health Care Reform). (From chapter VII - Palliative Sedation or Terminal Sedation to Hasten Death – section: Hospice Can Mis educate Physicians to Facilitate Ending Lives). www.hospicepatients.org/this-thing-called-hospice.html (Last accessed 24/05/2013)
9. Levin Y. (2008) Imagining the Future: Science and American Democracy. New Atlantis Books. Encounter Books. New York, London.