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End of Life Protocols: Helping to die well or helping to die?

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Introduced in the 1990s and more fully developed by 2004, several protocols known as integrated care “pathways,” including the Liverpool Care Pathway, are in use in the UK as templates ensuring quality care and consistency of care for patients at end-of-life.¹

These pathways are intended to help ensure a peaceful death for the dying, without unnecessary interventions. They are meant to be a way of deciding when to stop using measures that perhaps become counterproductive nearing the end point of a person’s life. They are to help clinicians in their decisions to end treatment and allow the processes of dying to run their course. It was thought that they could a useful template for end-of-life decision-making in Canada and elsewhere.

ETHICAL QUESTIONS

Over the past few years, however, questions have been raised and alarms sounded that people on the Liverpool Pathway seem to be dying somewhat suspiciously earlier than perhaps would usually have been expected, and relatives are concerned that their loved ones’ deaths may have been hastened.

These concerns allege that nutrition and hydration are being withdrawn too soon, and sometimes without the patient’s or family’s consent.

It is true that the pathway does allow for such cessation of feeding, but the original understanding was that this would occur only in the final hours or days of the person’s life, when administration of food and fluids or ANH begins to be clearly counter to the patient’s comfort and wellbeing.

From a Catholic perspective, the withdrawal of food and fluids, whether given orally or by a feeding tube, always raises red flags in any situation, not just at end-of-life, ever since John Paul II stated in 2004 that food and fluids, even tube feeding (Artificial Nutrition and Hydration/ANH), are to be considered “ordinary” care, and always to be administered unless and until they begin to cause more problems than they solve.²

It would appear that it is in this area that claims have been made about those on the LCP having their food or ANH withdrawn earlier than their overall condition warrants. In these cases, the deprivation of food and fluid then becomes the cause of death, and the question of intentionality arises. The original point of the pathway is clearly being abused in cases where these claims are correct.

ARE SUCH PROTOCOLS WRONG IN THEMSELVES?

Some people are calling for these pathways to be discontinued because of these alleged abuses. It is important, however, to make a distinction between a morally acceptable practice and situations where the practice is abused. The fact that some people distort the practice does not necessarily mean that the practice is wrong in itself. It could be a perfectly acceptable practice, as long as those who use it do so virtuously. With this in mind, we can look at the practice of a protocol such as the Liverpool Care Pathway and assess it.

FIRST, SUPPORT FOR THE PROTOCOLS:

There are many voices in favour of the use of pathways such as the LCP. The latter has received support from many organizations dealing with end-of-life issues and good practice, including a consensus statement made in September 2012 by twenty such groups.³ The chair of one of those groups, *Dying Matters*, said that the LCP had enabled "...thousands of people to die well..." but that "...poor experience must be explored..."⁴ Some of those groups are currently working with hospital Trusts to find out about complaints received by families, while the Association of Palliative Medicine and other national groups are working with clinicians to hear their opinions about what works well at end of life.

Dr. Peter Saunders, well known in the UK because of his role as President of the Christian Medical Fellowship, called the pathway "a very good tool" in itself.⁵

Defenders insist that they themselves would like to have the LCP used when they are at

end of life. They say that the LCP is about care, and not about hastening death. The decision is not made by physicians alone, but in consultation with the patient and family, in situations where further treatment would be futile. They insist that if a patient's condition improves, the pathway can be discontinued. In a letter written to the *Daily Telegraph* and signed by over 1000 practitioners, they say that the pathway has improved end of life care, in doing away with unnecessary and intrusive treatments that were not in patients' best interests.⁶

SECOND, VOICES AGAINST THE PROTOCOLS:

In an audit by Marie Curie Cancer Care and the Royal College of Physicians in December 2012, it was found that patients or their families were not told in about 6% of cases that the pathway had been begun.⁷ In many hospital trusts, doctors did not inform families or patients. Apart from controversy over the whole question of patient autonomy and consent, this is clearly unethical and alarmingly dangerous. It goes counter to the claims of the pathway that family is involved.

That does not mean of course, that there is necessarily a problem with the concept of the pathway itself: as is so very often the case, the problem lies with those who are abusing the practice by taking it upon themselves to make decisions.

Without complete transparency and adequate consultancy with those concerned, users (rather, 'abusers') of the pathway cannot be trusted. A government enquiry is underway, partly because of complaints and enquiries made by the various end-of-life care groups

in the UK, and this should bring to light any misdeeds that have been taking place.⁸

BABIES AND THE PATHWAY

Although most of us think of end-of-life as involving older people, we tend to forget that even some babies can be terminally ill. A few reports indicate that some infants have been placed on the pathway, and some have had nutrition and hydration removed. If this has been done unnecessarily and, in fact, to bring about death, then we are no longer talking about slippery slopes: we are tumbling down it.

The pathways are to be used to prevent *unnecessary* and *disproportionate* treatment as life is ebbing, and patients are not to be deprived of treatment or food and fluids in any situation where they are not dying. In the latter case, what is happening is euthanasia, not the proper application of an end-of-life protocol.

PAYOUTS

Another factor which introduces an ominous note into the discussion about the LPC is the payment to hospital Trusts for meeting targets related to its use. According to reports in the *Daily Telegraph*, two thirds of these hospitals are meeting these targets, and will be rewarded to the tune of at least twelve million pounds (twenty million dollars).⁹ This sort of tactic casts a pall of suspicion over the whole enterprise, with opinion again divided into two camps.

One camp says that meeting targets is an acceptable form of ensuring quality outcomes for treatment, and is a tactic used in many areas of medicine. The elephant in the room here is that, with the LCP and other

pathways, the outcome that meets the target is the death of the patient. Many fear that death is being hastened in order to qualify for the payments, and although this sounds incredibly mercenary and downright disgraceful, it seems that that has happened in some cases. A coalition of physicians led by Professor Patrick Pullicino accuses other physicians of stopping fluids too early and giving narcotics and sedatives which hasten death.¹⁰ They say that "...the median time on the Liverpool Care Pathway is now 29 hours."¹¹ Yet "... statistics show that even patients with terminal cancer and a poor prognosis may survive months or more if not put on the LCP."¹²

A major problem in these areas is that diagnoses of impending death are not easy to make. Most physicians admit there is an element of "guess work," therefore stopping fluids too soon while increasing medication could be hastening and causing death, as against helping the patient cope with the natural decline that occurs as death approaches.

Other physicians say they allow for faulty diagnosis, and that fluids are resumed if a patient rallies. Not every Trust is involved in receiving payments, and not every Trust has seen an increase in the number of deaths among those placed on the LCP, although in some, the number doubled in 2011 from 2010.

The National Health Service has begun a review of the LCP and other pathways after several complaints of unethical behaviour were made. There is no doubt that physicians are divided on this issue. Those who claim to use the LCP ethically claim that the

pathways are intended to help patients die well, and insist on transparency, and full involvement of families. In other cases, families have said that their relatives were placed on a pathway without their knowledge and consent, and the ethics of such treatment are then clearly wrong. The practice of payments for meeting targets is prima facie worrying, especially in those areas where the numbers of patients who have died on the pathways have increased, sometimes dramatically. More recently, it appears that some babies with serious problems have been placed on the pathway at the request of their parents. This is completely unacceptable when the children are not dying. This practice is euthanasia by omission, and one can only hope that the public enquiry into the pathways will bring such practices into public scrutiny and they will be subsequently banned.

ENDNOTE

Should use of the LCP be banned? It would seem that used in the right hands, for the right people, with full transparency and consent that it is not wrong in itself. But when used to hasten death, or, shockingly, to meet some type of arbitrary target, it is completely abhorrent and clearly wrong. We must make that crucial distinction, and it is to be hoped that the results of the enquiry will insist that doctors do the right thing: protect vulnerable patients and help them to live out their last days in dignity. ■

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¹ Originally developed at the Royal Liverpool University Hospital and Liverpool's Marie Curie Hospice, setting out principles to relieve suffering in dying patients by withdrawing treatments of forgoing tests which doctors think would cause more harm than good. This sometimes includes withdrawing of feeding tubes.

² Pope John Paul II, *Address to the Participants in the International Congress on 'Life Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas.'* March 20, 2004.

³ Consensus Statement, September 2012, signed by twenty two groups, including The National Council for Palliative Care, Marie Curie Cancer Support, the Royal College of General Practitioners, etc. http://www.rcn.org.uk/__data/assets/pdf_file/0011/477677/Liverpool_Care_Pathway_consensus_statement.pdf (Accessed January 23, 2013)

⁴ Professor Mayur Lakhani, Chair: Dying Matters Coalition, quoted in eHospice, October 26, 2012. <http://www.ehospice.com/uk/Home/tabid/1030/tabid/2950/ArticleId/1459/language/en-Default.aspx#UQA99TdGI3s> (Accessed January 23, 2013)

⁵ Dr. Peter Saunders, of Care Not Killing Alliance, quoted in *The Daily Telegraph*, October 23, 2013. <http://www.telegraph.co.uk/health/9647141/Liverpool-Care-Pathway-use-must-not-be-driven-by-other-agendas.html> (video). (Accessed January 23, 2013)

⁶ Letter in favour of the LCP signed by over 1000 doctors, nurses and carers. *The Daily Telegraph*, <http://www.telegraph.co.uk/health/healthnews/9659561/Doctors-defend-Liverpool-Care-Pathway-as-dignified-way-to-die.html> (Accessed January 23, 2013)

⁷ *Ibid.*

⁸ <http://www.catholicherald.co.uk/news/2012/11/28/government-opens-inquiry-into-liverpool-care-pathway/> (Accessed January 23, 2013)

⁹ <http://www.telegraph.co.uk/health/healthnews/9644287/NHS-millions-for-controversial-care-pathway.html> (Accessed January 23, 2013)

¹⁰ <http://www.telegraph.co.uk/health/healthnews/9630194/Doctors-to-launch-investigation-into-Liverpool-Care-Pathway.html> (Accessed January 23, 2013)

¹¹ *Ibid.*

¹² *Ibid.*