A comment on the Liverpool Care Pathway by Professor David Albert Jones

The Liverpool Care Pathway for the Dying Patient (LCP) was developed in 1997 by the specialist palliative care team at the Royal Liverpool and Broadgreen University Hospital Trust together with the Marie Curie Hospice in Liverpool. The Marie Curie Palliative Care Institute Liverpool (MCPCIL) has led the dissemination of the LCP nationally and internationally as a continuous quality improvement programme to support care in the last hours or days of life. The generic core document of the LCP (MCPCIL 2009) can be found on the MCPCIL website (www.mcpcil.org.uk) along with other supporting material. The core document does not stand on its own but needs to be used within a system of training and audit. The LCP has been developed by and should be understood in relation to the Marie Curie Palliative Care Institute Liverpool and the hospice movement and palliative care profession more generally. The document should be interpreted in this context and also in the light of guidance from the General Medical Council on treatment and care towards the end of life (GMC 2010). This context is acknowledged explicitly on the MCPCIL website, for example, “the LCP prompts clinicians to consider the need for CANH [clinically assisted nutrition and hydration]. All clinical decisions must be made in the patient’s best interest and tailored to the patient’s individual needs. The GMC guidance provides specific information regarding this issue” (MCPCIL 2012).

The main principles behind the Liverpool Care Pathway are those of good palliative care and are fully in accordance with Catholic moral theology and with a Catholic understanding of a good death. Nevertheless, in practice it is clear that there is scope for patients to suffer if the LCP is misunderstood and used inappropriately, and the LCP may need to be improved in order to reduce the scope for such misunderstandings. There are a number of pressures that might subvert the proper implementation of the LCP. These might include:

- the subjective character of judgments about how soon someone is going to die, and the lack of explicit evidence-based criteria for this judgment in the case of the imminently dying;
- the fact that the LCP may be initiated by people who are not senior clinicians, or are not familiar with the individual patient’s case, or who have not consulted with palliative care physicians;
- the influence of managerial pressures to reduce bed occupancy or meet targets of one kind or another;
- reluctance to face the problems of continuing care of certain difficult patients;
- the euthanasiaist outlook of some clinicians;
- the possibility of doctors or nurses regarding the LCP as a set of “tick boxes” (which is part of a larger cultural problem in the health service);
- that rather than assessing, and regularly re-assessing, the needs of the patient, fluids might be withdrawn automatically, where they could, for example, have been useful in alleviating thirst, (in some cases patients have been deprived even of sips of water or of the moistening of their dry mouth);
- Other NHS organizational/ staffing procedures or constraints that may prevent an essential step or dimension of the LCP from being properly applied.
- Lack of discussion with patients (if they are competent) and relatives or carers.

The hospice movement, which is widely admired and supported, is often successful in meeting the needs of dying people for adequate symptom relief, for human support, and for spiritual care.
However, most of us in Great Britain and Ireland do not die in a hospice, nor do most of us die at home. We die in hospitals which have as their main aim to get people better, to cure, or at least improve people’s state of health. In the context of a system that focuses on cure it is difficult both for clinicians and for relatives to admit that a patient is dying and might need care appropriate to the dying. Research shows that care of the dying is poorest in the hospital setting.

The LCP may be regarded as an uneasy compromise because it seeks to deliver what would be better delivered, but cannot (within realistic resource constraints) be delivered, by universal availability of hospice care. It is for this reason that the MCPCIL website acknowledges that the LCP “is not the answer to all our needs for care of the dying but is a step in the right direction”.

The LCP is not the only approach to improving the quality of end of life care but it has been recommended by the Department of Health, the End of Life Care Programme and by the NICE Quality Standard for End of Life Care. It has also been taken up by a number of other countries (including majority-Catholic countries) and is the focus of international research and collaboration with the aim of improving standards of care.

As with palliative care more generally, the LCP when properly implemented does not aim to hasten death but aims to support doctors and nurses to give the treatment and care that is appropriate for a dying patient and to withdraw any treatments or forms of care that are futile, burdensome, or counterproductive.

The *Catechism of the Catholic Church* is very clear that medical treatment can sometimes be withdrawn:

“Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to their expected outcome can be legitimate: it is the refusal of ‘overzealous’ treatment. Here one does not will to cause death; one’s inability to impede it is merely accepted. The decision should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected” (paragraph 2278).

The view of the Catholic Church, as expressed by Pope John Paul II and by the Congregation for the Doctrine of the Faith, is that food and drink, even when provided by tube (CANH), should not be regarded as medical treatment but rather, as ordinary care, which is, in principle, obligatory. Nevertheless, when death is imminent, this form of care may no longer be needed. Thus Bishop Anthony Fisher OP (who delivered the Anscombe Memorial Lecture in 2012 on discrimination against older patients), states that, “it will sometime be appropriate to withhold, reduce or withdraw assisted nutrition and hydration” (Fisher 2012, p. 232).

From a traditional Catholic perspective it is not always mandatory to institute clinically assisted hydration (CAH) in an imminently dying patient. The question, therefore, is whether a particular patient might benefit from CAH in regard to sustaining life or relief of adverse symptoms. From a traditional Hippocratic perspective it is absolutely clear that CAH should never be withheld or withdrawn in order to hasten death. On the other hand it is not clear that most patients who are entering the last phase of dying would benefit from CAH. Physicians in different countries have adopted different practices and the evidence is mixed. Within the hospice movement in the United
Kingdom it is relatively rare to institute CAH. Nevertheless, good practice (as reflected in the GMC guidance and in the LCP) is not to have a blanket policy but for each patient to be regularly assessed as to how best to address nutritional and hydration needs (“You must assess their needs for nutrition and hydration separately and consider what forms of clinically assisted nutrition or hydration may be required to meet their needs” GMC 2010, paragraph 111). A good summary of the current evidence in relation to the benefits and burdens of instituting CAH at the end of life is provided in a recent paper by Anna Nowarska (2011, see also Dalal, Del Fabbro and Bruera 2009, Keeler 2010).

The Church has also made clear that pain relief and sedatives may be given where they are needed, even if this reduces lucidity and even if it were to shorten life, though the evidence is that opiates titrated for symptom relief do not shorten life (Sykes and Thorns 2003a; 2003b; Maltoni et al. 2009).

“Human and Christian prudence suggest for the majority of sick people the use of medicines capable of alleviating or suppressing pain, even though these may cause as a secondary effect semi-consciousness and reduced lucidity... [and even] if one foresees that the use of narcotics will shorten life... In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively” (SCDF 1980).

The LCP encourages a system of anticipatory prescribing, so that pain relief is available as soon as it is needed, but both pain relief and sedatives should be given only as necessary to bring symptoms under control. In the United Kingdom and the Republic of Ireland it is not considered good practice in palliative care to aim at producing continuous deep sedation. While sedatives might sometimes be given in excess of what is needed, audit evidence shows that levels of sedation on the LCP have generally been relatively modest and there has been no evidence of continuous deep sedation (Gambles et al 2011). The contrast between the aim and typical outcome of sedative practice on the LCP, and the practice of continuous deep sedation, as used in the Netherlands as an alternative to active euthanasia, is best illustrated by a comparison of the doses used and recommended. This is helpfully set out by Dr Jeff Stephenson, a Consultant in Palliative Medicine based in the UK.

“The second national audit [of the LCP] found that drugs prescribed for agitation and restlessness were given in only 37% of cases, and the median dose of midazolam, the most frequently used drug for this indication, was 10mg/24hrs. This contrasts markedly with guidance on continuous deep sedation from the Royal Dutch Medical Association which recommends a starting dose of 1.5 – 2.5 mg per hour, with progressive escalation until unconsciousness is achieved, up to a maximum of 20mg per hour. Interestingly, the use of the LCP in the Netherlands has been reported to reduce the extent to which physicians use medication that might hasten death” (Stephenson 2012 citing NCDAH 2012 and KNMG 2009, emphasis in the original).

Thus, the LCP is an approach to improving standards of end of life care and is not either in intention or in practice, when properly implemented, a form of euthanasia. The LCP is a means to promote palliative care and research has shown that, among doctors, palliative care physicians are the least likely to hasten death and the least likely to intend to hasten death (Seale 2006, Seale 2009). According to the MPCPI, “the LCP exists to support good decision making in the last hours or days of life which will focus on ensuring good quality of care. The provision or withdrawal of interventions
with the direct aim of hastening death is contrary to the rationale of the LCP, contrary to GMC guidance, and illegal” (MCPCIL 2012).

As patients or relatives of patients, we may sometimes resist the recognition that we or our loved one is dying and may push for unnecessary treatments or procedures which are burdensome or harmful and which do not improve the quality of the person’s life. On the other hand, we all wish to know that proper care is given until the end, and that a person who dies has not been deprived of treatments that would have been beneficial or even deprived of further weeks or months of life. The Catholic perspective on this will show concern both to avoid the danger of overtreatment and to avoid the danger of undertreatment. This understanding of virtue as lying between opposite vices was clearly set out in the bishops’ conference document on the Spiritual Care of the Dying:

“There are two things that need to be kept in mind in end of life care: respecting life and accepting death. Respecting life means that every person must be valued for as long as they live. One implication of this is that death should never be the aim of our action or of our inaction. We should never try to bring about or to hasten death. On the other hand, accepting death means that we should prepare properly for death. One implication of this is that we should not deny the reality of the situation or flee from the inevitable by seeking every possible treatment.” (CBCEW 2010, paragraph 2.1)

There is a danger that media reporting of claims of abuse may not always present a true and balanced view of the LCP and its purpose, although all such claims should be taken seriously. Understanding of current practice should also be informed by evidence from national audits and from empirical research published in peer review journals (for example, National Audit Office 2008, NCEPOD 2009, NCDAH 2012, Veerbeek et al. 2008). The principles behind the LCP are compatible with a Catholic understanding of morality and of the meaning of life and death. Nevertheless, as the LCP has been used more extensively there may well have been increasing occasions where someone supported by the LCP has not been provided with adequate care, or where someone has been referred to the pathway inappropriately. Examples of these cases, reported in the media or not, should be used to improve the pathway in future iterations. In the meantime, Catholic doctors, nurses, relatives and patients should continue to take care that the Liverpool Care Pathway, or indeed any other integrated care pathway, is used correctly, to identify and address the patient’s actual needs (Atkins 2012). In some situations, this may involve being aware of and seeking to address some of the pressures (described above) that have the potential to subvert proper implementation of the LCP.

There are different levels of ethical analysis of an integrated pathway for the care of the dying: its fundamental rationale; the precise wording of its documentation; the possibility of using it ethically in the best case; the possibility of its ethical use in the typical case (in general or for the most part); the actual pattern of use of the pathway; the possibility of abuse; the possibility that flaws in the pathway might make some kinds of abuse more likely; the further ethical guidance that might be necessary for healthcare professionals in applying the pathway; and the ethical guidance that may be necessary for patients and relatives to mitigate the chance of abuse on the pathway.

This comment has focused on the rationale of the pathway and thus the very possibility of good use. It suggests that the LCP can be used ethically when applied by skilled and ethically committed professionals. Used correctly, the LCP can and does help support the kind of good death for which
Catholics pray, a peaceful death that is not hastened but is accepted consciously with faith in God and hope of everlasting life in the world to come.

In regard to the wording of the core documents, while the LCP is already in its twelfth iteration, there are ways in which this wording could be improved further, for example by making use of the wording of the GMC guidance in relation to CANH, and no doubt in other respects. There is more work to be done here.

In regard to actual use, there is certainly evidence of abuse and failures of care of people on the LCP, but such evidence does not show that its use in general or for the most part is unethical. There is more to be learned about how the LCP is being applied in general and how this may be improved and failures avoided. It is to be hoped that the current Department of Health review of individual cases and of systematic data will shed some light on this.

There is thus more work that needs to be done in relation to ethical analysis of the LCP. This comment is intended to help clarify some of the key ethical and clinical questions raised by the pathway in the hope of contributing to the eventual resolution of this complex and important area.

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