Submission to the Review of the Liverpool Care Pathway (LCP) on behalf of the Department of Christian Responsibility and Citizenship of the Catholic Bishops' Conference of England and Wales[1]

Summary

0.1 This submission sets out:

- *0.1.1 The background to the debate over the LCP within the Catholic community*
- *0.1.2 The call for an inquiry into the use of the LCP*
- *0.1.3 The main principles of the ethics of end-of-life care*
  - *0.1.3.1 Key principle: life as a penultimate reality*
  - *0.1.3.2 Euthanasia and the prohibition of taking innocent life*
  - *0.1.3.3 Double effect in the use of analgesia and sedation*
  - *0.1.3.4 Withdrawal of clinically assisted nutrition and hydration (CANH)*
- *0.1.4 Some allegations made in relation to the LCP*
- *0.1.5 Some concerns expressed by supporters of the LCP*
- *0.1.6 The investigations needed to assess these allegations*
- *0.1.7 Some empirical evidence relevant to the investigation of the following questions:*
  - *0.1.7.1 Is clinically assisted hydration (CAH) in the dying needed to ameliorate thirst?*
  - *0.1.7.2 Does withholding or withdrawing CAH in dying patients hasten death?*
  - *0.1.7.3 Does the use of opioids and/or sedatives in the dying hasten death?*
  - *0.1.7.4 Is it possible to predict imminent dying accurately?*

0.2 This submission recommends that the Review Committee systematically investigate:

0.2.1 Whether commissioners, managers and healthcare professionals who have encouraged the use of the LCP have or have not had any intention of hastening death;

0.2.2 Whether, to what extent and with what consequences, the LCP has been initiated without the agreement of the multidisciplinary team;

0.2.3 Whether sedatives and analgesics at the end of life are being used in excess of the doses needed for symptom relief, and if so, whether practice on the LCP is better or worse than practice outside the LCP;

0.2.4 Whether the most commonly used sedatives and analgesics at the doses typically used are within the proper limits of safety and toxicity;

0.2.5 Whether there is a wide scale problem of untreated pain and whether there is evidence that presence of the LCP improves the level of pain relief;

0.2.6 Whether the consensus of a multidisciplinary team can reliably diagnose imminent dying, and to what level of accuracy, and the risks involved if this diagnosis is mistaken;

0.2.7 Whether the media reporting of the LCP has been accurate and responsible and whether misreporting has had a detrimental effect on the ability to deliver end of life care;

0.2.8 Whether the LCP is being used as intended or whether further training, guidance, and investment is needed.

[1] Prepared by Prof David Albert Jones, director@bioethics.org.uk. This submission was prepared in an individual capacity at the request of the Department of Christian Responsibility and Citizenship of the Catholic Bishops' Conference of England and Wales.

1 Background

1.1 The first reason that Catholics have an interest in the operation of an end-of-life pathway is that it affects them as providers and recipients of healthcare, as healthcare professionals, as patients or potential patients, as relatives and carers. As 'the joys and the hopes, the griefs and the anxieties of the men of this age, especially those who are poor or in any way afflicted, these are the joys and hopes, the griefs and anxieties of the followers of Christ'[2], then Catholics, as responsible citizens, will be concerned about the implementation of end-of-life care, both for their own sakes and for the sake of others.

1.2 There are additional reasons why Catholics specifically are concerned about end-of-life care, reasons related directly to the Catholic faith. Christianity is concerned with the most vulnerable in whom Christians are called to see the person of Christ who said, 'as you did it to one of the least of these my brethren, you did it to me'.[3] While Christians have not always lived up to this injunction, the desire to serve the most vulnerable is evident in the founding of care homes, nursing homes, asylums, and orphanages, and more recently in the pro-life movement which has sought to protect the vulnerable, especially the unborn, the elderly, and those with disabilities from having their lives deliberately ended by abortion or euthanasia.

1.3 The Gospel also commands Christians to heal and, more generally, to care for the sick. The model of Christian love is provided by the Good Samaritan[4] who comes across a man who has been injured and who binds his wounds and pays for his care. From the earliest centuries Christians have cared in particular for the sick.[5] The influence of Christianity on medicine is seen in the very existence of hospitals,[6] in the profession of nursing in its modern form and in the idea of health*care* and of a National Health *Service*. The ancient world had doctors but it did not have hospitals or a nursing profession and medical treatment was not seen principally as a form of 'care' or 'service'. Together with Judaism and Islam, Christianity has also been responsible for the promotion and refinement of a Hippocratic ideal of ethical medicine, which is directed towards benefiting the sick by knowledge and skill and which opposes the practice of physician assisted suicide. For all these reasons Catholics have a particular interest in ensuring that healthcare is delivered in an ethical manner.

1.4 The New Testament also enjoins Christians to call for a priest (*presbuteros*) if one of the community is sick, so that the priest can anoint him or her.[7] Again from the earliest times there has been an awareness of the spiritual needs of the sick especially, but not only, at the point of death.[8] This concern for the spiritual needs of the sick and the dying is evident in the Catholic Church's provision of hospital chaplains.

---

[2] Vatican II, *Gaudium et Spes* preface, 1.
[3] Matthew 25:40
[4] Luke 10:30-37.
[5] Gary B. Ferngren, ed., *Medicine and Health Care in Early Christianity* (Baltimore, MD: Johns Hopkins University Press, 2009).
[6] Guenter B. Risse, *Mending Bodies, Saving Souls: A History of Hospitals* (Oxford: Oxford University Press, 1999).
[7] James 5:14
[8] Catholic Bishops' Conference of England and Wales: Department for Christian Responsibility and Citizenship, *A Practical Guide to The Spiritual Care of the Dying Person* (London: CTS, 2010). It should, however, be noted that in current Catholic understanding it is in fact a mistake to understand the anointing of the sick as a sacrament for the imminently dying: the sacrament of immediate preparation for death is rather the viaticum, the final communion.

1.5 Finally, the Catholic Church has a specific doctrine about death and what may happen after death, and this has implications for how Catholics should prepare for death and how the Church prays for the dead.[9] There is a rich tradition of piety concerned with making a good death,[10] [11] [12] within which it is of great importance that death be accepted consciously. Hence traditionally Catholics have prayed that death not come suddenly in a way that prevents adequate preparation.

1.6 From a Catholic perspective, therefore, death is not to be resisted at all costs through the imposition of futile treatments, but neither are dying patients to be abandoned. Dying patients have human, emotional, and spiritual needs which must be acknowledged. The concern to address the needs of dying patients and not to deny the reality of approaching death through the imposition of futile treatments has inspired the hospice movement.[13] The hospice movement is not exclusively Christian but it has roots in a Christian understanding of care for the dying, and especially a Catholic understanding. The hospice movement and palliative care generally thus reflects a Catholic spirit and it is not surprising that there are many Catholic physicians and nurses who choose to specialise in end-of-life care. These professionals and those who appreciate their work also have a particular concern with end-of-life care.[14]

[9] Eamon Duffy, *Faith of Our Fathers: Reflections on Catholic Tradition* (London: Continuum, 2004).
[10] Philip Egan, Bishop of Portsmouth 'The Care of the Dying' Pastoral Letter, 8 December 2012.
[11] Michael Levering, *On Christian Dying: Classic and Contemporary Texts* (Lanham, MD: Rowman and Littlefield, 2004).
[12] David Albert Jones, *Approaching the End: a theological exploration of death and dying* (Oxford: Oxford University Press, 2007).
[13] David Clark, 'Religion, Medicine, and Community in the Early Origins of St. Christopher's Hospice', *Journal of Palliative Medicine* 4(3) (2001): 353-360.
[14] Thomas A. Williams, Auxiliary Bishop of Liverpool 'Palliative Care – light of experience' *The Tablet* (26 January 2013): 18.

2 The call for an inquiry into the use of the LCP

2.1 It is thus no surprise that Catholics, including a number of Catholic doctors, were among those to raise concerns about the Liverpool Care Pathway.[15] [16] [17] [18] [19] These concerns stem from that commitment to care for and safeguard the vulnerable which is characteristic of Catholic Christianity. Catholic critics have raised a number of concerns about the LCP but central is the concern that people who are not imminently dying may have their deaths hastened by inappropriate treatment and/or withdrawal of treatment once the pathway is commenced, and that those who are imminently dying may be caused unnecessary suffering or the unnecessary deprivation of awareness. These claims will be examined further below.

2.2 Less well known is that Catholic doctors and Catholic hospital chaplains have been prominent in the origin and development of the LCP and of its current implementation. This involvement stems from a commitment to care of the dying, which is also characteristic of Catholic Christianity. Catholic supporters of the LCP have raised concerns that the pathway is being misrepresented in the media, and that if it is abandoned, and if nothing similar replaces it, then this could lead to a return to the imposition of aggressive treatment on people very unlikely to benefit, to a neglect of symptom control and spiritual care, and to a worsening of communication with those who are dying and with those close to them.[20] [21] [22] [23] [24]

2.3 It was with an awareness of concerns from both directions, and of the uncertainty expressed by many lay Catholics, that the Archbishop of Southwark called for an inquiry to help resolve whether in practice the LCP was hastening death and causing other serious harms, or whether the allegations were not justified but were themselves causing anxiety and undermining efforts to improve care of the dying. This call was not intended to prejudge the results of such an inquiry or to take a position on whether the allegations were justified. Rather, given that very serious allegations had been made and were a cause of concern within the Catholic community and within wider society, an inquiry was needed to examine the evidence.

[15] Patrick Pullicino, 'The Dangers of Abandonment of Evidence-Based Medicine in the use of the Liverpool Care Pathway', *Catholic Medical Quarterly* 62(4) (November 2012).
[16] Philip Howard, 'Not so Peaceful an End', *The Tablet* (15 September 2012): 8-9.
[17] Philip Howard, 'Care of the Dying', *The Tablet* (6 October 2012): 19.
[18] Rebecca Smith, 'Patient death pathway "based on guesswork"', *Telegraph* (22 October 2012).
[19] Adrian J. Treloar, 'The Liverpool care pathway is not safe' in 'BMJ Rapid Response to The Liverpool care pathway: what do specialists think?' (6 March 2013).
[20] Patrick C. Stone, 'Care of the Dying', *The Tablet* (22 September 2012): 17-18.
[21] Margaret Guy, 'Letters Extra: Can Catholic doctors condone the Liverpool Care Pathway?', *The Tablet* online edition (21 September 2012).
[22] Paul Salter, Edwin Pugh, Mel McEvoy, 'Letters Extra: Questions and concerns about the Liverpool Care Pathway', *The Tablet* online edition (28 September 2012).
[23] Elizabeth Toy, 'Care at the end of life', *The Tablet* (2 February 2013): 17-18.
[24] Lynn Bassett, 'The Liverpool Care Pathway: A chaplain's perspective', *The Pastoral Review* 9(2) (March/April 2013): 39-43.

'It does seem to me that a thorough and urgent investigation needs to take place, examining the evidence on which the criticisms that have been made of the LCP rest, so that conclusions can be reached as to whether any corrective action is needed.'

'If the allegations that are being made can be substantiated, there is serious cause for concern either that the LCP is in some way structurally unsound and needs to be modified or that some doctors and nurses are failing to implement the guidelines as intended. Equally, if the allegations are without substance, dying patients and their loved ones are at risk of being caused needless anxiety as a result of which they may well seek to avoid treatment and care from which they would benefit.'[25]

2.4 The announcement of a review of the LCP was welcomed by the Archbishop and widely welcomed within the Catholic community. It is important, if the Review is to accomplish the aims of addressing allegations and assessing whether or not they can be substantiated, that the scope of the Review not be interpreted too narrowly.

2.5 While the Review is and ought to be about the implementation of the LCP in practice, and should focus on the actual complaints that have been made about the poor care of some people who died while supported by the LCP, the Review needs also to assess scientific and clinical factors in these cases, and questions of causality. In considering these cases it must be asked whether the problems are due to simple misapplications of the LCP of a kind that are easily remedied or whether, as alleged, the LCP is in some way 'structurally unsound'. The Review cannot assure people of the benefits (or otherwise) and safety (or otherwise) of the LCP unless it addresses these more fundamental criticisms.

[25] Archbishop Peter Smith, Letter to the Health Secretary Jeremy Hunt (27 September 2012).

3 The ethics of end of life care

3.1 Key principle: life as a penultimate reality

3.1.1 There are some key issues which relate to the ethical assessment of an end-of-life pathway, common to the Western tradition of ethical medicine,[26] [27] and we summarise them here. From a Catholic perspective life is to be cherished, not as the ultimate good but as a 'penultimate' reality. This mortal life 'remains a sacred reality entrusted to us, to be preserved with a sense of responsibility and brought to perfection in love', but at the same time the supernatural end of human life highlights 'the relative character of each individual's earthly life'.[28] A failure to accept death may reflect a failure to see the limits of this mortal life, and its penultimate character. From this it follows that 'in healthcare there are two goods: cherishing life, and accepting death ... ... both matter and neither need nor should be done at the expense of the other.'[29] These two goods each have implications for medical practice:

- '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.'[30]

3.2 Euthanasia and the prohibition of taking innocent life

3.2.1 A key element of ethical end-of-life care is the prohibition on intentional killing of the innocent (for lethal force is justified only when used to oppose injustice and under various further conditions[31] [32]). The belief that intentional killing of the innocent is unethical is common to many traditions of law and ethics, as well as the Catholic tradition, and in particular to the tradition of ethical medicine exemplified by the Hippocratic Oath.[33]

3.2.2 Sometimes this prohibition is thought to apply only to actions and not to omissions. However this is a misunderstanding of the ethical principles involved. As it is possible to cause someone's death by a deliberate omission (for example, by deliberately starving someone to death) then where this action is omitted precisely in order to bring about death, it constitutes killing by omission. An adequate definition of euthanasia will therefore cover both actions and omissions and must include the intention to cause or to hasten death, as was made clear by Pope John Paul II:

'For a correct moral judgment on euthanasia, in the first place a clear definition is required. Euthanasia in the strict sense is understood to be an action or omission which of itself and by

[26] David Albert Jones, 'A comment on the Liverpool Care Pathway' (21 January 2013)
[27] Catholic Bishops' Conference of England and Wales *Practical Guide to The Spiritual Care*.
[28] John Paul II, *Evangelium Vitae*, 1996, paragraph 2.
[29] Cormac Murphy O'Connor, 'Spiritual Challenges in Healthcare Today' an address to 'Faith in Health' Conference (unpublished) quoted in L. Bassett, 'The Liverpool Care Pathway: A chaplain's perspective' *The Pastoral Review* 9(2) (March/April 2013): 42.
[30] Catholic Bishops' Conference of England and Wales *Practical Guide to The Spiritual Care*: paragraph 2.1.
[31] Vatican II *Gaudium et Spes*, paragraph 79.
[32] Catholic Bishops Conference of England and Wales *Cherishing Life* (London: CTS, 2004): paragraphs 195-201.
[33] David Albert Jones, 'The Hippocratic Oath III: Hippocratic principles applied to the withdrawal of treatment and the mental capacity act', *Catholic Medical Quarterly* 57(2) (2007): 15-23.

intention causes death, with the purpose of eliminating all suffering. "Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used"'.[34]

3.3 Double effect in the use of analgesia and sedatives

3.3.1 Intention is essential to the definition of euthanasia, so that actions that cause death but are not intended to cause death are not acts of euthanasia and fall outside the absolute prohibition. If an action is not done in order to cause death, but the person knows or suspects that it will cause death, then the action may well be wrong for other reasons. It may be negligent, or unfair, or an expression of discrimination or indifference. It may be a failure to value the other person's life. Nevertheless, for sufficiently good reason an action which has a good intended effect might sometimes be justifiable even if, as a side effect, it hastens someone's death. This possibility is sometimes referred to as the 'principle of double effect' (though the philosopher Elizabeth Anscombe thought it was clearer to call it the principle of side-effects[35]). The classic example of this principle was the use of pain-relieving drugs, as set out by Pope Pius XII in 1957:

'The suppression of pain and consciousness by the use of narcotics... is permitted by religion and morality to the doctor and the patient (even at the approach of death and 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, using for this purpose painkillers available to medicine.'[36]

3.3.2 This quotation, reiterated by the Congregation for the Doctrine of the Faith in 1980[37] and by Pope John Paul II in 1995,[38] makes it clear that, if opioids are necessary to suppress pain in a dying person, then their use is ethically acceptable, even if death is hastened by their use. The hastening of death is a side-effect which is tolerated for the sake of the pain relief. However, while this example is often used to illustrate the principle of double effect, it is now known to be misleading, in that the best evidence is that opioids titrated for symptom relief do not generally shorten life.[39] [40] [41] It is a false dilemma and dying patients should be reassured that in accepting pain relief they are not likely to be shortening their lives.

3.3.3 Whereas the concern about shortening life has not been borne out by the evidence, a side-effect which may well accompany analgesia (pain relief) or sedatives (treatment of agitation) is the possibility of reduced lucidity. This side effect is very serious as it may prevent communication with others and may hamper someone's spiritual preparations for death. Nevertheless, the Catholic Church is very clear that analgesia and sedatives may be used *if they are needed*, even if they reduce consciousness as a side-effect.

'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-

[34] John Paul II, *Evangelium Vitae*, paragraph 65.
[35] Elizabeth Anscombe, 'Action, Intention and "Double Effect"' in Geach, M., Gormally, L. (eds.) *Human Life, Action and Ethics* (Exeter: Imprint Academic, 2005): 207-226.
[36] Pius XII, 'Address to an International Group of Physicians', (24 February 1957): AAS 49, 147.
[37] Congregation for the Doctrine of the Faith, *Declaration on Euthanasia Iura et Bona*, (1980): AAS 72, 547-548.
[38] John Paul II *Evangelium Vitae*, paragraph 65.
[39] Nigel Sykes and Andrew Thorns, 'The use of opioids and sedatives at the end of life', *The Lancet Oncology* 4 (5) (2003): 312-318.
[40] Nigel Sykes and Andrew Thorns, 'Sedative Use in the Last Week of Life and the Implications for End-of-Life Decision Making', *Archives of Internal Medicine* 163 (2003): 341-344.
[41] M. Maltoni et al., 'Palliative sedation therapy does not hasten death: results from a prospective multicenter study', *Annals of Oncology* 20 (2009): 1163–1169.

consciousness and reduced lucidity. As for those who are not in a state to express themselves, one can reasonably presume that they wish to take these painkillers, and have them administered according to the doctor's advice'.[42]

3.3.4 It is noteworthy that Pius XII shows more concern about the suppression of consciousness than about the hastening of death. The honest acceptance of death, in a Catholic understanding, may well involve foregoing aggressive medical treatment, but it also involves various duties which medicine should not impede. A person has a duty not to die in enmity with others if it is possible to be reconciled. The approach of death is also the last opportunity people have to be reconciled with God before the moment of judgment in death. Hence Pope John Paul II reiterates the warning of Pius XII that 'it is not right to deprive the dying person of consciousness without a serious reason'.[43]

3.3.5 This concern about maintaining alertness is not special to Catholics. According to one report, 'The irony of incorporating continuous deep sedation into the practice of palliation is that 96% of terminally ill patients and 65% of treating physicians in the United States consider mental alertness an important attribute at the end of life'.[44] It is noteworthy that alertness was more frequently valued by patients than by physicians and that it was valued by the great majority of people as the prerequisite for making the best of their final hours and days (notwithstanding different views of what makes for a good death). This is just one of the reasons why the Review should investigate whether, as a matter of fact, sedatives are being used on the LCP in excess of what is needed for symptom relief.

3.3.6 It should, however, also be noted that a drift into unconsciousness as death approaches is a common phenomenon even when there has been no change in a drug regime and even without any use of sedatives at all. For example, in a study of nursing home patients in The Netherlands, 25% of patients had slipped into unconsciousness by 24 hours prior to death and a further 19% slipped into unconsciousness in the last 24 hours.[45] This shows the need for caution in assuming that where a dying person on a moderate dose of a sedative drifts into unconsciousness, this has been *caused by* the sedative. It may well be due to the underlying condition and may not be reversible.

3.4 Withdrawal of treatment and the status of clinically assisted nutrition and hydration (CANH)

3.4.1 As it would be acceptable to give palliative treatment which had a side-effect of hastening death, so it can be acceptable to withdraw burdensome treatment even if this hastens death. If the intention is simply to avoid the burdens of treatment then the death is not intended and is not suicide or euthanasia:

'Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to their expected outcome can be legitimate: it is the refusal of "over-zealous" 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

[42] Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*.
[43] John Paul II, *Evangelium Vitae*.
[44] Mohamed Y. Rady and Joseph L. Verheijde, 'Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death?' *American Journal of Hospice & Palliative Medicine* 27(3) (2010): 205-214. It should be noticed that continuous deep sedation (as opposed to the proportionate use of sedatives for symptom relief) is not a practice that is advocated by palliative care physicians in the UK or by the LCP.
[45] Hella E. Brandt et al., 'The last two days of life of nursing home patients - a nationwide study on causes of death and burdensome symptoms in the Netherlands'. *Palliative Medicine* 20 (2006): 537.

entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.'[46]

3.4.2 It is clear that not all medical treatment is obligatory and that medical treatment may reasonably be withheld or withdrawn if it has become futile or too burdensome in relation to its limited benefits. However, there are some forms of healthcare which have a more fundamental significance and cannot simply be regarded as optional. Among these, first place goes to the provision of nutrition and hydration. This is because food and drink are the basic sustenance that everyone needs to survive. They are not special to the sick, as medicines are. The sharing of food and drink is also a fundamental expression of human solidarity. Etymologically, to be a com-panion is to share bread together and sharing food and drink has a common meaning of hospitality across many cultures. To deny such hospitality would undermine the very meaning of a 'hospital'. In line with this understanding, Pope John Paul II clearly stated that nutrition and hydration are part of the ordinary care that everyone has the right to expect. This applies also to clinically assisted nutrition and hydration (CANH):

'I should like particularly, to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering. The obligation to provide "the normal care due to the sick" in such cases includes, in fact, the use of nutrition and hydration.'[47]

3.4.3 This teaching caused controversy and confusion among some Catholic theologians, especially in the United States of America.[48] [49] [50] The Catholic bishops of the United States therefore asked for clarification from the Congregation for the Doctrine of the Faith (CDF), who reiterated and further expounded the teaching.[51] The teaching of Pope John Paul II and/or of the CDF was incorporated into guidance by the United States Catholic Bishops' Conference,[52] by the Australian Catholic Bishops' Conference,[53] and by the Catholic Bishops' Conference of England and Wales.[54]

3.4.4 It should be noted that Pope John Paul II addressed the issue of CANH in the context of patients in a so called 'persistent vegetative state', whose lives may be sustained for months or years by CANH. The Pope was clear that such patients had full human dignity and were not beyond care and thus, if CANH was effective in sustaining life then it was *in principle* obligatory. However, the

[46] Catechism of the Catholic Church, paragraph 2278.
[47] John Paul II, Address on 'Life-sustaining treatments and the vegetative state' (20 March 2004).
[48] Thomas A. Shannon 'Nutrition and Hydration: An Analysis of the Recent Papal Statement in the Light of the Roman Catholic Bioethical Tradition' *Christian Bioethics* 12 (1) (2006): 29-41; see also articles by James F. Drane, Peter Clark, Kevin O'Rourke and John C. Harvey in the same issue.
[49] R.P. Hamel and J.J. Walter (eds). *Artificial Nutrition and Hydration and the Permanently Unconscious Patient: The Catholic Debate* (Washington: Georgetown University Press, 2007).
[50] Christopher Tollefsen (Ed.). *Artificial Nutrition and Hydration: The New Catholic Debate* (Dordrecht: Springer, 2008).
[51] Congregation for the Doctrine of the Faith, 'Responses to Certain Questions of the United States Conference of Catholic Bishops concerning Artificial Nutrition and Hydration, with Commentary' (1st August 2007).
[52] United States Conference of Catholic Bishops 'Ethical and Religious Directives for Catholic Health Care Services Fifth Edition' (17 November 2009).
[53] Australian Catholic Bishops Conference, 'Briefing Note on the Obligation to provide Nutrition and Hydration', (3 September 2004).
[54] Catholic Bishops' Conference of England and Wales Department for Christian Responsibility & Citizenship, *The Mental Capacity Act and "Living Wills": a practical guide for Catholics* (London: CTS, 2008).

Pope was also clear that, while the provision of nutrition and hydration is ordinary care of the sick and thus in principle, obligatory, this may cease to hold where it can no longer 'attain its proper finality', which consists 'in providing nourishment to the patient and alleviation of his suffering'.[55] Thus the US Conference of Catholic Bishops is explicit that the obligation to provide CANH may cease in patients who are imminently dying.

'Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed." For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.'[56]

3.4.5 The same point was expressed in a document of the Department of Christian Responsibility and Citizenship of the Catholic Bishops' Conference of England and Wales, which states that 'In the last few days of life it may not be in someone's best interests to give food and fluids by tube if, for example, food and fluids can no longer be absorbed by the body.' [57]

3.4.6 Similarly, a Catholic Guide to End-of-Life Decisions produced by the National Catholic Bioethics Center (of the United States) states is that 'There is a presumption in favor of continuing to provide food and water to the patient, but there is a stage in the dying process when even these may no longer be obligatory because they provide no benefit.'[58]

3.4.7 The Australian Catholic Bishops are helpfully explicit that withholding or withdrawing CANH, where this is done for a good reason such as futility (i.e. its inability to sustain life or alleviate symptoms) would not be euthanasia, 'Whenever medical treatment or the provision of nutrition and hydration is withheld or withdrawn for legitimate reasons (futility, burdensomeness), this is not euthanasia. As the Pope wrote in *Evangelium Vitae*, "Euthanasia must be distinguished from the decision to forgo… medical procedures which no longer correspond to the real situation of the patient"'.[59]

3.5 Agreement on ethical principles

3.5.1 The foregoing discussion does not cover all ethical issues relating to end-of-life care, but highlights some key elements that are relevant to the ethical assessment of the implementation of an end-of-life care pathway. It is clear that the key moral principles needed to evaluate the care of the dying are not special to the Catholic tradition. They are, rather, common to the Western tradition of ethical medicine.

3.5.2 This tradition excludes deliberate killing of the innocent but sometimes permits provision of treatment which as a side-effect might hasten death, and sometimes permits withdrawing or withholding or medical treatment even if this might hasten death.

[55] John Paul II, 'Life-sustaining treatments': paragraph 4.
[56] United States Conference of Catholic Bishops 'Ethical and Religious Directives'.
[57] Catholic Bishops' Conference of England and Wales *The Mental Capacity Act*: paragraph 4.13.
[58] The National Catholic Bioethics Center, 'A Catholic Guide to End-of-Life Decisions: An Explanation of Church Teaching on Advance Directives, Euthanasia, and Physician Assisted Suicide' (revised 2010).
[59] Australian Catholic Bishops Conference, 'Briefing Note'.

3.5.3 The suppression of consciousness as a side-effect of pain relief or treatment of agitation is acceptable where the pain or agitation cannot be controlled in other ways. However, it is wrong to deprive people of consciousness in their last hours and days without serious reason.

3.5.4 The provision of nutrition and hydration (whether orally or by clinical means) is regarded as the ordinary care to which everyone has a right and is in principle obligatory. Nevertheless, the reasons for this obligation may well no longer hold as death draws near (if clinically assisted nutrition or hydration have no benefit in relation to sustaining life or in relation to alleviating distressing symptoms).

3.5.5 The ethical principles outlined here are compatible with best practice in the palliative care of the dying (whether supported through an integrated care pathway or otherwise), but only on the presupposition that treatments or procedures are given or withdrawn according to the actual needs of the patient, as accurately assessed by trained professionals. Harm could result both from the overuse and from the underuse of pain relief or sedatives. Similarly harm could result from the inappropriate withdrawal of treatment or from the unwillingness to withdraw futile and burdensome treatment.

3.5.6 There is thus a consensus within the Catholic community about the key ethical principles of end-of-life care, a consensus that is shared by many in society as a whole. Where there is controversy is over whether these principles are implemented well in practice, and whether they ever *could* be implemented well using a tool such as the LCP. For example, in assessing the needs of the patient, Catholic theologians frequently make a distinction between the proper treatment of the people who are imminently dying and the proper treatment of those who, while frail or disabled, are not imminently dying. There is a consensus that such a distinction, if it can be made reliably in practice, has implications for what treatment is appropriate. It is, however, an *empirical* question whether this distinction can be drawn reliably *in practice*. If, as has been claimed, there is no scientific basis on which to make such a prognosis, then it would seem hazardous to treat or to withdraw treatment on the basis of this distinction. This, if true, would imply that the Liverpool Care Pathway, other analogous end-of-life care pathways, and also the guidance of the GMC on Treatment and Care towards the End of Life (where that guidance relies on the distinction between the imminently dying patient and the patient who is not imminently dying[60]) are all 'structurally unsound'.

3.5.7 It is the contention of this submission that the controversy over the LCP, and in particular the controversy among clinicians, chaplains, patients and relatives who share a common ethical understanding, is due principally to differences of opinion over empirical questions. The key questions at hand are empirical in character and the Catholic community has welcomed this review of the LCP precisely as an opportunity for empirical evidence and arguments to be collected and assessed. The beginning of this assessment is the identification and clarification of some key clinical and scientific allegations that have been made against the LCP.

[60] General Medical Council, *Treatment and care towards the end of life*. (London: GMC, 2010): paragraphs 119-125.

4 Some allegations made in relation to the LCP

4.1 The most fundamental and troubling allegation against the Liverpool care Pathway is that, in practice, it is an 'assisted dying pathway',[61] that is, a framework for euthanasia by omission (or, more precisely, euthanasia by a combination of omission of CANH and provision of analgesia and sedatives). This claim has been repeated in national newspapers and other media and is the basis of considerable anxiety among patients and relatives.

4.2 An adequate ethical understanding of euthanasia, as set out for example, by Pope John Paul II, includes as a necessary element the *intention* to cause or hasten death. 'Assisted dying' is a euphemism that sometimes refers to assisted suicide, sometimes to euthanasia, and sometimes to both, but in all cases intention is a necessary part of the definition, properly understood.

4.3 The allegation, then, is that the LCP both *causes death* and is *intended to cause death*. There are various expressions of this allegation, but the linking of Commissioning for Quality and Innovation (CQUIN) payments to the LCP provides a clear and vivid example. The allegation is that these payments were decided precisely in order that people's deaths would be hastened and thus the cost of their treatment would be limited and beds would be freed: deliberate euthanasia as a cost cutting device. In this narrative, the intention to bring about death as a cost-cutting measure is first present in the minds of the commissioners who set the quality improvement goals, though it may come to be shared by managers and by doctors.

4.4 Another form of the 'assisted dying pathway' allegation is that the intention to use the pathway as a means to hasten death is not the result of planned action from above but that individual healthcare workers who are in favour of euthanasia use the LCP as a means to end the lives of patients whom they regard as 'better off dead'. It is alleged that the LCP not only provides cover for these activities but also promotes a culture in which such action is tolerated or even encouraged.

4.5 A worrying but rather different claim in relation to the LCP is that, while it does not involve a general intention to hasten death (either on the part of commissioners or providers) it nevertheless has the potential to cause unnecessary death and thus is unsafe.[62] One form of this, already adverted to, is that if people who are not imminently dying are placed on the LCP, then these patients might be endangered. Complaints against the implementation of the LCP often involve some concern about who took the decision to institute the LCP. The LCP recommends that this is the decision of a multidisciplinary team (MDT), including a senior clinician. However, it has been pointed out that in 28% of cases there is no documented evidence of endorsement by a senior clinician.[63] Similarly there are reported cases of a consultant initiating the pathway without consulting with the team, and there is concern as to how initiation of the LCP is managed in practice at weekends and out of hours.

4.6 Distinct from the evidence that the recommendations of the LCP are not being followed in a certain number of cases, in relation to initiating the pathway, is the more radical claim that the LCP is never properly initiated. It is alleged that there is no scientific basis on which to make a decision that someone is imminently dying, and thus even the consensus of the multidisciplinary team is not sufficient to give confidence that someone is dying. If prediction of imminent dying is prone to, at

[61] Pullicino, 'The Dangers of Abandonment'.
[62] Treloar, 'The Liverpool care pathway is not safe.'
[63] National Care of the Dying Audit – Hospitals (NCDAH), Rounds 1 (2006-7), 2 (2008-9) and 3 (2011-12), Marie Curie Palliative Care Institute Liverpool/Royal College of Physicians. Round 3: 80.

best ‘a 50% serious error rate’,[64] and if, as alleged, ‘it appears that 99.7% of those entered on the LCP died’, this suggests that around 50% of people on the pathway die because of the pathway rather than the underlying condition. Even if these deaths were unintended, if this allegation is true, then there are around 45,000 avoidable iatrogenic deaths per annum, which for comparison, is around 40 times the total excess deaths estimated for Mid Staffordshire. This, if true, would be clearly detectable through mortality statistics, and this has been alleged to be the case, ‘The LCP is already altering the natural history of disease and in this way negatively affects mortality statistics’.[65]

4.7 There are two possible mechanisms by which the LCP is believed to cause or hasten death. In the first place, if the patient is not imminently dying, then sedation combined with dehydration (in those who receive no hydration orally or by clinical assistance) certainly is able to cause death. In addition it is claimed that the LCP may hasten death through the excessive use of opioids, especially if these are combined with sedatives and dehydration. ‘It is clear that, if a decision is made that someone is dying and too much morphine is given, people may become unconscious and even die as a result. People with non-cancer diagnoses may be more likely to die from opiates.’[66]

[64] Celeste McGovern, ‘Thousands Die Prematurely on U.K. “Death Pathway”’, *National Catholic Register* (16 August 2012)..
[65] Pullicino, ‘The Dangers of Abandonment’.
[66] ‘How can I tell if the Liverpool care pathway is right to use?’ *Catholic Medical Quarterly* 61(3) (August 2011): 28-29.

5 Some concerns expressed by supporters of the LCP

5.1 While an essential function of the Review should be to investigate the allegations made in relation to the implementation of the Liverpool Care Pathway, including those set out in the previous section, it would be helpful if the Review also considered some of the concerns raised by supporters of the LCP.

5.2 One repeated concern is that the reporting of the Liverpool Care Pathway in the media, and especially in the *Daily Mail* and *Daily Telegraph*, has been unbalanced, frequently misleading and at times factually inaccurate. One example of factual inaccuracy would be the report in the *Daily Mail*[67] that babies were having nutrition and hydration withdrawn because of the LCP. The editor of the British Medical Journal, in which the paper was published that was the origin of the story, lodged a formal complaint about the accuracy of this report.[68] There is also concern that weight is being given to the medical views of 'experts' some of whom are not practising medicine or have little direct experience of the implementation of the LCP.

5.3 A second concern is that the nature of the reporting has increased the anxiety of patients and relatives, and introduced misconceptions about end-of-life care that are difficult to dispel. This, it is alleged, has led to fewer patients receiving the support of end of life care, or to patients receiving such care only at the last moment.

5.4 Related to this general concern is a specific concern that exaggerated fear of the prescription of analgesia could have or perhaps already has had the effect of leaving pain untreated or undertreated. This is a reiteration of claims made in the wake of the Harold Shipman case that doctors were unwilling to prescribe opioids and that this resulted in an increase in untreated pain.

[67] Sue Reid and Simon Caldwell, 'Now sick babies go on death pathway: Doctor's haunting testimony reveals how children are put on end-of-life plan'. *Daily Mail* 28th November 2012.
[68] Sophie Arie, 'Inquiry launched into newspaper story about babies on "death pathway"', *British Medical Journal* (1 March 2013).

6 Investigations needed to assess these allegations

6.1 These allegations and concerns against or in support of the Liverpool Care Pathway are, in principle, open to empirical investigation. Whereas differences in ethical worldview are notoriously difficult to resolve, the heart of the controversy over the LCP concerns not matters of principle but matters of fact. It should, therefore, be possible to assess the substance of these allegations and concerns by a thorough and transparent consideration of the evidence. This review is an opportunity to set out this evidence and quantify the benefits and the risks of the use of the LCP, and thus whether it is well-designed but misunderstood, whether it needs to be modified in some specific ways, or whether it is 'structurally unsound' to such an extent that it should simply be withdrawn from clinical practice. To address the allegations and concerns outlined above, the Review Committee needs to seek, set out, and evaluate evidence in the following areas:

6.2 The Review should investigate the intentions of commissioners, managers and healthcare professionals who have encouraged the use of the LCP (for example, by CQUINs). Is there evidence (from minutes of meetings, emails, witnessed conversations etc.) that commissioners, managers or doctors believe that the LCP hastens death and saves money for that reason? Clive Seale has done some work on the intentions of doctors when making end-of-life decisions. This seems to show that doctors in palliative care, in particular, are much less likely than other doctors to think or intend that death is hastened by their decisions.[69] [70] The question that needs investigating is whether the use of the LCP makes doctors more or less likely to believe, and to intend, that their actions hasten death.

6.3 The Review should also investigate cases where the LCP has been initiated without the involvement of the multidisciplinary team. This should involve consideration of the patient notes and not only of the LCP documentation. (On the importance of augmenting LCP data with patient notes see comments by Kite et al[71].) The Review should consider, in particular, whether in cases of complaint, the LCP has been initiated without the agreement of the whole team.

6.4 The Review should consider the evidence regarding whether sedatives and analgesics have been used in excess (that is, in excess of the doses needed for symptom relief) on the LCP and how this compares with use of sedatives and analgesics in dying patients who are not supported by the LCP. The Review should also investigate the safety of the most commonly used sedatives and analgesics at the doses typically used. All drugs cause side effects and carry risks, so what is needed is a realistic estimate of the risks and how these may be mitigated, for example by recognising the particular care that is needed in introducing medication to an opioid naïve patient. In internet discussion it is sometimes alleged that typical drugs used and doses used on the LCP are those used by the Netherland for what is effectively a form of euthanasia. It would be helpful for the general public to make both comparisons explicit.

6.5 Those who defend the LCP maintain that it has improved symptom control at the end of life. Concomitantly, the need for the LCP is allegedly shown by the level of untreated symptoms, including untreated pain. It would be helpful to set out the evidence for untreated pain, and the extent of this as a problem, and the evidence that the presence of the LCP improves level of pain relief.

---

[69] Clive Seale, 'National survey of end-of-life decisions made by UK medical practitioners'. *Palliative Medicine* 20 (2006): 1–8.

[70] Clive Seale, 'End-of-life decisions in the UK involving medical practitioners'. *Palliative Medicine* 23 (2009): 198–204.

[71] Suzanne M. Kite, Fiona Hicks, Elizabeth Rees, Claire Shepherd, et al., 'Re: The Liverpool care pathway: what do specialists think?' *British Medical Journal* Rapid Response (8 Match 2013).

6.6 The Review should also investigate whether the consensus of a multidisciplinary team can reliably diagnose imminent dying, and to what level of accuracy, and the risks involved if this diagnosis is mistaken. In particular, the Review should investigate the claim that the introduction of the LCP 'negatively affects mortality statistics',[72] as this is an empirical claim that should be testable. As important as the assessment which initiates the LCP is the process of *reassessment* including that by which some patients are taken off the pathway. If there is a need for further safeguards in the implementation of the LCP, and this is for the Review to determine, then the safeguards around the transition off the pathway will be as important as those at the transition onto the pathway.

6.7 It would be helpful if the Review considered the accuracy and adequacy of media reporting of the LCP and also the evidence for whether or not such reporting has had a detrimental effect on the ability to deliver end of life care. As the public understanding of the pathway is largely that mediated by the media, it is important to determine whether the press have behaved responsibly in highlighting a public safety issue and expressing the legitimate concerns of doctors, patients and relatives, or whether the view presented in the media misrepresents the typical clinical realities, or something of both.

6.8 Finally the Review should look at the evidence from relatives and from audit data and consider whether the LCP is being used as intended and whether failures to implement the LCP could be rectified by further training, guidance, and investment. The Review should also give some thought as to whether any misunderstanding of the LCP (by relatives or by healthcare professionals) may be due to the way the LCP is described. In particular, the Review should ask whether the term 'pathway' is helpful in relation to supporting care at the end of life. Whereas 'integrated care pathways' are well established for many aspects of medical care,[73] these generally focus on achieving some improvement in the patient's condition *at the end point* of the 'pathway'. In contrast, end-of-life care has as its focus the support of the patient during the last phase of his or her life. A 'pathway' can easily be misunderstood as a route from A to B, and thus a means of bringing about the end point (in this case, death). The name thus seems in danger of misrepresenting the fundamental aim of end-of-life care. Thus in addition to considering whether the LCP is structurally unsound and should be withdrawn from practice, or whether its implementation needs to be supported in certain specific ways, the Review should also give some thought as to how end-of-life care should be presented and communicated so that its aims are clear.

[72] Pullicino, 'The Dangers of Abandonment'.
[73] Sue Middleton and Adrian Roberts (eds.) *Integrated Care Pathways: A Practical Approach to Implementation*. (Oxford: Butterworth-Heinemann, 2000).

7 Some evidence relevant to these investigations

7.0 In order adequately to assess the allegations made in relation to the Liverpool Care Pathway, the Committee should commission or undertake a systematic review of the empirical evidence. The following evidence is intended as a contribution to that systematic review.

7.1 Is clinically assisted hydration (CAH) needed to ameliorate thirst in dying patients?

7.1.1 An allegation frequently made against the LCP is that, because it permits the withdrawing or withholding of CAH, it causes unnecessary suffering. This claim is usually made by reference to cases of patients who have not received CAH and who have shown signs of being in distress. Such cases have frequently been the subject of complaints raised by relatives, which have sometimes also involved claims that a patient has been deprived of oral hydration. There have also been some critics who have generalised this complaint by wider medical and scientific claims. For example, in a paper given at a meeting in the House of Lords, Dr Anthony Cole presented the following evidence for a general obligation always to provide CAH in order to ameliorate thirst:

'In fact Dr Peter McCullough[*sic*] a senior researcher at the John Curtain School of Medicine of the Australian National University in a review of the literature in 1996 quotes Fitzsimons and Barnard[*sic*]; "…moistening the mouth failed to relieve thirst in dogs and horses with oesophageal fistula …and it is evident that, whereas dryness of the mouth can aggravate a sensation of thirst resulting from body water depletion, its alleviation will not remedy thirst in the absence of correction of water depletion".'[74]

7.1.2 The McCullagh article is available online[75] and the Review Committee should consider the evidence and argument it presents. Nevertheless, the Committee should be aware that this publication was not subject to prior peer review,[76] and that the article by Fitzsimons cited by McCullagh was written over forty years ago.[77] Furthermore Fitzsimons himself was citing observations by the physiologist Claude Bernard in the mid-nineteenth century,[78] and these observations related to animals that had fistulae so that the water escaped before reaching the stomach, but that were otherwise healthy. It did not relate to dying animals or to human beings who were dying and had stopped drinking. This nineteenth century example does not constitute good evidence for the relationship between experienced feelings of thirst, internal fluid balance, and CAH in dying patients. For this, we need to look to more recent studies and undertake a proper search, assessment of evidential quality and review in order to reach secure conclusions.

7.1.3 There are a number of recent studies into the effect of hydration in dying patients.[79] These seem to show that, in this population of patients, it is common for thirst to decline[80] and that levels

[74] Anthony Cole, 'Talk for House of Lords Meeting 23rd January 1013'.
[75] Peter McCullagh, 'Thirst in relation to withdrawal of hydration', *Catholic Medical Quarterly* XLVI 3(269) (February 1996): 5-12.
[76] The *Catholic Medical Quarterly* is an important forum for Catholic medical and medical-ethical discussion in the United Kingdom, but it is not a Peer Review Journal and hence it is not listed in the Science Citation Index, the Philosophers Index, PubMed or similar indices.
[77] James Thomas Fitzsimons, 'Thirst', *Physiological Reviews* 52(2) (1972): 468-561.
[78] Fitzsimons, 'Thirst', 471 (McCullagh places the reference at page 499 but the citation is in fact on page 471) citing Bernard, C. *Leçons de Physiologie expérimentale appliquée à la Médicine faites au Collège de France* Paris: Baillière (2)(1856): 5051.
[79] Anna M. Nowarska, 'To feed or not to feed? Clinical aspects of withholding and withdrawing food and fluids at the end of life', *Advances in Palliative Medicine* 10(1) (2011): 3–10.

of thirst are not significantly related either to internal fluid balance markers or to the provision or non-provision of CAH.[81] [82] [83] Thus, in this group of patients, there is no evidence that CAH is more effective in alleviating the symptoms of thirst than is adequate mouth care.[84]

7.1.4 One of the most consistent critics of the lack of provision of CAH within common palliative care practice admits that whether or not thirst is present 'is difficult to substantiate' and bases her concern on the fact that 'Thirst may or may not bother the patient. Concern about thirst undoubtedly bothers relatives.'[85] However, the care of the patient should be the first aim of the doctor, and hence alleviating anxiety among relatives is not a good reason for providing an intervention unless it can be shown to be of benefit to the patient. Furthermore, while CAH can alleviate come symptoms in some patients,[86] it can also have adverse effects, especially in the dying.[87] [88] [89] [90] [91]

7.1.5 The current evidence from studies in dying patients thus does not suggest that clinically assisted hydration is generally beneficial for dying patients. However, this does not imply that CAH might not be useful in certain patients, or certain patient groups for the alleviation of symptoms. For example, there is some evidence that, in some patients, delirium can be ameliorated by provision of CAH. A recent systematic review of the evidence for benefits or harms of CAH in dying patients concluded that, 'Clinicians will need to make a decision based on the perceived benefits and harms of medically assisted hydration in individual patient circumstances, without the benefit of high quality evidence to guide them.'[92] Nevertheless, even if there is no evidence that CAH is generally beneficial for dying patients in relation to symptom relief, a greater concern is that without CAH the patient will die, and thus by withholding or withdrawing CAH, doctors are responsible for hastening the deaths of patients.

---

[80] Tatsuya Morita et al. 'Physician- and nurse-reported effects of intravenous hydration therapy on symptoms of terminally ill patients with cancer', *Journal of Palliative Medicine* 7 (2004): 683–693.
[81] R.M. McCann, W.J. Hall, A. Groth-Juncker, 'Comfort care for terminally ill patients: the appropriate use of nutrition and hydration', *Journal of the American Medical Association* 272 (1994): 1263–1266.
[82] C.F. Musgrave, N. Bartal, J. Opstad, 'The sensation of thirst in dying patients receiving I.V. hydration', *Journal on Palliative Care* 11 (1995): 17–21.
[83] Frederick I. Burge, 'Dehydration symptoms of palliative care cancer patients', *Journal of Pain and Symptom Management* 8 (1993): 454–464.
[84] L. Cerchietti et al. 'Hypodermoclysis for control of dehydration in terminal-stage cancer', *International Journal of Palliative Nursing* 6 (2000): 370–374.
[85] G.M. Craig, 'On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?' *Journal of Medical Ethics* 20 (1994): 412.
[86] E. Bruera et al. 'Effects of parenteral hydration in terminally ill cancer patients: a preliminary study', *Journal of Clinical Oncology* 23 (2005): 2366–71.
[87] S. Dalal et al. 'Is there a role for hydration at the end of life?' *Current Opinion in Supportive and Palliative Care* 3 (2009): 72–78.
[88] S. Ede, 'Artificial hydration and nutrition at the end of life', *European Journal of Palliative Care* 7 (2000): 210–212.
[89] R. Fainsinger, 'Non-oral hydration in palliative care', *Journal of Palliative Medicine* 9 (2006): 206–207.
[90] A. Sanders, 'The clinical reality of artificial nutrition and hydration for patients at the end of life', *The National Catholic Bioethics Quarterly* 2 (2009): 293–304.
[91] M. Ashby and B. Stoffell, 'Artificial hydration and alimentation at the end of life: a reply to Craig', *Journal of Medical Ethics* 21 (1995): 135–140.
[92] P. Good et al. 'Medically assisted hydration for palliative care patients', *Cochrane Database of Systematic Reviews* 16(2) (April 2008).

7.2 Does withholding or withdrawing CAH in dying patients necessarily hasten death?

7.2.1 A key element of the criticism of the LCP is the belief that, because it permits withholding or withdrawing CAH, it necessarily causes death. 'It is self-evident that stopping fluids whilst giving narcotics and sedatives hastens death.'[93] As stated above, deliberate omissions that necessarily hasten death, if intended to do so, would constitute euthanasia by omission.

7.2.2 It is clear that human beings need food and fluids to survive and that, in otherwise healthy adults, 'Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal'.[94] However, in the case of dying patients it is not 'self-evident' that non-provision of CAH, with or without the provision of analgesics and sedatives, necessarily causes death. This is for two reasons. In the first place those who are imminently dying may die from their underlying condition before being adversely effected by lack of hydration. In the second place, their condition may prevent nutrition or hydration from being assimilated effectively. In some cases hydration may even be detrimental to their condition.

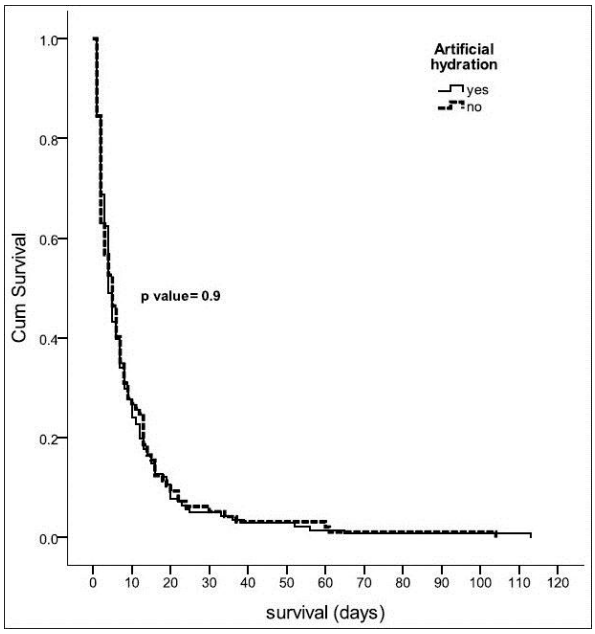
7.2.3 The question of whether CAH generally prolongs survival in dying patients is thus an empirical question that is not 'self-evident' one way or the other. It requires evidence. Whereas the great majority of patients and relatives (89%) believe that CAH will prolong survival,[95] it is far from clear that this belief is supported by good evidence. Indeed, it has been argued that this belief rests on a misconception as, 'There are no studies that would support these assumptions'.[96]

7.2.4 If there is a need for more and better quality evidence for the effects of CAH in dying patients in relation to symptom relief, this is even truer of the effect of CAH in relation to survival. The systematic review of the best evidence in 2011 (already referred to above) showed only a handful of high-quality studies in relation to symptom relief, and of these none provided 'information on the effect hydration may have on survival.'[97]

7.2.5 As an example of evidence that is indicative rather than conclusive, a study in 2010 of deaths of 238 patients in a cancer ward in Singapore found no evidence of impact of CAH on rate of survival.[98] The Kaplan-Meier survival curves did not show any significant survival difference between those who had been given CAH and those where CAH had not been given. This is brought out very clearly in the graph (Figure 1 reproduced here without permission and not for publication).

[93] Smith, 'Patient death pathway'.
[94] John Paul, 'Life Sustaining Treatments': paragraph 4.
[95] N.J. Raijmakers et al. 'Variation in attitudes towards artificial hydration at the end of life: a systematic literature review', OPCARE9 *Current Opinion on Supportive Palliative Care* 5(3) (September 2011): 265-72.
[96] Nowarska, 'To feed or not to feed?': 7 citing A. Sanders, 'The clinical reality of artificial nutrition and hydration for patients at the end of life', *National Catholic Bioethics Quarterly* 2 (2009): 293–304; A. Inui, 'Cancer anorexia-cachexia syndrome', *CA Cancer J. Clin* 52 (2002): 72–91; and T.E. Finucane, C. Christmas, K. Travis, 'Tube feeding in patients with advanced dementia: a review of the evidence', *JAMA* 282 (1999): 1365–1370.
[97] Good, 'Medically assisted hydration': 7.
[98] L.K. Krishna, J.V. Poulose, C. Goh, 'Artificial Hydration at the end of Life in an Oncology Ward in Singapore' *Indian Journal of Palliative Care* 16(3) (September 2010): 168-73.

Figure 1



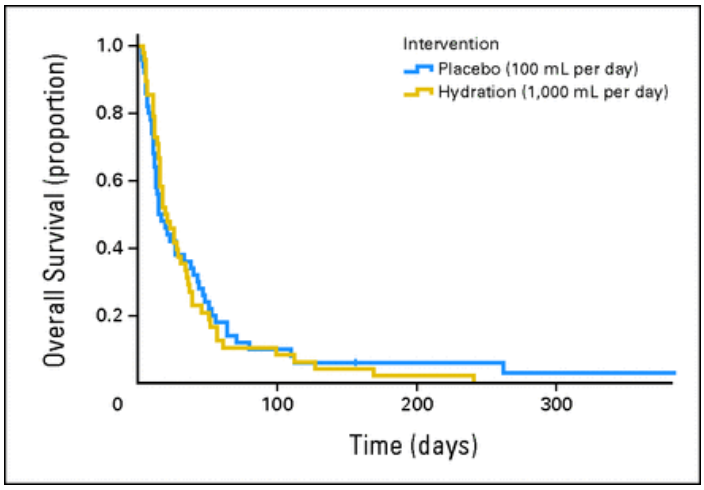
7.2.6 This study has a number of limitations: it was confined to cancer patients, it was retrospective, and it did not collect data on indications for the provision or cessation of CAH. Nevertheless, these limitations notwithstanding, it is striking that this study did not provide any evidence that withholding of CAH hastened death in this group of patients. The authors comment that 'Education on the reduced need for nutrition and hydration in this phase is imperative and needs to be actively propagated'.[99]

7.2.7 In the absence of a systematic review of randomised controlled trials (RCT), the most robust current scientific evidence is that provided by a single RCT. In 2012 for the first time a multicentre, double-blind, placebo-controlled randomized trial was conducted to assess the effect of CAH in advanced cancer patients.[100] The placebo was provided by the delivery of a small amount of saline (100ml as opposed to 1 L). The effects were measured by four dehydration symptoms (fatigue, myoclonus, sedation and hallucinations, 0 = best and 40 = worst possible) as well as by Edmonton Symptom Assessment Scale (ESAS), Memorial Delirium Assessment Scale (MDAS), Nursing Delirium Screening Scale (NuDESC), Unified Myoclonus Rating Scale (UMRS), Functional Assessment of Chronic Illness Therapy-Fatigue (FACIT-F), Dehydration Assessment Scale, creatinine and urea levels, and overall survival. The study found no significant differences between the hydration arm and the placebo on any these measures, including survival (where the median survival for this group was 17 days). See below Figure 2 (reproduced here without permission and not for publication).

[99] Ibid.

[100] Bruera et al., 'Parenteral hydration in patients with advanced cancer: a multicenter, double-blind, placebo-controlled randomized trial', *Journal of Clinical Oncology* 31(1) (January 2013): 111-8.

Figure 2



7.2.8 The authors conclude that 'our study supports current hospice practice of not administering hydration routinely'. Nevertheless, they go on to remark that 'further studies are required to determine whether any subgroups, such as delirious patients or those with longer survival, would benefit from parenteral hydration.'[101] It should also be noticed that both of these studies focused on cancer patients and the evidence base for benefits or risks of hydration is even weaker in relation to non-cancer patients. It is therefore unsurprising that end-of-life hydration practices vary greatly between parts of the world and also between different physicians. These variations seem to be determined in large part by the beliefs and feelings of families and healthcare professionals, rather than any difference in the evidence.[102] [103]

7.2.9 In the light of this evidence, or lack of it, it seems appropriate that an integrated end of life care pathway should maintain that, 'a blanket policy of clinically assisted (artificial) nutrition and hydration or of no clinically assisted (artificial) nutrition and hydration is ethically indefensible' and that 'All clinical decisions must be made in the patient's best interest'.[104] It would, however, be helpful if the documentation of the LCP also explicitly cited the relevant GMC guidance which states that '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'.[105]

7.2.10 It is recommended that the Committee itself reviews the available scientific evidence in relation to the provision of clinically assisted nutrition and hydration to dying patients, both in relation to symptom control and in relation to survival. In its review of complaints of relatives, the Committee should pay particular attention to those which maintain that nutrition or hydration needs were not met, and consider whether CANH may have helped in these cases, and how decision making and/or communication could have been improved.

[101] Bruera, et al, 'Parenteral hydration': 117.
[102] M.I. Del Río et al., 'Hydration and nutrition at the end of life: a systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff', *Psychooncology* 21(9) (September 2012): 913-21.
[103] Raijmakers, et al., 'Variation in attitudes: 265-72.
[104] Liverpool Care Pathway Generic document, version 12.
[105] General Medical Council, *Treatment and care*: paragraph 111.

7.3 Does the use of opioids and/or sedatives in the dying generally hasten death?

7.3.1 In relation to the potential for harm for patients whose care is being managed with the LCP, a key concern is that this can lead to overprescribing of sedatives and opiate analgesics. The documentation of the LCP only directs the use of such drugs when they are needed to alleviate symptoms. However, it is alleged that the system of 'anticipatory prescribing' and the effective delegation to the nursing staff of the decision to use medication has the potential to lead to overtreatment. This would expose patients to the risk of side-effects from unnecessary medication. In particular, it is alleged that because of a tendency to overprescription and overuse of these drugs, the LCP is potentially lethal, as some patients are 'likely to die from opiates'.[106]

7.3.2 In defence of the claim that use of opioids for symptom relief on the LCP could lead to death, especially for those 'with non-cancer diagnoses' some critics have cited Gomes [107] and Trescot.[108] These authors do indeed alert us to the possibility of very harmful side-effects from use of opioids in non-cancer patients, especially when used in high doses. However, it should be noticed that these papers are concerned with the long term use of opioids for managing chronic conditions, and the adverse reactions are due to accidental or intentional overdose, linked to the problem of addiction to prescription medication. This context is clinically and evidentially quite different from the use of opioids under medical supervision in the last hours or days of life. Gomes shows that in a particular population of patients (with chronic non-cancer conditions) being on relatively high doses of opiates (>200mg morphine or equivalent per day) was associated with 'a nearly 3-fold increase in the risk of opioid-related mortality' compared with doses lower than 20 mg.[109] However, a commentary on the paper[110] points out that the absolute risk is relatively low (<1%) even with these very high doses of opiate and that 'these higher-risk aspects of opioid exposure are more common in higher-risk patients with histories of substance abuse and mental health disorders'. The safety concerns for this population (chronic non-cancer conditions among patients with a history of substance abuse) are very different to those for typical patients in the last hours or days of life. Rather than refer in general and perhaps misleading terms to the dangers of these drugs, and indeed apply the wrong evidence in alleging risk of opiate use, what is needed is a realistic estimate of the risk for patients on the LCP at typical dosages. Treatment is always a question of managing relative risks rather than simple risk aversion, and an unwillingness to prescribe opioids when indicated could also result in real harm to patients: the harm of unnecessarily painful deaths and the harm of the fear of unnecessarily painful deaths engendered by watching deaths where adequate analgesia has been withheld due to clinicians loss of confidence.

7.3.3 It should also be noticed that there is considerable evidence that use of opioids in the dying does not generally shorten life.[111] Similar evidence has also been collected in relation to the effects of sedatives.[112] [113] [114] [115] According to a systematic review of the literature in 2008, a number of

---

[106] 'How can I tell?' *Catholic Medical Quarterly*

[107] T. Gomes et al., 'Opioid dose and drug-related mortality in patients with non-malignant pain', *Archives of Internal Medicine* 171(7) (2011): 686-691, 691-693.

[108] A.M. Trescot et al., 'Opioids in the Management of Chronic Non-Cancer Pain: An Update of American Society of the Interventional Pain Physicians', (ASIPP) Guidelines, *Pain Physician* (March 2008): Opioids Special Issue: 11:S5-S62.

[109] Gomes et al., 'Opioid dose and drug-related mortality'.

[110] Mark D. Sullivan, 'Limiting the Potential Harms of High-Dose Opioid Therapy: Comment on "Opioid Dose and Drug-Related Mortality in Patients With Nonmalignant Pain"', *Archives of Internal Medicine* 171(7) (2011): 691-693.

[111] Sykes, et al., 'The use of opioids': 312-318.

[112] Patrick C. Stone et al. 'A comparison of the use of sedatives in a hospital support team and in a hospice', *Palliative Medicine* 11 (1997): 140-144.

studies have shown that 'survival of sedated patients is not shorter than that of non-sedated patients'.[116] The classic example of 'double effect' cited by Pius XII and others is based on a false premise and leads, in general, to a false dilemma. Effective treatment of pain by opioids need not hasten death and generally does not do so when used in a palliative care context. All drugs have side effects and risks should be taken seriously but the idea that opioids generally hasten death is a myth that can produce unnecessary anxiety in patients and lead to under-treatment of tractable pain.

7.3.4 The moral principles relevant to use of pain-killing drugs at the end of life were set out clearly by Pope Pius XII. These imply that, even if opioids did hasten death, this side-effect could be justified by the intention of treating otherwise intractable pain. In more recent times, however, evidence from the practice of palliative care has in fact suggested that people overestimate these risks and that, properly used, opioids do not hasten death. There are, of course, still risks which may be greater for a particular patient, or a particular patient group (such as those who are opioid naïve), but what is needed is a relative estimation of the risks, the prevalence of untreated pain and the risk of under-treatment, and the prevalence and seriousness of side-effects and the risks of overtreatment.

7.3.5 The combination of sedation, if beyond the needs of symptom relief, and withholding of clinically assisted hydration, if done on people not believed to be dying and done with the intention of causing death, could be used as a means of euthanasia. This has been widely discussed and there is some evidence that in the Netherlands this practice of 'terminal sedation' or 'continuous deep sedation' may be used as an alternative to active euthanasia. However the phrase 'terminal sedation' is deeply ambiguous covering a wide variety of possible practices[117] and it is misleading to apply this phrase to palliative practice in the United Kingdom.

7.3.6 It is not considered good practice in the United Kingdom to aim at producing continuous deep sedation. Furthermore, 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.[118] 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 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][119] 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[120] 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

---

[113] T.Y. Chiu et al., 'Sedation for refractory symptoms of terminal cancer patients in Taiwan', *Journal of Pain and Symptom Management* 21 (2001): 467-472.
[114] Sykes, et al. 'Sedative Use': 341-344.
[115] Maltoni, et al., 'Palliative sedation therapy': 1163–1169.
[116] P. Claessens et al. 'Palliative sedation: a review of the research literature', *Journal of Pain and Symptom Management* 36 (2008): 310-333, at 329.
[117] David Albert Jones, 'Death by Equivocation: A manifold definition of terminal sedation' in S. Sterckx, et al. *Continuous sedation at the end of life: Ethical Perspectives* (Cambridge: Cambridge University Press, 2013 [forthcoming, available from the author on request]).
[118] M. Gambles, et al. 'Continuous Quality Improvement in Care of the Dying with the Liverpool Care Pathway for the Dying Patient', *International Journal of Care Pathways* 13 (2009): 51–56.
[119] NCDAH, Round 2.
[120] Royal Dutch Medical Association, *Guideline for Palliative Sedation* (2009).

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'.[121]

7.3.7 Good practice in the provision of analgesia for pain relief and of sedatives to alleviate agitation is that medication should be given in proportion to symptoms, and neither in excess of this nor in insufficient doses. This is true whether the patient is imminently dying or whether the patient suffers from some transient or chronic condition. The concern of critics of the LCP is that it can lead to routine overtreatment. The concern of supporters of the LCP is that exaggerated concern about the dangers of opioids can lead to unwillingness to prescribe adequate pain relief. Clearly both concerns should be acknowledged. At the same time it would be of great help to discussion to have greater clarity about the realistic risks and the prevalence of overuse of opioids and under-treatment of pain.

7.4 **Is it possible for multidisciplinary teams to predict imminent dying accurately?**

7.4.1 The most substantial and clearly argued clinical argument for the inherent unsoundness the LCP is that presented by Professor Patrick Pullicino first as a conference paper[122] and subsequently as an article in the *Catholic Medical Quarterly*.[123] This conclusion, if it is true, has very serious implications, far more wide-ranging than would be implied by the sensationalist headlines it generated in the *Daily Mail*[124] and elsewhere. If valid, this argument would demonstrate that any end-of-life care pathway or indeed any method of caring for or helping the dying, which aims to support people in the last hours or days of life will inevitably be either pointless or damaging; and that such care could harm large numbers of people, in some cases cutting life short by months or years.

7.4.2 Pullicino's argument in the *Catholic Medical Quarterly* (henceforth *CMQ*) takes as its basis the fact that there is no scientifically validated tool for prognosis of imminent dying (dying within hours or days). Without such a tool, prognosis of imminent death is no better than a prediction, based on subjective judgement and prone to a large degree of error, for example one study showing 49% serious error in prognosis[125] and another showing only 25% prognosis accurate to within one week.[126] If it is the case that once the LCP is initiated 'by far most patients die, with only a tiny percentage coming off the pathway',[127] the implication seems to be that this accuracy of prediction is suspiciously high and must therefore due to the effect of the pathway itself. Determination of imminent dying prior to use of the LCP is thus 'a self-fulfilling prophecy'.[128] There are other subsidiary elements to the argument that support one or other of these moves but this is the basic architecture of the *CMQ* argument.

7.4.3 It seems best to take these points one by one. In the first case it must be acknowledged that there is no validated tool that would support prognosis of imminent dying, and that the LCP does not recommend any such tool. The LCP recommends, rather, that the prognosis should be based on the

---

[121] J. Stephenson, 'The Liverpool Care Pathway', *Triple Helix* (Winter 2012): 14-15, emphasis in the original.
[122] P. Pullicino. 'Can We Predict Impending Death?: The Scientific Evidence', presented at Medical Ethics Alliance conference: "Natural Death - is a pathway needed", at the Royal Society of Medicine (18 June 2012).
[123] Pullicino, 'The Dangers of Abandonment.'
[124] S. Doughty, 'Top doctor's chilling claim: The NHS kills off 130,000 elderly patients every year', *Daily Mail*, (20 June 2012).
[125] R. Henderson, N. Keiding, 'Individual survival time prediction using statistical models', *Journal of Medical Ethics* 31 (2005): 703-706.
[126] P. Glare et al. 'A systematic review of physicians' survival predictions in terminally ill cancer patients', *British Medical Journal* 327 (2003): 195-198.
[127] Howard, 'Not so Peaceful': 9.
[128] Pullicino, 'The Dangers of Abandonment.'

consensus of the senior doctor and the multidisciplinary team (MDT).[129] However, it is a *non-sequitur* to conclude that because MDTs do not make use of a validated tool, they are therefore inaccurate or unreliable in their prognoses. The question of how accurate MDTs are is an empirical question and should be the subject of empirical investigation.

7.4.4 A recent study to develop and cross validate a prognostic score for cancer patients found that the models 'performed significantly better than did either the doctors or the nurses but were not significantly better than the multi-professional estimate'.[130] This gives good reason to discourage prognosis by one clinician alone or by nurses alone without consultation with the MDT, but does not indicate the need to use of a particular tool to support prognosis, until a tool is developed which can be shown to be significantly better that the consensus of the MDT. Nevertheless, this does not address the key question which is not whether the MDT is as accurate as current validated tools for prognosis of imminent dying, but whether the predictions of MDT, with or without the support of such tools, is sufficiently safe and reliable to guide clinical judgements.

7.4.5 The second plank of the *CMQ* argument is thus that prognosis of imminent dying (whether by MDT or by a prognostic tool) is prone to significant error and that, in general prognosis may be inaccurate as much as 50% of the time. Nevertheless, while 'agreement between actual survival and predicted survival is poor' (*CMQ* quoting Glare[131]), it should be noted that this is generally because 'clinicians consistently overestimate survival' (Glare,[132] not quoted in *CMQ*). In Glare's study, only 12% of predictions were significant underestimates. Similarly, while one study showed that '49% of clinicians' predictions… were in 'serious error' (Henderson[133] cited in *CMQ*), this was because predictions were overestimates in 32% of cases and underestimates in 17%. These studies are consistent with others that have shown a systematic bias towards optimism in clinicians' predictions of survival times. It is noteworthy that statistical models show a similar degree of accuracy in prediction but without the element of bias towards overestimation. Thus, if our concern is that survival should not be underestimated, then the typical clinical bias towards overestimation is positively helpful.

7.4.6 In a recent prospective study involving over 1000 patients with advanced cancer,[134] the MDT was asked to predict how long they expected patients to survive (Days: 1-13 days, Weeks: 14-55 days, or months: 56 or more days). Overall MDT predictions were correct on only 57.5% of occasions (31.1% optimistic, 11.4% pessimistic). However, if one only looks at the positive predictive value of MDT predictions of a prognosis of 'days', then clinicians were accurate 87.5% of the time (on 147 out of 168 occasions). The study also showed that predictions of a shorter survival time (days) were generally more accurate than predictions of a longer survival time (weeks or months).

7.4.7 There is certainly a need for more and better evidence of the accuracy for predictions of imminent dying. In this, as in other areas of end-of-life care, more research is needed to guide and improve quality of care. The studies cited thus far are indicative of accuracy of prognosis at around two weeks but do not engage directly with prognosis of imminent dying (within two or three days).

---

[129] Marie Curie Palliative Care Institute Liverpool (MCPCIL), Liverpool Care Pathway Generic Version 12 (2009), example core document.

[130] Bridget Gwilliam et al., 'Development of Prognosis in Palliative care Study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study', *British Medical Journal* Open Access (2011).

[131] Glare, et al., 'A systematic review': 195-198.

[132] Ibid.

[133] Henderson, et al., 'Individual survival time', 703-706.

[134] Bridget Gwilliam et al. 'Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians' and patients' estimates of survival'. *Annals of Oncology* 24 (2) (2013): 482–488.

There have, however, been some retrospective studies of the medical notes of people who have died in hospital which include time intervals of hours and days. One such study concluded that 'it is possible to anticipate a large proportion of deaths within an acute setting, but this is generally achieved very close to the end of life'.[135] A similar audit of patient notes found 61% of deaths were predictable such that the patients would have been eligible for the LCP, but in fact only 41% received care on the LCP.[136] These studies seem to support the view that the dying phase is something that can be recognised in many patients and thus that prediction of imminent dying may be more reliable than prognosis over the timescale of weeks or months. However, to provide a realistic estimate of reliability of such predictions, these studies would have to look back to examine whether, and how commonly, the medical notes had indicated an expectation of imminent death where patients had subsequently recovered.

7.4.8 In the context of this evidence (such as it is) of what might be expected for accuracy of prediction of imminent dying, how accurate is prediction of imminent dying on the LCP? Earlier iterations of the generic documentation of the pathway, some other analogous pathways for the imminently dying, and some current descriptions of the LCP define this stage as 'the last 48 or 72 hours'.[137] Aware of the difficulty of predicting within this degree of accuracy, the current generic documentation of the LCP adopts a much more general formula that patients are 'within hours or days of death'.[138] This has the advantage of acknowledging the imprecise nature of this prediction, but does not help in relation to quantifying its accuracy. If, for the sake of argument, 48 to 72 hours is taken as the benchmark for expectation of survival on the LCP, then it is clear that most patients die before this period (current median 29 hours)[139]. The interquartile range is 11-72 hours.[140] This implies that 25% of patients live longer than 72 hours and a significant proportion live beyond five days (in one audit, 13%)[141] and may live beyond this (in same audit, up to 31 days).[142] There are also a proportion of patients who are taken off the pathway, though there is no national audit data concerning these patients (either in relation to how many leave the pathway or how long they live subsequently). Different sources cite the proportion leaving the pathway as 3-5%,[143] 5-10%[144] or 10%.[145]

7.4.9 There is clearly an urgent need for research on reliability of prediction of imminent dying. However the evidence from audit data on the LCP shows that, if one takes the expectation as death from 48 to 72 hours, then MDTs predictions generally overestimate survival, and survival is either overestimated or accurate in 75% of those cases in which the person remains on the pathway.

---

[135] J. Gibbins et al., 'Diagnosing dying in the acute hospital setting – are we too late?' *Clinical Medicine* 9 (2009): 116–9.
[136] E.J. Pugh, M. McEvoy, 'The Imminence of death and the Liverpool Care Pathway', *British Medical Journal* Rapid Response to J. Ellershaw, 'Achieving a good death for all' (29 October 2010).
[137] Andrew Hindle and Alison Coates, *Nursing Care of Older People: A Textbook for Students and Nurses* (Oxford: Oxford University Press, 2011): 255.
[138] MCPCIL *Liverpool Care Pathway for the Dying Patient (LCP) - FAQ* August 2012.
[139] NCDAH. Rounds 3, p. 38.
[140] Ibid.
[141] Pugh, McEvoy, 'The Imminence of death'.
[142] Ibid.
[143] J. Ellershaw, 'Re: Continuous Deep Sedation in the UK - Dutch research reflects problems with the Liverpool Care Pathway', *British Medical Journal* Rapid Response (4 May 2008).
[144] K. Mannix, 'The Liverpool Care Pathway for the Dying Patient' Presentation at Conference on "Death and Dying in Catholic Perspective" sponsored by The Centre for Catholic Studies (Durham University), the Newman Association, the Departments of Spirituality, Formation and Education of the Diocese of Hexham and Newcastle, the National Board of Catholic Women, and St Cuthbert's Catholic Chaplaincy, Durham (9 March 2013).
[145] Stone, 'Care of the Dying.'

Survival is significantly underestimated in around 13% of cases of those who die on the pathway (i.e. those who live beyond 5 days) plus a proportion of the 3-10% of those who leave the pathway (some, though they leave the pathway, will nevertheless die within a further 72 hours). Thus the general pattern of clinical prediction is to overestimate survival in 50% or more of cases and underestimate it something between 10% and 20% of cases. The difficulty of giving a more precise estimation for this figure is the lack of national audit data on those patients who are initially supported by the LCP but then are taken off it. Nevertheless, it should be clear that this pattern of over and underestimates is broadly similar to the pattern of prognostic accuracy found in studies such as Gwillam (12.5% underestimations),[146] Glare (12% underestimations)[147] and Henderson (17% underestimations).[148] The available data for the LCP does not show suspiciously high accuracy of prediction nor does it support the claim that the LCP is a self-fulfilling prophecy. Rather it draws attention to the minority of patients (somewhere between 10% and 20%) who are either taken off the pathway or who live for more than a week on the pathway.

7.4.10 One area where prognosis may well appear to be a 'self-fulfilling prophecy' is where it is premised on a withdrawal of treatment decision which is itself based on cost-benefit analysis (including the opportunity cost of not treating other patients who may benefit more). It may be that treatment is withheld or withdrawn from a patient not because it would be futile for that patient but because of overt or covert rationing decisions. This is most evident when a patient is denied the possibility of an organ transplant or of an expensive drug that is not recommended by NICE. It may also be the case in relation to provision of intensive care. In such circumstances the poor prognosis may be, at least in part, a function of a human decision taken not to treat. These issues are difficult and merit their own consideration,[149] but in relation to the LCP what is imperative is that the decision to use the LCP is taken separately and only after concerns about treatment-limiting decisions have adequately been addressed.

7.4.11 Much attention has focused, quite rightly, on the initial diagnosis of imminent dying and the decision of the MDT to initiate the pathway. Some people have also expressed concerns that patients die very rapidly on the LCP. However, the evidence considered here suggests that an equal concern should be for the care of those who live *longer* than expected and for those who leave the pathway. The fact that a significant proportion live longer than expected, 'reinforces the need for meticulous regular monitoring and clinical assessment for each patient placed on the LCP. It highlights the need for particular consideration for hydration'.[150] It is a matter of concern that, whereas clinically assisted hydration is maintained in more than a third of cases where it is already in use (16% from an initial 44% of the total),[151] it is very rarely initiated once the patient is supported by the LCP (in only 0.4% of cases).[152] This raises a question as to whether the needs of patients who live longer than 72 hours are being reassessed adequately, not only in relation to assessment of need for nutrition and hydration but perhaps more generally.

7.4.12 It is noticeable that among complaints in the press concerning care on the LCP, a significant number relate to these two groups: those who leave the pathway and those who are supported for more than a week on the pathway. In considering evidence that the Review receives from patients and relatives, it would be helpful to see whether there are patterns that emerge in relation to these

[146] Gwilliam et al., 'Prognosticating in patients'
[147] Glare, et al., 'A systematic review': 195-198.
[148] Henderson, et al., 'Individual survival time', 703-706.
[149] Ashley Beck, Paul Gately and David Albert Jones, *Healthcare Allocation and Justice: Applying Catholic Social Teaching* (London: CTS, 2010).
[150] Pugh, 'The Imminence of death'.
[151] NCDAH. Rounds 3, p. 82.
[152] Ibid.

two groups and how care may be improved for these patients. It seems clear that the transition from the pathway poses challenges for communication and decision making. The Review should examine whether in training and in documentation this transition is adequately supported so that it is not seen, either by relatives or by clinicians, as implying that the decision to initiate the pathway was necessarily inappropriate, although, of course, this may have been the case. Similarly the Review should consider the reassessment that is recommended by the LCP after 72 hours: whether there are failings in the way this reassessment is conducted or in the way that subsequent care and communication is managed, especially in those who live for longer than one week.

8 Conclusion and Recommendations

8.1 The aim of this document has been to articulate a Catholic understanding of some key ethical principles pertaining to end-of-life treatment and care, and to place the ethical concerns about the Liverpool Care Pathway in that context. This analysis identifies the differences of opinion about the LCP within the community, not as due to differences of ethical principle, but primarily as empirical in character, relating to specific claims that can and should be investigated. The LCP is ethically acceptable if and only if it rests on a secure clinical foundation. The Review will not achieve its aims of improving care and restoring public confidence unless it examines clinical and scientific evidence and arguments which have been made against the structural soundness of the LCP.

8.2 To achieve its aims, and to address the allegations and concerns of those who called for an inquiry into the LCP, the Review needs to investigate a number of issues as set out in section 6:

> 8.2.1 Whether commissioners, managers and healthcare professionals who have encouraged the use of the LCP have or have not had any intention of hastening death;
>
> 8.2.2 Whether the LCP has been initiated without the involvement of the multidisciplinary team;
>
> 8.2.3 Whether sedatives and analgesics have been used in excess (that is, in excess of that needed for symptom relief) on the LCP, and if so whether this is better or worse than practice outside the LCP;
>
> 8.2.4 Whether the most commonly used sedatives and analgesics at the doses typically used are within the proper limits of safety and toxicity;
>
> 8.2.5 Whether there is a wide scale problem of untreated pain and whether the presence of the LCP improves the level of pain relief;
>
> 8.2.6 Whether the consensus of a multidisciplinary team can reliably diagnose imminent dying, and to what level of accuracy, and the risks involved if this diagnosis is mistaken;
>
> 8.2.7 Whether the media reporting of the LCP has been accurate and responsible and whether, as claimed, irresponsible misreporting has had a detrimental effect on the ability to deliver end of life care; and
>
> 8.2.8 Whether the LCP is being used as intended or whether further training, guidance, and investment is needed.

8.3 This submission has uncovered a general weakness in the evidence base for end-of-life care which needs to be rectified if end-of-life care is to improve over the medium to long term and is to rebuild trust with patients and relatives. The Review of the LCP is an opportunity to call for further research of this kind.

8.4 A preliminary consideration of the evidence in this submission has not demonstrated that the LCP is structurally unsound or inherently unethical or that it is a ‘self-fulfilling prophecy’, at least in general or for the most part. Nevertheless, it is essential that the Committee commission or undertake for itself a systematic review of the scientific literature in order to reach secure conclusions.

8.5 This submission has not considered in detail particular cases in which it is alleged that patients have been harmed by the misuse of the LCP. The Review is urged to examine such cases in relation to whether patients supported by the LCP have been harmed, whether any such harm is due to the use of the LCP, and what corrections are needed in the light of these examples.

8.6 The submission has highlighted a number of concerns, especially in relation to the quality of care, decision making and communication in the treatment of those who, while expected to die within two to three days, live considerably longer, and are either taken off the pathway or die having been supported on the pathway for more than one week. If the Review concludes that the LCP, or something like it, should be continue to be used then it should consider whether the training and documentation of the LCP adequately supports the care of these patients, and more generally, what improvements in the LCP and in the communication surrounding the use of the LCP may be needed to avoided future cases of poor care.

BIBLIOGRAPHY

Anscombe, G.E.M. 'Action, Intention and "Double Effect"' in Geach, M., Gormally, L. (eds.) *Human Life, Action and Ethics*. Exeter: Imprint Academic, 2005: 207-226.

Arie, S. 'Inquiry launched into newspaper story about babies on "death pathway".' *British Medical Journal* 1 (March 2013). doi: http://dx.doi.org/10.1136/bmj.f1273 (accessed 4 April 2013).

Ashby, M., Stoffell, B. 'Artificial hydration and alimentation at the end of life: a reply to Craig.' *Journal of Medical Ethics* 21 (1995): 135–140.

Australian Catholic Bishops Conference, 'Briefing Note on the Obligation to provide Nutrition and Hydration', 3 September 2004.

Bassett, B. 'The Liverpool Care Pathway: A chaplain's perspective.' *The Pastoral Review* 9 (2) (March/April 2013): 39-43.

Beck, A., Gately, P., Jones, D.A. *Healthcare Allocation and Justice: Applying Catholic Social Teaching* London: CTS, 2010.

Brandt, H.E., Ooms, M.E., Deliens, L., van der Wal, G. and Ribbe M.W. 'The last two days of life of nursing home patients - a nationwide study on causes of death and burdensome symptoms in the Netherlands.' *Palliative Medicine* 20 (2006): 533–540.

Bruera, E., Sala, R., Rico, M.A., Moyano, J., Centeno, C., Willey, J., Palmer, J.L. 'Effects of parenteral hydration in terminally ill cancer patients: a preliminary study.' *Journal of Clinical Oncology* 23 (2005): 2366–71.

Bruera, E., Hui, D., Dalal, S., Torres-Vigil, I., Trumble, J., Roosth, J., Krauter, S., Strickland, C., Unger, K., Palmer, J.L., Allo, J., Frisbee-Hume, S., Tarleton, K. 'Parenteral hydration in patients with advanced cancer: a multicenter, double-blind, placebo-controlled randomized trial.' *Journal of Clinical Oncology* 31(1) (January 2013): 111-8. doi: 10.1200/JCO.2012.44.6518. Epub 2012 Nov 19.

Burge, F.I. 'Dehydration symptoms of palliative care cancer patients.' *Journal of Pain and Symptom Management* 8 (1993): 454–464.

Catechism of the Catholic Church.

Catholic Bishops Conference of England and Wales *Cherishing Life*. London: CTS, 2004.

Catholic Bishops' Conference of England and Wales: Department for Christian Responsibility and Citizenship. *The Mental Capacity Act and 'Living Wills': a practical guide for Catholics*. London: CTS, 2008.

Catholic Bishops' Conference of England and Wales: Department for Christian Responsibility and Citizenship. *A Practical Guide to The Spiritual Care of the Dying Person*. London: CTS, 2010.

Cerchietti, L., Navigante, A., Sauri, A., Palazzo, F. 'Hypodermoclysis for control of dehydration in terminal-stage cancer.' *International Journal of Palliative Nursing* 6 (2000): 370–374.

Chiu, T.Y., Hu, W.Y., Lue, B.H., Cheng, S.Y., Chen, C.Y. 'Sedation for refractory symptoms of terminal cancer patients in Taiwan.' *Journal of Pain and Symptom Management* 21 (2001): 467-472.

Claessens, P., Menten, J., Schotsmans, P., Broeckaert, B. 'Palliative sedation: a review of the research literature.' *Journal of Pain and Symptom Management* 36 (2008): 310-333.

Clark, D. 'Religion, Medicine, and Community in the Early Origins of St. Christopher's Hospice.' *Journal of Palliative Medicine* 4(3) (2001): 353-360.

Cole, A. 'Talk for House of Lords Meeting 23rd January 1013.' www.medethics-alliance.org (accessed 4 April 2013).

Congregation for the Doctrine of the Faith. *Declaration on Euthanasia Iura et Bona* (1980): AAS 72, 547-548.

Congregation for the Doctrine of the Faith. 'Responses to Certain Questions of the United States Conference of Catholic Bishops concerning Artificial Nutrition and Hydration, with Commentary.' 1st August 2007.

Craig, G.M. 'On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?' *Journal of Medical Ethics* 20 (1994): 139–143.

Dalal, S., Del Fabbro, E., Bruera, B. 'Is there a role for hydration at the end of life?' *Current Opinion on Supportive Palliative Care* 3 (2009): 72–78.

Del Río, M.I., Shand, B., Bonati, P., Palma, A., Maldonado, A., Taboada, P., Nervi, F. 'Hydration and nutrition at the end of life: a systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff.' *Psychooncology* 21(9) (September 2012): 913-21. doi: 10.1002/pon.2099. Epub 2011 Dec 8.

Doughty, S. 'Top doctor's chilling claim: The NHS kills off 130,000 elderly patients every year.' *Daily Mail* (20 June 2012).

Duffy, E. *Faith of Our Fathers: Reflections on Catholic Tradition.* London: Continuum, 2004.

Ede, S. 'Artificial hydration and nutrition at the end of life.' *European Journal of Palliative Care* 7 (2000): 210–212.

Egan, Philip Bishop of Portsmouth 'The Care of the Dying' Pastoral Letter 8 December 2012.

Ellershaw, J. 'Re: Continuous Deep Sedation in the UK- Dutch research reflects problems with the Liverpool Care Pathway.' *British Medical Journal* Rapid Response (4 May 2008). http://www.bmj.com/rapid-response/2011/11/02/re-continuous-deep-sedation-uk-dutch-research-reflects-problems-liverpool- (accessed 4 April 2013).

Fainsinger, R. 'Non-oral hydration in palliative care.' *Journal of Palliative Medicine* 9 (2006): 206–207.

Ferngren, G.B., ed. *Medicine and Health Care in Early Christianity.* Baltimore, MD: Johns Hopkins University Press, 2009.

Finucane T.E., Christmas C., Travis K. 'Tube feeding in patients with advanced dementia: a review of the evidence'. *JAMA* 1999; 282: 1365–1370.

Fitzsimons, J.T. 'Thirst.' *Physiological Reviews*, 52 (2) (1972): 468-561.

Gambles, M., McGlinchey, T., Aldridge, J., Murphy, D., Ellershaw, J. 'Continuous Quality Improvement in Care of the Dying with the Liverpool Care Pathway for the Dying Patient.' *International Journal of Care Pathways* 13 (2009): 51–56.

General Medical Council, *Treatment and care towards the end of life*. London: GMC, 2010. http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp (accessed 4 April 2013).

Gibbins, J., McCoubrie, R., Alexander, N., Kinzel, C., Forbes, K. 'Diagnosing dying in the acute hospital setting – are we too late?' *Clinical Medicine* 9 (2009): 116–9.

Glare, P., Virik, K., Jones, M., Hudson, M., Eychmuller, S., Simes, J., Christakis, N. 'A systematic review of physicians' survival predictions in terminally ill cancer patients.' *British Medical Journal* 327 (2003): 195-198.

Gomes, T., Mamdani, M.M., Dhalla, I.A., Paterson, J.M., Juurlink, D.N. 'Opioid dose and drug-related mortality in patients with non-malignant pain.' *Archives of Internal Medicine* 171(7) (April 2011): 686-691; 691-693.

Good, P., Cavenagh, J., Mather, M., Ravenscroft, P. 'Medically assisted hydration for palliative care patients', *Cochrane Database of Systematic Reviews* 16(2) (April 2008): 7. CD006273. doi: 10.1002/14651858.CD006273.pub2.

Guy, M. 'Letters Extra: Can Catholic doctors condone the Liverpool Care Pathway?' *The Tablet* online edition (21 September 2012). http://www.thetablet.co.uk/letters-extra/2012-09-21/0 (accessed 4 April 2013).

Gwilliam, B., Keeley, V., Todd, C., Gittins, M., Roberts, C., Kelly, L., Barclay, S., Stone, P.C. 'Development of Prognosis in Palliative care Study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study.' *British Medical Journal* Open Access (2011). http://www.bmj.com/highwire/filestream/392950/field_highwire_article_pdf/0/bmj.d4920 (accessed 4 April 2013).

Gwilliam B., Keeley V., Todd C., Gittens M., Roberts C., Kelly L., Barclay S., Stone P. c. 'Prognosticating in patients with advanced cancer – observational study comparing the accuracy of clinicians' and patients' estimates of survival' *Annals of Oncology* 24(2) (2013): 482-488.

Hamel, R.P. and Walter, J.J. (eds). *Artificial Nutrition and Hydration and the Permanently Unconscious Patient: The Catholic Debate*. Washington: Georgetown University Press, 2007.

Henderson, R., Keiding, N. 'Individual survival time prediction using statistical models.' *Journal of Medical Ethics* 31 (2005): 703-706.

Hindle, A., Coates, A. *Nursing Care of Older People: A Textbook for Students and Nurses*. Oxford: Oxford University Press, 2011.

'How can I tell if the Liverpool care pathway is right to use?' *Catholic Medical Quarterly* 61(3) (August 2011): 28-29.

Howard, P., 'Not so Peaceful an End.' *The Tablet* (15 September 2012): 8-9.

Howard, P., 'Care of the Dying.' *The Tablet* (6 October 2012): 19.

Inui A. 'Cancer anorexia-cachexia syndrome: current issues in research and management' *CA: A Cancer Journal for Clinicians*. 2002; 52: 72–91.

John Paul II. *Evangelium Vitae*.

John Paul II. Address on 'Life-sustaining treatments and the vegetative state.' 20 March 2004.

Jones, D.A. 'A comment on the Liverpool Care Pathway' (21 January 2013) http://www.bioethics.org.uk/images/user/CommentonLCPbyDirectorofABC.pdf (accessed 4 April 2013).

Jones, D.A. *Approaching the End: a theological exploration of death and dying.* Oxford: Oxford University Press, 2007.

Jones, D.A., 'The Hippocratic Oath III: Hippocratic principles applied to the withdrawal of treatment and the mental capacity act.' *Catholic Medical Quarterly* 57(2) (2007): 15-23.

Jones, D.A. 'Death by Equivocation: A manifold definition of terminal sedation' in S. Sterckx, et al. *Continuous sedation at the end of life: Ethical Perspectives.* Cambridge: Cambridge University Press, 2013.

Kite, S.M., Hicks, F., Rees, E., Shepherd, C., Stothard, C. 'Re: The Liverpool care pathway: what do specialists think?' *British Medical Journal* Rapid Response (8 Match 2013), http://www.bmj.com/content/346/bmj.f1184/rr/634951 (accessed 4 April 2013).

Krishna, L.K., Poulose, J.V., Goh, C. 'Artificial Hydration at the end of Life in an Oncology Ward in Singapore.' *Indian Journal of Palliative Care* 16(3) (September 2010): 168-73. doi: 10.4103/0973-1075.73668.

Levering, M. *On Christian Dying: Classic and Contemporary Texts.* Lanham, MD: Rowman and Littlefield, 2004.

Maltoni, M., Pittureri, C., Scarpi, E., Piccinini, L., Martini, F., Turci, P., Montanari, L., Nanni, O., Amadori, D. 'Palliative sedation therapy does not hasten death: results from a prospective multicenter study.' *Annals of Oncology* 20 (2009): 1163–1169.

Mannix, K. 'The Liverpool Care Pathway for the Dying Patient.' Presentation at Conference on 'Death and Dying in Catholic Perspective' sponsored by The Centre for Catholic Studies (Durham University), the Newman Association, the Departments of Spirituality, Formation and Education of the Diocese of Hexham and Newcastle, the National Board of Catholic Women, and St Cuthbert's Catholic Chaplaincy, Durham (9 March 2013).

Marie Curie Palliative Care Institute Liverpool (MCPCIL). Liverpool Care Pathway Generic Version 12 (2009), example core document http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/documentation-lcp/ (accessed 4 April 2013).

MCPCIL Liverpool Care Pathway for the Dying Patient (LCP) - FAQ August 2012 http://www.liv.ac.uk/media/livacuk/mcpcil/documents/LCP,FAQ,August,2012.pdf (accessed 4 April 2013).

McCann, R.M., Hall, W.J., Groth-Juncker, A. 'Comfort care for terminally ill patients: the appropriate use of nutrition and hydration.' *Journal of the American Medical Association* 272 (1994): 1263–1266.

McCullagh, P. 'Thirst in relation to withdrawal of hydration.' *Catholic Medical Quarterly* XLVI 3 (269) (February 1996): 5-12. http://www.cmq.org.uk/CMQ/1996/Thirst-and-PVS.html (accessed 4 April 2013).

McGovern, C. 'Thousands Die Prematurely on U.K. "Death Pathway".' *National Catholic Register* (16 August 2012). http://www.ncregister.com/daily-news/thousands-die-prematurely-on-u.k.-death-pathway (accessed 4 April 2013).

Middleton, S., Roberts, A. (eds.) *Integrated Care Pathways: A Practical Approach to Implementation*. Oxford: Butterworth-Heinemann, 2000.

Morita, T., Shima, Y., Miyashita, M., Kimura, R., Adachi, I., Japan Palliative Oncology Study Group. 'Physician- and nurse-reported effects of intravenous hydration therapy on symptoms of terminally ill patients with cancer.' *Journal of Palliative Medicine* 7 (2004): 683–693.

Murphy O'Connor, C., Cardinal Archbishop Emeritus of Westminster 'Spiritual Challenges in Healthcare Today.' An address to 'Faith in Health' Conference (unpublished) quoted in Bassett, L. 'The Liverpool Care Pathway: A chaplain's perspective.' *The Pastoral Review* 9(2) (March/April 2013): 42.

Musgrave, C.F., Bartal, N., Opstad, J. 'The sensation of thirst in dying patients receiving i.v. hydration.' *Journal on Palliative Care* 11 (1995): 17–21.

National Care of the Dying Audit – Hospitals (NCDAH). Rounds 1 (2006-7), 2 (2008-9) and 3 (2011-12). Marie Curie Palliative Care Institute Liverpool-Royal College of Physicians. http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/national-care-of-dying-audit/ (accessed 4 April 2013).

National Catholic Bioethics Center, The. 'A Catholic Guide to End-of-Life Decisions An Explanation of Church Teaching on Advance Directives, Euthanasia, and Physician Assisted Suicide.' (Revised 2010).

Nowarska, A.M. 'To feed or not to feed? Clinical aspects of withholding and withdrawing food and fluids at the end of life', *Advances in Palliative Medicine* 10(1)(2011): 3–10.

Pius XII. Address to an International Group of Physicians, III (24 February 1957): AAS 49, 147.

Pugh, E.J., McEvoy, M. 'The Imminence of death and the Liverpool Care Pathway.' *British Medical Journal* Rapid Response to Ellershaw, J. 'Achieving a good death for all' (29 October 2010) http://www.bmj.com/rapid-response/2011/11/03/imminence-death-and-liverpool-care-pathway (accessed 4 April 2013).

Pullicino, P. 'Can We Predict Impending Death?: The Scientific Evidence.' Presentation given at a conference of Medical Ethics Alliance: 'Natural Death - is a pathway needed' at the Royal Society of Medicine (18 June 2012).

Pullicino, P. 'The Dangers of Abandonment of Evidence-Based Medicine in the use of the Liverpool Care Pathway.' *Catholic Medical Quarterly* 62(4) (November 2012). http://www.cmq.org.uk/CMQ/2012/Nov/LCP-Pullicino.html (accessed 4 April 2013).

Rady, M.Y., Verheijde, J.L. 'Continuous Deep Sedation Until Death: Palliation or Physician-Assisted Death?' *American Journal of Hospice & Palliative Medicine* 27(3) (2010): 205-214.

Raijmakers, N.J., Fradsham, S., van Zuylen, L., Mayland, C., Ellershaw, J.E., van der Heide, A. 'Variation in attitudes towards artificial hydration at the end of life: a systematic literature review.' *Current Opinion on Supportive Palliative Care* 5(3) (September 2011): 265-72. OPCARE9. doi: 10.1097/SPC.0b013e3283492ae0.

Reid, S., Caldwell, S. 'Now sick babies go on death pathway: Doctor's haunting testimony reveals how children are put on end-of-life plan'. *Daily Mail* 28th November 2012.

Risse, G.B. *Mending Bodies, Saving Souls: A History of Hospitals.* Oxford: Oxford University Press, 1999.

Royal Dutch Medical Association. *Guideline for Palliative Sedation* (2009).

Salter, P., Pugh E., McEvoy, M. 'Letters Extra: Questions and concerns about the Liverpool Care Pathway.' *The Tablet* online edition (28 September 2012). http://www.thetablet.co.uk/letters-extra/2012-09-28/0 (accessed 4 April 2013).

Sanders, A. 'The clinical reality of artificial nutrition and hydration for patients at the end of life.' *The National Catholic Bioethics Quarterly* 2 (2009): 293–304.

Seale, C. 'End-of-life decisions in the UK involving medical practitioners'. *Palliative Medicine* 23 (2009): 198–204.

Seale, C. 'National survey of end-of-life decisions made by UK medical practitioners'. *Palliative Medicine* 20 (2006): 1–8.

Shannon, R.A. 'Nutrition and Hydration: An Analysis of the Recent Papal Statement in the Light of the Roman Catholic Bioethical Tradition' *Christian Bioethics* 12 (1) (2006): 29-41.

Smith, R. 'Patient death pathway "based on guesswork".' *Telegraph* (22 October 2012).

Stephenson, J. 'The Liverpool Care Pathway.' *Triple Helix* (Winter 2012): 14-15.

Stone, P., Phillips, C., Spruyt, O., Waight, C. 'A comparison of the use of sedatives in a hospital support team and in a hospice.' *Palliative Medicine* 11 (1997): 140-144.

Stone, P., 'Care of the Dying.' *The Tablet* (22 September 2012): 17-18.

Sullivan, M.D. 'Limiting the Potential Harms of High-Dose Opioid Therapy: Comment on "Opioid Dose and Drug-Related Mortality in Patients With Nonmalignant Pain".' *Archives of Internal Medicine* 171(7) (2011): 691-693. doi:10.1001/archinternmed.2011.101.

Sykes, N., Thorns, A. 'The use of opioids and sedatives at the end of life.' *The Lancet Oncology* 4 (5) (2003): 312-318.

Sykes, N., Thorns, A. 'Sedative Use in the Last Week of Life and the Implications for End-of-Life Decision Making.' *Archives of Internal Medicine* 163 (2003b): 341-344.

Tollefsen, C. (Ed.). *Artificial Nutrition and Hydration: The New Catholic Debate*. Dordrecht: Springer, 2008.

Toy, E. 'Care at the end of life.' *The Tablet* (2 February 2013): 17-18.

Treloar, A.J. 'The Liverpool care pathway is not safe.' *British Medical Journal* Rapid Response to 'The Liverpool care pathway: what do specialists think?' (6 March 2013). http://www.bmj.com/content/346/bmj.f1184/rr/634583 (accessed 4 April 2013).

Trescot, A.M., Helm, S., Hansen, H., Benyamin, R., Glaser, S.E., Adlaka, R., Patel, S., Manchikanti, L. 'Opioids in the Management of Chronic Non-Cancer Pain: An Update of American Society of the Interventional Pain Physicians (ASIPP) Guidelines.' *Pain Physician* (2008): Opioids Special Issue: 11: S5-S62.

United States Conference of Catholic Bishops. 'Ethical and Religious Directives for Catholic Health Care Services Fifth Edition.' (17 November 2009).

Vatican II *Gaudium et Spes*.

Williams, Thomas A., Auxiliary Bishop of Liverpool 'Palliative Care – light of experience' *The Tablet* (26 January 2013): 18.