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The Liverpool Care Pathway: A chaplain's perspective

The author reflects on the use, understanding and value of Liverpool Care Pathway in the light of recent media interest. Lynn Bassett is Spiritual Care Co-ordinator at The Peace Hospice in Watford and Catholic Chaplain at Mount Vernon Hospital, Northwood.

The Liverpool Care Pathway (LCP), is an integrated care pathway, used at the bedside of the dying and designed to 'drive up sustained quality'[1] of care in the last hours and days of life. It has recently become the focus of a severe campaign of criticism from some sectors of the media. Concern has become so great that Norman Lamb, Minister of State in the Department of Health, has commissioned an extensive review into end of life care and the use of the Pathway chaired by Baroness Neuberger, the results of which will be published later this year. This has been welcomed by both proponents and opponents of the Pathway.

History

The Liverpool Care Pathway was so named because it was developed by the collaboration of the Liverpool Marie Curie Hospice and the Royal Liverpool Infirmary. Led by Professor of Palliative Medicine John Ellershaw, it began to be disseminated across the county in 2005. It offered a programme of palliative care as practiced in the hospice environment as a model for better care of the dying in hospital and other care settings. It recognised that as people reach the end of their lives their needs change; they may not need regular blood tests, or certain medication. Other aspects of their care should be reviewed including need for hydration and nutrition and conditions for comfort and quality of life. Additionally, provision should be made for things that might be required: symptom control for nausea, pain relief and possibly a relaxant or sedative.

From a chaplain's point of view, the Liverpool Care Pathway was a breakthrough in the opportunities it offered for spiritual care giving. First, because the checklist included a question about the patient's and their family's spiritual and religious needs, it prompted nurses to ask, and it prompted families to think about this deeply personal and important subject which they may not have otherwise known how to broach. Patients and their family members had the opportunity to decide whether or not they would like a visit from the chaplain. Of course this offer remained open throughout their stay, but it was a timely prompt. In the case of a Catholic patient, a visit from a priest could be arranged, if required; family could choose to be present at a pre-arranged time, the Sacrament of the Sick could be administered in a calm and dignified manner and on-going pastoral support and Holy Communion as Viaticum arranged, thus eliminating, or at least reducing, panic calls to the priest, and the stress of waiting, as the patient drew their final breaths. Secondly, the Liverpool Care Pathway offered a set of patient notes that were available to all. Where, following the Data Protection Act 1998, the chaplain was refused access to medical and nursing notes, the Liverpool Care Pathway provided a space where spiritual and religious needs and pastoral visits could be documented. Staff and family members knew if the chaplain or priest had visited, the uncertainty of whether an unconscious patient had been anointed or not was relieved.

Use of the Liverpool Care Pathway offered opportunities for strengthening team working between the chaplain and nursing staff and research shows that where chaplains are routinely involved in the delivery of the LCP, staff stress is reduced and complaints from families go down.[2]

It seems that the very qualities that make the Liverpool Care Pathway of high value to me as a chaplain are the issues of concern highlighted by those who have shared their stories of dissatisfaction with the press.[3] As is often the case, the prime concerns are communication; 'we were not told', but also shortening of life or hastening of death, discontinuation of treatment, matters of nutrition and hydration. Some families have complained of being 'shunted into a side-room and ignored', something which the four hourly checks of the Liverpool Care Pathway is designed to address.

Communication

One of the main charges raised against the LCP by angry and grieving relatives is that they were not told. The judgement about what this actually means will be different in each individual case. Perhaps the medical team did think they had communicated that the loved one was dying; perhaps the distraught family did not 'hear'. Perhaps the team did not find the words to say, hoping to spare the patient's hope or the relative's feelings. Perhaps they talked about dying but not the Liverpool Care Pathway; perhaps they introduced the Liverpool Care Pathway without mentioning that the patient had entered the dying phase. Dr Bee Wee, president of the Association of Palliative Medicine has emphasised the need for training and education to encourage confidence in staff, contributing to better communication and the avoidance of unhelpful euphemisms.

Shortening of life or hastening death

To sit and watch while a loved one dies is perhaps the most painful experience that many of us will have to endure in our lives. The feeling of helplessness can be overwhelming. Family members and patients themselves often wish that the suffering could come to an end. The healthcare system is criticised both for 'keeping people alive too long' and, in this case, for bringing about premature death.

The deeply entrenched public belief that opiates hasten death is still widely held despite significant research evidence that, when prescribed and administered in accordance with best practice, this is not the case.[4] Doctors are bound by the law (the Mental Capacity Act 2005), by guidance of the General Medical Council,[5] and by traditional Hippocratic ethics not to initiate any action or omission which is motivated by the desire to bring about death, and whilst the principle of double effect recognises that some treatments to improve quality of life may also shorten life, this should never be the primary intention.

Withdrawal of treatment

Some sectors of the media have consistently linked the Liverpool Pathway with 'the withdrawal of life saving treatment'. Aside from being highly emotive, this is a conflation of two distinct decisions: withdrawal of treatment, and commencement on an integrated pathway for the dying. Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to their expected outcome is an everyday clinical decision which should be made in conjunction with the patient if he or she is competent or, if not, by those legally entitled to act for the patient. The concept of 'futility' must be understood in its medical context. The Liverpool Care Pathway should only be initiated when all possibilities of 'life-saving treatment' have been considered and discounted and the patient is recognised to be in the last hours or days of life. If the patient shows signs of recovery, the pathway is no longer appropriate and a new plan of treatment should be put in place.

Nutrition and hydration

Perhaps most controversial is the discussion about those basic essentials of life, food and water, and the desire we all have as human beings to continue to nurture another to the end. It is hard to sit with someone who is thirsty and not give them a drink, but it is harder to see them choke because they are no longer physically capable of swallowing. Often good mouth care is enough. There are

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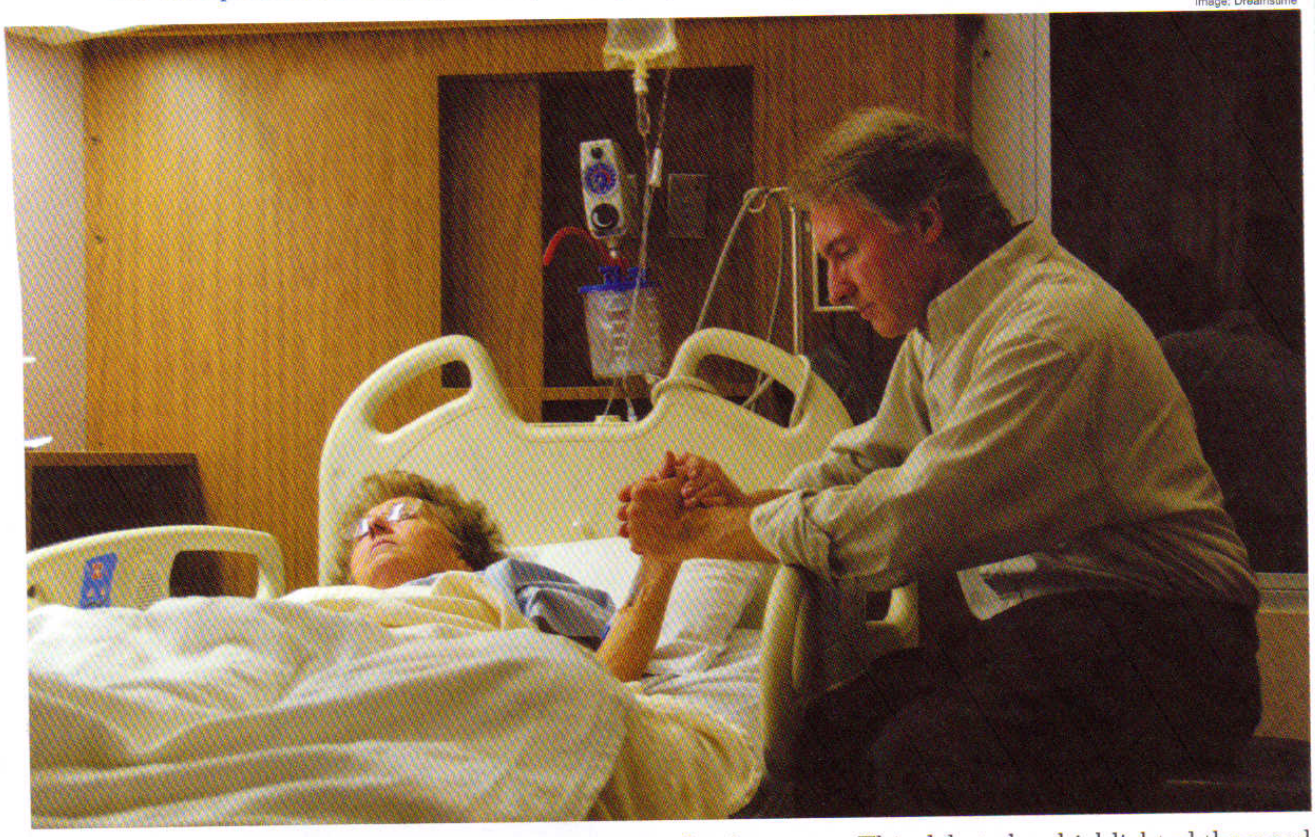


complex ethical discussions about artificial nutrition and hydration and whether this is considered to be treatment or basic care.[6] The Church is clear that it is the latter, but at the very end of life it may be that assisted provision of nutrition and hydration is no longer needed, and may even be counter-productive.[7] The debate about the Liverpool Care Pathway has revealed stories of people who have 'revived' after food and drink[8] but, as a condemnation of the Pathway this is misplaced; the Pathway does not prohibit food or fluids, rather it recommends that a patient's needs are regularly reviewed.

All of the above concerns may be resolved with sensitive and open communication between the healthcare team, the patient and their family and, in the busy environment of an acute hospital, the challenge is to find time when all parties are available. These are challenges that must be met in order to ensure that the aspirations of the End of Life Care Strategy (2008)[9] are met; that good palliative care is available to all who need it in whatever healthcare setting. The Liverpool Care Pathway is recognised as an important contribution, but it is only as good as the staff who administer the care. This debate has highlighted the need for more training for healthcare staff but there is another area where communication and education is becoming increasingly important.

Death in the twenty-first century

Death is sometimes described as 'the last taboo' in our society. It is a taboo that the Dying Matters Coalition, set up by the National Council for Palliative Care in 2009, is working hard to break but is there a role for the Church too?

Speaking to a gathering of healthcare chaplains, Rt Revd James Newcome, Bishop of Carlisle, and Lead Bishop on Healthcare Issues for the Church of England, highlighted the changing nature of death in our society. In an age where the majority of deaths occur in hospital, death has become medicalised and in an institution focused on cure, it can be seen as failure. At the same time autonomy has become the favoured ethical stance, individual choice the ideal. For some, 'dignity' has become associated with personal control over the end of life including support for legalising assisted suicide or euthanasia.

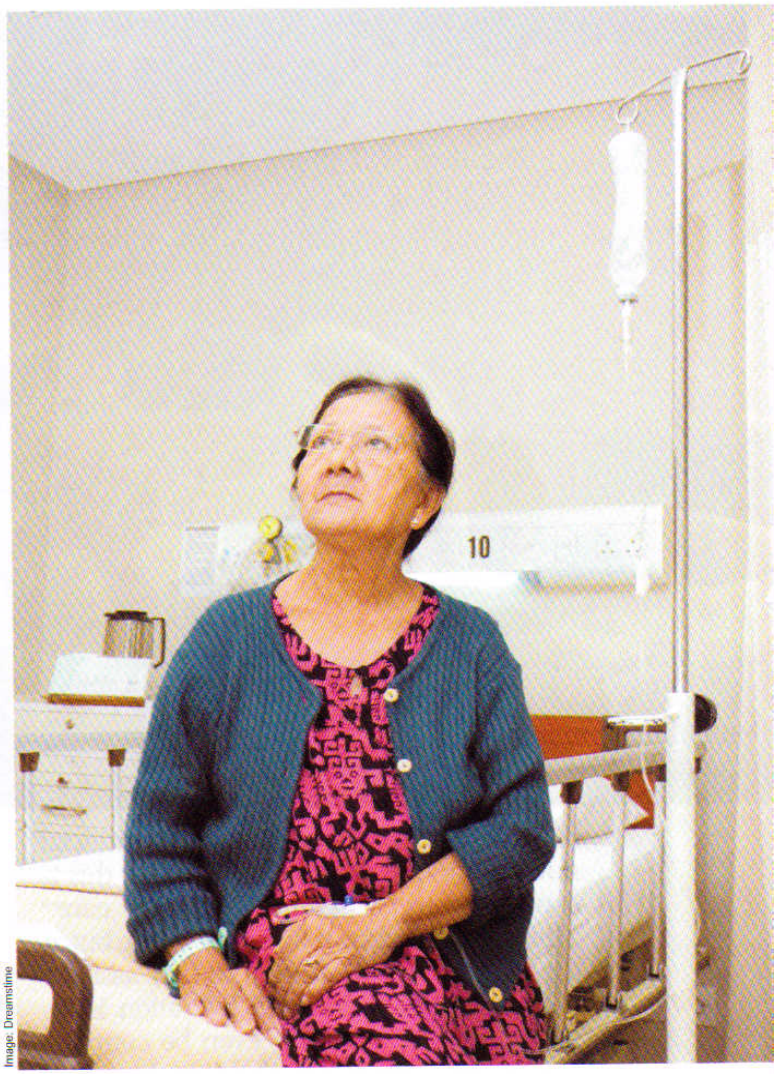
Palliative care is sometimes heralded as the antidote to these arguments; by making life as pain free and quality filled as possible, right to the end, people may be encouraged to continue the journey until the end comes.

A priest at the funeral of a person who had suffered with cancer for many years said, 'Just as a baby who is tired has a right to lie down and sleep, so a very sick person who has come to the end of their life has the right to die'. This 'right' to be allowed to die well, with dignity and in an environment of good, appropriate care is very different from the right to die proposed by supporters of assisted dying and euthanasia. It is the distinction between acceptance and autonomy. Along with Muslims, many Christians consider the moment of death to be in the hands of God. Along with Buddhists, Hindus and people of other faiths, many Christians recognise the importance of preparation for the acceptance of this moment by the practice of 'small dyings' throughout our lives.

For the Church there will always be that tension between the preservation of life and the welcoming of death because of the promise of life, and a better life, still to come.

In 2008 Cardinal Murphy O'Connor wrote, 'What we have to recognise is that in healthcare there are two goods: cherishing life, and accepting death ... both matter and neither need or should be done at the expense of the other. The problem is, as I see it, that we have not yet done enough particularly in training of staff and in the deployment of resources to recognise that dying is not a failure but a human reality that we can and should honour and fully respect in the way people are cared for.'[10]

Perhaps there has been too much emphasis in the past on preserving life at all costs; to 'give up', to turn 'face to the wall' seems wrong, even a sin. It is not uncommon for frail patients who have expressed a sincere wish for death to come quickly and easily to



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ask, with real concern, 'is it wrong for me to be talking like this?' Another example is the devout Catholic lady who has fought cancer bravely for twenty years attributing much of this success to her faith, and storms heaven daily for her ongoing health and strength and well-being, but now finds the side effects of chemotherapy too burdensome and is ready to decline further treatment. This is not inconsistent with medical common sense or Church teaching.

Our Christian faith offers a hope that is unique and enduring for those approaching the end of their lives and for those who are left behind. Dame Cicely Saunders, a Christian and founder of the modern hospice movement, stated that 'All the careful details of the Pathway are a salute to the enduring worth of an individual life, such an ending can help those left behind to pick up the threads of

memory and begin to move forward.'[1]

What can we, as Church, do?

I believe there is a pressing need for education, in our parishes, in our communities, about the reality and acceptance of death as a natural part of life. Fifty years after Vatican II there is still a need for catechesis on the Sacrament of the Sick. It is recognised that a 'good death' can lead to an easier bereavement, but as increasing numbers of families opt for a civil funeral service, the opportunities for the Church community to offer bereavement support are declining. Seemingly the search for forums where these matters can be openly discussed is not declining. The development of 'death cafes'[11] is one secular manifestation of this need. Could the Church develop similar supportive ways to welcome searchers in?

In conclusion, in my experience as a chaplain the Liverpool Care Pathway, when used well, offers good care for patients and their families; quality holistic care, appropriate pain relief and symptom control available when it is needed. It is not appropriate for every death in an acute environment, it has faced challenges in translation from a hospice and oncology background to other medical disciplines but, as Dr Max Pemberton, giving a personal account of his own grandfather's death, writes, 'Without the LCP we are catapulted back to the days of lingering, distressing and needlessly uncomfortable deaths'.[12] The media attention and the government review offer us the opportunity to open up discussions in our parishes and communities, to dispel unhelpful myths, to empower people to challenge bad practice but not to assume that all practice is bad, to develop a healthy understanding of the balance between cherishing life and, when the time is right, welcoming death as the friend that St Francis described.[13]

1 For the core document and other supportive material see the website of The Marie Curie Palliative Care Institute, Liverpool http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/

2 Detain, J. and Salter, P., 'Meeting the Spiritual and Pastoral Needs of Patients and their Families at the End of Life' *The Journal of Healthcare Chaplaincy* Winter 2011.

3 Though it should be noted that disaffected families only represent a small portion of those 130,000 people who were cared for using the Pathway last year, and that other families have reported good outcomes from this method of palliative care.

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

5 General Medical Council, *Treatment and care towards the end of life: good practice in decision making*, GMC, 2010.

6 For further discussion of the ethics of end of life care, including the issue of assisted nutrition and hydration, see Catholic Bishops' Conference of England & Wales Dept. for Christian Responsibility & Citizenship, *A Practical Guide to The Spiritual Care of the Dying Person*, CTS, 2010.

7 Nowarska, A., '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, 2009.

8 For example: Fricker, M., '"I saved my mum from hospital's path to death": TV chef Rustie Lee slams plan to halt treatment even though mum wasn't dying' *Mirror*, 1st November 2012.

9 Department of Health, *End of Life Care Strategy*, HMSO, 2008.

10 Murphy O'Connor, C., 'Spiritual Challenges in Healthcare Today' an address to 'Faith in Health' Conference (unpublished) in Detain, J. and P. Salter, 'Meeting the Spiritual and Pastoral Needs of Patients and their Families at the End of Life' *The Journal of Healthcare Chaplaincy* Winter 2011.

11 Death Café, http://www.deathcafe.com/

12 Pemberton, M., 'The Liverpool Care Pathway to dignity in death', *Telegraph* 13th January 2013.

13 St Francis of Assisi *Canticle of the Sun*, 1225.