

The Liverpool Care Pathway

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AT THE END OF LIFE

For many practising doctors, especially in general practice or in general internal medicine, decisions at the end of life are often some of the most difficult. Not only is decision making difficult, but implementation may create a further set of problems. Most of us are orientated to *doing* something – usually something that is active, promoting life or health. Many end of life decisions demand something different: the acceptance that life is coming to an end and that the quality of the final phase of the patient's illness is to offer a good death. The doctor must reorientate his or her thinking to a different, less distinct target. Yet the old aphorism still rings true that the aim of medicine is to cure sometimes, to alleviate often and to comfort always, (*guérir quelquefois, soulager souvent, consoler toujours*) (Payne 1967, pp.47-48).

As an aside, the origin of this saying is uncertain; it is associated with Dr EL Trudeau and inscribed on his statue in the grounds of the Trudeau Institute at Saranac Lake New York and also on the fireplace beneath an oil painting in the library. But it is found too in a window in the New York Academy of Medicine and variously attributed to Oliver Wendell Holmes, Paré, Florence Nightingale and Hippocrates.

Within that aphorism, comes the need to understand 'comfort' in terms of ultimate aims and desires: the explanation or meaning attached to the illness experience. Comfort is different from alleviation in this respect. A book such as Jeremy Taylor's *The Rule and Exercises of Holy Living, Holy Dying* of 1651 sets out what is comforting in mortal illness. From Taylor's perspective, this is unashamedly religious: reflections on the brevity of life, length of years, charity and alms, fear of death, hope of heaven. Comfort is here not symptom relief, but a more positive view of life's ending. Similarly in Tolstoy's novella *Ivan Illich*, the comfort is the light: 'In place of death there was light' 'So that's what it is! What joy!' And Illich escapes from his 'black hole'.

For a previous generation, the increased place of technology in medicine often seemed to have displaced the willingness to sit by the bedside and wait. Senior doctors in particular often rushed by, ignoring the needs of those who had moved beyond the stage of curative

or even alleviative medicine. It was forgotten that 'they also serve who only stand and wait' (Milton 1655). The dying patient was moved into a side-ward where he or she would not be seen, sometimes ignored by all but the most junior doctor on the team. Outside hospital, it was the nurses in the community who played the key role in care. Medicine had forgotten something of its vocation. It was into the world of this (admittedly sweeping) generalisation, that the new specialty of palliative medicine was born – its chief midwife that remarkable nurse, social worker and doctor, Cicely Saunders (1996, p.1599). From a UK perspective, the hospice movement - spearheaded in the east end of London in St Joseph's Hospice and in south London in St Christopher's - rapidly gained momentum. It received strong support from the voluntary sector, especially Christian organisations, but as it grew also gained grant support from government. The work of Saunders in her concept of 'total pain' was important, as was the adoption of the World Health Organisation's (1990, p.11) subsequent definition of palliative care as 'total active care':

"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families."

The benefits of hospice care, with support from dedicated professionals, became obvious enough. Yet it was clear that hospice provision could not be extended to all dying patients. In the UK, those dying in hospices make up less than 5% of total deaths. The lessons of the hospice had to extend beyond its walls to other institutions – principally hospitals, but also to those dying at home or in residential care homes or nursing homes. This led to the development of the Liverpool Care Pathway for the dying patient (LCP).

The LCP was the product of a collaboration in 2004 between the University of Liverpool, Marie Curie Cancer Care and the Royal Liverpool and Broadgreen University Hospitals NHS Trust – that is to say, a collaboration between the voluntary sector, academia and the UK's National Health Service. The pathway continues to

be a focus of collaborative work with various national organisations, including the National Council for Palliative Care, the Royal College of Physicians and the Care Quality Commission (The Marie Curie Palliative Care Institute Liverpool, 2013). The LCP has both a national and international programme and has a role in the provision of end of life care in at least 17 countries. Its primary aim is to improve care in the last hours or days of life – that is to say, it is not a programme for terminal illness overall, but for its final stages. Cicely Saunders herself said:

“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” (Saunders 2011, p.xiii).

As the Marie Curie Institute states, the LCP was recognized as a model of best practice in the NHS Beacon Programme – 2001 (Ellershaw and Wilkinson, 2011), incorporated into the NHS National End of Life Care Programme (2010) for 2004-7, recommended in the National Institute of Clinical Excellence guidance (2011) in 2004 and recommended in the End of Life Care Strategy by the English Department of Health (2008). For the dying patient, it was thought by those with expertise in palliative medicine to represent the best standard of care.

THE PATHWAY

A pathway is a complex intervention for the mutual decision making and organization of care processes for a well defined group of patients during a well defined period – in this case, those with a prognosis of days or hours of life only. Its five key elements consist of

- An explicit statement of goals or of the key elements of care based on evidence and best practice;
- The facilitation of the communication among team members, with patients and families;
- The coordination of the care process by coordinating the roles and sequencing the activities of the multi-disciplinary team (MDT), patients and carers;
- The documentation, monitoring and evaluation of variances and outcomes;
- The identification of the appropriate resources.

The advice in the Liverpool Care Pathway (2013) document is entirely compatible with other end of life guidance, which it supplements. In the UK, this includes

guidance from the General Medical Council (2010), the Royal College of Physicians (2010) and the British Medical Association (2007). Most of this guidance is now available free of charge online. The pathway aims not only to improve care in the last few hours or days of life, but also to improve knowledge related to the dying process. Research into end-of-life presents particular challenges, but there is a need for better knowledge on patient views on dying well as well as on techniques of palliative care. Better data on how people die, as opposed to what they die of, is required (Royal College of Physicians of London, 2007).

The LCP has *three key sections*: initial assessment, ongoing assessment and care after death; and *four key domains of care*: physical, psychological, social and spiritual; and *five key requirements* for organisational governance: clinical decision making, management and leadership, learning and teaching, research and development, governance and risk. Simply setting that out makes it immediately apparent that using the pathway will only be as good as the teams using it. It cannot be applied without education and training.

Some of those features require emphasis in the light of recent controversy. The LCP is not designed to either hasten or prolong death and its application requires good communication with all involved: patients, professionals, families and carers. Not only does it not preclude a policy of no hydration or nutrition, but it considers a blanket policy of no artificial hydration or nutrition to be unethical. It does not recommend continuous deep sedation. Continuous reassessment is a feature with a formal full MDT meeting every 3 days. By law, all decisions must be made in the patient's best interests. A properly constituted advance refusal of treatment by a patient has full legal force in the UK and cannot be over-ruled. The emphasis on reassessment reflects little more than the uncertainties under which all medicine is practised (Saunders 2004, pp.97-110). Prognostication is often inaccurate, especially in the dying patient. The ability for self-care, oral intake, conscious level and so on, may all change and make a review of needs essential.

THE CONTROVERSY

It was against this background that from 2010 onwards a series of concerns was expressed in the UK about the use of the LCP. For example, a psychiatrist expressed concerns that artificial nutrition and hydration was not given to patients on the LCP; another consultant alleged 'backdoor euthanasia' in a major broadsheet

newspaper, the *Daily Telegraph*. The *Telegraph* was joined by the *Daily Mail* and the two papers maintained a campaign of criticism against the “pathway of death”. For example, in one widely publicised case, Susan Goold complained that her father had been placed on the LCP without permission and had suffered a “barbaric death” deprived of food and fluid for 8 days, without being able to say farewell to his wife and with no record in his case notes about the LCP (Watson, 2013). The daughter’s claim was reported that “You wouldn’t treat a dog the way my poor dad was treated. We are all devastated, the best interests of the patient was not starving him to death.” The hospital, Addenbrooke’s in Cambridge, was left to investigate. Similar reports of this sort appeared throughout this period and the press campaign widened to further allegations. Thus the *Daily Mail* reported that “Hospitals were bribed to put patients on the pathway to death... The incentives have been paid to hospitals that ensure that a set percentage of patients who die on their wards have been put on the controversial regime. At least £ 30 million in extra money from taxpayers has been handed to hospitals in the last three years to achieve these goals” (McCartney 2012, e7316). Addenbrooke’s Hospital, involved in the Goold case, for example, had received over £1 million according to the *Daily Telegraph*. A BBC investigation reported that only 57% patients had their care plan discussed with relatives or carers. And in a story in November 2012, the *Daily Mail* ran a story on its front pages entitled “Now sick babies go on death pathway.” The story (Arie 2013, f1273) claimed that NHS hospitals were discharging sick children and babies to hospices or their homes, where food and fluid were withdrawn until they died. The story was based on the testimony of a doctor practising in another country, never disclosed. Further criticisms followed against a well know UK children’s hospital with as little substance. But the *Daily Mail* did not remove the story from its website or correct or clarify it. It was published in a different version in the *Daily Telegraph* and inspired scores of responses from readers expressing disgust that the NHS permitted such practice – which of course it doesn’t.

A prominent *Daily Mail* columnist, Melanie Phillips, wrote rhetorically “Care?” and replied to herself, “No, this is a pathway to killing people that doctors deem useless” (Phillips, 2012a) Further inflammatory allegations and opinions followed from Phillips’ pen: “In other words, they are killed. What’s more, they are killed in a most cruel and callous way through starvation and dehydration.” Patrick Pullicino, a consultant neurologist

and professor of clinical neurosciences at Kent University, was reported as telling a conference that the LCP had become an ‘assisted death pathway’ for more than 100,000 patients each year. ‘Very likely, many elderly patients who could live substantially longer are being killed by the LCP,’ he said. “Horribly, (Phillips went on) the LCP has become a self-fulfilling prophecy. When people are put on it, they are said to be dying. But they may not be dying at all — not, that is, until they are put on the ‘pathway’, whereupon they really do die as a result.... This really is an obscene abuse of people who expect the NHS to care for them, not kill them. And how appalling that this has made patients terrified that the hospitals supposedly taking care of them may try instead to kill them.” The LCP was being driven both by crude economic calculations and by a wider brutalisation of our culture at the heart of which lay the erosion of respect for the innate value of human life supported by the “lethal arrogance” of the medical profession (Phillips, 2012b). Phillips had her sympathisers among doctors too. One wrote to the *BMJ* stating that she should be applauded for highlighting an area of practice that the letter writer thought “clearly” warranted investigation (Teo 2012, e7316).

THE RESPONSE

There was a strong professional response. Doctors do not commonly write *en masse* to the press, but on November 6, 2012 a letter was sent to the *Daily Telegraph* signed by 1300 doctors who said that they supported the pathway. The Press Complaints Commission received 311 complaints about one of the *Daily Mail*’s article. Nevertheless, there were conflicting voices (O’Dowd 2012, e7644) even if few doctors would support the inflammatory critique advanced by Phillips. Most believed, along with a *BMJ* columnist, that end of life care had been transformed (Spence 2012, e7308). A group of organisations issued a consensus statement backing the LCP and reiterating that it was about excellence in care: “Published misconceptions and often inaccurate information...risk detracting from the substantial benefits it can bring to people who are dying and to their families” (Kmietowicz 2013, e6654). Those backing the statement included the Royal College of Physicians, the Royal College of General Practitioners, the British Geriatrics Society, charities, organisations representing care homes, social services, hospitals and palliative care services. It had already been pointed out that the alleged payments concerned incentives to achieve the

multiple targets and frameworks used to judge hospitals' performance; these were not bribes but typical sources of income and entirely usual. Moreover conversations were happening. The perception that patients were placed on the LCP without discussion reflected the failure to name the LCP rather than a lack of description of the care being offered.

An investigation of doctors' views was carried out by the BMJ in association with the television programme *Dispatches* on Channel 4 tv (Chinthapalli 2013, f1184). This surveyed 563 doctors who had used the pathway. They comprised 185 consultants in palliative medicine, 168 in training or career grade posts in palliative medicine and 210 doctors in other specialties. The survey demonstrated widespread concern and reluctance to use the LCP due to requests from relatives or apprehension about relatives' complaints. Negative press was leading to more distress and a fear that discussion would increase those anxieties. Almost none thought that bed pressures had led to LCP use. However only 13% of respondents thought that financial incentives should be used to encourage use of the LCP. As one said, "Setting targets for the use of a tool that was intended simply to ensure best practice was never wise and always open to misinterpretation." Training needs were often not met, but the respondents were clear in pointing out that the problem was not primarily with the LCP – it was as foolish as blaming insulin for the damage and deaths it has caused due to misuse. 91% thought the LCP represented best practice and 98% thought that it allowed patients to die with dignity. 90% said they would want the pathway themselves in a terminal illness (and some of the remaining 10% may represent confusion from the use of a modified version in Welsh respondents). "Scaremongering was putting end of life care back about twenty years, where dying patients were hidden in side rooms and not seen by a consultant."

FURTHER CONSIDERATIONS

Certainly it is true that the LCP should not be used as a way to indicate that the patient's care is 'palliative' (or worse, 'patient is palliative'); or a way to ensure that appropriate medication is prescribed for patients *not* judged to be in last hours/days of life; or a way to stop clinicians thinking about that particular patients' needs, or avoid using clinical judgement; or a way to prescribe a syringe driver for a patient being on a syringe driver does not indicate that the patient is dying or on the LCP.

Whether the patient is dying in hours or days is a clinical judgement which sometimes we will get wrong and the LCP should be discontinued if the patient's condition improves. The problem now is that patients, relatives, carers and some staff are worried about the LCP and may wrongly feel it is 'euthanasia', or to hasten death. There is the spectre of a belief that the LCP represents the concept of a 'pathway' to lead to death. And with successive versions, the LCP is now a large document, extended to avoid problems of earlier versions. For example, 'Variance' takes time to complete so nurses may just put 'A' for 'achieved' beside goals. If misapplied or misused due to lack of education or training that practice carries risks for patients. Already many proposals have been discussed about possible improvements. Some suggest getting rid of the terms 'pathway' and 'Liverpool'; considering whether there ought to be national guidance on care and prescribing for patients imminently dying but not in 'pathway' format. Others suggest that there are problems with the term 'care plan' as the latter is particular to a patient, and the term has multiple uses. Certainly if the LCP (or similar) continues, it must have dedicated mandatory training, with funding, to avoid known risks of misapplication and misuse. And financial incentives or penalties should be removed as they plainly lead to misunderstanding.

What was this heated debate about? Was it that there are fundamental problems with the LCP, despite the accolades that it has received by expert bodies? Was it improper use of the 'pathway', perhaps due to misapplication (to the wrong patient), or to misuse (not following it properly), arising, for example, in relation to a lack of the necessary specific training? Or was it misrepresentation and scaremongering by the media, especially the *Daily Mail* and *Daily Telegraph*? Certainly there has been evidence of patients put on the LCP without the specified MDT approval, patients who are terminally ill but not in the last few hours or days of life, and those who have not had all reversible pathologies treated. In a population of about 60 million in the UK, there are about 550,000 deaths each year. It would be surprising if everyone went according to plan, noble though that aspiration may be. Probably all of these factors have played their role.

CONCLUSION

And it seems likely that some continued debate will remain even after the detailed inquiry that is now close

to reporting. National debate has led to government action – to reassure an anxious public or reform a faulty policy. Any provisional conclusion must await the inquiry set up by the health minister, Norman Lamb, under the chairmanship of Rabbi Baroness Julia Neuberger. This should report soon. In the meantime, LCP remains a valuable tool in end of life care. It is however only a small part – even smaller in delivering best care for all conditions. But it needs education, training and an adequate workforce.

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Further reading

The European Journal of Palliative Care published three articles discussing the Liverpool Care Pathway this May. A group of international co-authors, including Professor John Ellershaw, summarise the history of the LCP, how it came to be acknowledged as best practice for the care of patients in the last days or hours of their life, and how it has been adopted by countries internationally. Dr Carol Davis and Chrissie Guyer, of University Hospital Southampton NHS Foundation Trust, seek to dispel the myths about the LCP, explaining what it is and what it isn't. Editor Dr Julia Riley addresses the need for better communication with the public and patients including raising questions of advance care planning in the wider debate surrounding palliative care.

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