

The Liverpool Care Pathway: what went right and what went wrong

The history of the Liverpool Care Pathway shows how the best of intentions, and good guidelines, can be perverted by poor practice, lack of thought, poor training and inadequate communication. Good clinical leadership can encourage high quality care of dying people, whatever guidelines are being used, or not.

The Liverpool Care Pathway was developed by Professor John Ellershaw in the late 1990s and published as guidance in 2003 (Ellershaw and Wilkinson, 2003). Given strong evidence of very poor quality care of the dying, particularly but by no means exclusively in acute hospitals, it had been developed to help staff think through what needed to be done to help people to have a dignified, comfortable and pain-free death. The Liverpool Care Pathway was hugely welcomed at the time and widely adopted. It took the lessons of the hospice movement and adapted them for more general use.

Along with many others interested in how we care for dying people in the UK, I welcomed it at the time. Like many others, professionals and lay people alike, I had been shocked to find that dying people were still routinely put into side wards and left alone within acute hospitals, with little staff attention, that care homes still routinely sent their dying residents to hospital (where all too frequently they lay on trolleys for hours) rather than care for them within their 'home', and that palliative care services were patchy in the community, while patients and their families and friends were extremely fortunate to find themselves living in an area where there was 24-hour palliative care advice available, or even a specially trained community nursing night team. And, even worse, many palliative care and hospice services, where they did exist, only looked after people with cancer, motor neuron disease, or AIDS, when most of us die of other conditions altogether.

So the Liverpool Care Pathway was widely welcomed, gradually introduced, hugely supported by Marie Curie Cancer Care, and recommended as a key part of the government's own *End of Life Care Strategy* (Department of Health, 2008). That particular moment, with the publication of the strategy, was also remarkable because it marked a turning point; there was finally recognition

that care of all people who were dying needed to be a focus of national attention within our health and social care services. That strategy also recommended, as did my review (Independent Review of Liverpool Care Pathway, 2013) and various other publications since, that we need a national conversation about dying. One reason for problems with the Liverpool Care Pathway, and more generally in care of dying people, is a general lack of familiarity with the dying process, a lack of discussion and a lack of involvement in it. Many young hospital doctors, nurses and other health professionals will never have been involved in the dying process, will be unfamiliar with recently dead bodies unless they have experienced a case of sudden death, and never have been to a funeral – and they will have no experience in caring for the dying, even though death comes to us all. And training of young health professionals around death and dying is, as our review heard, woefully inadequate, often not compulsory, and inadequately examined.

Poor care of the dying

Roll forward to 2012, 4 years on from the publication of the *End of Life Care Strategy*. Reports began appearing in national newspapers of very poor care of dying people. Some of those stories were lurid, and some frankly unbelievable (although a few later turned out almost certainly to be true, as far as my review panel could tell without forensic examination). They also appeared to be coming from all over the UK, which suggested that this was not just an isolated incident or two, or a couple of areas of bad practice. At first, civil servants and ministers ignored the furore – suspecting an orchestrated campaign and local disaffection.

At this point, the Department of Health made a fundamental mistake. They decided to conduct an internal review; they did a great deal of work, literature searches, collation of evidence and so on, but there was no outside independent examination of what was going on. The stories were multiplying and the press was getting fractious, notably the *Daily Mail* and the *Daily Telegraph*. In late 2012, ministers began to read headlines such as these: 'Care? No, this is a pathway to killing people that doctors deem worthless' (Phillips, 2012) and '60,000 patients put on death pathway without being

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told but minister still says controversial end-of-life plan is “fantastic” (Groves et al, 2012), ‘Half of those on Liverpool Care Pathway never told’ (Donnelly, 2012), and ‘NHS millions for controversial care pathway’ (Bingham, 2012). And so on. Facebook and Twitter campaigns took off. And ministers and civil servants began to realize that something was going very wrong, even though the Liverpool Care Pathway had been designed to improve the care of dying patients.

Review of the Liverpool Care Pathway

At that point, the then Care Minister Norman Lamb MP asked me to lead a review of what was going on, with an excellent panel drawn from widely different backgrounds (David Aaronovitch, columnist for *The Times*; Tony Bonser, fund-raiser for Macmillan Cancer Support and North Western Champion for the Dying Matters Coalition; Denise Charlesworth-Smith, national campaigner on the use of the Liverpool Care Pathway after her father’s death in January 2012; Dr Dennis Cox, Royal College of General Practitioners; Lord (Charles) Guthrie, Chief of the Defence Staff 1997–2001, Chancellor of Liverpool Hope University and Chairman of both the Hospital of St John and St Elizabeth and St John’s Hospice; Lord (Khalid) Hameed, Chairman of the Alpha Hospital Group, Chairman and CEO of the London International Hospital; The Rt Revd Richard Harries, former Bishop of Oxford; Professor Emily Jackson, Professor of Law at the London School of Economics; and Sarah Waller CBE, former trust chief nurse and director of human resources, leader of The King’s Fund’s Enhancing the Healing Environment Programme). We were asked to complete our review in 3 months, which was impossible, but we did manage to finish it in 6 months. This meant that it could not be a scientific study; much of the work had to be in pulling together material which was already available. We were ably supported by a small but formidable team and, to our considerable surprise, we were helped by large numbers of both senior and junior health professionals who came to speak to us both on and off the record.

What emerged was a very mixed picture. At its best, the Liverpool Care Pathway was being used sensitively and well. Where there was good training and clinical leadership, care of the dying tended to be good. Not always – things go wrong in big institutions. But on the whole, where senior clinicians took a lead, where leadership around care of the dying was acknowledged from the top, we saw excellent care. And in these places, irrespective of whether they were using the Liverpool Care Pathway, the Gold Standards Framework, the Amber Care Bundle, or some other guidance or none, people were thoughtful, communication was good, care was tender, and satisfaction rates were high. However, when we looked at places with poor clinical leadership, no training or, even worse, inadequate training of staff, with junior doctors being left to make these decisions during the night or at weekends, alongside a sometimes callous attitude towards

older people, practice could be awful. One appalling signal was when we heard about people being LCP-ed, as a transitive verb. This was as if a single action meant a decision had been made for no further treatment, often without consultation or even discussion with family or the individual concerned. And we heard all too often about patients desperate for a drink of water or a cup of tea, and it being refused.

We heard real distress. We met families of people who had died on the Liverpool Care Pathway, who were shaken by the experience. These people were not lying, and some had appalling stories to tell. And so, after considering the evidence we had before us, we concluded reluctantly that we needed to recommend the withdrawal of the Liverpool Care Pathway, a conclusion accepted by ministers. It was not because it was poor guidance. It was not, although we might have wished for more evaluation and monitoring of its use along the way, and some considerable modifications around nutrition and hydration. But it had become a toxic brand. Once we’d heard people say they did not want to go to Liverpool, and they did not know what the pathway was, nor had they had it explained, it was too late. So, too, was it too late once it had become clear that hospitals had received payments for putting patients on the Liverpool Care Pathway, even though that was done with the best of intentions, to improve practice (Independent Review of Liverpool Care Pathway, 2013).

Lessons to learn

This review taught us many lessons, which are lessons for the wider health community. First, this sits within the wider context of how we think about older people in our society. Some of what we found could be said to be a microcosm of what was found by the Mid-Staffs inquiry around treatment of older people (Francis, 2013). At worst, dehydrated older people coming into hospital were perceived as moribund by inadequately trained and insufficiently sympathetic young staff. Second, guidance being used does not mean guidance being read in full or even understood. The guidance some clinicians followed was not the whole Liverpool Care Pathway – they had not read it but were just using the checklist off the top. And, without having really thought hard about the issues, they used the Liverpool Care Pathway because it was there.

It is hard to say whether, at best, the use of the Liverpool Care Pathway improved care of dying patients. It may have done, but it was at a time of greater focus on the dying experience anyway, so it is hard to be clear. Many reports in the late 1990s and early 2000s suggested that it had improved practice, but the first randomized controlled trial of the Liverpool Care Pathway, held in Italy, reported that it made no difference to symptom control, although it did improve kindness and communication (Costantini et al, 2014). The jury is out as to whether it improved practice – what it did when used badly, however, was lead to panic and distress.

KEY POINTS

- Well-constructed, properly examined hands-on training in care of dying patients is essential for all health-care professionals. Nothing less will do.
- The use of a checklist attached to guidance, without reading or understanding that guidance, is a sure sign of lazy, unthinking practice, and should not happen.
- Young and not-so-young health-care professionals need to think hard about the way they care for older people, and show more empathy.
- The willingness of so many health-care bodies to come together to look at a way forward is a positive sign.
- High quality clinical leadership, training and enthusiasm for 'getting it right' is key to improving care for dying patients.

There are few excuses for poor practice. But there is praise to be given to the various health and professional organizations, the Leadership Alliance for the Care of Dying People, who sat down together in the wake of our report, developed some principles (which we were asked to examine in draft by the minister), and worked out broader guidance without a tick-box system. *Priorities for Care for the Dying Person*, published in 2014 (Leadership Alliance for the Care of Dying People, 2014a), was designed to ensure that the wishes of patients are respected and that care is tailored to their needs. Those principles form part of a wider report, *One Chance to Get it Right* (Leadership Alliance for the Care of Dying People, 2014b), and stress the importance of clear and sensitive communication between staff and the person who is dying, their family and friends. They spell out the need for individual care plans and place a particular emphasis on ensuring dying patients are helped to eat and drink for as long as they wish to do so, emphasized because of all we had heard about withdrawal of fluids from dying people who were desperately thirsty. There was general support too for our review's strong recommendation for availability of specialist palliative care advice (which could be by phone) 24 hours a day, to help people caring at home or in acute or other settings without specialized staff present. As yet, there is no funding for that and that would make a huge difference.

But along with that funding, and the need for a national conversation which includes younger people, health professionals and others, the question of training still needs to be resolved. E-learning may help in some ways, but training in end of life care needs to be hands on. It needs to be compulsory and it needs to be examined, and it seems to me extraordinary, as we were told by several junior doctors and doctors in training, that one can go through medical school without learning about end of life care. All patients will eventually die, but apart from birth there are few other events attached to our health systems which are so absolutely universal. The lack of focus on that education is symptomatic of what went wrong. Guidance cannot replace learning and thought. However wonderful, principles cannot replace experience

and a familiarity with what individuals and their families want at the end of their lives.

The way forward

Things are, I believe, getting better, although some health-care staff are still mourning the passing of the Liverpool Care Pathway. But truly excellent end of life care in all settings will not be standard, I believe, until training in end of life care is universal, money has been provided for 24-hour palliative care advice, and health-care professionals themselves take a lead in advocating for excellent end of life care. When that care is superb, you can feel it as you walk in. It is both possible and achievable. And people are at least talking about it within health care. But without major changes in funding, training and attitude, good quality end of life care will still not be available everywhere, throughout the land. **BJHM**

Conflict of interest: Rabbi Baroness Neuberger is an honorary fellow of the Royal College of Physicians, the Royal College of General Practitioners, the Royal College of Obstetricians and Gynaecologists, the Faculty of Public Health and the Royal College of Psychiatrists.

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