

VIEWS & REVIEWS

PERSONAL VIEW

Liverpool care pathway: doctors have always aimed to ease distress in dying

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Some years ago I was working as a junior doctor in a busy teaching hospital in northwest England. I was part of a team in a regional renal unit. We had many patients with end stage renal failure. On regular dialysis many had no hope of recovery; some had unsuccessful renal transplants, and many were too unwell to be considered for a transplant.

After years of itching, twitching, failed fistulas, infections, nausea, oedema, and breathlessness, some patients would reach the inevitable end stage. The senior registrar with whom I worked was a former army officer. We worked in a rigid regime of discipline and protocol, and I remember wondering aloud to the consultant if I had joined the armed forces. This approach to the management of the patients, however, was effective and efficient. Nothing was missed, and all data were recorded in rigid fashion. I was taught a discipline to carry with me throughout my working life.

You might think that this obsessive approach would leave little room for compassion. Quite the opposite. Once all criteria pointed to the end of life, as all options had failed, a further set of rules applied. The family was summoned, nurses were called in, and this commanding officer would become a gentle, softly spoken, caring, and compassionate physician. He would reassure the family that we were all part of the same team. Caring for their relative was our primary aim, and experienced and compassionate professionals would ensure a gentle end to the suffering.

Appropriate drugs would be prescribed just in case. I have heard this described as a “comfort kit.”¹ This was in fact a pathway. It took place in Liverpool. But it was not then called the “Liverpool care pathway.” It was simply tender loving care. As Hippocrates said, a physician should “cure sometimes, treat often, comfort always.”

At the same time as this, my sister in law was dying from breast cancer. She was 42 years old. She was a loving mother, wife, daughter, and sister. She had been the centre of the family, full of life and enthusiasm. She developed the full package of metastasis—bone, liver, lung. She had bilateral pleural effusions, which had been drained several times; she had large ascites, a total hysterectomy, and bilateral salpingo-oophorectomies. She

was cachectic, and, just to ensure nothing was left out, she had cerebral metastasis that rendered her blind and hemiplegic.

In the weeks before her death her oncologist told her, “Enjoy this Christmas; you won’t see the next.” She was sent home to die. Little was offered by way of palliative care at home. When she became incontinent her teenage daughter covered the bed with sanitary towels because the family had not been given a care plan or the telephone number for the district nurses.

The night before she died the family called a general practitioner out to see her, who hesitated to give her any analgesia because she couldn’t swallow and was hallucinating. She finally received a small dose of intramuscular pethidine. She died the next day. The deathbed looked like a scene from Dickens, her children lying with her, the rest of the family waiting downstairs. With no syringe driver to control the pain, she’d been crying out, with the family weeping and helpless. There were no nurses, and no doctors. This was 1995. Regrettably there were no integrated pathways then.

What benefit would my sister in law have had from a saline drip? She would have had a less painful and distressing death had her symptoms been controlled and her care standardised by using an evidence based model, fulfilling national guidelines, instead of relying on poorly coordinated care.

For religious and ethical reasons I must emphasise that I do not support euthanasia and would actively campaign against it. The Liverpool care pathway was developed as a model of integrated care for dying people. It is recommended by the National Institute for Health and Clinical Excellence as an ideal of integrated care, which is standardised for all patients wherever they choose to die, be it hospice, hospital, or home.²

The pathway is recognised by 20 respected organisations, including Age UK, the Alzheimer’s Society, the British Heart Foundation, the Macmillan and Marie Curie organisations, and the British Geriatrics Society, which have issued a consensus statement in support.³

NICE guidelines also recommend it to support dying patients.⁴ The General Medical Council’s guidelines for good clinical care at the end of life direct every doctor to ensure that the dying patient is treated with dignity and respect, encompassing

longstanding ethical principles.⁵ Decision making must comply with the principles of the Human Rights Act: everyone's right to life is protected by law.⁶

The pathway provides for communication with the family and discussion with the multidisciplinary team. It does not aim to hasten death, and it does not preclude the use of artificial hydration. The aim of the pathway is to ease distress in a dying patient. We must reassure our patients that as doctors the very essence of our working lives is the preservation of life and the easing of suffering. We must not allow the detractors to demonise and undermine our wonderful health service and the work we do.

Compassion cannot be enforced by legislation, and we must not lose our souls to a tick box. When we speak to a family we do it because we care for them as we would our own. Every one of us will experience this situation at some point. I have watched my dear husband and my father die. I take comfort in knowing they did not suffer. They died in an NHS hospital with all the love and care we could hope for.

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- 2 Marie Curie Palliative Care Institute Liverpool. What is the Liverpool care pathway for the dying patient (LCP)? April 2010. www.liv.ac.uk/media/livacuk/mcpicil/migrated-files/liverpool-care-pathway/updatedlcpdfs/What_is_the_LCP_-_Healthcare_Professionals_-_April_2010.pdf.
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- 6 UK Human Rights Act 1998. www.legislation.gov.uk/ukpga/1998/42/contents.

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