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Don't push me onto the death path, doc

Patient resistance is growing to an NHS 'care pathway' for the terminally ill that critics fear is euthanasia by the back door

Zoe Brennan Published: 29 July 2012



Rantzen, with late husband Desmond Wilcox, says NHS handles death poorly (Landmark Media)

When Mary Jones popped in to the hospital to see her elderly mother-in-law, Jane, she was given news that chilled her. The 88-year-old had been admitted after a fall. Although she was weak, her family hoped she would make a full recovery. As Jones was leaving, reassured that the old lady was comfortable and happy, a nurse took her aside. She referred to something called the "Liverpool Care Pathway".

"I said, I'm sorry, I don't know what you are talking about," Jones recalls. "The nurse explained it was some sort of kind exit from life. I was very upset and shocked."

Back home she tapped the words Liverpool Care Pathway (LCP) into her computer. What she read left her with a sense of dread: "It was like a horror story. The suggestion was that water and food should be withdrawn. This was an elderly lady who just needed some medical care and they were talking about this gold standard in helping people to die."

The more she found out, the more upset she became: “Care home staff get a certificate in completing the course on the pathway. People are trained to do it. We found it abhorrent that they were talking like this about someone we loved. We just couldn’t believe it.”

Jones’s husband Ian is more succinct. “I don’t see how it’s different to murder. They shouldn’t be doing this, it should be stopped,” he says.

“My mother had weakened because she had been in a rehabilitation unit where they kept delivering her meals when she was asleep and taking them away uneaten. But we were horrified that her carers were ready to throw the towel in. It really scared us.”

Anxious about her mother-in-law, Jones went to talk to managers of the nursing home where Jane lived who had suggested to the hospital that she might be a suitable candidate for the LCP. One told her: “You don’t know what it’s like with these old people. They clench their teeth and won’t take their medicine.”

“I was appalled,” Jones says. “Jane is a very amiable old lady. She’s no trouble and has a good standard of life. I was quite rude and said they were not to do anything without talking to us. The awful thing is, if I hadn’t visited her in hospital that day we might never have known this was being discussed.”

Three years on, Jane has made a full recovery and is happily settled in her Blackpool nursing home. “All my mother needed was looking after,” Ian Jones says. “She’s a tough old bird, she’d had a tumble but she wasn’t ready to give up. When we hear about people having died, we wonder now if they were on a care pathway.”

Horrific as this situation is, it is one being played out across Britain as doctors and carers increasingly manage the death of patients.

A senior consultant claimed recently that National Health Service doctors were prematurely ending the lives of thousands of elderly hospital patients simply because they are difficult — or to free up beds.

Professor Patrick Pullicino said doctors had turned the use of the “death pathway” into the equivalent of euthanasia of the elderly.

He claimed there was often a lack of clear evidence for initiating the LCP, which is used to look after terminally ill patients in hospitals across the country.

It is designed to be used when doctors believe it is impossible for a patient to recover and death is imminent. Supporters say it is the kindest way of letting people slip away, rather than dying in pain. It can include the withdrawal of treatment — including the provision of water and nourishment by tube while they are sedated — and on average brings a patient to death in 33 hours.

There are about 450,000 deaths in Britain each year of people in hospital or under NHS care. About 29% of deaths — 130,000 — are of patients who were on the LCP. This figure has increased dramatically since 2004 when the figure was 8.5%.

In a backlash against the scheme, terminally ill patients are being issued with cards warning doctors that they do not want to be placed on a “death pathway”. These “advance refusal” notices operate like an organ donor card, enabling people approaching the end of their life to make their wishes clear while they still have the capacity. The cards are being distributed by Alert, an anti-euthanasia charity.

Leslie Burke is among those who have requested a card telling doctors not to place him on a “death pathway”. The 52-year-old former postman from Lancaster has a degenerative brain disease that will one day leave him unable to move or speak. He has fought a long legal battle to ensure that his life is not terminated unnaturally through the withdrawal of treatment once he is unable to communicate.

Regarding the LCP, he says he is concerned that starving and dehydrating patients to death in the NHS is “becoming the norm”. The cards read: “Please do not give me the Liverpool Care Pathway treatment without my informed consent or that of a relative.”

Does the LCP ensure a kind end or is it tantamount to murder? Developed at a Marie Curie hospice in Liverpool with the intention of making the last days of cancer sufferers as easy as possible, it was recognised as a model for the NHS in 2001 and approved as a recommended practice in 2004. In 2006 a government white paper said it should be used across the country, not just for cancer patients but for all.

Under the programme, doctors identify a patient who will soon die and institute the plan. Although it can include the withdrawal of sustenance, this is not always the case and it does not preclude the use of artificial hydration. Patients are often heavily sedated.

Experts such as Peter Millard, emeritus professor of geriatrics at the University of London, and Dr Peter Hargreaves, palliative care consultant at St Luke's cancer centre in Guildford, Surrey, have warned of "backdoor euthanasia" and the risk that economic factors, such as savings in hospital costs, are being brought into the treatment of vulnerable patients.

What is clear is that the manner of our dying is in need of debate. Joan Bakewell, the Labour peer and broadcaster, says: "This is something we have all got to consider: easing the way to death is something we've got to resolve. People have said to me, 'I'm not frightened about dying, I am fearful of the process of death'. Many people worry about the painfulness of the very end. That is a terrible fear to have."

What is a good death? Esther Rantzen, the journalist, recalls the death of her husband Desmond Wilcox, the film-maker, in 2000: "I remember I was lying in his arms in the intensive care unit when a nurse came to say she had to do a routine blood test. It was a pointless blood test. I never got back into his arms again. I very much regret that."

She has since campaigned for a better understanding of the importance of a good death: "I became aware that while the NHS was set up to save lives, it was not very good at handling death. That's why we need a system like the LCP. The dying need privacy, dignity and the absence of pain."

Jane Jones has gone from strength to strength since her close encounter with a planned death. The family says she receives exemplary care at her nursing home, but her tale is surely a salutary one. "She sings songs at the musical afternoons, particularly songs from the war," Mary Jones says. "She eats well, she has her hair and nails done and remembers who we are when we visit. She's doing brilliantly.

"We're on the alert now, though — we visit several times a week and make sure we know what's happening. Because we spoke out, we feel she's one of the safest at the home. We didn't want to get rid of her, not in the least."