

The Liverpool Care Pathway to dignity in death

My grandfather's lingering demise shows why we need protocols for palliative care

By Dr Max Pemberton

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The Association for Palliative Medicine, which represents 1,000 doctors specialising in care for dying people, published new guidance last week and warned of a growing shortage of clinicians with expertise in the field. They also warned that inadequate monitoring of the use of the Liverpool Care Pathway (LCP) as well as wide variations in standards have helped sow confusion and fear among patients – and even among doctors.

What really shocked me was the claim by the head of the association, Dr Bee Wee, who said she'd heard that, because of recent media reports about the LCP, some patients were now so afraid of being placed on the pathway that they were reluctant to be admitted to hospital to get the treatment they needed. This is a desperately sad situation and confirmed my worst fears about the fallout from the recent media horror stories.

When I wrote defending the LCP in this newspaper a few months ago, warning of the sort of deaths that people might face without similar treatment protocols, I was inundated with correspondence from people who had been worried and frightened by misleading news reports. But, in light of DrWee's comments, I now want to go one step further and tell you a very personal story to illustrate what can happen without the LCP.

Before Christmas, my grandfather became ill. He was 91 and for the past year, since my gran died, he had been in a nursing home where he was cared for admirably. But he had a fall and was admitted to hospital. He was stabilised, discharged, but fell again and was readmitted.

He was refusing food and water by this point and his organs were beginning to fail. He drifted in and out of consciousness. Everyone waited for him to die. And waited. Then the ward closed to visitors due to an outbreak of norovirus. When it reopened my father visited, and was shocked at what he saw.

By this stage, my grandfather had been dying for two weeks. One of his eyes had remained open and become infected, weeping a thick discharge. It then became opaque and shrivelled. His tongue became swollen, and then began to peel, a sign of severe dehydration.

When my father told me this over the phone, something didn't seem right. This wasn't how someone on the LCP should die. This was reminiscent of the sort of deaths that were commonplace before protocols like the LCP were introduced.

In fact, it was precisely because of prolonged, unpleasant and cruel deaths that the LCP was developed. Was he receiving any morphine, I asked? No, said my father. Any other sedatives? No. Something had gone seriously wrong in my grandfather's management.

My father questioned one of the nurses, who looked at him with a slightly worried expression and hurried off to ask a senior clinician who was in a side room. But what the nurse hadn't realised was that my father, standing outside, heard everything that was said. The hospital had "forgotten" fully to implement the LCP. In someone with kidney failure, intravenous fluid can accumulate in the lungs and cause the person effectively to drown, which is why they had not put my grandfather on a drip to combat dehydration. But they had not provided any medication to ensure that he was comfortable either, as the LCP dictates.

When the nurse emerged from the side room, she hurriedly informed my father that they felt it was time to start some morphine, which was duly prescribed and given. My grandfather died the next day. It was obvious to us all that if the hospital had properly initiated the LCP earlier, things would have been very different for him, and it's doubtful he would have languished, barely alive, for over a fortnight.

It serves no real purpose to wonder if my grandfather suffered in those last two weeks. It is impossible to know if he was aware of a sensation of thirst or if he was uncomfortable or even to what extent he was aware of his surroundings. I've deliberately not named the hospital where this happened because it doesn't matter. What does matter is that people realise how palliative care pathways such as the LCP are designed to ensure that people die a dignified and comfortable death.

Of course, carers and loved ones should be consulted, and there needs to be good communication between doctors and nurses and a patient's family when a decision to withdraw treatment is taken. But let's remember exactly what this pathway gives us. I saw at first hand the value of the LCP last year, when my grandmother was dying. She had a gentle, humane and peaceful death. She didn't linger and she took comfort in the knowledge that, as her health failed, this would be the case. It saddens me to think that things didn't work out like that for my grandfather. And I wouldn't want that for anyone else.

Some years ago, when he was gravely ill in another hospital on the other side of the country, my grandfather had been placed on the LCP as doctors were convinced he was about to die. To everyone's amazement, he unexpectedly rallied, was taken off the pathway and, not long afterwards, discharged. It is with a bitter irony that, when he actually needed the LCP, he didn't get it. But it is a salutary lesson for us all in what happens when it isn't initiated. Without the LCP we are catapulted back to the days of lingering, distressing and needlessly uncomfortable deaths.

The postcode lottery of stroke treatment

There was widespread shock last week on hearing that Andrew Marr had suffered a stroke, especially as he was relatively young – just 53 – and a lifelong runner. Thankfully, he is said to be making a good recovery in hospital, but his case is proof that strokes, like heart attacks, are not the preserve of the elderly.

A report published last year by the Royal College of Physicians and the Vascular Society revealed considerable variation across the UK in the management of strokes. Some hospitals,

such as large teaching institutions like Edinburgh Royal Infirmary and University College Hospital, London, have dedicated on-call teams rapidly to assess stroke patients and initiate specialist clot-busting drugs or refer them for surgery. In others, there are significant delays between patients experiencing symptoms and receiving specialist stroke input. The report found that while some who need surgery receive it within a couple of days, others can wait almost two months. How on earth can such variation be justified in the modern NHS?

Bring back 'hygienic' brass door handles

It is reassuring to know that, with a few exceptions such as casual racism and shell suits, most things will eventually come back into fashion. Brass door handles are the latest case in point: research suggests they should be brought back because they are associated with lower rates of hospital-acquired infections.

Every hospital I have worked in over the past decade has undergone "refurbishment", whereby all the original fittings, including wonderful brass fixtures, have been ripped out and replaced with bland plastic. However, plastic and stainless steel surfaces have now been shown to allow bacteria to survive and spread.

Even if the bacteria die, DNA that gives them resistance to antibiotics can survive and be passed on to other bacteria. Copper and brass, however, can kill the bacteria and also destroy this DNA.

I hope this means we can return to the hospitals of yesteryear: big, imposing Victorian architecture, with wood-panelled corridors and parquet flooring. It might not all have passed infection control, but it looked wonderful.

Max Pemberton's latest book, 'The Doctor Will See You Now', is published by Hodder. To order a copy, call Telegraph Books on 0844 871 1515