

Paralysed, mute and in pain but I was desperate to live



Compassion: A nun nurses an elderly man in a palliative care ward

A woman who survived being 'locked in' tells **Geraldine Durrant** of her fight against assisted dying

It was developed to help medical staff provide quality end-of-life care to dying cancer patients.

But a positive reception to the Liverpool Care Pathway (LCP) has been replaced by growing alarm that it is being used routinely and indiscriminately to hasten the end of the elderly and disabled.

Families say relatives have been put on the pathway to death without their consent or that of their relatives, and without documentary proof that they could not recover from the illness for which they had been admitted to hospital.

And figures released in 2012 showed that hospitals which reach targets associated with their use of the LCP are receiving financial rewards from NHS commissioners for "excellence".

At the Bradford Hospitals Trust, which received almost £500,000 under the reward scheme, the number of patients dying on LCP more than doubled between 2009 and 2012.

That is a situation which should terrify us all, says disability rights campaigner Nikki Kenward, because what starts out as the seemingly compassionate right-to-die choice of an individual can all too easily become the imposed norm for society.

Nikki knows first-hand just how vulnerable that makes all of us.

In 1990, she was a happy wife and mother running her own business when she was struck down by Guillan Barre syndrome. Within 24 hours she was paralysed, unable to talk and "completely useless".

But although she understands the glib judgement of people who say that in such circumstances they would "rather be dead", the reality when it actually happens to you is rather different, says Nikki.

With a husband and a one-year-old son to care for, her most profound desire was to survive.

"I was trapped within my own body and stayed that way for several months. I felt very broken and I was in terrible pain, but I believed I could get better.

I wanted to be there, living in whatever way I could, and I believe there are people lying in intensive care wards all over the country who feel the same way.

"The will to live is much greater in most people than the desire to die - which is why not a single group representing the disabled supports the abolition of laws forbidding assisted suicide.

"Yet we are being constantly told that death - a slow, inhumane, painful death - is what sick people lying at our mercy really want."

Nikki, from Aston on Clun, Shropshire, remains in a wheelchair, and never picked up her son again - but because her life is different from the one she expected, she doesn't value it any less. She is loved and fulfilled despite her daily difficulties, and very grateful that at the time she fell ill no one had "the right to turn me off".

But she increasingly believes neither the disabled nor their carers are respected for their intrinsic worth.

"I do a lot of human rights work, but somehow even that is devalued by my disability - people give me a patronising pat on the head, and say 'well it keeps you busy' as though I would be better off spending my time playing bingo at a day centre."

Meanwhile, her husband Merv has been labelled "a saint" for sticking around and continuing to love his wife.

"But if he is the hero, what does that make me?" asks Nikki.

The idea that the lives of the old, the disabled and the not-quite-perfect should be ended at the stroke of a doctor's pen leaves Nikki too afraid to go back into hospital. And it's a fear we should all share, because in the brave new world of death on demand, the bell tolls for all of us, says Nikki.

The Netherlands already have mobile death teams ready to make housecalls on patients whose own doctors are unwilling to kill them. And while many in the UK would still find such an idea abhorrent, if they are repeatedly told that a culture of death is the humane choice, it could eventually be adopted as the norm, says Nikki.

She quotes the case of nine-year-old Daisy Healey as an example of how disabled people are treated differently - with sometimes trag-

ic consequences. In 2005, she was taken to Kettering hospital for the third time because of continued bleeding after three teeth had been removed.

Daisy received no diagnosis, no treatment was given to her, and she died the following day from a severe infection and blood disorder.



A nurse on the ward told her mother "they all die sooner or later", while a doctor sympathised with the chilling words, "it's awful, it must be like losing a child".

Blinded by her disabilities, medical staff had apparently failed to recognise, Daisy's mother Amanda said afterwards, "that she was in fact our daughter, and we loved her". "I will never forget Daisy because her story changed my life," said Nikki. "It made me realise we have to speak up for those who cannot speak for themselves."

This is why Nikki has challenged Sarah Wootton, the chief executive of Dignity in Dying, to a public debate on the issue, before it is too late – because while Ms Wootton is urging a change in the law, Nikki says the only people who haven't had their say are those the proposed changes are most likely to affect.

"If Ms Wootton has her way we all face a future full of greedy relatives, dodgy doc-

tors, grabbing insurance brokers and mealy-mouthed horrors of parliamentary rogues whose careless and care-less attitude will bring children, old people and the vulnerable flocking to her door," says Nikki.

So in her powerfully-worded open letter she issued her challenge to discuss the subject in an arena where the frightened and the vulnerable could be heard for the first time.

"I suggest a public debate, me, you, and maybe one or two of my 'supporters', instead of yours, just for a change. Prove to me I am just one of those disabled people cynical with the world and closed to the kindness you offer me. Go on talk to me Sarah, talk to us. We could be 'dying' to listen."

Nikki believes the debate is not about how we die, but about how we live with ourselves.

"If assisted suicide becomes the law what sort of people will we be? We will be moving a lot closer towards what the Nazis did and a lot further away from Christ. If we allow this to happen to our society, what will happen to compassion? What will happen to love?"

■ **Distant Voices and Alert have launched a new website – noliverpoolcarepathway.com – and will offer 'risk bands' for patients to wear in hospital. The wrist bands bear the words 'No LCP without informed consent'.**

