

I was in a 'locked-in' state for five months. So would this new euthanasia ruling have condemned me to an agonising death?



by Nikki Kenward

THE slide towards legalised euthanasia in Britain continues to accelerate, as the judiciary systematically demolishes protections for the lives of the vulnerable.

This week the Supreme Court, in a disturbing landmark decision, ruled that patients in a permanent vegetative state will be allowed to die without any intervention from a judge. No court approval will now be required before doctors can embark on the fatal course of withdrawing food and water from patients in such a condition, as long as their families agree.

The move has inevitably been hailed by the so-called 'Assisted Dying' lobby as a triumph of compassion that will help to end the suffering of people trapped in 'living deaths'. But to my mind there is nothing humane about the Supreme Court's judgment.

Emotive

Of course, I understand how emotive this issue is, and that many people genuinely feel it is kinder to allow people in a vegetative state to die.

The case that prompted the Supreme Court's decision — concerning a man who suffered a cardiac arrest that left him

permanently unconscious with severe brain damage and who was fed through tubes — was hugely complicated and must have proved agonising for his family, who agreed with doctors they wanted to withdraw those tubes.

But it is precisely because of the momentous nature of this decision — one of life and death — that I believe a judge must be involved.

By removing independent legal checks from the process, you are placing unacceptable power in the hands of doctors and relatives and displaying a callous disregard for human life. Indeed, I would say that this week's Supreme Court decision is another grim milestone on the road to state-sanctioned killing.

The reason I feel so strongly on this issue is because of my own experience. Nearly three decades ago, I found myself suddenly locked into agonising immobility, with my whole

body paralysed except for my right eyelid. If the Supreme Court decision had been made before I went through my terrifying ordeal, it could have been me that faced death by dehydration and starvation.

What this nightmare taught me was not only to cherish the preciousness of life, even when trapped in an immovable state, but also to see the dangers of allowing the medical profession to wield untrammelled authority.

It was in 1990 when the blow hit me. I was enjoying life to the full, as a wife and a mother to a one-year-old son Alfie, and as a therapist and lecturer.

One day, I contracted what at first I thought was flu. I had actually been struck down by a severe strain of a virus called Guillain-Barre Syndrome, which, by stopping the muscles from working, has much the same impact as motor neurone disease.

Within 24 hours I was in intensive care, unable to breathe without a ventilator. Half blind and devoid of speech, I was helpless — like a piece of alabaster. Yet throughout, I was still conscious and could hear voices and feel agonising pain in my body.

I had to endure this condition in hospital for five months, and was only able to communicate after I eventually learnt how to flicker my eyelashes.

If someone had asked me before I was stricken with the virus whether I would have been able to endure such a quality of life, I might have said no. But I was determined to hold on because I so wanted to be with my son and husband. Even in the darkness, my love for them was the light that gave me purpose.

When I was finally released from hospital, after nearly six months, there were still tough times ahead. It was two years before I was even able to pick up a cup of tea, and my husband had to give up work to become my full-time carer.

I remain confined to a wheelchair, though the biggest obstacles I face are the

attitudes towards disabled people, where we are too often seen as a burden on society.

Such an attitude will only have been inflamed by the Supreme Court judgment, with its inference that a life of severe impairment is not worth living. In the brave new world fostered by the assisted dying movement, it seems that only the fit and well really count.

All human life should be valued, no matter how bleak the circumstances might appear. With innovations in technology, experts are now able to communicate with patients who seem to be in a permanent vegetative state.

Recent studies have shown that, in the majority of cases, patients do not want to die — a finding that contradicts all the 'quality of life' rhetoric from the pro-euthanasia lobby.

Moreover, advances in science have also shown that the permanent vegetative state is frequently misdiagnosed — possibly in as many as 40 per cent of cases — while claims that a certain patient is 'brain dead' can be wrong.

In one example, a team of Cambridge neuroscientists discovered a woman who had sustained a severe injury and seemed unable to respond to any stimulus, played tennis in her head and could offer a mental tour of her home when asked to by the researchers.

Torture

The high level of flawed diagnoses in such cases has huge implications. Firstly, it makes a nonsense of the notion that there is anything painless about this type of killing.

The assisted dying brigade talk about 'dignity in death', but what could be more cruel than starving a person who is still conscious of nourishment and water. It is a terrible way to go; a form of slow torture.

Secondly, in view of the limits of our medical understanding, we should still be profoundly wary of making doctors the key arbiters in this process. Most doctors and nurses are clearly

highly professional and conscientious, but there have been appalling scandals over the years — from the horrors of Dr Harold Shipman, who murdered more than 200 of his patients, to the systematic neglect at Mid-Staffordshire hospital which led to hundreds of needless deaths, and the recent revelations about deliberate drug overdoses which shortened the lives of 450 patients at Gosport War Memorial Hospital.

We should also recognise that even if the medical professionals are not being wilfully dangerous, they are under tremendous pressure within the NHS because of limited funding.

It is estimated that every patient in a permanent vegetative state costs the health service at least £100,000 a year. How tempting it would be for a doctor with the power to play God to divert that money to other forms of healthcare deemed to be more 'useful'.

Avarice

I had an insight into that mentality towards the end of my hospital stay when a physiotherapist said to me: 'It's a good job you came in when you did. I'm not sure we could have afforded to help in the future.'

Relatives may also collude with the doctors, partly out of respect for the professionals, partly out of a genuine belief they are doing good by ending the patient's ordeal. 'It is what he would have wanted,' in the time-honoured phrase.

But there may also be, in a few cases, the malignancy of financial greed, where a wealthy relative or property is concerned. In the name of compassion, the Supreme Court could end up promoting morbid avarice rather than familial altruism.

There is also the broader and deeply concerning point that, in making their decision, the Supreme Court has colluded in the drive to normalise state-sanctioned killing.

This is not civilization but barbarity. It is not what we need in Britain. We need more legal restraints, not fewer. The Supreme Court's ruling represented a dark day for our nation's morality.

■ **NIKKI KENWARD** is campaign director of *The Distant Voices*, working to improve end of life care.