

It's my life –it's my decision?

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As many of you will know, on July 30th 2004, Judge Munby delivered his verdict in the High Court, in the case of Regina versus the General Medical Council. Regina in this case acted for Mr. Oliver Leslie Burke, a 43-year-old man with cerebella ataxia. Mr Burke challenged the GMC's guidelines set out in its pamphlet, "Withholding and Withdrawing Life Prolonging Treatments: Good Practice and Decision Making" 2002.

In the main the Court found for Mr. Burke, although the GMC was given leave to appeal. The Disability Rights Commission intervened in the case and I gave evidence as an expert witness. We support the decision of the Court and will seek for it to be upheld on appeal.

I want to take the time this morning to explain our reasons and to give you examples, demonstrating the importance of the case to me personally as well as other severely disabled people.

We see the Court's verdict as marking a significant event in the history of disability rights within UK healthcare provision. It aims to balance the power relationship between Doctor and patient. Both have a breadth of knowledge and experience not available to the other. The Court considered the knowledge base of both patient and doctor to be of equal merit and that neither should take precedence over the other as a matter of course. And that in the final analysis the patient's wishes to life prolonging treatment should be provided for unless if by doing so, it prolonged an **intolerable** situation.

When I heard the verdict I felt a surge of euphoria for two reasons. Firstly, for my own future safety, secondly, because the Court understood, perhaps for the first time, that Doctors should not be asked or expected to pass sole judgement on what is "in the best interest" of the severely ill or disabled patient. I know that many physicians across the UK were

equally relieved. When life and death decisions have to be taken it is time to share the burden. Who better than with the patient or their chosen close relatives, friends and advocates that they trust?

Society is changing. There is a growing acceptance of diversity, which includes the most profoundly disabled people. Yet we must not forget the social backdrop to severely impaired lives.

When I was born, doctors told my mother to take me home and enjoy me, as I would die within a year. As so often with severe impairment and medical diagnosis, there was no certainty, it is not an exact science. Fortunately, they were wrong. I have good reason to thank the many doctors and other hospital staff who got me through a childhood of chest infections and other life threatening illnesses.

Yet 40 years later, doctors treating an eighteen-month-old child, with the same impairment (Spinal Muscular Atrophy) decided they would not provide ventilation to help her through a chest infection. Her parents did not accept this decision and challenged it in Court. There she was known as

'Baby C'. Her doctors argued that her "disability was too terrible to live a quality life". In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support"¹. The Court ruled for the hospital having received advice from a range of doctors, who all categorically stated that no one with this diagnosis could live beyond the age of 2 and that if they did, life would be a living hell.

Adults with SMA, including me, could have told a very different story but we only found out about the case after the child's death.

The doctors' evidence to the Court made value judgments about dependency, which really bothered me. If they consider 'Baby C's of this world would be better off dead then surely I would be too?

In fact, during the winter before last, I was rushed into A&E with severe pneumonia in both lungs and nearly faced the same fate as baby C. The consultant who was treating me said: 'You're very ill. If you go into respiratory failure I

¹ Daw R (2000), The Impact of the Human Rights Act on Disabled People, Report prepared for DRC & RNID

presume that you won't want to be resuscitated and ventilated.' I was taken aback by this and asked, 'Well, why?' He answered that the chances of weaning me off would be very remote – 'And you wouldn't want to live on a ventilator.' I replied that meant I would die. So, of course, I wanted to be ventilated. He looked a little puzzled but let it drop.

I thought that was the end of the matter. The next day I was in intensive care when another consultant in a very senior position said the same thing. 'If you go into respiratory failure - and it's looking likely - then I'm sure you won't want to be anywhere near a ventilator.' Again I protested but by now I was very scared that lifesaving treatment would be withheld. My husband rushed home, got a picture of me in my graduation gown receiving my doctorate, came back to the hospital and screamed that 'This is my wife, not what you think she is and has. You do everything for her just as you would for anybody in this situation. She has everything to live for.'

Then they changed their minds. Excellent treatment kicked in. But surely such extreme measures should not be needed

for me to access life-saving treatment? This should be my right – a right to life. Nevertheless I forced myself to stay awake for the next 48 hours, fearful that if I went to sleep I'd never wake up.

The doctors' view of both my life then and how it might be affected if I should become ventilator dependant led them to make assumptions about my "best interests" that were wholly misguided. Doctors, especially in emergency treatment settings, see disabled people at their most vulnerable. This is why it is so important that doctors understand the lives of disabled people no matter how seriously they may present. You cannot go on diagnosis alone – the lived experience is often drastically different from the textbook example.

These two examples go some way to demonstrate why it is imperative to change the way quality of life judgments are made. Medicine is not immune to society's deeply held prejudices about severe impairment. Doctors operate in a world that still sees disabled people as tragic victims of our condition or diagnosis, being without dignity or purpose

It is not unusual for me to overhear “I would rather be dead than live like that”. Terms such as “wheelchair bound”, and “handicapped” appear daily in the press without their pejorative meaning being questioned. This backdrop influences the medical profession as it does everyone else. Doctors are subject to the same influences and negative stereotyping of disability as everyone else. For example, “research on the attitudes of accident and emergency doctors found that only a fifth imagined they would be glad to be alive if they were quadriplegic, whereas over 90% of people with quadriplegia reported they were glad to be alive”².

The drip-drip of negative opinion is not limited to the ordinary man or woman on the street. Just two weeks ago the Nobel Laureate Sir John Sulston, stated “parents should not bring a clearly disabled child into the world”. He went onto say, “If we can select children who will not be severely disadvantaged then we should do so”.³

² Paper presented by Dr Ian Basnett, Labour Party fringe 2004

³ Sunday Times 24 October 2004

Only last month Minette Marrin, the Sunday Times columnist, wrote of a visit to a hospital ward for people with severe learning difficulties. “The air was full of the noise of pain”. The patients “all appeared to be in great distress”. She noted that they were “tenderly cared for by wonderful nurses” but concluded, “they were absolutely wretched”. In her view, “there are times when medicine, which is supposed to relieve suffering, can be even more cruel. There are fates worse than death”.⁴ She couldn’t be clearer than that – **better dead than disabled**. Her message to the medical profession was equally clear – **do less, not more**.

This for me is why the Court’s judgement in the Leslie Burke case is so important. It recognises that pivotal importance must be attached to the patient’s view of quality of life. I believe Mr Justice Munby sought to strike a balance between the patient’s wishes and the doctor’s professional judgement. He highlighted parts of the GMC’s guidance that failed to give equal weight to patients’ expertise in their own situations and their right to make decisions about the withdrawal of their end of life treatments.

⁴ **Sunday Times**, 1st August 2004

1. For example, the doctor's only obligation under part of the guidance is to "take account of" (though without being under any obligation to give effect to) what are referred to as the competent patient's "wishes", "preferences" and "views". It is the responsibility of the doctor in charge of the patient's care to "make the decision".
2. The Guidance placed too much reliance on the doctor's assessment of the patient's "quality of life" in determining "best interests". The Court decided that the higher test of "intolerability" was needed.⁵

This judgement in my view, redresses the balance of power over who decides and on what grounds, life-prolonging treatment is withheld or withdrawn. I now feel we have a more healthy relationship between doctor and patient. Safer too. Where decisions are made in an environment of knowledge about the life, or expected life, of the patient, beyond their diagnosis.

⁵ July 30th 2004, Justice Munby, Judgement on Burke versus the General Medical Council

At SCIE (the Social Care Institute for Excellence), where I have a great fortune to be the first chair, I have come to value the importance of using knowledge from three distinct sources when making critical and important professional judgements:

- service user experience,
- research evidence
- and practice knowledge.

At SCIE we call this an inclusive knowledge base.

When making his judgement Judge Munby said how useful the Disability Rights Commission's intervention had been in understanding the complexity of making decisions concerning disabled people.

“I have been greatly assisted by the DRC and by the submissions of its counsel, Mr David Wolfe. In this case, ..., the DRC was able to deploy, to the great assistance of the court, a particular and highly relevant informed expertise which none of the other parties could bring to the task in hand”⁶

⁶ 6 July 30th 2004, Justice Munby, Judgement on Burke versus the General Medical Council

The DRC and organisations of disabled people have come to understand that processes of life and death decision-making desperately needed a radical overhaul to meet a desired cultural shift towards inclusivity and human rights. Now a shared decision-making relationship leaves doctors less vulnerable to bad judgements about quality of life and “best interests” can emerge. However, like any change it contains intellectual challenges and a need to grapple with deep prejudice.

Until now debate on issues of medical ethics have involved doctors, clerics, ethicists, the great and the good. But patients, disabled people, users remained outside the door. This is now changing.

The courage of Leslie Burke – as so often, one person - will be remembered in years to come. There are many doctors who are willing to take up the baton and run with this new relationship. Our chief medical officer is currently grappling with how to support a new healthcare service that can see and challenge health inequalities.

You can imagine my sincere pleasure, when Liam Donaldson said in a recent lecture, “Jane Campbell’s story...crystallized the centrality of the balance of power between doctors and patients to the debate about what represents good medical care.” (Liam Donaldson, p. 8)

The planning committee for this symposium asked both Tim Helme and me to speak from the point of view that “It is my decision”. **But there should be no absolutes in the decision-making process because every circumstance is different and no individual can have absolute autonomy within an interdependent society.** That may infuriate some who view this in black and white terms. But we need to focus on how decisions are made now and on how we want them to be made in the future. I feel the journey to good decision-making on withholding or withdrawing treatment, is going in the direction of shared ownership between patient and doctor, let us not turn back now.

Thank you

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