

HMV-UK Meeting

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What disabled patients want from the NHS in the 21st century

Dame Jane Campbell DBE

Britain faces major health challenges, including rising rates of obesity and diabetes; persistent premature mortality from cancer and heart disease; and growing health inequalities – for example, between people according to their geography and ethnicity. Whilst the overall population becomes healthier, a significant minority has been left behind.¹

Amongst those still missing out on good health are **disabled people. This is not just as a result** of their primary disability or long-term health condition. It is also because social deprivation, unequal access to health services and other factors put them at greater risk of illnesses, many of them preventable.

The challenge of improving the health care of disabled people will grow as Britain's population ages. It is generally assumed that our changing age profile will be accompanied by improvements in the health and well-being of older people. However, the likelihood of

¹ DH (2005) Status Report on Health Inequalities.

disability and poor health increases with age.² More disabled children and young people are living longer with complex conditions. These issues require specific focus if people are to stay as healthy and active as possible.

So what is to be done and what do disabled people (patients) want from the NHS in the 21st century?

Well, today I thought I would take us on a journey from the personal to the political.

I have had the best of times and the worst of times at the hands of the NHS. When I was born my mother was told to take me home and enjoy me because I would be dead within the year. Well here I am at 47 still defying that medical prediction! My survival has been the result of a combination of bloody-mindedness and at times fantastic health care interventions.

I am very lucky. I am a fully signed up member of the Lane Fox Gold Card facility, in my view, one of the best respiratory units in the country, a unit which celebrates disabled people's lives; a unit that understands patients are far more than our diagnoses, leading ordinary lives which include work, parenting, education and leisure; a unit that recognises the need for treatment to fit in with the demands of life, rather than the other way round.

² The Family Resources Survey 2003-2004 suggests 45% of people over the age of 65 have a disability or 'limiting long-standing illness'. In the next twenty years the number of people aged 85 and over is set to grow by two thirds, compared to a 10% growth in the overall population.

Why is the Lane-Fox Unit so good at this? In my view it is because the unit has a history of partnership between patient and doctor that goes back to its foundation, combined with continued emancipatory leadership. While many consultants saw patients with long-term irretractable disabilities as victims best left to Social Services and charity to look after, Geoffrey Spencer pioneered the use of home ventilation which would free us to live our lives to the full. He even went as far as to organise trips abroad for people in iron lungs: totally contrary to every risk assessment but liberating and empowering! The Unit has always benefited from a strong Patients Association. This has supported the Unit in many ways, not least by purchasing much of the home ventilation equipment used today. It means that no matter what your disability is, anything is possible. Holistic solutions are the Lane Fox Unit's mantra.

Sadly patient collaboratives remain the exception rather than the rule in the UK and throughout Europe. And even a seasoned Lane Fox patient can experience the dark side.

Let me tell you a story about an experience I had in January 2003.

...I was rushed into A&E with severe pneumonia in both lungs. I was very ill.

The consultant who was treating me said to me: 'You're very ill. If you go into respiratory failure I presume that you won't want to be resuscitated with a ventilator.' I was a little taken aback by this and said, 'Well, why?' he replied that the chances of weaning me off would be very remote – 'And you

wouldn't want to live on a ventilator.' When I said that meant I would die, and of course I want 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 this looks likely – then I'm sure you won't want to be anywhere near a ventilator.' Again I protested but by now was very scared.

My husband tore home, got a picture of me in my graduation gown receiving my doctorate, came back to the hospital and shouted: 'This is my wife, not what you think she is and has. You do everything for her just as you would for anybody else in this situation. She is young and has everything to live for.'

Then they changed their minds. Surely extreme measures should not be needed for me to access life-saving treatment. This should be my right – a right to life.

I forced myself to stay awake for the next 48 hours, fearful that if I went to sleep I'd never wake up.

So why was my experience three years ago so different from a non-disabled 47-year-old professional woman entering A&E? Some of the answers lie in the negative beliefs about severe disability that are still so prevalent in our society. Yes, society is changing. Yes, there is a growing acceptance of diversity, which includes the most profoundly disabled people. But we must not

forget that the social backdrop to severely impaired lives is still pretty negative.

Sadly, society still sees severely disabled people as tragic victims of their condition or diagnosis. In my case, many people who do not know me believe I live without dignity because I need all physical tasks to be done for me. It is not unusual for me to hear, even today, 'I would rather be dead than lie like that.'

Views such as these are just as likely to be held by those in the medical profession as by anyone else. After all, you are all part of society, subject to the same influences and negative stereotyping of disability as everyone else.

It takes incredible strength to rise above these stereotypes and not to perceive them as fact. Some of us are fortunate enough to be able to challenge these assumptions. But stop and think: What if I couldn't speak up for myself; if I'd had no partner or carer that night to fight for my right to live?

Now I am sure some of you may be thinking, 'But I work with disabled people, I would never behave like that and nor would my colleagues!'

Well two years ago, doctors treating an eighteen-month-old child, with the same impairment as mine (spinal muscular atrophy, type 2), 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'.³ The Court ruled for the hospital, having received advice from a range of medics, who all stated that no one with this diagnosis could live beyond the age of two, 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 that the 'Baby C's' of this world would be better off dead then surely I would be too?

Terms such as 'wheelchair bound' and 'handicapped' appear daily in the press without their pejorative meaning being questioned. This backdrop influences every reader. it is the drip-drip effect. 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'.⁴

I believe that acceptance and celebration of our diversity at this level, is absolutely necessary for our feeling of self worth and safety. Without Society's belief that we are ordinary human beings

³ Daw R (2000), *The Impact of the Human Rights Act on Disabled People*, report prepared for DRC & RNID.

⁴ Paper presented by Dr Ian Basnett, Labour Party Fringe, 2004.

capable of achieving and participating, we will in turn internalise that view.

Rachel Hurst, in her plea to the bioethics community at their 5th World Congress, said:

It takes a particular sort of courage to rise above these negative impacts and have a faith in your own worth, or the worth of your disabled family member. It takes courage and a clear understanding that disability arises from the social barriers of attitude and environment to your impairment, not the impairment itself. A similar sort of courage and understanding has been needed by women as they overcame the discriminatory images of subservience and earth mother, or the courage and understanding that has been needed for black people to overcome slavery and apartheid. Just as we all recognise that society need the difference of women and people of different races and backgrounds, so society needs people with impairments.⁵

So what is to be done?

The Disability Rights Commission and organisations of disabled people have come to understand that we need to assist the medical profession through education, training and, on occasions, legal enforcement. It is vital that severely disabled people are seen as equal citizens who, with the right medical support, can exercise their civil rights to work, rest and play. We also need to be involved

⁵ Hurst, R (2000) 'Ethics and Disability, Celebrating Diversity', paper to the 5th World Congress on Bioethics.

within the medical professions – to work alongside doctors and to train as doctors ourselves.

Until now, debate on issues of health improvements, ethics, or medical intervention have involved doctors, clerics, ethicists – the Great and the Good. However, patients, disabled people and other service users have largely remained outside the room; or a few of us are described as ‘expert patients’ and channelled into an ‘expert patients programme’. This is now changing. Look, I’m here today!

We need to support and encourage doctors willing to take up the baton and run with this new relationship. I suspect there are many of you in this room. Professor Sir Liam Donaldson, the Chief Medical Officer, is currently grappling with how to support a new health-care service that, with patients’ help, can see and challenge health inequalities. In fact, there is limitless practice guidance on public and patient involvement. The literature is enormous. However, it is time to move on from reading and talking about inequalities; to really be doing something to address them.

You can imagine my pleasure when Sir Liam said in a recent lecture, ‘Jane Campbell’s story...crystallised the centrality of the balance of power between doctors and patients to the debate about what represents good medical care.’⁶

Progress has been made but there is still a long way to go before prejudices of the kind I’ve experienced are eliminated. I would like to leave you with some key messages:

⁶ Liam Donaldson, p.8.

1. That we start from the premise that all life is of equal value. Assumptions about a person's life based on their diagnosis must be left outside the room.
2. Doctors should not be asked or expected to pass sole judgment on what is 'in the best interests' of a severely ill or disabled patient. Healthcare should be a partnership based on the expertise brought by both to the table.
3. The best healthcare must be based on clinical need. It must not be dispensed on the basis of views about a patient's quality of life.
4. Opinions regarding treatment should be imparted to the patient and his/her supporters in a neutral, calm manner using open non-prejudicial language. People can only make appropriate choices when they have clear, honest information.
5. 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.
6. Resources must be invested in developing a new relationship between disabled people and the medical profession, where both have the opportunity to learn from the other.

I believe that acceptance and celebration of diversity at this level, is absolutely necessary for disabled people's equality and feelings of self worth and safety.

So long as society continues to see us in terms of our diagnosis, we will never have equal access to, or choice about, healthcare.

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