

Ethics briefings

Incapacitated patients and treatment refusal

Confusion still appears to exist about what constitutes informed consent or refusal in some circumstances. In September 2004, the Royal Devon and Exeter hospital paid £8 500 compensation in an out of court settlement to a renal patient who had been given a blood transfusion 3 years previously.¹ All agreed that dialysis and a blood transfusion would have normally been the correct course of action for the condition, but in this case the patient was known to be a Jehovah's Witness. Nevertheless, in 2001, a transfusion was carried out without consent. There were no English legal precedents since in previous instances, applications to court for permission to provide transfusions concerned only prospective situations. The circumstances echoed, however, the 1988 Canadian case of *Malette v Shulman*² where an unconscious patient carrying a Jehovah's Witness card was given blood and later awarded compensation. In the Canadian case, however, it had been argued that doctors had insufficient evidence that the patient had been fully informed at the time of signing the card, nor was it clear whether she intended to refuse blood in the circumstances which arose. In the Devon case, the patient had been attending the hospital for 20 years, had previously refused a blood transfusion in life-threatening situations and this was clearly marked on his medical records.

Informed consent

The degree of information needed for informed consent was also the subject of further legal debate. In October 2004, the House of Lords ruling in the appeal case of *Chester v Afshar*³ focussed on a neurosurgeon's omission to forewarn a patient of a 1–2% risk that a back operation could cause cauda equine syndrome and paralysis. Previously in the same case in 2002, a court had ruled against the surgeon who carried out the operation resulting in this rare condition. There had been no question of

negligent performance since the operation had been skilfully carried out and the patient later said that she would probably have gone ahead with the operation even if she had been informed of this risk. Nevertheless, the surgeon was judged to have failed in his duty to mention it and to obtain properly informed consent. The previous classic English legal case covering this issue was the 1985 *Sidaway* case⁴ where the neurosurgeon had warned the patient of a risk of nerve damage of about 2% but not a less than 1% risk of spinal cord damage, which actually occurred. In that case, the patient lost the case when judges upheld the "Bolam"⁵ principle that doctors would not be considered negligent if they conformed to the practice of most responsible practitioners in that sphere of care. Since the *Sidaway* case, there has been considerable debate about how much information should be routinely given about very exceptional risks. Legal experts,⁶ however, now warn that more information is needed about rare and exceptional hazards. They say that the ruling introduces the doctrine of fully informed consent rather than valid consent and is likely to put increased pressure on health professionals to inform patients of all risks to the fullest possible extent.

A right to require treatment

Legal and ethical guidance has long espoused that while competent patients have a right to refuse treatment, they do not have the right to demand it. This principle has now been called into question by Mr Justice Munby's ruling⁷ in a legal challenge to the General Medical Council's (GMC) guidance *Withholding and withdrawing life-prolonging treatments*.⁸

Mr Oliver Leslie Burke suffers from cerebella ataxia with peripheral neuropathy, a progressively degenerative condition that follows a similar course to multiple sclerosis. His mental capacity is not currently impaired by the condition but it is highly likely that he will lose capacity in the future; he may also need artificial nutrition and hydration (ANH). Mr Burke was concerned that the GMC's guidance gave doctors the discretion to decide whether ANH should be provided and allowed them to withdraw ANH even if his death was

not imminent. He challenged the guidance, claiming that it was incompatible with Articles 2, 3, 6, 8, and 14 of the European Convention on Human Rights.

Mr Justice Munby said that he had no difficulty at all with the vast bulk of what the guidance said but held that certain aspects of the guidance were not compatible with the Human Rights Act. In particular, he said the guidance focused on the right to refuse treatment but did not state that patients have the right to *require* treatment. He ruled that rights guaranteed under both Article 3 and Article 8 meant that if the patient is competent (or is incompetent but has made a valid advance directive) "his *decision to require* the provision of ANH, which he believes is necessary to protect him from what he sees as acute mental and physical suffering, is ... in principle determinative".⁹ In summarising his conclusions, Mr Munby extends this principle beyond ANH, and beyond life-prolonging treatment, saying "it is for the competent patient, and not his doctor, to decide what treatment *should or should not be given*".¹⁰

This judgment has far-reaching implications. The GMC has appealed against the ruling and the BMA has publicly supported this decision. One of the implications of the ruling appears to be that doctors and NHS Trusts will be required to provide treatment requested by the patient, even if they consider the treatment to be contrary to the individual's interests. It has also been suggested that the ruling will "lead doctors to routinely provide artificial nutrition and hydration – and arguably other life-prolonging treatments – for all legally incompetent patients unless they have previously competently rejected it by a valid advance directive or its provision would be regarded by all involved as 'intolerable'".¹¹ While those who believe there to be intrinsic value in being alive, irrespective of the quality of that life, may applaud this outcome, many people are more concerned about being kept alive by medical technology beyond the point where, for them, treatment would provide a benefit. Although the ruling was hailed by many so-called "pro-life" groups as a victory, the very strong focus on autonomy reflected in the judgment, has been referred to as "the single greatest judicial gift the Voluntary Euthanasia Society has had in the UK".¹² The GMC's

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appeal is expected to be heard in late Spring.

The representation of the Mental Capacity Bill in the English media

On the 10 January 2005, the Mental Capacity Bill for England and Wales began its Second Reading in the House of Lords. Although the Bill was initially regarded as an uncontroversial statutory restatement of the existing common law, it had an extremely difficult passage through the Commons. The problems that the Bill encountered were exacerbated by its media coverage. Two aspects of the Bill proved controversial. The first was the introduction into statute of advance refusals of treatment; the second was the introduction of proxy decision-making powers via lasting powers of attorney. Opponents of the Bill saw these combined aspects of the Bill as a Trojan horse that would put euthanasia on the statute books. In order to understand the extent of media distortion in relation to the Bill, it is necessary to put these parts of the Bill into context. Advance statements, including advance refusals of life-sustaining treatment, currently have common law force – the Bill is providing statutory clarification.¹³ As regards delegated powers to make treatment decisions under the Bill, a patient has to specifically nominate an individual while they retain capacity, who can only make decisions in relation to refusing life-sustaining treatment where the donee has specifically given this power. If an Attorney makes a decision that clearly contradicts the incapacitated person's best interests, health professionals can refer the matter to the new Court of Protection.

Serious problems began for the Bill with the intervention in the Commons' debate of Mrs Curtis-Thomas, Labour MP for Crosby. Mrs Curtis-Thomas gave a powerful account of the experiences of

her mother.¹⁴ She suffered from a massive bipolar stroke. On recovery she informed her daughter that if she suffered a similar stroke she would not want to continue in such a condition and would not want to be treated. She made an advance statement to that effect. Five years later she had a similar stroke. As her mother was apparently unable to communicate, Mrs Curtis-Thomas informed the doctor of the existence of the advance directive. The doctor did not follow the directive and Mrs Curtis-Thomas gradually came to realise that her mother retained capacity, could communicate by blinking, and had no wish to die. Mrs Curtis-Thomas' intervention was both thoughtful and effective in moving opinion against the Bill. It highlighted some of the problems associated both with advance directives, and with assessing capacity where communication is difficult. Although effective, Mrs Curtis-Thomas' comments did not, however, relate directly to the Capacity Bill. The Capacity Bill does not legalise advance statements. Where they are valid and applicable, they are already recognised in common law. Furthermore, when it became clear that her mother retained capacity, the Bill would not apply.

In December 2004, the week before the Bill began its report stage in the Commons, Mrs Curtis-Thomas appeared on the front page of the *Daily Mail* under the headline "Charter for Euthanasia".¹⁵ Inside, the paper ascribes powers to the Bill, such as discontinuing treatment, including ANH where it is no longer in the patient's best interests, which exist independently of the Bill. Criticisms levelled at the Capacity Bill were in fact veiled criticisms of the judgement in *Bland*.¹⁶ In the same paper, Melanie Phillips explored some of the ethical issues raised by both the use of advance statements, and the withdrawal of ANH, as though they were criticisms of the Bill.¹⁷ Here again, the Capacity Bill was used as a vehicle for attacking common law and practice, and the Bill's legitimate purpose, which is to promote

autonomy and to protect vulnerable adults, was ignored.

Balanced coverage, pointing to extensive protections that the Bill extends to vulnerable adults was not easy to find. In the Summer of 2004, *The Guardian* and *The Independent* both pointed to some of the benefits of the Bill, and reported the Government's insistence that it did not introduce euthanasia.^{18 19}

As a result of both media and Parliamentary activity, the Government has undertaken to introduce changes to the Bill. It is questionable how helpful media input has been. A principled piece of legislation, designed to protect the interests of vulnerable people, is being amended to take account of opposition to an earlier ruling by the House of Lord that is unrelated to the Bill.

References

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