

STRICT EMBARGO: NOT FOR USE BEFORE 10.30 am
Friday 30th July 2004

Doctors must fulfil patient's 'dying wishes'

Doctors must unequivocally fulfil a patient's wishes to life-prolonging treatment and, if no "living will" exists, they must presume that treatment should be given unless the patient would deem their life to be 'intolerable', the High Court has ruled today.

The landmark case tested the validity of General Medical Council (GMC) guidelines for doctors deciding whether to withhold or withdraw artificial nutrition and hydration (ANH) ⁽¹⁾. The High Court ruled that if a patient has made a living will or expressed that they would want life-prolonging treatment, doctors must fulfil that wish. If a patient is incompetent and has not expressed any prior view, doctors must make their decisions based on an "intolerability test".

Doctors currently make life and death decisions based on a "quality of life" assessment. The Disability Rights Commission (DRC) ⁽²⁾ challenged the "quality of life" assessment as it relies not only on a doctor's medical opinion of whether treatment should be given or withdrawn, but also on the social welfare of the patient. Whilst doctors can claim to have medical expertise, they can claim no special expertise in non-medical matters which go to form the basis of what is in the patient's best interests. Those opinions could be based on a backdrop of negative images and poorly informed assumptions of intolerable suffering, unacceptable dependence on others or that a particular disability makes life not worth living. These have led in some cases to inappropriate decisions to withhold

or withdraw life-prolonging ANH, including contrary to the expressed wishes of close relatives.

The 'intolerability test', which is already used by the courts, is set much higher than the current GMC guidelines. If life-prolonging treatment is providing *some* benefit it should be provided unless the patient's life, if thus prolonged, would from *the patient's point of view* be intolerable.

Les Burke, 43, who brought the case against the GMC, has Cerebella Ataxia which is a degenerative condition and is very likely to deteriorate and will result in him needing ANH at some time in the future. At this point doctors could make the decision to withhold or withdraw ANH based on the "quality of life" assessment. Medical evidence indicates that Mr Burke will retain his full cognitive faculties even during the end stages of the disease and that he will retain, almost until the end, insight and awareness of pain, discomfort and extreme distress that would result from withdrawal of food and fluid - leading to malnutrition and dehydration. If food and water were to be withheld he would die of dehydration after some two to three weeks.

1/3

The judgement also confirmed that if a patient has a living will or expressed that in certain circumstances they would not wish to receive life-prolonging treatment then those wishes should be adhered to. However, if there is a lack of consensus by medical professionals about treatment being withheld or withdrawn and the patient's best interests, such decisions must be authorised by the court. It should also be referred to court if

there is a dispute between any of the medics and relatives or carers as to whether ANH should be ceased or withheld.

Bert Massie, Chairman of the DRC, said:

"Until now doctors had the power to refuse or withdraw life-prolonging treatment and to disregard a disabled person's wishes based, in some cases, on a set of assumptions that disability equals a very poor quality of life. This judgement provides genuine protection for disabled people with serious long-term conditions. They want health professionals to do as much as possible to preserve life - as they would do for non-disabled people. Instead, numerous cases that have come to our attention show that sometimes they opt for the easy exit without even troubling to tell family, relatives or disabled people themselves of their decisions.

"There is no greater example of how discriminatory attitudes can have a fatal effect in the treatment of disabled people."

For further information contact Sue Pratt or Patrick Edwards at the DRC Press Office on 020 7543 7042 or 020 7543 7040.

Ends

Notes to Editors

1. The GMC guidelines are contained in *'Withholding and Withdrawing Life-Prolonging Treatments: Good Practice and Decision Making'* 2002.

2. The DRC intervened in this case as an interested party and sought to establish four key elements for future decision making on withholding or withdrawing treatment:
- (1) The right of the competent patient to be able unequivocally to require continuation of ANH either at the time or through a statement made while competent taking effect even when they are no longer competent.
 - (2) That if quality of life was to be a factor in deciding when to cease ANH for an incompetent patient who had expressed no prior view, that quality was to be assessed from the point of view of the patient/disabled person, and
 - (3) Quality of life, as assessed that way, was only to be treated as justifying cessation/withholding of ANH if the patient would consider their life to be "intolerable" if continued, and
 - (4) In the event of a dispute between any of the medics and/or relatives/carers/etc as to whether ANH should be ceased/withheld, that should be referred to court.

The Disability Rights Commission (DRC) is an independent body set up by an Act of Parliament in 2000 to enforce the rights of Britain's 9.8 million disabled people.