

American financing system, however, than that of provider competition itself, particularly the absence of an effective budget constraint on either insured purchasers or, under retrospective reimbursement, on hospitals, and on failures to embody agreements about quality in contracts.<sup>20</sup> There is, moreover, evidence of cost savings under selective contracting, particularly through reductions in length of stay. So there is no particular reason to suppose that the worst features of the American system of health care will be imported lock, stock, and barrel into the United Kingdom.

### Envoi

There is a set of principles, the ethical nature and economic rationality of which are of a high order, that can be seen to underlie the reforms but which have sadly received little prominence. It would be a great pity if this, together with an inevitable obsession with just keeping the NHS going in turbulent times, should mean that the wood is lost for the trees. It is to be hoped that we can all keep a sense of vision (the right angle on things) so that the promise that can be discerned is actually realised, and we do not suffer yet another "redisorganisation" of the NHS in accordance with a new set of vaguely felt aspirations as it becomes clear that we have loused this one up, or the oil price rockets, or the government changes—whichever hits us first.

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1 Cochrane AL. *Effectiveness and efficiency: random reflections on health services*. London: Nuffield Provincial Hospitals Trust, 1972.

- 2 Glantz SA. Biostatistics: how to detect, correct and prevent errors in the medical literature. *Circulation* 1980;61:1-7.
- 3 McPherson K. International differences in medical care practices. *Health Care Financing Review* 1990 (suppl):9-20.
- 4 Rachlis M, Kushner C. *Second opinion: what's wrong with Canada's health care system and how to fix it*. Toronto: Harper and Collins, 1989.
- 5 Sackett DL. Evaluation of health services. In: Last JM, ed. *Public health and preventive medicine*. New York: Appleton-Century Crofts, 1980:1800-23.
- 6 Sheehan TJ. The medical literature: let the reader beware. *Arch Intern Med* 1980;140:472-4.
- 7 McKeown T. *The modern rise of population*. London: Arnold, 1976.
- 8 Williams AH. Economics of coronary bypass surgery. *BMJ* 1985;291:326-9.
- 9 Pickard JD, Bailey S, Sanderson H, et al. Steps towards cost-benefit analysis of regional neurosurgical care. *BMJ* 1990;301:629-35.
- 10 Williams AH. Need as a demand concept (with special reference to health). In: Culyer AJ, ed. *Economic problems and social goals*. London: Martin Robertson, 1974:60-76.
- 11 Culyer AJ. *Need and the National Health Service: economics and social choice*. London: Martin Robertson, 1976.
- 12 Culyer AJ. Need, values and health status measurement. In: Culyer AJ, Wright KG, eds. *Economic aspects of health services*. London: Martin Robertson, 1978:9-31.
- 13 Williams AH. Need—an economic exegesis. In: Culyer AJ, Wright KG, eds. *Economic aspects of health services*. London: Martin Robertson, 1978:32-45.
- 14 Le Grand J. The distribution of public expenditures: the case of health care. *Economica* 1978;45:125-45.
- 15 Le Grand J. *The strategy of equality*. London: Allen and Unwin, 1990.
- 16 Le Grand J. Equity, health and health care. In: Le Grand J. *Three essays on equity*. London: London School of Economics. Discussion Paper WSP/23, Suntory Toyota International Centre for Economics and Related Disciplines, 1990.
- 17 Culyer AJ. Health, health expenditures and equity. In: van Doorslaer E, Rutten F, Wagstaff A, eds. *Proceedings of the conference on equity in European health services, 12-16 November 1990, Bellagio, Italy*. (In press.)
- 18 Culyer AJ. *Ethics and efficiency in health care: some plain economic truths*. Hamilton, Ontario: Centre for Health Economics and Policy Analysis, McMaster University, 1991. 1990 Perey Lecture. Paper No 91-1, Health Policy Commentary Series.
- 19 Cooper MH, Culyer AJ. An economic assessment of some aspects of the organisation of the National Health Service. In: Jones I, ed. *Health services financing*. London: British Medical Association, 1970.
- 20 Culyer AJ, Posnett JW. Hospital behaviour and competition. In: Culyer AJ, Maynard AK, Posnett JW, eds. *Competition in health care: reforming the NHS*. London: Macmillan, 1990:12-47.

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## Persistent vegetative state and the right to die: the United States and Britain

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Patients in a persistent vegetative state have permanently lost the function of the cerebral cortex.<sup>1</sup> Their prolonged survival presents dilemmas for their families and carers as well as for society. In the United States families of such patients often seek court rulings to discontinue life sustaining treatment when hospitals refuse such requests. In more than 80 cases the courts have supported the wishes of families, but the refusal of the Missouri Supreme Court to follow these precedents brought the United States Supreme Court its first "right to die" case in 1990.

### The vegetative state

According to surveys in Japan<sup>2</sup> and The Netherlands,<sup>3</sup> about 40% of survivors in a vegetative state after acute insult have had a head injury. In most, severe diffuse axonal injury at impact severed white matter connections to and from the cerebral cortex, but secondary ischaemic cortical damage is sometimes dominant. In most non-traumatic cases diffuse hypoxic necrosis of the cortex due to cardiac arrest or hypotension or medical accident has occurred.<sup>4</sup> Hypoglycaemic crises in diabetic patients and various acute cerebral diseases account for the remainder.

Patients in a persistent vegetative state spend long periods with their eyes open but have no voluntary activity or meaningful response to the environment. Their spastic limbs can withdraw reflexly from painful stimuli, the face may grimace, the eyes may briefly turn to light or sound, and groans and cries may occur.

Diagnosis depends on skilled observation over time because available investigations (for example, computed tomography, magnetic resonance imaging, or electroencephalography) are not helpful. Research investigations with positron emission tomographic scanning have shown metabolic activity in the brain at the level of deep anaesthesia.<sup>5</sup>

In a well documented series no patient who was still in a vegetative state three months after injury became independent subsequently; the few who regained consciousness remained very severely physically and mentally disabled and dependent.<sup>6</sup> Of patients in a vegetative state three months after injury, about half die by 12 months but more than half of those still alive at one year live for three years or more, some surviving for 12, 15, 18, and 36 years.<sup>2,3</sup> Prolonged survival depends only on basic nursing care and on adequate nutrition by nasogastric or gastrostomy tube.

### Ethical issues

There seem to be no self regarding interests for patients in having their survival prolonged in a vegetative state—which many people regard as worse than death.<sup>7,8</sup> Because such patients have lost the mechanisms by which they can experience distress the burdens of prolonged survival therefore fall on their families and friends, who have to witness its indignities. Health care staff know that they are engaged in a futile endeavour and that their skills are denied to other patients who might benefit. However, the reasons that usually

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justify withdrawal of life-sustaining measures do not apply because vegetative patients are neither suffering nor terminally ill, nor can they refuse treatment.

None the less, in the United States a consensus has developed that the life-sustaining treatment of such patients should be discontinued, which probably relates to the strength of the informed consent movement in that country. The consensus aims at protecting the rights of competent patients to refuse treatment, including treatment that may save or sustain life, an attitude reflected in do not resuscitate orders and living will legislation, both introduced in 1976. But there is concern also that incompetent patients should not have their lives prolonged inappropriately. Declarations by the American Medical Association in 1986<sup>9</sup> and 1989<sup>10</sup> specify that treatment, including artificially provided nutrition and fluid, may properly be withdrawn from patients in a vegetative state. Most American courts agree with this principle, which the Supreme Court recently confirmed. There is, however, still some debate about who should make this decision for incompetent patients and whether evidence is needed about the attitudes or wishes of a particular patient.

### The case of Nancy Cruzan

Nancy Cruzan was 25 when she sustained a head injury in 1983 which left her in a vegetative state. In 1987 her parents requested the removal of the gastrostomy tube to allow her to die. The hospital sought a legal ruling before allowing the doctors to do this, and in July 1988 a state court found in favour of the family's request. The attorney general appealed and the Missouri Supreme Court reversed the decision, maintaining that the state had an unqualified interest in preserving life and that treatment could be terminated only if there was clear and convincing evidence that Nancy would have refused it. The state undertook to pay the medical expenses of continued survival, estimated at \$130 000 a year.

The family appealed to the United States Supreme Court, which took oral evidence in December 1989, and that same night doctors, lawyers, philosophers, and clergy debated the case for two hours on public service television. In June 1990 the Supreme Court decided by five votes to four that constitutionally the Missouri court could require a high standard of evidence of Nancy's wishes before it allowed withdrawal of treatment. In the event further witnesses came forward to testify that Nancy had expressed such wishes before her accident. In December 1990 the Missouri State Court that had first heard Nancy's case ruled that feeding could be stopped. When she died 12 days later she had been in a vegetative state for almost eight years, and her parents had petitioned eight times in court that she should be allowed to die. Yet during those last 12 days anti-euthanasia groups attempted to secure injunctions to restore feeding, but these were denied by both state and federal courts.

### Supreme Court's decision

In its first "right to die" case the United States Supreme Court upheld the right of a competent patient to refuse treatment. Delivering the majority opinion on the Cruzan case, Chief Justice William H Rehnquist said: "Missouri may legitimately seek to safeguard the personal elements of this choice between life and death through the imposition of heightened evidentiary requirements." He went on: "Close family members may have a strong feeling—a feeling not at all ignoble or unworthy but not entirely disinterested either—that they do not wish to witness the continuation of the life of a loved one which they regard as hopeless, meaningless, and even degrading. But there is no automatic

assurance that the view of close family members will necessarily be the same as the patient's would have been, had she been confronted with the prospect of her situation while competent." One dissenting justice said that Missouri was "imposing improperly biased procedural obstacles in the way of the constitutional right to be free of unwanted medical treatment... that would limit the right to those who had had the foresight to make an unambiguous statement of their wishes."

Noting that the decision did not set new standards for medical practice, the *New England Journal of Medicine* was concerned by the almost complete lack of attention to medical reality and that the professional and personal roles of the patient's physician were completely ignored.<sup>11</sup> An accompanying statement from 36 bioethicists attempted to prevent misrepresentation of the ruling, which they thought might lead to serious adverse consequences for hopelessly ill patients, and they urged physicians to encourage their patients to make advance directives.<sup>12</sup> In fact most American states already have natural death acts that recognise living wills and allow a person to let a family member or friend make medical decisions for him or her (durable power of attorney). In the absence of such directives many state courts before the Cruzan case allowed feeding to be discontinued, relying on the family's judgment of what the patient would have wished. This was based on the constitutional right to privacy, which includes the right to decline life-prolonging treatments. From November 1991 federal legislation will require hospitals to inform all patients on admission of their right to make an advanced treatment declaration or to appoint a decision-making proxy.

### The British position

There is no constitutional right to privacy and no legislation to underpin the use of living wills in Britain. In 1987, however, a working party on living wills concluded that English law would already require doctors to act according to a patient's previously expressed wishes.<sup>13</sup> However, it recommended that patients in Britain, like those in the United States, should be able to rely on living wills or durable powers of attorney to ensure that their decisions about treatment are respected and are not overruled by doctors who think that they know best. Recent changes to English and Scottish law provide for a power of attorney to remain in force even though the person who made it becomes incompetent.

However, powers of attorney are limited to decisions about property and finance. Scots law, however, has a useful device which has recently been used more frequently for making decisions about incapacitated persons. On petition, the Court of Session can appoint a tutor dative, who may make decisions relating to welfare, which could include medical treatment. This device is recommended to its members by the Voluntary Euthanasia Society of Scotland, which issues a living will to its members. Outside such specific arrangements, however, family members in Britain have no legal right to make treatment decisions for incompetent adults.

The issue of withdrawing life-sustaining treatment from patients in the vegetative state has so far not reached the courts in Britain, leaving doctors and families to operate in a legal vacuum. In practice, doctors do take decisions to discontinue treatment in consultation with families and without involving the courts. In common with the American Medical Association, the BMA accepts that patients may refuse treatment and that artificial feeding is a treatment. It is, however, uncertain whether English or Scottish courts would adopt this line and follow American courts

in rejecting the suggestion that discontinuation of nutrition for a patient in a vegetative state would constitute criminal homicide. When a district coroner in England was consulted last year by doctors proposing to do this for an accident victim he is reported to have stated that he would have no choice but to refer the case for criminal investigation.<sup>14</sup> When the same question was asked of the central legal office for the Scottish health boards, however, it advised that the procurator fiscal service (which investigates suspected crimes in Scotland) would not consider such a medical decision in any way inappropriate. It advised that a second medical opinion should be obtained and that the relatives be consulted—but not asked for their consent to withdrawing life support; in Scotland, as in England, relatives have no legal right to consent on behalf of an incompetent adult.

The question of mentally incompetent adults and consent to treatment has been considered by the English courts in a series of cases entailing the sterilisation of mentally handicapped women. In *Re F* the House of Lords ruled that the court could not consent to treatment but could declare that it would not be unlawful.<sup>15</sup> The Law Lords relied on the common law doctrine of necessity, which allows the treatment of unconscious patients in casualty in their best interests. English and Scottish courts have traditionally been more inclined to adopt the “best interests” approach to taking decisions on behalf of another, rather than that of “substituted judgment” (trying to decide what the person would have wished if competent). The difficulty with patients in a persistent vegetative state is that to them life and death are the same, making it difficult to argue that death is in their best interest. The Law Commission, the official law reform body for England and Wales, is currently reviewing the law on decision making and mentally incapacitated adults. It published a consultation paper in April, to be followed by proposals for legislation.<sup>16</sup> The Scottish Law Commission is expected to produce a discussion paper on the subject soon. The BMA recently suggested that committees should be established in each health district to take decisions about treatment on behalf of mentally incapacitated adults.<sup>17</sup>

In Britain there has been little public discussion of the issue of withdrawing treatment from patients in a

persistent vegetative state. Few would like to see the courts interfering in what most regard as clinical decisions, a view shared by most doctors and many judges in the United States.<sup>18</sup> Legislative backing for living wills and enduring powers of attorney for medical decisions might be helpful but would provide only for the minority of people who had chosen to make advance directives. The recent report from the Institute of Medical Ethics aims at promoting wider discussion between the public and medical professional bodies on whether the withdrawal of nutritional support is an appropriate way of dealing with patients in a persistent vegetative state.<sup>19</sup> Guidelines might be evolved as a safeguard, indicating the conditions under which a decision to withdraw nutritional support would be appropriate and who should share in it.

- 1 Jennett B, Plum F. Persistent vegetative state after brain damage. A syndrome in search of a name. *Lancet* 1972;i:734-7.
- 2 Higashi K, Sakata Y, Hatano M, et al. Epidemiological studies on patients with a persistent vegetative state. *J Neurol Neurosurg Psychiatry* 1977;40:876-85.
- 3 Minderhoud JM, Braakman R. Het vegeterende bestaan. *Ned Tijdschr Geneesk* 1985;129:2385-8.
- 4 Jennett B. Vegetative survival after brain insults: can anaesthetists reduce the frequency of a fate worse than death? *Anaesthesia* 1988;43:921-2.
- 5 Levy DE, Sidtis JJ, Rottenberg DA, et al. Differences in cerebral blood flow and glucose utilization in vegetative versus locked-in patients. *Ann Neurol* 1987;22:673-82.
- 6 Braakman R, Jennett B, Minderhoud JM. Prognosis of the post-traumatic vegetative state. *Acta Neurochir (Wien)* 1988;95:49-52.
- 7 Jennett B. Resource allocation for the severely brain damaged. *Arch Neurol* 1976;33:595-7.
- 8 Feinberg WM, Ferry PC. A fate worse than death: the persistent vegetative state in children. *Am J Dis Child* 1984;138:128-30.
- 9 American Medical Association Council on Ethical and Judicial Affairs. Withholding or withdrawing life-prolonging medical treatment. *JAMA* 1986;236:471.
- 10 American Medical Association Council on Scientific Affairs. Persistent vegetative state and the decision to withdraw or withhold life support. *JAMA* 1990;263:426-30.
- 11 Annas GJ, Nancy Cruzan and the right to die. *N Engl J Med* 1990;323:670-3.
- 12 Bioethicists' statement on the US Supreme Court's Cruzan decision. *N Engl J Med* 1990;323:686-7.
- 13 Gillon R. Living wills, powers of attorney and medical practice. *J Med Ethics* 1988;14:59-60.
- 14 Brahmans D. The euthanasia debate. *Lancet* 1988;i:779-80.
- 15 *Re F* 1990. 2. Appeal Cases. 1.
- 16 Law Commission. *Mentally incapacitated adults and decision making: an overview*. London: HMSO, 1991.
- 17 Medical Ethics and Mental Health Committees. *Proposals for the establishment of a decision making procedure on behalf of the mentally incapable*. London: BMA, 1991.
- 18 Lo B, Rouse F, Dornbrand L. Family decision making on trial: who decides for incompetent patients? *N Engl J Med* 1990;322:1228-32.
- 19 Institute of Medical Ethics Working Party. Withdrawal of life-support from patients in a persistent vegetative state. *Lancet* 1991;337:96-8.

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## ANY QUESTIONS

*A professional man in his 60s had type II diabetes diagnosed; this responded satisfactorily to an appropriate diet and tolbutamide. He reported that for 30 years he has had three or four attacks a year, usually mid-morning and associated with exercise, of slight trembling, clumsiness, confusion, sweating, and hunger, all relieved by eating food. These are continuing and usually occur about 15 hours after the evening dose of tolbutamide. Are these attacks related to the diabetes of recent onset and what is the explanation?*

The most obvious cause of this patient's 30 year history of attacks is hypoglycaemia. The symptoms are a mixture of those produced by adrenaline response and by neuroglycopenia. The mid-morning timing is more likely to fall into the reactive hypoglycaemia category than fasting hypoglycaemia, with exercise after breakfast causing an accentuation in the usual response. As in all such cases, it is essential that a low blood glucose concentration is recorded. Marks and Rose emphasised the variability in blood glucose responses after meals and after an oral glucose load and the variability in symptoms.<sup>1</sup> There is a clear category of people who have characteristic symptoms but normal blood glucose values. These have been dubbed as having “non-hypoglycaemia.”<sup>2</sup>

The relation of reactive hypoglycaemia to diabetes is

interesting. It has been suggested that in impaired glucose tolerance and very early non-insulin dependent diabetes mellitus there is delayed hypersecretion of insulin after a meal (or glucose load) with a subsequent fall in blood glucose concentration.<sup>1</sup> This is almost certainly a rare phenomenon and in the current case unlikely as a cause of 30 years of attacks. Tolbutamide is equally unlikely to be the cause as it is short acting (four to five hours), is rare as a cause of hypoglycaemia, and is highly unlikely to be responsible for hypoglycaemia 15 hours later. The relation of the attacks to food intake is critical, and it is uncertain whether the patient was fasting at the time of symptoms.

Investigation is required. A prolonged glucose tolerance test, perhaps a meal tolerance test, and fasting with measurement of insulin, C peptide, and glucose (and perhaps tolbutamide) concentrations would be important, together with the ruling out of rare entities, such as Addison's or pituitary disease, which may coexist with diabetes, or insulin autoantibodies.—K G M M ALBERTI, professor of medicine, Newcastle upon Tyne

- 1 Marks V, Rose FC. *Hypoglycaemia*. 2nd ed. Oxford: Blackwell, 1981.
- 2 Hofeldt FD. Reactive hypoglycemia. *Endocrinol Metab Clin North Am* 1989;18:185-201.
- 3 Cahill GF, Soeldner JS. A non-editorial on non-hypoglycemia. *N Engl J Med* 1974;291:905.