

## *Ethical dilemma*

### Discontinuation of ventilation after brain stem death

Confusion among the public over the difference between brain stem death and a persistent vegetative state can make it difficult to obtain consent to withdraw ventilation. Clinicians who have been faced with this dilemma outline their strategies for coping with such a situation, and a neurologist and a neurosurgeon offer their opinions.

### To whom is our duty of care?

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The concept of brain death is not often discussed in the public arena. According to the royal medical colleges in the United Kingdom and their faculties death of the brain stem is a component of brain death, and brain death is death.<sup>1</sup> The criteria for brain stem death are well established,<sup>2</sup> and their use in intensive care units enables treatment to be withdrawn from patients with brain stem death without recourse to the courts. Conversely, as a result of several high profile cases, persistent vegetative state has been reported on frequently in recent years. The application to the High Court in 1992 to discontinue life sustaining treatment for Tony Bland, who had been injured in the tragedy at Hillsborough football ground, brought the ethical debate to the front pages of the national press. Occasional stories of "miraculous recoveries" from comas are widely reported and may have led to an exaggeration of the small chances that patients have of recovering from a persistent vegetative state among a public that is increasingly well versed in this condition. This contrasts with the inevitable death from asystole which occurs within a few days for patients who are brain dead.<sup>3</sup>

We have experienced a case in which, although the patient had been declared brain stem dead, the patient's family prevented us from switching off the ventilator. On this occasion our intensive care unit was full, and maintaining this patient on a ventilator might have forced us to transfer any new critically ill patients to another hospital, with the associated increase in life threatening complications that this would have entailed.<sup>4</sup>

### Case report

An 18 year old girl was brought to the accident and emergency department of our hospital. She had been found collapsed at home by her family who had begun basic life support. After unsuccessful attempts at advanced life support by the paramedic crew at the

scene she was transferred to hospital, where a cardiac output was achieved after further defibrillation. We estimated that she had been without spontaneous cardiac output for at least 30 minutes. She was transferred to the intensive care unit for full ventilatory and inotropic support. Blood concentrations of tricyclic antidepressants were high, confirming the family's suspicion of an overdose. Activated charcoal was given nasogastrically. From the beginning of treatment the family was made aware of the patient's poor prognosis and the high probability of her death.

After 72 hours blood concentrations of the ingested drug had fallen to the lower end of the therapeutic range, and two sets of brain stem tests were performed according to national guidelines.<sup>2</sup> The family had been kept fully informed of the patient's condition up to this point and were aware that brain stem testing was being performed. The significance of the tests had already been explained to them, and they had already ruled out the possibility of organ donation.

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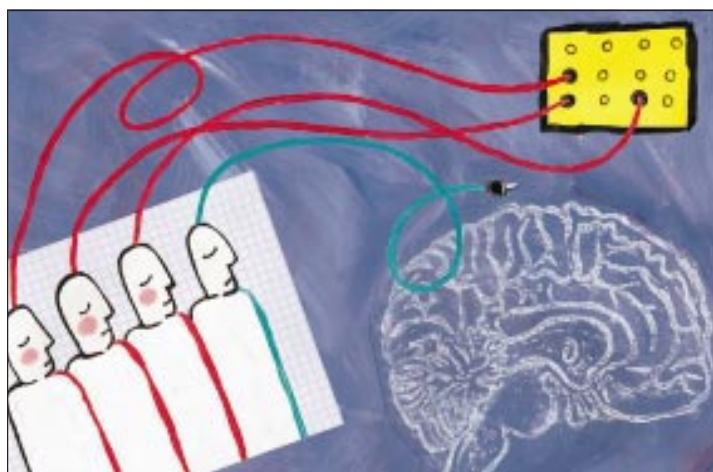
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However, after the declaration of death the family refused to allow the ventilator to be switched off. We believe that a good relationship had been maintained with the family at all times, but they were unable to accept that the patient was dead while her heart was still beating. We were contacted by a lawyer acting for the family and threatened with an injunction to prevent us from switching off the ventilator. We sought advice from the management of the hospital, the hospital's legal advisers, and a medical defence union. They all advised us not to stop artificial ventilation. Only after 48 hours, and after discussions with representatives of the family and their general practitioner, did the patient's family eventually agree to allow us to switch off the ventilator.

In discussing this case with colleagues we were made aware of two other similar cases that had occurred in our intensive care unit in which, despite the declaration of brain death, patients were ventilated at their family's insistence until they became asystolic.

### Conclusion

We believe that there is confusion among the public over the differences between brain stem death and a persistent vegetative state. This, combined with high profile reporting of miraculous recoveries from comas, has led to the development of unrealistic expectations of the potential for recovery of patients who are brain dead. The confusion is further complicated by cultural and religious beliefs about death which may vary from the medical and legal definitions.

This case also highlights the ethical issue of priorities of care. For two days we ventilated a patient who was legally dead. For most of that time our eight bed unit was full with patients who required ventilation.

Had we had a request to admit a patient who required ventilation we would have been unable to accept the patient and would instead have had to transfer him or her to another hospital. To whom is our duty of care greatest? Is it to the grieving family of a dead patient or is it to the critically ill patient who is placed at greater risk by an unnecessary transfer between hospitals?<sup>4</sup> According to Sprung et al, brain death is one of the few situations for which there are accepted medical criteria that enable the autonomy of the doctor to prevail over the requests of the patient's surrogate.<sup>5</sup>

It is important to raise the public's awareness of brain stem death and its implications. The public needs to know that by definition there is no chance of recovery from brain stem death, and the differences between brain death and a persistent vegetative state need to be explained. In this case we were grateful for the involvement of the family's general practitioner, and we believe that general practitioners might also benefit from having a clearer understanding of brain stem death. Sensitive and thoughtful explanations from medical and nursing staff combined with a better understanding of the nature of this condition will help grieving families cope with this difficult situation.

Competing interests: None declared.

- 1 Conference of Medical Colleges and their Faculties. Diagnosis of brain death. *BMJ* 1976;iii:1187-8.
- 2 Criteria for the diagnosis of brain stem death: review by a working group convened by the Royal College of Physicians and endorsed by the Conference of Medical Royal Colleges and their Faculties in the United Kingdom. *J R Coll Physicians Lond* 1995;29:381-2.
- 3 Pallis C. Prognostic significance of a dead brain stem. *BMJ* 1983; 286:123-4.
- 4 Braman SS, Dunn SM, Amico CA, Millman RP. Complications of intrahospital transport in critically ill patients. *Ann Intern Med* 1987;107:469-73.
- 5 Sprung CL, Eidelman LA, Steinberg A. Is the physician's duty to the individual patient or to society? *Crit Care Med* 1995;23:618-20.

## Policy should be balanced with concern for the family

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The ethical and legal concept of brain stem death is still in transition in the United States, the United Kingdom, and elsewhere.<sup>1</sup> It has not yet been fully accepted by practitioners, by the general public, or by patients and their families. The concept of brain stem death as a neurological syndrome has only existed for the past 40 years or so, and as an ethical and legal concept (that is, brain stem death is death) it has existed only for 30 years. Many more years probably will go by until this concept reaches a high degree of medical and social acceptance.

In the clinical setting the diagnosis of brain stem death, the pronouncement of death, and the raising of issues of organ donation are usually compressed into a matter of hours or a few days. Unlike the persistent vegetative state—which it may take weeks, or even months, to diagnose and establish irreversibility—the diagnosis of the irreversible loss of brain stem functions can be determined with a high degree of certainty within a short time. Because of this, family members should be approached in steps so that they are able to fully comprehend the process. The first step

should be to inform the family of the poor prognosis for recovery of neurological functions. The second step should be to raise the possibility that the patient may be brain dead; at this point families should be told that studies are being performed to determine whether this is the case. The third step should be taken when it seems fairly certain that brain stem death has occurred, and the family should then be told clearly and unequivocally that the usual practice at the hospital is to pronounce a person dead once neurological criteria have been confirmed. With this approach, a family should be able to fully understand that the pronouncement of death is not their decision and that the determination of brain stem death as death is a medical determination just as cardiorespiratory death is.

At the same time, practitioners should be sensitive to the feelings of families who are suddenly confronted with the death of their loved one, who may still look "alive" and who may have been a healthy and vibrant human being just a few hours ago. Thus, it seems reasonable and humane to give the family some time to understand the process and integrate the concept. But

for how long, and under what circumstances should the time be given? There are no clear cut answers to these questions and there never will be. Under what other circumstances and for how long is it permissible to delay, or hasten, the pronouncement of death and termination of support systems? Should the pronouncement of death be delayed, or not made at all, if the family is in a state of denial and completely unable to accept the concept of brain stem death for religious or other reasons? What should be done in cases in which brain stem death has apparently been caused by the actions of the doctors providing treatment, or in cases in which the pronouncement of death will cause charges against an alleged assailant to be changed from attempted murder to murder? Should time be taken to find family members to gain consent to organ donation? Or should the need for beds in the intensive care unit be considered when there is a shortage?

If practitioners really believe that brain stem death is death then hospital policies and the actions and practices of practitioners should be as uniform as pos-

sible. Pronouncements of death should not be speeded up because of a shortage of beds in the intensive care unit nor should they be delayed unnecessarily to look for relatives to consent to organ donation.

In this case the doctors acted wisely and humanely, balancing a uniform policy on brain stem death with appropriate concern for the family. Involving the general practitioner who knew the family well was also wise. Only when practitioners have more experience in handling cases of brain stem death and when there is more widespread acceptance among the public will these controversies diminish. Until then, dilemmas like the one discussed by Swinburn et al will continue to arise. Neurological and neurosurgical specialists, legal advisers, and ethics committees at individual hospitals should discuss some of these issues in advance so that they know how to handle them when they occur.

Competing interests: None declared.

1 Youngner SJ, Arnold RM, Schapiro R, eds. *The definition of death: contemporary controversies*. Baltimore: Johns Hopkins University Press, 1999.

## Brain stem death defines death in law

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The concept of brain death was exposed to intensive public scrutiny in 1981 following a controversial *Panorama* programme on television in which it was asserted that the diagnosis of brain death could be uncertain.<sup>1</sup> A later programme, made by doctors nominated by the royal colleges, was specifically broadcast to rebut the assertions. A recent review by the royal colleges preferred the term brain stem death but found that there was no need to modify the original diagnostic criteria outlined in 1976, which require two doctors to carry out specific tests on two occasions.<sup>2</sup> There is no possibility of diagnostic confusion between patients who are brain stem dead and those who are in a persistent vegetative state. This should be explained to families who may, as Swinburn et al suggest, doubt the reliability of the diagnosis of brain death because of reports of the misdiagnosis of patients in a persistent vegetative state and of the few vegetative patients who make a partial recovery.

An essential component of all formal pronouncements by the royal colleges and the Departments of Health on this subject is that once a patient is declared brain dead he or she is also legally dead. The departments' 1983 code of practice specifically states that the time of death is the time at which brain death is established and not some later time when ventilation is withdrawn or the heartbeat ceases.<sup>3</sup> Clinicians should emphasise this when explaining the situation to relatives, and they should make it clear that ventilation is not being withdrawn to let the patient die but because continued ventilation is inappropriate for a patient who is already dead. The only justification for maintaining ventilation for a short time is to preserve the condition of organs when it has been agreed that they are to be made available for transplantation.

In the United Kingdom no one other than a doctor can decide about the provision or withholding of treat-

ment from an adult who is unable to give consent, although good practice dictates that the family should be consulted and kept informed. Parents have more rights in regard to their children. In 1992, a 19 month old child was declared brain dead after suspected non-accidental injury but an emergency protection order was granted to require the consent of those who had parental responsibility before a life support machine could be switched off. A High Court judge declared that the child was undoubtedly dead and that if the doctor considered it appropriate to withdraw ventilation this would not be contrary to the law.<sup>4</sup>

There has been much discussion in recent years about the ethical propriety of doctors deciding, on the grounds of the fair allocation of resources, to treat one patient rather than another because one is considered more likely to benefit. Some have challenged the appropriateness of such decisions because they are based on the value judgments of doctors rather than on the wishes of patients. However, even those who believe this admit that brain death is one of the few conditions about which such an argument is not relevant.<sup>5</sup> This is because there is no question of balancing the comparative benefits expected from treating two different patients, as the brain dead patient can derive no benefit from maintaining ventilation.

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1 Jennett B. Brain death. *Br J Anaesth* 1981;53:1111-9.

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4 Re A (a minor) [1992] 3 Med LR 303-5.

5 Sprung CL, Eidelman LA, Steinberg A. Is the physician's duty to the individual patient or to society? *Crit Care Med* 1995;23:618-20.