Developing communication skills in medicine

Summary

One to two per cent of admissions to Paediatric Intensive Care Units eventually fulfil the criteria for brain death, implying the need for very difficult decisions. Brain death is defined as irreversible loss of function of the whole brain. The diagnostic criteria caused a great deal of anxiety but are now the subject of a consensus approach.

When the situation can be anticipated it is of immense value for the professional staff to develop a good working relationship with the parents to help and support them through the phase of impending disaster and facing the issue when the time actually comes. However, it is vital to help parents to make their own decision regarding continuation or otherwise of life support and they should be supported in whichever decision they take. They must be absolutely convinced that the child is brain dead and this territory may have to be covered again and again in discussion, questions must be answered factually, and time allowed for reflection.

Stage management of the process of 'switching off' is vital and the parents' wishes may vary widely from one family to another. They must be warned what is likely to happen and provided with appropriate privacy and support for expression of their grief. The question of asking for *post-mortem* permission has to be handled sensitively and long-term support for the parents must be offered.

Education of undergraduate and postgraduate doctors in this area is now receiving more attention with skills being increased by video teaching and role play. It should not be overlooked that the professional staff attending such patients sometimes require counselling and support themselves.

Keywords: children, brain death, counselling

Victoria Hospital, Kirkcaldy, Fife KY2 5AH, UK
AW Blair
CR Steer

Accepted 14 August 1995

Your child is brain dead

Alastair W Blair, Christopher R Steer

The daunting situation of dealing with brain death, with the implied requirement to decide whether continuation of life support is appropriate, is a relatively uncommon challenge in paediatrics. However, with the advent of increasingly sophisticated intensive care, this problem arises sufficiently frequently to mean that most paediatricians in acute hospital practice will be confronted with it at intervals during their professional careers. The literature suggests that 1% of neonates who die are determined 'brain dead' and that in paediatric intensive care units, between 1 and 2% of admissions eventually fulfil the criteria for brain death.^{2–5} Ischaemic anoxic insults and brain trauma account for more than two-thirds of brain deaths in paediatric intensive care units (box 1).⁵

What is brain death?

Brain death may be defined as irreversible loss of function of the whole brain.^{6–9} Absent cerebral cortical and brainstem function are regarded as constituting the death of the individual. Irreversible absence of all brainstem functions is the cornerstone of diagnosis in brain death.^{7,10,11} Since loss of lower brainstem function implies loss of the capacity to breathe spontaneously, brain death can only be 'observed' in patients undergoing artificial ventilation. Because of the need for viable whole organs for transplantation, criteria are therefore required for brain death which allow physicians to perform tests to fulfil those criteria while the patient (potential donor) is haemodynamically stable with organs which are in an optimal condition for transplantation. The well known Harvard criteria were first drawn up in 1968⁶ and were designed to determine 'whole' brain death, including death of the neocortex, ie, excluding the persistent vegetative state. These original criteria have been extensively discussed and modified for use in paediatric practice^{1,12–15} and, in spite of some controversy, particularly with regard to assessment of brain death in neonates, a consensus approach to the determination of brain death in children has been generally agreed.^{5,16–18} The criteria for determination of brain death in children are summarised in box 2.

Preparing the ground

Progress of a child towards brain death can sometimes be anticipated and in this situation it may be useful to help the parents realise the gravity of the situation before pronouncement of brain death is actually made. Even when the diagnosis is clinically evident to attending medical staff, it is sometimes appropriate to allow time to pass so that the parents realise for themselves, possibly assisted by discussions with the nursing and medical staff, the reality of the situation. Sufficient length and depth of relationship between the attending professionals and parents is helpful in assisting relatives to cope with a tragic experience that none of them will ever forget. When time is available, this allows exploration of the beliefs and faiths of parents and may help to identify which agencies in the community they are likely to turn to, or find acceptable, in the aftermath, when formal contact with the intensive care unit will have ceased. Time also helps to generate a degree of mutual respect upon which mutual support can be based. This mutuality of support is important because intensive care staff often suffer considerable stress in these situations and parents may themselves play an enormously important role (sometimes unwittingly) in helping staff to cope.

Families, of course, vary considerably in how they react to these situations; for example, grandparents or other members of a wider family can be brought into the process by parents and may be of great value in helping them to approach issues which they find difficult to confront. Formal meetings with parents form an important part of information giving and gathering, for example, planned meetings with the consultant who has overall responsibility for a child's care. These meetings are probably best regarded as 'way points' in a continuing process of contact with the intensive care unit professionals. It is obviously necessary that parts of the process such as disclosing the diagnosis of brain death,

Aetiology of brain death in paediatric intensive care units ⁵	
ischaemic anoxic insults	41%*
CNS trauma	32%*
infections	10%
cerebrovascular disease	8%
metabolic	6%
structural	3%
n	387**
*Particularly when combined in child abuse	
**66% aged < 5 years	

Box 1

Brain death guidelines in children (modified from ¹⁶)
<p>The examination should be carried out by two physicians:</p> <p><i>History:</i> determine the cause of coma to eliminate remediable or reversible conditions eg, drug effects; hypothermia; metabolic disorders; surgically remediable brainstem compression</p> <p><i>Physical examination:</i></p> <ul style="list-style-type: none">• coma and apnoea• absent brainstem function<ul style="list-style-type: none">– mid position or fully dilated pupils– absent oculocephalic ('doll's eye') movement– absent caloric-induced eye movement– absent corneal, gag, cough, suck and root reflexes– absent respiratory movement with standardised testing for apnoea– patient not hypothermic or hypotensive– flaccid tone and absent spontaneous or induced movement (excluding reflex, spinal flex or activity)– consistent examination findings throughout a predetermined period of observation <p><i>Suggested period and investigation according to age</i></p> <ul style="list-style-type: none">• up to 2 months: two examinations with isoelectric EEGs 48 h apart• 2 months and over: two examinations 12–24 h apart depending on age with corroborative EEG (electrocerebral silence) if possible and where feasible radionucleotide scanning or cerebroangiography demonstrating absent cerebral flow* <p>*For more detailed discussion of age-dependent examination techniques and role of ancillary tests see refs⁵ and¹⁹</p>

Box 2

and deciding whether to continue life support should be a more formal, and duly recorded and witnessed process; but the continuum of contact will identify those people within the professional team to whom the parents relate best.

Facing the issue

Once the diagnosis of brain death has been realised, the obvious next issue is whether to continue or discontinue life support. If this is delayed for too long and there is any question of organ donation for transplantation purposes, organ viability may suffer as a result of loss of homeostasis which accompanies brain death.⁵ Many parents will arrive at their own decision regarding life support unprompted but in any case it is wiser to 'stage-manage' the process so that the parents are allowed to arrive at their own decision on the matter whilst feeling that they are taking the initiative. Even though some will turn to professionals for their support and advice it is important to remember that in future years these same parents will go over the decision-making processes in their minds again and again. It is crucial for them to feel that they were in no way pressurised. In determining the final decision whether to discontinue life support the parental decision is obviously paramount and takes precedence.

The second point is to support parents in whichever decision they make. If they agree that life support should be discontinued then it is of fundamental importance that they should be absolutely convinced that the child *is* brain dead and they should, therefore, have the matter explained to them in detail and should be encouraged to ask any questions or even witness any of the testing personally. This is time well spent because the agonies of doubt which may assail parents who feel that they may have made the decision too hastily must be hard to bear. There are reports of patients recovering from persistent vegetative states after prior periods of life support. These must be very disturbing to parents who have elected to discontinue such life support and it is therefore important to explain clearly the difference between ventilator-dependent brain dead individuals and those who are in a persistent vegetative stage. The natural tendency to spare parents' sensitivities by using euphemisms and not fully including them in the very stressful process of switching off, is misguided. Their questions must be answered sensitively but factually. They must be allowed time for reflection and any re-iteration of the questioning should be accepted sympathetically.

Once the decision is taken to discontinue life support it should not be implemented with undue haste and the parents should be allowed time to decide, after consultation with the wider family if desired, how they wish it to be effected. Some will wish the involvement of religious ceremonies and some may wish independent counselling; such things are usually possible to arrange in the circumstances. At the stage of managing the switching off process, some may wish to be present, some may not. At this juncture the clinician in charge of the case must give due consideration to the other staff working in the unit who may themselves require some support. In general it should be the most senior person available who actually turns the switches. For the purposes of higher medical training it may be necessary and desirable for other members of the junior or middle grade staff to be present in order to witness and learn from the process. Delegation of a 'switching off' task to junior staff is inappropriate and is best avoided wherever possible.

Continuation of cardiac impulses after switches have been turned off can be found by some to be quite distressing. Parents and less experienced staff should be given due warning about this; continuing a visible and audible ECG monitor is usually inappropriate where auscultation will suffice to determine asystole. In the case of children, many parents will wish the child to die in their arms and the life support systems can be disconnected for this purpose, along with the monitoring equipment. Due attention must be given to the degree of privacy which is appropriate for parents in this phase of acute grief. Experienced nursing staff are invaluable in giving appropriate weight to this kind of detail. Side-room accommodation is obviously ideal, but where this is not available consideration has to be given to such matters as the number of the professional attendants present in the room at the time of death, the possibility that there may be visitors to other children in the unit and the intrusion by clinical routines being carried out nearby.

Should the parents decide against discontinuation of life support, the immediate process of decision-making is postponed but the overall situation is, if anything, rather more difficult to manage. As mentioned above, the clinician's duty is to support the parents in their decision and not to try and influence it otherwise. It is quite likely that they will finally arrive at the decision to switch off at a later date and there is no way of anticipating when that point will be reached.

Immediate provision following death must allow parents an expression of

Case history

Hearsay from other cases
Parents report they have heard of comatose cases on life-support systems for long periods of time eventually making full recovery

Reassurances:

- these cases are persistent vegetative state which, if looked into in detail, would not fulfil the present criteria of brain death
- some of these anecdotal examples date back to the controversies that led to definition of brain death, and still circulate
- a great deal of account has to be taken of the matter of irreversibility, particularly prompted by the need to make organ donation acceptable. There is therefore more professional conviction that the criteria are satisfactory

Box 3

Case history

Differing view between parents
A couple agree to proceed to 'switch off' their dead infant but senior nursing staff report suspicion that father wants this and mother agrees verbally but seems unhappy and unconvinced.

Suggested action:

- senior decision maker meets couple together and re-iterates the ground
- emphasis is on **not** to rush or pressurise the decision
- opportunity is sought to confront the issue of non-concordance of view and implications discussed
- offer opportunity of other counselling agencies
- indicate the undesirability of acting until unanimity reached
- fix a review of the situation after a short interval

Box 4

Aftermath

- identify an appropriate time and place for acute grief
- emotional and related care needs of family other children to be catered for by involving minister, priest, rabbi or social agency to provide emotional support and comfort
- involve primary care team – general practitioner, health visitor
- follow-up visits, eg, to discuss outstanding issues, *post-mortem* reports, etc.
- care, counselling and support of medical and nursing team

Box 5

acute grief in private or in the company of the people they request to be present. An appropriate quiet room or area should be identified for this beforehand; experienced nursing staff are usually particularly helpful and thoughtful with regard to practical issues, such as providing tea and tissues at this stage and are often less reticent than many medical staff in providing direct emotional support. Effectiveness in breaking bad news and dealing with distressed relatives is something that improves with experience. Increasingly, however, these skills can be improved by teaching, eg, using video or role-play. The literature contains some useful pointers,^{20–24} and for example, explores such issues as non-verbal communication and the role of touch.^{25–27} 'Non-touching' is described as the 'English disease'.²⁷

It seems harsh that in this phase parents are likely to be asked to give their permission for a *post-mortem* examination, although this will be easier for them if the matter has been the subject of discussion beforehand. It is important to most parents that the availability of contact with the professionals in the intensive care unit is not simply 'turned off' at this point. They need to know that the people who have been expressing concern and support really *do* care about their child and about the outcome (such seemingly trivial matters as, for example, what happens to the child's favourite toys is of help). Parents may develop acute anxieties about some particular question, logical or illogical, and wish to speak to senior medical or nursing staff to have their anxieties alleviated. This should be done by the most expeditious means possible, eg, by telephone or an informal follow-up visit, without the delays implied by a need to make appointments, etc.

Longer term support

A formal follow-up appointment may be a useful means of allowing parents to bring up any questions or comments that may linger in their minds and to discuss the *post-mortem* results. Many parents will have found their own source of support without the hospital, but it is useful to have some information about bereavement and counselling services offered either at interview or in the form of a pamphlet. It is appropriate to raise this subject with them at some point as many parents will feel inhibited to make the contact on their own initiative, but will accept the offer of help from people they know to put them in touch. The general practitioner should always be informed and may play a key role in supporting the family. If there is evidence of a prolonged or maladaptive grieving process either in parents or siblings of the dead child, counselling and psychology follow up services may be required.

Ultimate overall management comprises a combination of common sense, sensitivity and compassion on the part of medical and nursing staff dealing with these tragic situations. With attention to detail and careful planning the process can be made less painful for all concerned, with an emphasis on an understanding and positive approach rather than one is either 'blunt and unfeeling' or 'kind and sad'.^{22,23} Historically education of nursing and medical staff in this area has been on an 'apprenticeship' basis through experience rather than formal teaching and in some cases junior staff have been placed in inappropriate situations of managing brain death. There is some evidence that the education needs of undergraduate and postgraduate students in this area are now beginning to be addressed.^{28–32}

Many units are also developing follow-up counselling and support groups for medical and nursing staff to help them cope with the processes outlined above. Such critical incident 'debriefing'³³ is certainly desirable and necessary, particularly in paediatric intensive care units with a high patient turnover. This helps to minimise chronic anxiety and burn-out in staff and promotes the concept of team work which is so vital in the management of sick children and their families. Some of the points discussed above are summarised in boxes 5 and 7.

1 Ashwal S, Schneider S. Brain death in the newborn. *Paediatrics* 1989; **84**: 429–37.

2 Edmonds JF, Wong S. Pediatric brain death and organ transplantation. In: Kaufman HH, ed. *Pediatric brain death and organ/tissue retrieval: medical, ethical and legal aspects*. New York: Plenum Publishing Corp, 1989; p89.

3 Bruce D. Brain death in children: the Philadelphia experience. In: Kaufman HH, ed. *Pediatric brain death and organ/tissue retrieval: medical, ethical and legal aspects*. New York: Plenum Publishing Corp, 1989; p83.

4 Black PM, Torres ID. Brain death in children: guidelines and experience at the Massachusetts General Hospital. In: Kaufman HH, ed. *Pediatric brain death and organ tissue retrieval: medical, ethical and legal aspects*. New York: Plenum Publishing Corp, 1989; p75.

5 Ashwal S, Schneider S. Pediatric brain death : current perspectives. *Adv Pediatr* 1991; **38**: 181–202.

6 A definition of irreversible coma: Report of the Ad Hoc Committee of the Harvard Medical School to examine the definition of brain death. *JAMA* 1968; **205**: 337.

7 An appraisal of the criteria of cerebral death : a summary statement *JAMA* 1976; **237**: 982.

8 Conference of the Royal Colleges and Faculties of the United Kingdom. Diagnosis of brain death. *Lancet* 1976; **2**: 1069.

9 Report of the Medical Consultants on the diagnosis of death to the Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research: Guidelines for the determination of brain death. *Neurology* 1982; **32**: 395–9.

Some ‘do nots’

- do not rush or pressurise a decision
- do not become impatient with request to cover the same ground many times
- do not withhold information
- do not peripheralise the parents in the decision processes
- do not over-promote the issue of organ donation
- do not withdraw contact after the ‘switch off’

Box 6

Summary points

- establish brain death with *certainty* using recognised criteria
- prepare and discuss with parents/family
 - the underlying condition
 - what constitutes brain death
 - why and how it has occurred
 - differences between brain death and persistent vegetative state
- provide emotional and practical support – continual contact between the family and
 - a responsible decision maker
 - the intensive care staff providing hour by hour care
- allow time for acceptance of the situation
- involve the parents centrally in final decision making and participation in the ‘switch off’ process if requested
- when counselling sit close enough to be easily seen and heard in an area where you won’t be disturbed; avoid physical barriers such as tables or desks; achieve and sustain eye contact; extend a comforting touch to the relative’s shoulder or hand, if appropriate.

Box 7

10 Black PM. Brain death. *N Engl J Med* 1978; **299**: 393–400.

11 Ad Hoc Committee on Brain Death, The Childrens Hospital Boston. Determination of brain death. *J Pediatrics* 1987; **110**: 15–9.

12 Volpe JJ. Commentary. Brain death determination in the newborn. *Pediatrics* 1987; **80**: 293–7.

13 Coulter DL. Special article. Neurologic uncertainty in newborn intensive care. *N Engl J Med* 1986; **316**: 840–4.

14 Watchko JF. Neurologic uncertainty in newborn intensive care. *N Engl J Med* 1987; **317**: 960.

15 Ashwal S. Brain death in the newborn. *Clin Perinatol* 1989; **16**: 501–8.

16 Guidelines for the determination of brain death in children. *Pediatrics* 1987; **80**: 298–300.

17 Stephenson C. Brain death in children. *Focus Crit Care* 1987; **14**: 49–56.

18 Moshe SL, Alvarez LA. Diagnosis of brain death in children. *J Clin Neurophysiol* 1986; **3**: 239–49.

19 Farrell MM, Levin DL. Brain death in the pediatric patient: historical, sociological, medical, religious, cultural, legal and ethical considerations. *Crit Care Med* 1933; **21**: 1951–65.

20 Campbell ML. Breaking bad news to patients – clinical guidelines. *JAMA* 1994; **271**: 1052.

21 McLaughlan CAJ. Handling distressed relatives and breaking bad news. *BMJ* 1990; **301**: 1145–9.

22 Charlton RC. Breaking bad news. *Med J Aust* 1992; **157**: 615.

23 Brewin TR. Three ways of giving bad news. *Lancet* 1991; **337**: 1207–9.

24 Kaiser RMM. The challenge of breaking bad news. (editorial). *Hosp Pract* 1993; **28**: 13–4.

25 Breaking bad news – knowledge for practice – professional development. *Nursing Times* 1994; **90**: (suppl) 1–4.

26 Buis C, De Boo T, Hull R. Touch and breaking bad news. *Fam Pract* 1991; **8**: 303–4.

27 Heylings PNK. Personal View. *BMJ* 1973; **2**: 111.

28 Sykes N. Medical students fears about breaking bad news. *Lancet* 1989; **2** (8662): 564.

29 Knox JDE, Thomson GM. Breaking bad news: medical undergraduate communication skills teaching and learning. *Med Educ* 1989; **23**: 258–61.

30 Pearce P. Breaking bad news. *Med J Aust* 1993; **158**: 137.

31 Charlton RC. Letter in reply to Bruyn NJ. Breaking bad news. *Med J Aust* 1993; **158**: 137–8.

32 Gillard JH, Dent THS, Aarons E, et al. Preregistration house officers in the Thames Regions: changes in the quality of training after four years. *BMJ* 1993; **307**: 1176–9.

33 Swanson RW. Psychological issues in CPR. *Ann Emerg Med* 1993; **22**: 350–3.

Appendix:

SOME USEFUL ADDRESSES

‘SANDS’

Stillbirth and Neonatal Death Society,
28 Portland Place,
LONDON W1N 4DE
Helpline: 0171 436 5881
Publications: 0171 436 7940
Fax: 0171 436 3715

Local group contact numbers should be available at every maternity unit. Self-help and support in stillbirth and neonatal deaths. (Each hospital should have contact arrangements for their own Regional Transplant Co-ordinator, who usually offers counselling and follow up arrangements directly or via other agencies.)

COMPASSIONATE FRIENDS

6 Denmark Street,
BRISTOL BS1 5DQ
Tel: 01179 292778

Nationwide network for self help for bereaved parents

BRITISH ORGAN DONOR SOCIETY (BODY)

Balsham,
CAMBRIDGE CB1 6DL
Tel: 01223 893636

Self help and support on organ donation issues

CRUSE (FOR CARE OF THE BEREAVED)

CRUSE House,
126 Skene Road,
RICHMOND,
Surrey TW9 1UR
Tel: 0171 940 4818