Transplantation: The relatives' view

Priscilla M Demetrius and the Parents of John

The following short contributions add to the debate on transplantation: one describes the distress of a woman recently widowed when asked for the organs of her dead husband for transplantation, and the other the eagerness with which a boy awaits the death of a potential kidney donor – not a heartless emotion but the longing for a new lease of life.

Donor consent

In a recent report from the British Transplantation Society¹, it was stated that the serious shortage of vitally needed organs for transplantation is due to deep-seated apathy and ignorance among doctors and the public.

I write this note from personal experience, having recently lost my husband, a chartered accountant, at the age of 30. He was in hospital for exactly one week suffering from severe hypertension. It was thought that he was responding to treatment, when quite unexpectedly a brain haemorrhage occurred. On my arrival at the hospital's intensive care unit, I was told that my husband's condition was extremely critical and that it was unlikely he would survive through the night.

The next day I was again called in by the hospital. On this occasion I was informed that my husband had only a few hours to live and asked if I would give my permission for an examination to be carried out to determine the extent of the brain damage. This in itself was a difficult and painful decision to have to make, as I was fully aware that such a test was not going to help my husband to recover. However, in addition to this, I was then asked if I could consider also the donation of his kidneys.

In my state of acute shock, distress and grief, there suddenly came this totally unexpected question – I was astounded and utterly appalled at such a complete lack of feeling. It was dreadful enough to make the decision about the brain examination, but the suggestion of offering his kidneys also was just too much to endure at that precise moment. To make such a decision for oneself is hard enough but to be asked to make it on behalf of another, while one is so shocked and grief-stricken, is both harrowing and cruel. When I remarked that I thought people filled in forms when they wished to donate

their organs, the reply given to me was that unfortunately they do not and that is why relatives are asked instead.

I now try to look at the situation as objectively as I can – as a mother of two children under 4 years of age, I know that if they desperately needed a kidney transplant, I should probably want them to receive one. However, I should want it to be from a patient who had genuinely expressed his own wish to donate organs. Never would I want any close relative to suffer as I had done in making such an agonizing decision during the worst moment of a life time.

At such a time of intense grief and shock, one is by no means ignorant or apathetic – one simply feels that where there is life there is hope and one wonders where science and technology end and where humanity and compassion begin.

PRISCILLA M DEMETRIUS

Availability of kidneys

Our son John formed kidney stones at an early age. His two brothers also showed signs of this complaint but as far as we know there is no family history of such a condition. At the age of 13 John had an operation to remove a large stone from one of his kidneys. The kidney did not recover its function afterwards and we learned that the other kidney had very little. The eventual outcome was that John required haemodialysis. He was selected to have this treatment – one of the youngest patients 'on the machine'. It was interesting to us that one of the main reasons for his selection was that he had, in the opinion of the doctors, a stable home background.

John, who is now 17½, has been kept going on his home machine. We cannot speak too highly of the medical expertise which has been at his disposal, and the way in which the local hospital pharmacy supplies all that is required. From our point of view the National Health Service is a very wonderful thing.

John's health has been reasonable, although many others, especially older patients, we think, keep on the whole in better health. He has been able to go to school for the most part of the time. In June of last

¹British Medical Journal (1975). 1, 251-255.

year he was given a cadaver kidney. The transplant to begin with looked like being a success but the kidney was rejected within six weeks. One of John's problems was his sensitivity to an antirejection drug which had to be discontinued after a time.

Once again the medical team did all they could and were naturally very disappointed at the result. It must be said, however, that those looking after John at this time did not know his past medical history, and that appeared to us to be a breakdown in communication.

John's hopes were dashed after such a long wait for a kidney. He had planned to do so much with better health. It has been said that there is no such person as a thalidomide child but rather a thalidomide family, and we think that this is also true in the case of families with our problem. John's morale is wonderful, and he looks forward to receiving a second kidney.

The problem of course is the availability of kidneys for transplantation. In the early days John would read of a road accident in the papers and wonder if there would be a kidney for him. This way of thinking is not really morbid when one is waiting desperately for a new lease of life.

Recent figures published by the British Transplantation Society reveal the acute shortage of kidneys for transplantation. Four hundred and fifty kidneys a year were being transplanted in the UK whereas around 2000 people a year need transplants. For a number of years now we have carried around with us a kidney-donor card which gives written

consent, in the event of accidental death, for doctors to make use of the kidneys for grafting. These cards are seldom if ever available in local doctors' surgeries, and one cannot help feeling that there is still widespread ignorance of this pressing problem. We managed to get a supply of these cards (old form) from the hospital, and found our best outlet for them in a petrol pump attendant, a medical student doing a holiday job, who generously distributed them to his customers.

Although in our own case we now feel that a kidney from one of us may be the answer to John's need, and hope to persuade the medical team that this is so, we are glad when attempts are made legally to increase the availability of kidneys. We should certainly have supported Tam Dalyell's Private Members Bill (see page 61) which made provision for the 'opting-out' principle on accidental death, allowing perhaps for certain exceptions.

We should like to add a footnote. It is when one is involved with this kind of illness and when visiting in renal wards in our hospitals and seeing so many young people, whose lives could be transformed by receiving a kidney, that one would gladly do all in one's power to secure this. On the question of keeping a body alive so as to make use of spare parts, we might hesitate to say 'Yes'. Yet when we have no longer need of the 'house of this tabernacle', which is the body, then we would be glad to think that a part of it might help another to live.

PARENTS OF JOHN