that Andrew’s pain, as well as our own, was finished at last; relief that we had all escaped the clutches of Pediatric Hospital at last.

We have taken the money that might have gone under different circumstances for a graveside marker and committed it to the only memorial which can have any meaning for us now: to the sponsorship of a living child, an impoverished child whose only problem at birth was that he was born into an affluent society that does not choose to put his well-being at very high priority. For we believe Andrew’s case raises broad and difficult questions which the medical profession in particular and society as a whole must face up to.

What sort of memories or thoughts could we have of Andrew? By the time he was allowed to die, the technology being used to ‘salvage’ him had produced not so much a human life as a grotesque caricature of a human life, a ‘person’ with a stunted, deteriorating brain and scarcely an undamaged vital organ in his body, who existed only as an extension of a machine. This is the image left to us for the rest of our lives of our son, Andrew.

SINCERELY YOURS

How did the hospital reply?

The administration agreed to drop the $2,100 charge and think about ways of improving parent–staff relations, but Mr Clark’s response did not address seriously any of the issues Andrew’s case raised. The official reply cited the progress in infant survival that had come about ‘because of perseverance in units such as ours,’ and regretted that we had interpreted Dr Farrell’s behaviour as offensive. His ‘very behaviour reflects the hospital’s mission of providing tertiary care,’ Mr Clark explained.

No one can deny that there has been progress in saving premature infants, and we are happy for the children and families who can benefit from the experimentation that made this possible. But there will always be a frontier to challenge neonatologists—an ‘Andrew’ of 600 grams or 300: of 20 weeks, or 16, or 12. Success even at these levels may someday be possible, but as doctors press onward they will inflict pain and heavy costs on tiny subjects and their families.

Who will set the limits? Can society afford to pay? If research must proceed, can’t we at least limit it to consenting families?

We referred Andrew’s case to the hospital’s patient care committee, but without apparent result. We sent twenty copies of our letter to people involved in Andrew’s life and death and asked most for a response, but only two replied.

Aren’t these issues of interest? Shouldn’t we all be discussing them? If there are others who do not wish to deal with hospitals whose mission is to act as Pediatric Hospital did, they must make their wishes known.

Commentary I

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My immediate reaction to the story of Andrew Stinson is primarily one of horror. The faults appear to be entirely on the side of the hospital and the doctors. Over enthusiastic recourse to a multitude of treatments, many burdensome to the infant, with complications that they, the doctors themselves, should have foreseen; the lack of personal, continuous care of the infant in the hands of one senior responsible clinician; the failure to discuss the child’s illness with the parents, the initiation of intricate and risky procedures without prior consent, and, finally, the threat to the parents of a Court Order to give the hospital doctors the right to carry on with their treatment, even if the parents objected.

It is impossible at this distance and time to assess the validity of such criticisms, but the fact that parents have felt impelled to write in detail of these harrowing six months, is cause enough for those with the responsibility for care of neonates to reconsider their objectives, their techniques, their capacity to keep the parents informed and, above all, the ethical basis on which their actions are based.

The emotional burden on the parents during Andrew’s short life is evident from the story they write, a history which at times is couched in emotive terms, ‘a desperately premature baby’, ‘cruel institutionalised life’, ‘state of painful deterioration’, but this in no way invalidates their critical theme.

Relying, as we must do, only on the evidence put forward in the letter of the parents, it appears that even at the Community Hospital, where the child, although extremely premature, was able to receive ordinary baby care, the parents insisted there should be ‘no heroics’. Now it may well be that if the baby had been brought to the attention of the special baby-care unit straight away, the outcome might have been different; one cannot ignore the enormous advances made in the care of very premature babies in many special-care baby units, for example at University College Hospital in London. As for ‘no heroics’, how do you translate such a simplistic lay term into professional care? Does it mean no intubation and assisted respiration? The point I am making is that it would be tragic if an article like this were to set parents against special baby-care units, so that they might refuse to allow their infant to be transferred to such a unit.

It appears that the parents on their first visit to the special baby-care unit ‘tried to raise the same issues of extraordinary treatment and quality of life that we had been discussing at Community Hospital’. Although one may be critical of the tepid
reaction of the doctors in the special baby-care unit, no doubt heavily involved in their very difficult and intricate work, one wonders what might have been their underlying feelings. Was it a wish to put to the parents the question 'Do you wish to have a long discussion about the issues of extraordinary treatment and quality of life, or do you want me to get on with the immediate problem of attending to your baby?' For in these circumstances minutes may be important. It must have placed the doctors at the special baby-care unit in a difficult position when at the first meeting with the parents they were told that they, the parents, opposed extraordinary efforts to keep Andrew alive, and that if his troubled breathing failed, they opposed placing him on a respirator.

The first extraordinary effort was the transfer of Andrew to the special baby-care unit, and since the parents must have given consent for this transfer the doctors were surely entitled to think that their special expertise was needed, and was in fact being requested by the parents, who had agreed to the transfer of the baby. It must have been extremely frustrating to have the parents express opposition to one type of specialist treatment, the respirator, particularly when it was clear to everyone that the respiratory system was the basis of the child's disease.

The publicity that has surrounded the long-continued use of respirators in certain patients who eventually died, may lead lay people to have a horror of its suggested use for their child, when it is one of the most widely used and successful techniques in all patients from premature babies to old age, a technique which modern medicine and surgery simply could not do without.

It seems quite clear that the parents did not understand that the use of a respirator was a perfectly ordinary and everyday method of handling a patient in a special baby-care unit—but it is not the parents who are to blame for this lack of knowledge. It is partly the publicity given to certain cases by the media, but I think very largely the failure of communication between the doctors and the parents, and the blame for this lies fairly and squarely on the doctors.

One has the impression in reading this account of Andrew's hospital life that there did not appear to be one doctor in overall charge, but that the system involved a rotation between the senior doctors and, of course, a lot of junior doctors must have been involved as well, so that possibly none had a complete picture of Andrew's management which they were prepared to discuss with the parents. I wonder if the parents can realise how disappointing, frustrating and even heart-breaking it can be for the various measures which the doctor institutes to be failures or to lead to further complications. These feelings must have been exaggerated if the parents made it clear that the doctors were 'arrogating decisions' to themselves when they made some of the hundreds of decisions which they must make every day in doing the best they can for their patient.

It is particularly distressing to me as a clinical teacher in a University Hospital to read that junior doctors were prepared to come to the opinion and even write in the records that 'the parents were difficult' or 'not cooperative'. If I have found similar statements about the attitude of parents in the records of my patients, I have made a special point of having a talk with the parents, and although on some occasions I have had to agree with the comments, in most cases I think it is the doctor who has been difficult. Of course, I realise that the attitude of the parents may change enormously when they are confronted by a senior consultant, and that they may quickly abandon any high-handed approach which they have been using with junior staff.

However, the explanation surely is that the parents are anxious, probably over-anxious, and it is the doctor's job to find out what they are worried about and it is his duty to find a point of contact with them and not the other way round.

It is clear, however, that for a number of months the doctors did not give up hope that the outcome might be successful. In general terms, if spontaneous ventilation of the lungs is not enough, it is wise to assist respiration in the hope that the spontaneous control will return. In the same way, if satisfactory nutrition by mouth is impossible, intravenous alimentation, with all its risks and difficulties, may well be worthwhile, even if it is to last for a good many weeks. However, an important aspect of the parents' criticism is that the doctors continued their treatment for far too long. I think one ought to give the doctors credit for giving treatment for as long as they thought there was the chance of it improving the quality of life of the patient; the doctor at some time has to make up his mind whether the burden of continued treatment is disproportionate to its possible benefit and to the chances of that benefit being realised.

This is a field in which there are likely to be differences in judgement among doctors whose experience and skill vary from one to another. The course of the illness may also be very different from the expectations of parents, who, without adequate background knowledge, may feel their baby is being 'kept alive' without adequate reason, or on the other hand, may feel that doctors are giving up too easily.

Should doctors abandon treatment or even fail to begin treatment which has a reasonable chance of saving the patient's life and perhaps improving his overall health, if in the doctors' opinion the residual disability makes 'life not worth living'. I do not believe this to be the role of the doctor—to decide what degree of disability makes life unbearable for
the patient. His purpose, whatever the disability, is to improve the quality of that life and to alleviate the burden—not to end that life by failing to give appropriate treatment or even more so by direct action to terminate that life. An important guiding principle for those doctors proposing active treatment is that the therapy should not be disproportionately burdensome to the patient, taking into account the benefit which might be expected.

Most doctors are only too aware of their own fallibility in prognosis. I well remember a child of nine months of age whose abdomen was full of tumour at the time of operation and I could do nothing. I went round to the mother’s house and told her the outlook was hopeless, and that I did not expect him to live for more than a few weeks. That was 18 years ago and he is very well.

A newborn baby had a bowel obstruction and at operation the entire small intestine was black. To remove it all would be certain to lead to the child’s eventual death in spite of perhaps weeks or even months of intravenous feeding. I removed most of the small intestine, but left a small portion at the upper end, near the stomach, and a similar portion at the lower end, near the large bowel. I thought the outlook was hopeless. To my astonishment, these portions of bowels survived and eventually were sufficient to maintain adequate nutrition of the baby.

The point I am making is that, even to the most expert doctors, it is not as easy as many patients or many parents think to give a clear idea of the outcome, and doctors have a duty not to give up too easily.

It is now appropriate to consider in more general terms the responsibilities of the doctor in treating seriously ill patients, especially those in whom recovery is likely to leave residual disability, of greater or less degree. It should be said at the outset that most doctors realise full well that they are not called upon to prolong the process of dying, but this clearly implies that death is imminent and inevitable. It certainly should not apply where death from the disease can be prevented, or the patient’s condition improved even for a number of months.

There is a tendency to rely on totally different criteria in management of the newborn from those which are accepted in an adult. Many an adult has treatment, medical or surgical, for conditions which can be alleviated but not cured, and in which there may be considerable residual disability, whereas a rather more selective approach is now being used in the management of similar conditions in infancy. One has only to think of the contrast in the attitude among some doctors between the management of an adult with paralysis of the lower limbs, following a fracture of the spine, and a baby born with spina bifida who has a similar type of paralysis. Nor does the discrimination against the newborn stop there. Not only are a number of such babies denied ordinary, good baby-care, but many have been put on a regime of hypnotic drug therapy and underfeeding so that they will die, a practice which would cause an uproar if applied to adults.

Perhaps the most serious aspect of this regime is the deception of parents. They are told the baby will die without operation and that he will have a little sedative to make his short life easier. Yet, with ordinary, good baby-care, even without operation, it is by no means certain that the child will die and the sedative, which is ostensibly given to relieve pain, is not a pain-relieving drug but a hypnotic drug which is given for the purpose of ensuring that the child will die. Parents are not told this.

Here we have the other side of the important aspect of communication between the doctor and the parents. It is not even enough for the doctor to say words which are true. The information he gives to the parents should be put in such a way that what the parents understand is true; and if this does not happen the doctor is failing in his duty. It is wrong for the doctor to give hypnotic drugs in order to accomplish the death of an infant, even though he thinks the residual disability will make ‘life not worth living’. It is also wrong for him to deceive the parents into thinking that their child is dying spontaneously.

On the other side of the coin, the doctor is not justified in telling the parents untruths; that the prognosis is good, when in fact it is bad, and it is almost as bad to leave parents in ignorance, as apparently happened to the Stinsons.

The doctors must have thought that their strenuous efforts were not disproportionate to the chances of success and the degree of improvement to be expected, and they must have judged that in the circumstances they were not unduly burdensome to the patient. I think we ought to give them credit for this at least, and if only they had taken the parents into their confidence and not only told them what they, the doctors, believed to be true, but told it in such a way that what the parents understood was true, the letter from the parents to the Hospital Administrator could have been very different.

Commentary 2

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Unfortunately, this experience is not unique to the Stinsons. It is not unique to this particular ‘Pediatric Hospital Center’ (PHC) intensive care unit and, perhaps with the exception of the financial cost, it is not unique to the United States. What is unusual, if not unique, is that the Stinsons had the courage