Lives in Question

HOW FAR should we go in prolonging the lives of severely disabled new born babies? This is a question at the heart of widespread public debate brought to the fore by the recent Dr Arthur case. This Supplement attempts to clarify some of the issues by carrying the views of some leading professionals, and of parents.

Association for Spina Bifida and Hydrocephalus/ASBAH

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This introduction is by Mr Duncan Forrest, Consultant Paediatric Surgeon at Westminster Children's Hospital, and Chairman of ASBAH's Medical Committee.

Medical science has made it possible to prolong life . . . it is easy to go to unnatural extremes . . .

But where to draw the line?

IN RECENT years we have lived through a period of great change. Our ability to prolong life, as much by the general raising of the standard of living and society's expectations of survival as by improved methods of treatment, has made it imperative to face facts which have always been there but previously of only marginal importance.

Natural miscarriage still accounts for a large number of lost babies, often from mothers who desperately want a child. The majority of these natural abortions are of abnormal fetuses—nature's way of ensuring healthy children. Those who favour abortion for abnormalities may be regarded as carrying to a logical conclusion a process which nature has failed to complete. By a logical extension of this thinking it can be argued that the early death of those born with severe malformations is justified, but clearly there must be a strict limit to what could be tolerated in a civilised society. It is still illegal, and probably will remain so, to do anything to deliberately shorten a life.

Nobody would argue for a complete return to a totally natural state of affairs—our whole way of life has become far too far removed from a state of nature for that, yet many people use phrases such as "let nature take its course"—phrases which have lost all meaning.

At the other end of the scale many people feel strongly that any child they bear must be given every encouragement to live and thrive. They emphasise the way in which a handicapped child can enrich the lives of the whole family, and the fact that many disabled people live full and useful lives. It must be acknowledged, though, that in other cases the birth of an abnormal baby destroys the family.

Medical science has now made it possible to prolong life so successfully that it is easy to go to unnatural extremes. Everyone, whatever his beliefs, must draw the line somewhere. Where that line should be drawn is the difficult question that can have no single answer.

All the views put forward on these pages are held by thinking, compassionate people who honestly believe that they have the best interests of the patient and his family at heart. With such a variety of responses to these complex moral and practical problems, ASBAH cannot have a single official policy but must work for the good of all.

There have been spectacular advances in pre-natal diagnosis with refinement of the bio-chemical estimations and techniques of ultra-sound inspection of the fetus, but nobody would pretend that early detection, however accurate, followed by abortion is an ideal solution. Nor can examination after birth ever hope to give foolproof prediction of how handicapped the individual will be, so advice to new parents about selection can only be approximate. Further investigation into the causes of spina bifida with true prevention of the defect by dietary or other means as suggested by Professor R W Smithells of the Dept. of Child Health and Paediatrics, University of Leeds, is the path to the true solution of the spina bifida tragedy.

The wide publicity given by the media to the problems of spina bifida and other malformations has made the public at least aware of the possibility of a child being born abnormal. In spite of this, most parents are caught completely unprepared after pre-natal diagnosis or when a handicapped child is born to them. It is often suggested that ante-natal clinics should give more emphasis to such a possibility. However, it would be wrong to spoil the natural joy of pregnancy by introducing too many morbid fears. On the other hand, it is sensible to encourage prospective parents to crystallise their ideas in general on subjects such as abortion, selection and the place of the handicapped in the community, so that if they find themselves in such a crisis they will have some knowledge of the issues involved.

Those who already have a handicapped child are, of course, only too well aware of the problems they face if they embark on another pregnancy. They have been helped enormously by the development of pre-natal testing, especially when accompanied by compassionate counselling.

The author of this article is Ian Kennedy, Reader in Law at King's College, London, and the 1980 Reith Lecturer.

The article first appeared in the magazine New Society.

The judge has made new law . . . is it good law?

Reflections on the Arthur Trial

THE TRIAL of Dr Arthur came to an end on Thursday, 5 November. He was acquitted by a jury of the charge of the attempted murder of a three day old boy with Down's Syndrome. Some may argue that its significance, if not its newsworthiness, was very limited: all it decided was that twelve people found that the particular facts alleged were not proved. No more, no less.

This view would be mistaken. What makes the case important is what it tells us about medical law and ethics, and about the process of public decision-making.

In my view, Mr Justice Farquharson, the judge in the Arthur case, has made new law on the crime of murder. In his directions to the jury at Leicester crown court, he indicated that it was lawful to treat a baby with a sedating drug and offer no further care by way of food or drugs or surgery, provided certain criteria were met. These criteria appear to be, first, that the child must be "irreversibly disabled", and, second, "rejected by its parents."

By way of clarification for the jury, the judge drew a distinction between (a) sedating the baby and then passively letting it die—"allowing nature to take its course"; and (b) doing a positive act to kill the baby—for example, giving it a death-dealing dose of drugs. The latter, he said, would be unlawful; the former, lawful.

Clearly we as a society need to decide just how to respond to a severely handicapped new-born baby. In practice, doctors vary widely in their response. They have been making literally life-or-death decisions without it being questioned publicly whether this was proper.

This is an unsatisfactory state of affairs. Painful as it may be, we ought to turn over this stone, and examine what is underneath.

Some people argue that things are best solved in private, behind closed doors. Where the future life of a child is involved, I cannot agree. For the most part, my concern is with the *process* of decision-making, rather than the merits of the particular decision arrived at. But if we get the process right, I happen to think we shall also probably arrive at the right decision.

Is it right to involve the law at all? Some say not, but I would argue the law is already inevitably involved. We are talking about whether a child lives or not. The state takes very seriously conduct which is life-threatening: so seriously that (in most cases) it outlaws it, making it a crime. As *The Times'* leader pointed out the day after the Arthur trial: "It is, of course, parents and doctors on whom it falls to take these agonising decisions in the first place, and they deserve the understanding and support of society. But they are decisions of a kind that require to be taken inside a framework of public morality which finds its expression and sanction in the law."

The rights of the child

Of course, we are entitled to hope that the law we have is good law—sensitive to all the claims of the parties, not least the child who cannot speak for himself. We have been less than imaginative in our ways of shaping new law. Particularly in medical law, guidance is sorely needed.

Does the Arthur case give us good new law? What are its wider implications?

I would criticise, first of all, the distinction Mr Justice Farquharson drew between letting the child die ("allowing nature to take its course") and doing some positive act to bring about its death.

The distinction between omissions and commissions has, of course, a respectable pedigree in the criminal law. But here it is not a good distinction to draw.

In law and in morals, the doctor stands in a special relationship with his patient. Once he has embarked on a course of treatment, he has a duty to act affirmatively in the interests of his patient. He breaks that duty if he stands by and does nothing in circumstances in which both law and morals indicate that he ought to act.

It may well be possible to argue that certain conduct amounts to an omission, rather than a commission. But this, in no way, determines whether it is *justified*. It is linguistic or metaphysical sleight of hand to avoid the central issue: What ought the doctor to do? What is his duty?

Mr Justice Farquharson could have arrived at precisely the same conclusions if he had concentrated on the notion of duty, and avoided his unsatisfactory reference to ommission and commission. The question should properly have been: What is the doctor's duty to such a child?

The jury could then have stipulated that, in certain prescribed circumstances, the doctor is not under a duty to do anything more than sedate the child and give it "nursing care only." He could have said that in such circumstances the law absolves the doctor from a duty to feed the child, or give it drugs, or whatever. This would be analytically sounder. It would save us from a future of interminable wrangles about what conduct should properly be regarded as an omission.

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I would also take issue over the circumstances in which the judge thought a doctor may lawfully adopt a policy of sedation and nursing care only.

Mr Justice Farquharson offered two sets of circumstances. The first was if the child was irreversibly disabled. But this cannot be satisfactory. The law must be made far more clear. We have to build on the court's decision, to articulate what disabilities if any we think should qualify. Is it, for example, necessary that the child should be mentally handicapped? A Down's Syndrome baby will be, but what of a *spina bifida* baby who may be severely physically disabled but whose mental capacities cannot be measured for weeks or months or longer, and who may turn out to be as bright as a button?

The judge's other criterion—that the parents reject the child—seems to me even more unsatisfactory. The life of a child should not depend on whether its parents want it. It has never been part of our law or morality that parents may choose death for their children. Indeed, such a decision, in other circumstances, would render the parents liable to criminal prosecution, and cause the child to be taken into care.

This is not to belittle the enormity of the tragedy suffered by the parents. We offer parents little support, whether in the form of practical help or professional advice, which may persuade them to keep a handicapped baby at home. And the fate which awaits the baby, if it is not kept at home, is for the most part one which many parents and others would think was not far removed from a living death—lost in the back wards of some soulless institution.

But this need not be so, as other countries, like Sweden, have demonstrated. To mark the child for death is to bury the problem, rather than to demand we do better in terms of what we provide, whether home support or institutional care.

The Arthur case raises very important questions of medical ethics. The duty a doctor owes to his patient is as much an ethical issue as a legal one. It was important for the court to consider what were the relevant principles of medical ethics, and to attempt to take account of these in shaping the law. But the whole of the evidence on medical ethics came from doctors, and, furthermore, from doctors who spoke in Dr Arthur's defence.

These doctors said it was ethically sound and acceptable to do what Dr Arthur did. But medical ethics are merely part of general ethics. Doctors, as doctors, have no particular skill or training in ethics and ethical analysis. Nor is it for doctors alone to decide what is ethical in medicine. Yet no other views were heard.

This omission takes on increased significance if you consult the results of a poll conducted by the BBC *Panorama* team. They sent out 600 questionnaires to British consultant paediatricians and paediatric surgeons. Dr Arthur himself is a senior consultant paediatrician. By 7 November, they had received 340 replies, of which 280 were fully completed.

Not one of the doctors in the poll would have done what Dr Arthur did.

So even if doctors were the arbiters of medical ethics—which I am convinced they are not—none of them in the sample regarded what was done as appropriate.

A further criticism of the case follows on from this. It seems to suggest—and some have greeted it as legal authority for the proposition—that the issue of the treatment of a severely handicapped new-born child is a private matter between doctor and parent. But where life or death is at stake, the ethical principles cannot be left to the private negotiation of doctor and parent.

The decision in the Arthur case might seem to lend support to the proposition that principles, or guidelines, cannot be worked out except in the vaguest, most general way. The situation is too complicated, or so the argument would go. This approach is sometimes called *situation ethics*: the situation dictates the response.

But situations do not dictate responses; people do. The person making the decision brings certain values and principles to bear, but is perhaps unwilling or unable to articulate them. Alternatively, appeals may be made to common sense, but these are only valid if there is demonstrably a *common* sense. In many of the ethical dilemmas of medicine, there decidedly is not.

Whether it is realised or admitted, principles and values *are* being employed already in decision-making. My point is that they should be worked out in the form of guidelines. These would narrow down, and bring into sharp focus, the general criteria so far offered by the court. Opposition to the idea comes, I think, more from a professional hostility to control—to "interference"—than any inability to articulate such guidelines.

This does not mean that we would have "decision by committee." This is a silly argument. The principles would, of course, be established by committee, or by some other appropriate mechanism. But the professional, the doctor, would still have to exercise his discretion, within the limits of the guidelines, in the particular case.

There are already precedents for committees laying down guidelines in, for example, the Codes of Practice on Transplantation and on the Determination of Brain Death. There is even a code in legal form in the Abortion Act. But a code on the new-born need not necessarily be passed into law by parliament. It could take such a form as to indicate that compliance with it would be deemed lawful, whereas to deviate from it would be *prima facie* evidence of unlawful conduct.

It's hard to persuade doctors codes of practice are possible. So many variables must be taken into account, the argument goes, no predetermined rules can be devised. But compare a policeman and *his* discretion.

A policeman has the power to arrest. In exercising it, he is confronted by a number of variables. The first may be the weather and the time of day. It may be foggy, snowing, icy (he should be careful if running), night, day, and so on. The second variable is the person he is planning to arrest. He could be a man with a cleaver standing a few feet away, someone with a gun running towards the policeman, or an old lady in a quiet street who is clearly the worse for wear after drinking too much and could well fall over if touched on the shoulder. A third variable is the circumstances of the arrest. The person to be arrested could be at the head of a mob threatening a riot, on a picket line, or an old man on his own in a lonely Dorset road.

Does this great range of variables persuade us that we cannot establish in advance guidelines which regulate the power of arrest and reflect our ethical commitment to the freedom of the individual? Do we argue that no predetermined rule is of any use? No. We have not only drawn up ethical guidelines, we have gone further and made law (case law and statute), setting down carefully and precisely the boundaries of permitted action allowed to the policeman who would arrest someone.

The police grumble sometimes, not surprisingly. But we think it of such importance to hold the balance between the supposed needs of the executive, and the claims of the individual, that we tell the policeman he must accept it. We'd run a mile from a proposition like: A policeman may arrest someone whenever he thinks it appropriate.

If a decision which affects the freedom of movement of the individual is thought so important, then any decision which affects life or death must attract the most careful regulation of all.

A final criticism of the Arthur case is that it leaves the law in something of a mess. How can we reconcile its view of the law with that propounded in the Hammersmith case, *Re* B (a minor), in August 1981.

In that case the baby girl was more severely disabled than the boy in the Arthur case. Besides being a Down's Syndrome child, she needed life-saving surgery. The parents indicated they did not want her to live, and doctors decided not to operate. The guidance of the courts was sought, and the Court of Appeal authorised the necessary surgery, despite the parents' wishes. *The Times* of 10 August said: "It must almost inevitably be right for the court to come down on the side of life." And in the Court of Appeal, Lord Justice Templeman stated: "It was wrong that the child's life should be terminated because, in addition to being a mongol, she had another disability."

There is a conflict here, and a curious one, in that the Court of Appeal's decision came before the Arthur case, and yet seems not to have been followed by the Mr Justice Farquharson's lower court at Leicester. This adds urgency to the need to clarify the law, and in my view, guidelines would be better than waiting for prosecutions or civil suits slowly to tie up the loose ends.

Of course, the implications of the Arthur case go much further than the rather emotional scenes in Leicester in November. It must be asked, for example, if the case says anything about society's attitude, our ethical posture towards the disabled. Obviously it does. It says some ought not to live.

This conclusion must be seen in the light of another important criminal prosecution which ended only a few days before the Arthur case—the trial of two members of Exit. There, the two accused were convicted of an offence under the Suicide Act and one was sentenced to two and a half years in jail. Undoubtedly he broke the law. But the breach consisted in helping (beyond what is allowed) elderly and very ill people to give effect to a decision to kill themselves, which had been made autonomously by them, and which represented, it could be said, a final act of self-determination. For this Nicholas Read was sent to jail.

But when a doctor stands by and allows a child to die, because the child is disabled and unwanted, professionals fall over themselves to praise him (at least in public) and he is acquitted. There is no question of any autonomous decision by the child.

Now I happen to believe that an ethically respectable argument *can* be made out for not striving to keep alive those babies who, soon after birth, can be shown to have no capacity ever to flourish as human beings. But this would need careful definition, and would (in my view) depend very much on the degree of mental impairment of the baby. Modern medicine has brought us to the point where nearly all babies are salvageable in some form. But because we can save them does not mean we must.

We must, however, ensure that the class of the disabled marked for death is kept as narrowly and strictly defined as possible, even if we accept that such a class should exist.

I am not persuaded of the inevitability of the wedge argument—that one step down the road towards removing one class of the disabled, the very severely disabled child, from our midst—means that we must inevitably take the next step. But we must be vigilant, as a society, to ensure that *no* step is taken, in *whatever* direction, without proper care and deliberation.

The question of the treatment of the severely handicapped new-born child has to be seen in the context of the growing pressures for widespread genetic screening within the womb, and selective abortion. We more and more want children made in our own image. We demand that doctors achieve this for us or allow us to abort.

The risks of screening

I am not saying this should not sometimes be so. But we should think carefully about extending screening. We ought to consider what this says about our attitude to life and to disablement. More and more variations from the genetic norm (whatever that may be) may be discovered by medical scientists. If these are characterised as disabilities, then parents may be encouraged to abort their child.

And there will be those who are born because of their parents' opposition to abortion. The danger may grow that we will shun, or even penalise, such parents and children (by, for example, suggesting the child need not have been born, so ought not to be supported by the state's care).

We should also think carefully about screening programmes because, as a result, our attitudes to those among us who are disabled for whatever reason, at whatever stage of their lives, may change subtly and slowly, from tolerance and some care to less than caring warmth.

The ethical and legal implications which arise from the Arthur case are hard to face, let alone resolve. But we must do so. We owe it to our doctors, and to ourselves.

Nevertheless, the satisfaction of seeing such a major achievement in this respect was tempered with increasing anxiety, because a progressively higher proportion of the survivors suffered from enormous irremediable permanent handicaps, broadly consisting of severe paralysis of the legs, absence of feeling in the lower half of the body, which frequently resulted in fractures and horrendous pressure sores.

They had multiple complex deformities of their legs and in spite of large numbers of orthopaedic operations relatively little could be achieved for the most serious deformities. Curvatures of the spine (kyphosis or hunchback) were often present from birth, and a twisting of the spine (scoliosis) very often developed later, and increased rapidly on reaching adolescence. Yet more, very major and hazardous surgery sometimes decreased the degree of these deformities or temporarily arrested their progress, at a price of a stiff spine and immense loss of time from home and school.

The severely affected practically all remained incontinent, many had major by-pass operations of the bladder. These operations (ileal conduits) were later found to be fraught with problems and complications and have now been largely abandoned. Incontinence of the bladder results in frequent infections and leads to destruction of the kidneys, eventually high blood pressure and often death from kidney failure. The social disadvantages of bladder and rectal incontinence are immense. These problems need constant hospital supervision, treatment, laboratory and X-ray examinations.

The immediate success achieved in the management of hydrocephalus with shunts was also fraught with hazards later. Blockages, breakages, infections and other complications constantly threaten life and 20% of our shunt-treated children died as a direct result of the complications of shunt treatment. Revisions of the shunt, often as emergencies, are very frequent and each complication, if not urgently and successfully dealt with, carries with it the risk of further handicap: intellectual loss, sometimes blindness and very often fits.

Over half the initially severely affected babies with hydrocephalus are subject to fits. The average intelligence of this group is some 25% lower than in the general population, or in children with spina bifida who do not have hydrocephalus. About half of this severely affected group are retarded, needing special education and a smaller proportion among them are profoundly retarded.

One could add a long list of other disabilities affecting the same children. They are dwarf, clumsy, often very fat and have squints. They are socially isolated and they will never have a chance to earn their own living in competitive employment or to be self-supporting.

All this was achieved at tremendous suffering of frequent hospital admissions, operations, blood tests, getting and wearing of heavy, clumsy appliances—or living in wheelchairs. Many have been abandoned by their parents.

The family suffered almost as much. Marital breakdown and divorce are common and a large proportion of parents are on tranquilising drugs or have suffered mental breakdown. One could go on.

All this does not take into account the hundreds who died in spite of all the treatment, who were, of course, an even more severely affected group, and who often underwent multiple operations and a great deal of suffering, all in vain.

A reassessment had to be made and a new policy to be adopted to prevent inflicting such terrible lives on so many innocent people. One had to recognise that while we did a lot of good to many, we also did a lot of harm to even more.

Fortunately, we had very detailed assessment of all babies and a complete follow-up examination. It was possible to find out which babies did consistently very badly and, if they survived, always had very severe physical handicaps affecting most of the body, often associated with mental retardation. It was established that it was possible to find certain relatively easily detectable criteria at birth, which precluded survival with an acceptable quality of life, and which the parents found acceptable.

These were principally: severe degree of paralysis with no active movement of the legs other than flexing the hip and perhaps straightening the knee; a very large spina bifida reaching high up on the back; gross deformities of the spine in addition to the spina bifida, *very* gross hydrocephalus at birth, or if they had other major congenital malformations, apart from those usually present in spina bifida. *Any one* of these was a contra-indication to active treatment, provided the parents agreed with this plan.

It is an essential part of treating spina bifida (or any other baby) to inform the parents very fully about the exact nature and degree of the baby's or child's future handicap and make sure that they understood all. It was most unfortunate that in the past, large numbers of babies were operated on all over the world, without such detailed explanation by the consultant in charge. All readers of LINK will understand what I mean.

The overwhelming majority of parents opted for the policy of selective treatment and in fact would like to have had even stricter criteria than were proposed. It is part of this policy to give the babies normal nursing care, feeding milk on demand, ensuring that they do not suffer and with free access by parents to the baby at any time. Should they wish to change their mind, they can do so. If a severely handicapped baby survives for a few months, and looks like living, then full treatment is offered, without the baby having had any additional handicap.

This is the only humane approach to this dreadful problem. The adoption of this policy has resulted in a much higher quality of survivors, who now can have better care than ever before.

This article is by the mother of a young boy with spina bifida. Here she explains why she wouldn't have a pre-natal test if she were to become pregnant again.

When our son was born
I asked, "Is he grotesque" . . .
my husband said, "He is quite
beautiful . . ."

Disability too is quite normal

PREGNANCY is an integral part of life's experience, therefore, the end product should be accepted even when the fetus is genetically damaged. New life is nature's way of ensuring man/woman's survival, and in my view new life itself has a right to survive. It is sacred. And no! we are not Catholics.

It follows that I am opposed to pre-natal tests and subsequent abortion.

When our son was born four years ago my first questions were, 'Is he going to be Spastic?' and 'Is he grotesque?' My husband replied: 'No he is quite beautiful'.

I was taken straight from the theatre recovery room to the special baby unit to see our new spina bifida son. Seeing the lump on his back I said: 'Oh! is that all?' Wrapped in a blanket, he was placed very gently on my sore Caesarian scar, and I was asked to cuddle him, but to mind his back. Looking at his pink, unwrinkled face, with the beautiful blue clear eyes the bond was formed.

I was encouraged to return six hours later to feed him. It was suggested at that time that surgery might be necessary right then, but this was delayed for over one year. Nobody ever suggested that he be whipped off anywhere, just left, or sedated. The special unit staff were supportive, and dedicated, devoting time to him, and caring for him as they did for the babies with perfect bodies.

For those seeking spiritual comfort Ecclesiastes Chapter 11 verse 5 tells us that—'as thou knowest not what is the way of the spirit, nor how the bones do grow in the womb of her that is with child; even so thou knowest not the works of God who maketh all'—

Malformation of a fetus is a natural growth, as is a normal fetus.

Selection prior to birth—amniocentesis, and blood tests to determine genetic abnormality—are not 100% effective, and the babies who pass through these tests, and are born with defects can be supported, and sustained by caring parents, and members of the community. They do not need to be vacuumed out of the womb, and disposed of.

The choice, for or against these very important decisions, should rest solely with the parents, and the medical teams, for it is most surely a matter of life, or death!

This article is by Anne Woods, the mother of a little girl with spina bifida who lived to the age of six years then died. Mrs Woods and her husband now foster a boy who has spina bifida.

We had many heartaches . . .
But the things we
remember are the happy times

Parents can cope—it's a gradual process

MARIA WAS our third child. We had two daughters aged four and 16 months when she was born on 29 May 1969. I remember that day well. She was born at home because I did not want to leave Susan and Annette. The birth was straightforward, apart from the fact that I had to push just that bit harder as Maria had no leg movement and could not help to push herself out.

The doctor was sent for and we had her admitted to hospital straight away. All we knew at the time was that she had some kind of handicap called spina bifida. We did not know what this meant, but we did know that Maria was our child and that we loved her as much as we loved Susan and Annette. She had the operation to close the hole in her back within a few hours of her birth, but she managed without the valve for her hydrocephalus until she was eleven months old.

In her short life, she lived until she was six, she had a number of operations on her legs and feet, which she accepted without complaining. She was doubly incontinent and was prone to urine infections. We had many heartaches with her, but her cheerfulness and love brought us through them all and the things we remember most are the happy times.

I remember when we were sent to Lourdes by members of our parish. Maria was only two years old but she gave so much love and happiness to the other sick people that they forgot their own troubles in their efforts to talk to her. When she was four and a half she started in the nursery of a normal school and then went into the main school at five. She was there for about six months and was loved by everyone, even the roughest of children were gentle with her, and would want to push her in her wheelchair. She managed to bring out the best in everyone.

In fact it was because everyone was so good to her that we decided to send her to a special school. This may sound silly, but she so enjoyed everyone

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running around after her that she was losing her independence.

Her death was sudden and came as a great shock to us, yet from the moment she died we knew she was in heaven and that she had achieved what we are still working for. We felt that we could talk to her when we prayed and that she would help us through all our difficulties. This was a great source of comfort to us and helped us to overcome the emptiness that her death left us with.

It was four years after Maria's death that a social worker called to see us. She had heard that we had had a spina bifida child and she wanted to know what was involved in looking after one. She had had Andrew on her list for quite a time and did not know what to tell prospective foster parents. As we talked I seemed to be the one who was asking all the questions. Did he have hydrocephalus? Was he incontinent? Did he wear calipers? etc. The answer to all these questions was "yes". All the time we talked I was thinking 'we are trained for this'. To cut a long story short we decided to foster Andrew.

We have had him for two years now and really feel he is one of the family. He is very lively and cheerful and takes a great interest in everything. Until he came to live with us he had spent his life in a children's home. People wanting to foster had felt that they could not cope with his physical handicaps, but to be quite honest we found his social handicap much more difficult to cope with.

After spending the first six and a half years of his life in a large community where helpers changed shifts and there was no-one for him to relate to on a one-to-one basis, and where he used to shout to get what he wanted, because he could not run and get it like the other children, it was very difficult for him to adjust to a small family group. He is well settled now though, and we cannot imagine life without him. He has had two operations to straighten his legs since he came to stay with us and we have had our family problems, but the rewards that these children bring far outweigh the problems.

We feel very upset when we read about Amniocentesis abortion and selection for treatment. What good is amniocentesis when all that can be offered to the mother is abortion or extra months of worry if she decides to keep the baby. We feel that most parents can cope with spina bifida children if they are given the chance. They are frightened of the unknown and therefore, think that they cannot cope with it, but what they don't seem to realise is that they are not suddenly faced with a handicapped child, but with a baby like any other baby. It is only as the baby gets older that you start to notice the difference, so it is a gradual process, and without realising it you are just coping with each thing.

When we look back over our life, since Maria's birth and think of the difference she has made to it—the friends we met through her and the way she changed our outlook on life—we thank God that we did not know about amniocentesis and that when she was born there was no question of selection for treatment. We feel that amniocentesis can only be of value if something can be done to put right whatever is wrong while the baby is still in the womb, and that all babies have the right to treatment at birth.

This article takes the form of a letter from a mother to the doctor. It poses the fundamental question, should my child have been allowed to live. The article is reproduced with the permission of 'World Medicine'.

Only parents of a handicapped child can really know what's involved

In some cases it would have been better had the baby died

When I had Joanne no one actually told me or my husband that she had spina bifida. We were informed that her spine was open and they would operate to repair it. No one explained that this would damage her nervous system and that she would be handicapped.

Parents at such a time need someone to help them think of the future, as they are too stunned to help themselves. Someone experienced should visit them and talk about the child and the future problems of which the parents at that time can have no idea.

Doctors and social workers were very reluctant to tell me anything. I was told Joanne had to have this operation and that she had a fifty-fifty chance of survival. I wasn't given a choice, which is wrong as it is the parents who suffer all their lives and have to carry the burden a handicapped child brings.

When a handicapped child is born, everything is done to keep that child alive, but in some cases it would be better if he or she died at birth or soon after for, although the parents would naturally be upset, after a time they can forget and perhaps have more children.

Until parents have been through life with a handicapped child, they can't imagine the ways in which it can affect them.

When the child is a baby, it doesn't seem to matter, as they can't do anything anyway. But it's when it can't sit up or walk or talk and people stare when one takes the child out, that it hurts, though people probably don't mean it to. Friends tend to be wary of talking about it. I think this is because they are afraid of upsetting people. It's something ordinary people don't wish to know about. If only people would be more open and talk about these things, perhaps a lot more would be done for these children.

When we go out as a family, we have to take the wheelchair, which means we can't go to the shops at busy times. In summer we rarely go to the beach as this usually means climbing endless steps. It means our other child has to miss out, though we try to see this doesn't happen very often. It is just every day things that can become a major effort.

Our family life has to be organised around Joanne to a great extent, as I always have to be with her, feeding or carrying or tending to her in some way. If we aren't at home we have to be sure there are facilities available for her to go to the toilet. Several times we have been out for the day and when Joanne wanted to go to the toilet the disabled toilet (if there is one) is a long way. I always have to take pants and tissues, if we are going to be out for any length of time just in case I can't get Joanne to a toilet quick enough.

No one can imagine how free we feel on the rare occasions when we do go out without Joanne, not having to take the wheelchair, no lifting in and out of the car which we normally have to to enable us to get out at all. And no pushing, as Joanne is heavy to push and it can be very tiring.

We have found that as Joanne gets older our problems get worse. Now she is 10 years old and weighs 6 stone and is heavy to lift. We are having to have our house adapted for her but soon we hope to move to a bungalow for easier mobility for Joanne and to ease our lives slightly. We have not had a holiday for years as so many places are not geared for wheelchairs or have the conveniences for Joanne. I feel at times I need a holiday, but it is difficult finding someone to take her and, even if there were, I couldn't relax as I'd be concerned that she was upset and missing home.

Having a handicapped child puts a great strain on a marriage and on any other children. One has to give so much attention to the handicapped child that other children can feel pushed out at times and it makes a mother weary and frustrated.

I think parents should be asked when the child is born handicapped if they wish it to be saved or not. It is obviously something parents should seriously consider as it can mean a lifetime of struggle, mental and physical.

It often concerns me that, when my husband and I get old or if something happens to us, what will happen to Joanne? The thought of her in a home or institution worries me sick. Is it fair on her to have to go through life being dependent on others.

Now she is older, she gets depressed and asks why the doctors couldn't cure her. What can a mother say? It can be heartbreaking; we'd give anything for her to be cured, but that's impossible.

A lot of people could be saved a lot of heartbreak if doctors and others concerned told parents everything at birth, no matter how great a shock it is. It is too late when the child is older and has become part of the family.

No one can imagine the stress, strains, worries, and many other problems bringing up a handicapped child can bring. No one seems to care; it's a case of bad luck, they seem to say, but it's your problem. Joanne is our family after all these years and we look on her as we do our normal child and she means as much to us. But in a way this makes it harder to bear her handicap.

The writer, Dr David Gompertz is the parent of a child with spina bifida and hydrocephalus and the Chairman of a local ASBAH association. He spent several years studying the biochemical aspects of genetic disease in children and has lectured widely on that subject. The views he presents below are his personal views and do not reflect those of any organisation, professional or voluntary, to which he belongs.

It is for parents to decide and for doctors to give all the help and advice they can

Three very important questions

MANY CONTRIBUTORS to the recent controversy concerning the treatment of handicapped babies at birth have not separated three different and important questions from each other. I would like to define these three questions and look at them in some detail. They are:

QUESTION 1

Are there any circumstances at all in which one may withhold treatment from a handicapped child after birth with the intention of shortening that child's life?

This is asked, not as a medical or legal question, but as an ethical question, and has YES or NO for an answer. My personal position is that I respect either answer and if your answer is NO, I will work to help you treat and cherish the child involved in every way. If the answer is NO, then it follows logically that the next two questions are irrelevant as far as you are concerned.

QUESTION 2

What are the circumstances in which it is reasonable to withhold treatment from a newborn handicapped child?

This is a very difficult question to answer as it involves a knowledge of the natural development of the handicap in question, the effect of the handicap on the immediate family and some sort of value judgement concerning the quality of life. Knowledge of the extent of the limitation of a normal existence, the development of social and intellectual skills, the need for medical and surgical intervention and the degree of suffering likely to be involved is usually restricted to members of the caring professions (medical, nursing and teaching) who have had a wide experience of the handicap over a number of years, so that they know the best and worst that can be expected. This knowledge may sometimes be available amongst experienced members of the relevant voluntary organisations. However, even if one has a clear picture of the likely development of the handicapped person over the years, the view of what consists of an adequate quality of life is subjective, and the answer one may give will obviously be affected by one's cultural background.

It was the attempt by Professor Lorber (see Professor Lorber's article, page 0) to define the medical outcome in terms of early diagnostic criteria, that initiated this important discussion concerning the selection of newly born children for treatment. Whatever one's criteria for quality of life, it can be argued that Professor Lorber was correct in trying to document the diagnostic pointers indicating the subsequent outcome of early treatment. It is always necessary to establish the range of possible consequences of important and irreversible actions before making decisions.

QUESTION 3

Who should make the decision concerning the withholding of treatment?

This is a difficult question to answer, especially as I have argued that the criteria for deciding the circumstances under which treatment might be withheld should ideally be with those who have a satisfactory knowledge of the natural evolution of the handicap. However, the initial act of creation of life should involve a degree of moral responsibility and it seems that the responsibility to make this next decision must be left with the parents. This involves a terrific burden for a young couple presented with an abnormal baby without warning and without the emotional calm required for such decisions. They will be faced by a group of well-wishing professionals who may have a range of ethical backgrounds, and these may be different from the parents and different from each other. It does not seem reasonable that a solution should be imposed on the parents by the random chance of one person rather than another being on duty that particular evening. If a decision has to be made, it must be in keeping with the parents' ethical position, and they must be given all the information necessary to make an informed choice.

This is easier said than done; we are not living in a perfect world. However, we must work towards a system that ensures that the parents are referred to medical advisers with an appropriate ethical standpoint. It should not be overwhelmingly difficult to ascertain, at an early interview with the parents, whether they would even consider withholding treatment. Few members of the caring professions would not respect a parental decision to ask for all to be done to ensure the survival of a badly handicapped child even if their experience indicates an impossible outcome. However, recent experience shows that it is more difficult for parents to receive support in the reverse position. If they are convinced that active treatment and support is inappropriate, their rights must be safeguarded in the same way and if the professionals in the case do not feel in their hearts that they can acceed to the parents' wishes, they must be prepared to refer the parents to a more sympathetic colleague who shares the parents' ethical standpoint.

Thus I have argued that decisions must be made by parents in keeping with their own ethical position; they have to accept the moral responsibility for the decision. However, there is a moral responsibility for the caring professionals to give them as much information and help as possible to come to the correct decision consistent with their own ethical standpoint. The alternatives to parental decision are decisions made by professionals, by committees, or by legal officials. It is difficult to argue from any form of experience that committees of worthies or of professionals or the considerations of a judge can be expected to produce more consistent and reliable decisions.

I have argued that these three questions must be taken in order. I have spent least time in discussing the first question. My answer to it is YES, but I respect the views of those who take the opposite position. I realise that it is pointless to discuss the position further with anyone who could not visualise any circumstances in which they might withhold treatment, and I wish them well. To those who might consider "yes" for an answer, but are undecided, I would ask them to consider the plight of our children with spina bifida and hydrocephalus. An adult faced with innumerable surgical operations, pain and discomfort, at least has the right to say "no more" and to refuse consent for any further surgery. Our children do not have the privilege. They are carried out to the operating theatre time and time again, and live in fear between the operations. In our civilised society we protect animals and prisoners from such suffering. I consider it morally responsible to say sometimes, enough is enough. The difficulty is that of deciding the circumstances—here we need knowledge, understanding, help and goodwill.

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