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CARE OF THE HANDICAPPED NEWBORN

**Parental
Responsibility
and
Medical
Responsibility**

**THE CATHOLIC BISHOPS' JOINT COMMITTEE
ON BIO-ETHICAL ISSUES
(ENGLAND, IRELAND, SCOTLAND, WALES)**

In the autumn of 1983 the Catholic Bishops' Joint Committee on Bio-Ethical Issues established a Working Party to consider the serious concerns of parents and others responsible for seriously handicapped new born babies, and to provide information and advice.

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The Committee is grateful to the members of the Working Party for this Report, which was presented to and accepted by the Bishops' Conference in November 1985.

Issued by the Catholic Bishops' Joint Committee
on Bio-Ethical Issues
(England, Ireland, Scotland, Wales)
1A Stert Street, Abingdon, Oxon, OX14 3JF

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First published 1986 by the Catholic Media Office
23 Kensington Square, London W8 5HN

Hypoplasia

Underdevelopment or defective growth in any organ or tissue.

Microcephaly

Lack of development of the skull and brain, accompanied by mental retardation and sometimes by blindness.

Myelomeningocele

The most serious form of spina bifida (q.v.), in which the spinal cord is exposed. The condition is usually associated with hydrocephalus (q.v.).

Orthopaedic

Pertaining to the correction of deformities in bones and joints.

Septicaemia

A morbid condition due to the invasion of the bloodstream by pathogenic bacteria.

Spina-Bifida

A congenital defect in which one or more of the vertebrae in the spinal column has failed to fuse, thus leaving a gap into which the membrane (meninges) covering the spinal cord protrudes. There are few problems with a minor degree of spina bifida, but in the most severe form of the condition, known as myelomeningocele, the spinal cord itself bulges through the gap and there is some paralysis, which can vary from a small amount of numbness to complete paralysis from the waist down. The severity of the defect will depend on the number of vertebrae affected.

Thoraco-Lumbar

Pertaining to the thorax (chest) and the lumbar region (loins).

Tracheo-Oesophageal Fistula

A deep ulcer which produces an opening between the trachea (wind-pipe) and the oesophagus (gullet).

body's cells of three chromosomes in position 21 instead of the normal two: hence this condition is also called Trisomy 21. The mental retardation involved may range from quite mild to severe, and some treatments can be effective in improving the child's intellectual capacity if they are applied sufficiently early.

Ductus Arteriosus

A foetal blood vessel which joins the aorta and the pulmonary artery, thus allowing the lungs to be bypassed before birth. Normally, it closes almost immediately after birth, thus allowing a proper circulation through the lungs. If the ductus arteriosus fails to close after birth we have what is called patent ductus arteriosus, which has to be corrected surgically by tying a ligature around the vessel.

Duodenal Atresia

Congenital atresia or blockage of the duodenum, that part of the bowel which is immediately beyond the stomach. Surgery is needed to remove the blockage so that food can pass through.

Dysplastic Thorax

Abnormality of development in the chest or thorax — that part of the body which is enclosed by the ribs.

Ectopia Vesicae

Condition noticeable at birth, in which the urinary bladder protrudes through the abdominal wall, the lowest part of which has failed to close. The bladder itself remains open, so that its inside red lining can be seen. The condition requires a delicate surgical intervention.

Encephalocele

Protrusion of the brain through a defect in the skull. It may be either congenital or acquired as the result of a wound involving the loss of bone material.

Gastrostomy

An opening made surgically into the stomach in order to feed a patient who is suffering from a blockage of the oesophagus.

Hydrocephalus

Enlargement of the cerebral ventricles, and, therefore, of the head of an infant, due to an increase in the volume of the cerebro-spinal fluid. The condition may result from one of two different causes; first, an over-production of the fluid, and secondly, an obstacle to its passage. The usual surgical treatment is the insertion of a valve which drains off excess fluid, usually into the vascular system: if this is not done the excess fluid will cause the head to grow and the increased pressure on the brain will damage the latter.

1. Introduction

Every child, however impaired, is a gift of God to his parents. In virtue of his humanity he is equal to them, and should enter their life together as an equal, a new member of a community already constituted by marriage. He is entitled (even if that community is broken or non-existent) to the care, support and guidance he needs as a dependant of that community, and if this natural support fails him, it becomes the task of others to replace it. Even parents who do not explicitly acknowledge the truth that a child is a gift of God can come to see that the very humanity of their child and the fact that he is their child imposes upon them obligations of care for him.

Very many children are welcomed as gifts by their parents. Other children are not so welcomed. When a child is born with significant handicaps the parents who recognise that child as a gift from God may nonetheless experience considerable difficulties in securing for him the care he needs. Parents not disposed to welcome a handicapped child as a gift of God may find themselves strongly tempted to deprive the child of the care to which he is entitled in justice.

2. The relationship of parents and doctors in the care of the handicapped child

Usually, the early care of a handicapped child will be the immediate responsibility of doctors and nurses, whose special skills may be needed by the child. Whether or not the child receives the care to which he is entitled will largely depend upon whether both the parents and the clinical staff have got a sound view of their responsibilities to the child. Since primary responsibility for the child belongs to the parents, close collaboration between parents and doctors in the care of the child is essential. There is a serious moral as well as legal obligation to consult parents over the clinical care of their children. Collaboration between parents and doctors will work in the interests of the child only if all adults involved have a clear view of the child's rights. It is certainly not sufficient that parents and doctors agree on a policy for the 'management' of the child. The *content* of what is agreed must respect the child's rights. It is a serious error to think that a doctor's primary responsibility is to accord with parental wishes. The error is that of assuming that parents may make whatever arrangements they wish for their children, as though a child was the disposable property of his parents.

Some paediatricians have a false conception of parental rights over children, and on that basis justify compliance with parental wishes which are contrary to the child's rights. In warning against that false conception, it is important not to go to the other extreme and minimise the rights of parents to speak for their children. A

parent's right to speak for his child is similar to his right to speak for himself. But there are limits to parental autonomy which justify recourse to civil authority, and the intervention of civil authority, when that autonomy is likely to be exercised in an abusive fashion. It is so exercised when a parent (even out of a morally unprincipled compassion) acts as the enemy of his child.

Ideally doctors will closely involve a child's parents in decision-making and will give a truthful and full picture of the child's condition and the prognosis for him. Most parents will have to rely on the doctor's expert opinion; but what a doctor recommends in regard to a baby with, say, spina bifida or Down's syndrome will be influenced as much by the doctor's general view of life with those disabilities as by his special clinical knowledge. So parents who seek the good of their child need to be assured that the paediatrician has a morally sound attitude.

As we have already noted, parents seeking proper care of their child can experience considerable difficulties when they encounter doctors, particularly paediatricians, who fail to recognise the rights of the child.¹ Conversely, doctors who encounter parents refusing permission for, say, an ordinary operation which the child needs and from which he would clearly benefit, may have to seek to override parental wishes in order to respect the rights of the child.²

Since the rights of the child are the most important elements in defining both parental and medical responsibilities to a handicapped newborn baby, it would help to recall just what those rights are. Before doing so, however, it would be useful to say something about the role of medical care in preserving and prolonging life.

3. Medical care and the prolongation of life

It is commonly said that the purposes of medical care are the restoration and preservation of health, the prolongation of life, and the alleviation of suffering. It would be a mistake, however, to think of these as unconnected purposes. The primary purpose of medical care is the restoration and preservation of health; it exists to serve the good of health. What is health? On a traditional understanding, health is essentially that condition of the body in virtue of which it works well as an organic whole, so that the individual enjoys physical vitality in itself and thereby is also well-placed to achieve some of the other goods of human fulfilment. Prolongation of a life which would otherwise come to an end is in general a justifiable aim only in so far as a patient has a continuing capacity for integrated organic functioning sufficient to allow him to continue to share in some of the goods of human life (e.g. communication, contemplation, or, especially relevant to babies, some form of play or the sheer appreciation of one's own vitality). And the alleviation of suffering (when cure is not achievable) aims precisely to restore some approximation to organic well-functioning, both as a good in itself and the condition of our achieving other goods.

APPENDIX

A Glossary of Terms Used in This Paper

Achondroplasia

A form of hereditary dwarfism, transmitted as a dominant character. In this condition, which begins in the foetus, bones in the limbs and the floor of the skull, which are formed from cartilage, fail to grow properly in length; instead, they become thicker. On the other hand, bones which had originally, in the embryo, been simple connective tissue — including those in the trunk and most of the skull — grow normally. This results in a type of badly-proportioned dwarfism, with a protruding forehead (since the vault of the skull grows ahead of the face), a normal trunk and very short but strong limbs.

Anencephaly

Failure of the brain to grow in the human embryo, so that at birth the major part of the brain and upper bones of the skull are absent. Most babies with this condition die very soon after birth.

Atresia

Absence of a normal opening in a hollow organ.

Cyanotic Congenital Heart Disease

Congenital malformation of the heart which results in a lack of oxygen in the blood. The condition is manifested in cyanosis, that is, a noticeable blueness of the skin.

Cystic Fibrosis

Also known as mucoviscidosis. An inherited disease which can affect many of the body's glands, such as the mucous glands of the lungs, the pancreas, the sweat glands, and the digestive glands. One result of this condition is the formation of abnormal fibrous tissue (fibrosis) — such as the thick mucus which blocks the lungs, thereby making breathing difficult and opening the way to lung infections — and cysts in the pancreas; hence the name 'cystic fibrosis'. The condition can be controlled by a combination of dietary and drug treatments, and also by physiotherapy, which can help to loosen and drain mucus. With the aid of these treatments many sufferers from cystic fibrosis can live to adult life.

Down's Syndrome

A congenital illness characterised by intellectual retardation and by a facial appearance said to resemble that of Mongols (hence the name 'mongolism'). Down's syndrome results from the presence in the

special demands on parents and impose particular burdens on families. Christians believe that the power of the Risen Christ is made available in their lives when they embrace the reality of the Cross in their lives. So there is no doubt that the parents of handicapped children may discover the resources which will enable them to give true love and care to those children.

A Christian family is not meant to be an isolated unit; a Christian family belongs to a Christian community. In so far as Christians are discovering, within the parishes in which they live, what it is to be a Christian community they will be learning to help bear one another's burdens and to bear the burdens of those in the wider community. Ideally, therefore, Christians united by the bonds of Christian community will seek ways in which to help the parents of handicapped children. The Christian community of the parish should certainly be sensitive to its responsibilities in this respect.

Beyond the bounds of the Christian community there is a need for the wider society to recognise the importance of support for parents with handicapped children and the importance of directly supporting those children when parents find themselves unable to care for them. The challenge to support the weakest and most vulnerable members of the human community is a challenge which touches the moral basis of a society. If we wish to oppose exploitation in the name of human equality, we should be clear that the only respect in which human beings are equal is in being living members of the human race. It is in virtue of our humanity — our mere humanity — that we have value. And it is because handicapped persons share our humanity that we should respect and cherish them, and protect them from treatment which is contrary to human dignity. A society concerned about the moral foundations of its common life will seek to ensure that handicapped people are treated in ways which are compatible with their human dignity.

Notes

1. For an account of one couple's difficulties in persuading a paediatrician to order the care needed by their child in face of his determination to impose a regimen of 'benign neglect' which would have led to the death of the child, see the article 'Lizzie's battle' by Peter Anderson in the Sunday Times 17 February 1985.
2. See the case of baby Alexandra, the so-called Hammersmith case. Reported in *Re B (A Minor)* The Times 10 August 1981; (1981) 1 Weekly Law Reports 1421.
3. British Medical Journal vol 286, 14 May 1983: 1593. Now in the most recent edition of the Handbook of Medical Ethics of the BMA, 1984, at p. 63.
4. According to the Court of appeal in *Jihbms and Proctor* a parent who fails to perform his duty to preserve the child's life. with the intention of bringing about the child's death, is guilty of murder. The Court held that the intent required to commit murder would be present if the parent(s) 'intended to set up such a set of facts by withholding food or anything as would in the ordinary course of nature lead gradually but surely to (the child's) death.' (1918) 13 Cr. App. R 134 at 138.

Some approximation to health in the sense defined must be achievable in order to justify medical efforts to prolong life. It is a mistake, leading to much confusion in medical ethics, to believe that prolongation of life is an independent aim of medical care.

One should not expect doctors to strive to prolong the lives of newborn babies who cannot achieve at least that degree of organic well-functioning which would be sufficient to enable them to share in some of the goods of human life. To ask whether the proper benefits of medical care are achievable and whether they are achievable without imposing undue burdens on a patient is not to ask whether that patient has a worthwhile life and whether for that reason he is worth treating. No human being is in a position to judge the worth of another's life; so it is an illusion to think that judgements about the worthwhileness of a patient's life can form the basis of clinical treatment.

4. The rights of the handicapped newborn

4.1 *The right not to be murdered*

The handicapped child, like every other child, possesses the dignity proper to human beings. It is incompatible with recognition of that dignity to kill a child on the grounds that he has not got a worthwhile life or will have a poor 'quality of life'. The value of a human life is not to be assessed in this way.

One may kill a child, i.e. intentionally bring about his death, either by action or by failure to act. If treatment is withheld in order to hasten death then a child is gravely wronged. It is important to be clear about what is being condemned here: a course of action or omissions (or a combination of both) which is chosen with a view to bringing about or hastening a child's death. This is not the same as withholding treatment on the grounds that it is useless or excessively burdensome to the child (see below), foreseeing that in consequence the child will die earlier than he might otherwise have done. In this latter kind of case it may be true that the child's death is hastened, but that consequence was not an objective of the decisions taken by the doctors.

It is clear that some doctors act with the gravely wrong purpose of killing handicapped newborn babies. Babies born with spina bifida who have not been selected for special surgical treatment have been placed, in some units, on a regimen of heavy sedation and underfeeding so that starvation has been a significant factor in causing their early and intended death. The point of the heavy sedation had been to ensure that the children did not demand normal feeds; the point of giving them less than adequate nourishment has been to hasten death.

4.2 *The right to ordinary nursing care*

All infants for whom doctors and nurses are responsible should receive nursing care, that is, the kind of care and sustenance which a mother would be expected to give her baby. The provision of such care is required by respect for the life of the child. In circumstances in which an infant is unable to take adequate sustenance normally, it will be usual to provide it artificially if there is a reasonable prospect of overcoming the obstacles to normal feeding. (There are conditions in which nutrition itself aggravates the state of a dying child, and in these circumstances it would be proper to withhold nutrition).

The differences between handicapped and normal babies do not in general affect the basic right which all of them have to adequate nursing care. This is a point explicitly recognised by the Council of the British Medical Association when reviewing in 1983 the advice given in the 1981 edition of the Handbook of Medical Ethics on 'severely malformed infants'. The revised advice begins by noting that 'A malformed infant has the same right as a normal infant. It follows that ordinary non-medical care which is necessary for the maintenance of the life of a normal infant should not be withheld from a malformed infant.'³

Apart from providing basic nursing care as a matter of right, clinicians should also regard it as their duty to control distressing symptoms to ensure comfort for the child, especially in those circumstances in which it is judged reasonable not to continue with or attempt curative treatment.

4.3 *The right to special medical care to help overcome/modify disability*

Since medicine exists to help patients secure and maintain the good of health, the good of organic well-functioning, and since the newborn handicapped patient is manifestly and seriously lacking in this respect, he has a special claim on the expert care of doctors and nurses. There are, however, limits, deriving from a number of considerations, on the responsibility doctors and nurses have to meet this claim. These limits are outlined in the following section.

5. Limits on the duty to provide special medical care

It is assumed in the present section that the handicapped newborn will receive ordinary nursing care, including nutrition adequate for life. We are not here discussing the withdrawal or withholding of such care which, with the exception mentioned in 4.2 (a relatively rare kind of situation), cannot be regarded as morally acceptable. This section is entirely concerned with the reasonable, and therefore morally acceptable, grounds which may exist for deciding to withhold special therapeutic or life prolonging treatment from a handicapped newborn.

doctors concerned, seeking if possible to alter their view of what is appropriate in the treatment of the child. Whatever the outcome of such exchanges, she should certainly not carry out orders which constitute gross injustice to the child, such as orders to sedate and give sub-caloric feeds. She should make clear to her nurse manager her position in this respect. However, when the wrong being done to the child is grave, the nurse's position is not exactly like that of the conscientious objector to abortion who merely seeks to refrain from cooperating in a morally wrong but legally accepted practice. Sedation and starvation of children is not legally acceptable (see 11 below): it is a crime. So a nurse, as a responsible citizen, cannot be content merely to be transferred to alternative work knowing that serious criminal offences continue to be committed in the paediatric unit. If the hospital authorities will not take rapid steps to rectify this state of affairs, then a conscientious nurse who knows for certain that serious wrongdoing is taking place has no alternative but to report the matter to the police.

11. The legal position in regard to withholding basic nursing care

Parents have a legal duty to look after their children. A parent who fails to carry out his or her duty, knowing that this is likely to cause the child's death or to cause really serious harm to the child, may be charged with manslaughter; if there is intent that the child should die from such neglect, the charge may be murder.⁴

Sometimes doctors, and nurses under the orders of doctors, embark on a regimen under which a child is deprived of adequate nourishment and sedated to suppress consciousness of hunger. They do so in the hope that death will ensue, either by starvation or by supervening infection, in the knowledge that it will inevitably ensue, and knowing that death would not otherwise ensue within such a short period of time. The regimen, particularly through the omission of proper nourishment, is intended to cause death. There is no doubt that in English law there can be murder by a series of omissions intended to cause death. It is a mistake to think that murder is committed only when death is caused by positive behaviour.

It will not suffice for doctors ordering a regimen of sedation and starvation, or for nurses acting on doctors' orders, to plead that they were doing no more than carrying out parental wishes. Since parents have a duty to care for their child, they cannot lawfully request, or consent to a proposal, that their child be deprived of basic care.

12. The need for community support of families with handicapped children

This document began by saying that every child, however impaired, is a gift of God. That truth does not make it any less the case that handicapped children make

Parents of babies born with spina bifida whom doctors decide to treat conservatively should seek a clear and convincing justification for this decision, obtaining, if necessary, a second opinion.

9. The responsibility of paediatricians faced with parents who reject their handicapped child

Initial rejection of a child can often be overcome if parents are helped to understand how they can cope with a child who will undoubtedly make special demands upon them. Sometimes, however, parents are not to be moved from their rejection; and on occasion this can be because the burdens of care for a handicapped child are truly beyond their resources.

It will be clear that parental rejection could never provide grounds for clinical management intended to hasten the child's death. Because the most basic task of civil authority is protection of the innocent, it follows that when a child is without parental support and protection, and therefore at risk, civil authority has an interest in providing for the basic care of such a child and has a duty to do so.

Is there in such circumstances, further to the duty to provide ordinary nursing care, a duty to provide special medical care? The answer must be: Yes, if the care in question is what is ordinarily given to a patient suffering from the disability or illness from which this child is suffering. To argue otherwise would be to admit parental refusal of responsibility as a ground for discriminating between children in the provision of medical care, and to do that would be to corrupt the profession of medicine which exists to serve human beings just because they are human.

Doctors therefore have a responsibility to take the measures necessary to ensure that rejected children receive the treatment which they need. There are in Britain ample statutory and other legal powers to enable this to be swiftly and effectively done (as was demonstrated in the case of baby Alexandra in 1981).

10. The responsibility of a nurse who is given immoral orders by medical staff

A nurse's primary responsibility is to her patient which, in the context of this paper, is the handicapped baby. As an independent professional person she is accountable — morally and legally — for what she does, and the fact that she is carrying out orders from medical staff in no way absolves her from that responsibility.

If a nurse sees that medical management of a child is contrary to the basic rights of that child she should in the first instance make her position clear to the

Before specifying these grounds, one should note two features of the newborn as a class which add to the difficulties of treating them.

5.7 Two features of the newborn which affect clinical decisions about their care

There are two facts about newborn children which indicate that the greatest caution is required in selecting and managing their clinical care.

Firstly, newborn children are incompetent and unable to speak for themselves. Assessment of the burdensome character of treatment (see 5.3 below) will sometimes depend on the view one takes of the particular sensitivities and sensibility of the patient. A competent patient can speak up for himself in this regard. This is not the case with the newborn. Hence there is a danger, in assessing possible burdens of treatment, of assuming that a handicapped child will find burdensome what a normal adult would find burdensome if handicap were to restrict severely the life he had hitherto led. But a contrast between normality and handicap does not occur within the experience of his own life for the handicapped child. It may be possible for a child to assume and accept handicap almost as second nature. Clinicians should remain open to this possibility.

The second fact about handicap and illness in the newborn, which affects decisions about clinical care, is that assessment of prognosis is in general more difficult with newborn than with adult patients.

5.2 Treatment of little or no benefit to a particular baby

Doctors are under no obligation to embark on treatment which they have good reason to think will be of little or no benefit to a child. They may have reached this view because they know that there are features (other than those treatable) of the child's condition which indicate that it has very little time to live. It would, for instance, be quite inappropriate to embark on major surgery in an infant with little or no kidney tissue, or in an infant with one of the more rare chromosome problems in which the malformations which can be corrected by surgery are a relatively minor feature of a condition with a very poor prognosis. In cases such as these, when it is judged that the infant's condition is untreatable and will lead to death within a short while, only the most basic care is required - warmth, food, comfort, affection and any medication that is required to relieve symptoms.

It needs to be recognised that some of the malformations with which children are born prove rapidly fatal and do not admit of curative treatment; all that can be given to such children is very basic nursing care and symptom control. Here are some cases from the practice of one paediatrician which illustrate some of the untreatable conditions from which newborns may suffer.

Inoperable congenital heart disease

William was diagnosed as having cyanotic congenital heart disease when a few days old. Investigations showed that the condition was inoperable; William would die when the patent ductus arteriosus closed. William was looked after in the special care baby nursery and his parents spent many hours with him. Normal feeds were given and drugs were not needed; it was almost six weeks before William died.

Anencephaly

Most children with anencephaly die before or shortly after birth. Caroline was unusual in that she was a very vigorous baby but had anencephaly. She showed all the normal newborn reflexes and had normal feeding reflexes. She received all the normal care for a newborn child and fed extremely well. Her mother visited her regularly and great care was taken to dress her like a normal baby and to achieve as normal an appearance as possible. No sedation was required. After about five days she died quite suddenly.

Dwarfism with a dysplastic thorax

Paul required resuscitation at birth, followed by intermittent positive pressure ventilation. Clinically he had severe achondroplasia with a dysplastic thorax. Even with the aid of positive pressure ventilation, his lungs were hydroplastic and it was impossible to maintain oxygenation. No treatment for this condition is possible. His parents were told of the diagnosis and the impossibility of curing him. With their consent the ventilator was disconnected and Paul died in his mother's arms.

Multiple congenital abnormalities

At birth, Mary was found to have multiple severe congenital abnormalities which included the following: microcephaly with a large encephalocele, a large myelomeningocele involving the thoracolumbar region with consequent extensive paralysis of both legs; ectopia vesicae and tracheo-oesophageal fistula with atresia. In view of the severity and number of these abnormalities, it was decided that only palliative treatment should be given. Feeding by the normal route was impossible and therefore a feeding gastrostomy was made. This enabled Mary to receive normal milk feeds but despite this she died after a few days.

In all the above cases there seems little prospect of combating the lethal effects of the abnormalities with which the children were born. Overcoming any one of these abnormalities would still have left another or others, likely to result in death within a few days or weeks, and radically destructive of health (see 3 above). Sometimes, however, one can embark on a course of treatment which offers some prospect of warding off death and restoring some degree of health but which also carries with it considerable risks and considerable burdens. Since the risks may be, for

documented case in England of a paediatrician who, prior to ascertaining the existence of any other complications in the child's condition, ordered that a child rejected by his parents should be given regular heavy sedation and should be fed with -no more than water. The arrangement was certain (unless countermanded) to cause the early death of the baby. Any such arrangement - and indeed any arrangement liable, of its nature, to cause early death — is, as we have said (4.1 above), a grave violation of the child's most fundamental legal and moral right not to be murdered.

7.3 Down's syndrome with duodenal atresia

A significant number of babies with Down's syndrome are also born with an intestinal blockage, called duodenal atresia (and about a third of babies with duodenal atresia have Down's syndrome). If the defect is not corrected surgically the child will die, and the death will be a miserable lingering death from starvation. The operation is a routine one with a good prospect of complete success.

The operation does not carry unacceptable risks, it does not have burdensome consequences, and it manifestly is highly beneficial to the child with Down's syndrome. None of the grounds recognised in section 5 for withholding special treatment hold good of this operation. So it is difficult to understand why it should not be regarded as mandatory. In fact the operation is frequently not done on children with Down's syndrome and the principal reason is an adverse judgement on the 'quality of life' of a child with Down's syndrome. As was noted in section 3, judgements which purport to assess the worthwhileness of a human life (as certain 'quality of life' judgements do) provide no valid basis for clinical practice. In circumstances in which the operation is routine for a child with duodenal atresia uncomplicated by Down's syndrome, denial of the operation to a child with Down's syndrome seems morally indefensible.

8. The responsibility of parents who have doubts about whether their children's rights are being respected

At the very least parents are entitled to the assurance from doctors that their children are receiving ordinary nursing care. They have the right and obligation to demand that care for their child if it is clear that it is not being provided.

Beyond this level of care, parent's knowledge of the special medical care required by their child must to a large degree depend upon the information they receive from doctors. Nonetheless, the special needs of children with some conditions is well known to laypeople. Parents in Great Britain, where the requisite surgical skills exist, are entitled to demand surgery to correct intestinal blockage in a Down's syndrome baby who is not suffering from any other rapidly lethal condition which is incurable. Indeed, they have an obligation to insist on such surgery.

In the case of babies with an open spina bifida but with little or only moderate nerve damage, an emergency operation to close the open wound on the back is the correct treatment since the condition of the nerves can deteriorate if left exposed.

Between the two extreme degrees of the condition is a large group of babies with varying degrees of paralysis who have a good prospect for survival if treated enthusiastically but who will undoubtedly be permanently handicapped to a significant degree. It is about this group that a great deal of controversy exists regarding the concept of 'selection' for treatment of only those babies in whom a good outcome can be predicted. In some centers 'selection' means that unoperated babies are given no treatment and are not simply allowed to die but are encouraged to die by sedation and inadequate nourishment. This, of course, cannot be justified. Selection can be justified if the choice lies between surgical treatment and conservative treatment. It needs to be emphasised that for some babies with open spina bifida conservative treatment is more suitable than surgery because of the shape or size of the lesion on the back and that many babies so treated will survive and do well within the limit of their handicap. It must be emphasised that, contrary to common belief, closure of the back lesion is not synonymous with survival and non-closure is not synonymous with death.

It is also important to realise that in almost all cases of open spina bifida, and certainly in the more severe cases, the outcome in the long term will depend not only on the treatment given in the neonatal period but also on after-care and the early recognition and treatment of complications, notably hydrocephalus, problems affecting the kidneys, and orthopaedic complications. In the developing countries and even in parts of Great Britain, as we have already noted, the facilities for comprehensive after-care of these babies is either non-existent or limited and this is a consideration that will have to be taken into account in decision-making about whether a particular infant's condition is treatable or otherwise.

7.2 Down's syndrome

Down's syndrome is a congenital defect of both physical and mental development. Children born with it have 47 instead of the normal 46 chromosomes. Their characteristic physical appearance is familiar ('mongoloid'). What is more significant is the mental retardation from which they suffer, which varies from mild to severe. It has been shown that concentrated efforts to stimulate these children in a variety of ways early in their development improves mental ability to some degree.

It is well known that these children are of a generally happy disposition, and, though demanding special attention and therefore liable to cause stress, they are also very frequently a source of happiness in the lives of those who care for them. Despite these generally recognised facts about children with Down's syndrome, there are parents who will reject such children. There is at least one recent and well-

example, risks of infection which itself will prove fatal, then (when those risks are known to be high) the treatment contemplated may be judged to be so doubtfully beneficial as to be unwarranted.

Doctors have to make judgements about the degree of risk attached to potentially beneficial treatment. The difficulties associated with this kind of judgement are well illustrated in the treatment of what is known as the short bowel syndrome. In some conditions affecting the bowel in the newborn baby, virtually all the small intestine may be lost and the baby is left with too little bowel to sustain life. In some borderline cases, provided the baby can be kept alive by intravenous feeding, what little bowel there is may gradually grow and eventually, after a year or more, the baby may be able to feed normally and thrive. In extreme cases, even though the baby can be kept alive by intravenous feeding, there is no real prospect of him ever being able to sustain his nutrition normally and the prospect is that after a few months or possibly years of continuous intravenous feeding, he will succumb to the complications of the treatment; for the treatment carries a continuous risk of infection and septicaemia. The probability of a fatal infection must be a factor which weighs heavily against persisting with intravenous feeding when it becomes clear that there is little or no prospect of the baby feeding normally.

5.3 Treatment which imposes an excessive burden on a baby

Another factor which clearly must influence decisions about the treatment of babies with short bowel syndrome is the burdensome character of the treatment. In general it is reasonable to withhold or withdraw treatment if it seems clear that the consequences of treatment involve burdens to the child which significantly outweigh the benefits that might be secured. Such a judgement should be made only with the greatest caution; it should indeed appear to be clear that the burdens do significantly outweigh benefits. In coming to this conclusion two points are of particular importance:

- (i) One should keep clearly in view that the reason for withholding treatment which we are discussing here concerns burdens which are involved in or are a consequence of treatment and not the burdensome character of the congenital disability or congenital malformation. The latter, of course, exist prior to treatment; they would constitute reasons for not undertaking special clinical treatment only if they were too little modifiable by that treatment.
- (ii) One should also resist any inclination to underestimate the benefits which treatment might offer.

5.4 Treatment which exceeds resources

Sometimes special treatment which can be offered in one hospital may not be available in another, either because necessary equipment is not available or because staff with the necessary skills are lacking.

Equipment may be available but not in sufficient quantity to meet demand. In such circumstances treatment may be withheld from one child and offered to another on the grounds that the second child is more likely to benefit medically from the treatment. In making such a choice one need not be involved in making any comparison between the fundamental value of each child's life (a comparison impossible to make); rather, one's legitimate concern may simply be to make best use of the limited resources available.

Sometimes in the intensive care of premature babies there are fewer ventilators than babies in need of them. Choices must be made, and where one child has a good prognosis while another has a poor prognosis it is reasonable, given that equipment is scarce, to employ it in treating the baby with a good prognosis.

Difficulties about embarking upon treatment may arise either from scarcity of skills, such as surgical skills, required to carry out the initial treatment, or from scarcity of staff sufficiently skilled to undertake after-care. There are parts of Great Britain, for example, which lack adequate facilities for the comprehensive after-care of babies who have received initial surgical treatment of spina bifida. That fact must affect decisions about whether or not to embark upon such treatment (see 7.1 below).

6. General considerations regarding neonatal surgery

Many of the decisions about special medical treatment of handicapped newborns are decisions about whether to carry out surgery. So it would be useful to outline in this section some general considerations about surgery in the early weeks of life.

Neonatal surgery is to a large extent the surgery of congenital malformations, although in recent years the incidence of acquired surgical conditions in newborns has steadily increased because of the survival of very low birth-weight babies, who are liable to develop problems requiring surgery (e.g. hydrocephalus due to brain haemorrhage, perforation of the bowel due to poor blood supply etc.).

Surgery is only performed in the neonatal period (by definition the first four weeks of life) if it is essential for the preservation of the child's life or the prevention of suffering or of handicap. It is only justifiable when there is a reasonable hope that the infant will derive some tangible benefit from surgery.

Infants whose condition is treatable by neonatal surgery can usefully be divided into five prognostic groups:

- (1) Infants who can be completely cured by surgery. Most babies born with a blockage of the gullet or bowel come into this category.
- (2) Infants who will be left with relatively minor handicaps after surgery, e.g. slight weakness of the legs after surgery for a minor degree of spina bifida.
- (3) Infants who, after surgery, will be left with severe physical handicaps e.g. infants with malformations of the urinary tract who are left with damaged kidneys; infants who are cured by surgery of a blockage in the bowel caused by cystic fibrosis but who will have permanent digestive problems and a tendency to lung infections; babies with the more severe degrees of spina bifida causing hydrocephalus and paralysis of the legs, bladder and bowel.
- (4) Infants in any of the above three groups who, in addition, are of subnormal intelligence. The well-known example of this group is the combination of Down's syndrome and duodenal atresia (a type of intestinal obstruction).
- (5) Infants in groups 1 to 3 who, in addition, are likely to be severely mentally retarded e.g. babies with severe degrees of hydrocephalus or other malformations of the brain; very low birth weight babies who need surgery for hydrocephalus but who also have severe brain damage as a result of haemorrhage.

It is often very difficult to predict at birth the category into which a particular infant belongs and this applies particularly to the prediction of intelligence.

7. Two conditions frequently discussed: spina bifida and Down's syndrome

7.1 Spina bifida

It is in the treatment of open spina bifida that paediatric surgeons, as well as paediatricians, are most frequently faced with complicated medical and moral problems. In this condition the spinal cord lies exposed in the lower part of the back. This is accompanied by a greater or lesser degree of paralysis of the leg muscles and of the bladder and bowel and in most cases there is the added complication of hydrocephalus: enlargement of the head due to an increase in the pressure of the fluid within the brain.

Some of these babies have such a severe degree of the condition, maybe aggravated by complications or by other malformations, that they will clearly only survive for a short time and are quite unsuitable for surgery. It is unusual for these babies to show evidence of pain but if they do so then pain-killing drugs must be given to ease any distress.