



CATHOLIC BISHOPS' JOINT BIOETHICS COMMITTEE

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CARE

Of babies born With disability

CARE OF BABIES BORN WITH DISABILITY: **INTRODUCTION TO THE MORAL PRINCIPLES**

“The courage and the serenity with which so many of our brothers and sisters suffering from serious disabilities lead their lives when they are shown acceptance and love bears eloquent witness to what gives authentic value to life, and makes it, even in difficult conditions, something precious for them and for others. The Church is close to those married couples who, with great anguish and suffering, willingly accept gravely handicapped children.”

Pope John Paul II (Evangelium Vitae, 1995)

INTRODUCTION

Most children are welcomed as gifts by their parents. However when a child is born with significant disabilities, parents may experience conflicting emotions ... the natural love of fatherhood and motherhood can be derailed by feelings of guilt, anger or even rejection.

Parents unable or unwilling to welcome a child with disabilities as a gift from God may find themselves strongly tempted to deprive that child of the care to which he or she is entitled in justice. The following little booklet is intended to offer some guidance to medical personnel, pastors and indeed parents themselves who find themselves facing the moral dilemmas which often accompany the birth of a disabled child.

1 SECTION ONE:

THE PARTNERSHIP OF PARENTS AND MEDICAL STAFF IN THE CARE OF THE CHILD BORN WITH DISABILITY WHO IS RESPONSIBLE FOR THE EARLY CARE OF THE CHILD?

The early care will be the immediate responsibility of doctors and nurses, whose special skills may be needed to protect, and even save the life of the newborn baby.

WHAT ABOUT THE PARENTS?

Since primary responsibility for the child lies with the parents, close collaboration between parents and doctors in the care of the child is essential. Medical staff have a serious *moral* as well as *legal* obligation to consult parents over the clinical care of their child.

IS IT SUFFICIENT THAT PARENTS AND DOCTORS AGREE ON A POLICY FOR THE MANAGEMENT OF THE CHILD?

No, agreement on clinical management cannot be made in a moral vacuum. Any decision must respect the child's basic human rights.

It is a serious error to think that the primary responsibility of medical staff is to agree to the wishes of parents, however misguided such wishes may be. Parents may not make whatever arrangements they wish for their children, as though children were their own disposable property.

WHAT, THEN, IS A PARENT'S RIGHT TO SPEAK FOR THE CHILD?

A parent's right in these circumstances is similar to his or her right to speak for himself. In other words, it is an extremely important factor to take into account when planning the care of the child, but it is not the only or the over-riding factor.

ARE THERE LIMITS TO PARENTAL AUTONOMY WHICH JUSTIFY RECOURSE TO CIVIL AUTHORITY?

Yes, for example, when parental autonomy is likely to be exercised against the child's best interests. In such circumstances it would be the right and indeed the duty of carers and medical staff to act to protect the child, if necessary, through resort to the courts.

WHAT SHOULD DOCTORS TELL PARENTS ABOUT A NEWBORN DISABLED CHILD?

Doctors should give a truthful and full picture of the child's condition and the outlook for the future.

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SECTION TWO: THE RIGHTS OF THE BABY BORN WITH DISABILITIES

WHAT IS THE MOST IMPORTANT RIGHT TO BE BORNE IN MIND?

The most important and most basic human right is the right not to be killed. This is recognised in the United Nations Universal Declaration of Human Rights, article 3 of which states: “Everyone has the right to life, liberty and the security of person.”

It is important to note, however, that though such formulations are valuable reminders of the truth, such rights derive not from any national or international agreement but from the natural law, written into the heart of the human person.

HOW MIGHT A DISABLED CHILD RISK BEING KILLED?

To kill means intentionally to bring about the death of another person, in this case the baby. This can be done either:

- by action or
- by a failure to act.

Thus a course of actions or omissions (or a combination of both) *which have as their intention* the bringing about, or hastening of a child’s death, is never morally acceptable.

HAS THE CHILD ANY OTHER RIGHTS?

Yes. All infants should receive NURSING CARE, which means the kind of care and sustenance which a mother would be expected to give her baby. This will include nutrition adequate for life, even to providing that nutrition artificially where there are obstacles to normal feeding. Only if feeding is itself futile or unduly burdensome, as in the case of a child close to death, may it be withheld.

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SECTION THREE: LIMITS ON THE DUTY TO PROVIDE SPECIAL MEDICAL CARE

WHAT PARTICULAR FACTORS RELATING TO NEWBORN CHILDREN SHOULD AFFECT CLINICAL DECISIONS ABOUT THEIR CARE?

Two features must be borne in mind when dealing with such children:

- Newborn children are incompetent (in the technical sense of the term) and unable to speak for themselves.
- Assessment of the prognosis or outlook is in general more difficult with newborn than with adult patients.

WHAT ABOUT TREATMENT OF LITTLE OR NO BENEFIT TO A PARTICULAR BABY?

Doctors are under no obligation to begin treatment which they have good reason to think will be of little or no benefit to a child.

HOW MIGHT DOCTORS HAVE REACHED THIS CONCLUSION?

They may have reached this conclusion because they know there are features (which are not treatable) of the condition which indicate that the baby has very little time to live.

WHAT CARE SHOULD BE GIVEN TO SUCH A CHILD?

The most basic care must be continue to be given: warmth, food, comfort, affection and any medication which may be required to relieve symptoms.

WHAT ABOUT TREATMENT THAT IMPOSES AN EXCESSIVE BURDEN ON A BABY?

In general it is reasonable to withhold or withdraw such treatment if it seems clear that the consequences of such treatment would involve burdens to the child which significantly outweigh the benefits which might be secured.

Such a judgement, however, should be made only with the greatest caution. It must be very clear that the burdens *do* significantly outweigh the benefits.

HOW WOULD SUCH A DECISION BE REACHED?

In arriving at such a decision two points are of particular importance:

- It should be kept clearly in view that the reason for withholding treatment concerns *burdens which are a consequence of the treatment*. Treatment should not be refused, withheld or withdrawn because of the burdensome character of the disability or malformation itself. However, treatment need not be initiated where the condition or disability would be barely modifiable by such treatment.
- Any tendency to underestimate the benefits which treatment might offer should be resisted.

WHAT ABOUT TREATMENTS WHICH EXCEED AVAILABLE RESOURCES?

Sometimes specialised 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. Alternatively equipment may be available but not in sufficient quantity to meet demand. In these 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, and thus does not suggest that one life is more valuable than another; although civil authorities should do all in their power to avoid such circumstances arising. There may be a legitimate concern to make the best use of limited available resources.

It should be remembered that difficulties about embarking upon treatment may arise either from scarcity of skills, such as surgical skills, required to carry out initial treatment, or from scarcity of staff sufficiently skilled to undertake after-care.

4 SECTION FOUR: THE RESPONSIBILITY OF PARENTS WHO HAVE DOUBTS ABOUT WHETHER THEIR CHILDREN'S RIGHTS ARE BEING RESPECTED

WHAT ARE PARENTS' BASIC RIGHTS?

Parents are entitled to the assurance from doctors that their children are receiving ordinary nursing care. They have the right and obligation to demand such care for their child if there is any doubt as to whether it is being provided.

WHAT ABOUT SPECIALISED TREATMENTS?

Parents' knowledge of the special medical care required by their child to a large degree depends upon the information they receive from doctors. Parents have the right to know all relevant information relating to their child's condition, so as to allow them to participate appropriately in the care of their baby. For example parents in the UK are entitled to demand surgery to correct intestinal blockage in a Down's Syndrome baby, who is not suffering from any other rapidly 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.

WHAT SHOULD BE THE REACTION OF PARENTS OF BABIES BORN WITH SPINA BIFIDA WHOM DOCTORS DECIDE TO TREAT "CONSERVATIVELY"?

Such parents should seek a clear and convincing justification for such a decision, obtaining, if necessary, a second opinion.

5 SECTION FIVE:

THE RESPONSIBILITY OF DOCTORS FACED WITH PARENTS WHO REJECT THEIR DISABLED CHILD

HOW CAN AN INITIAL REJECTION OF A CHILD BE OVERCOME?

An initial rejection may be overcome if parents can be helped to understand how they can cope with a child who will undoubtedly make special demands upon them.

WHAT IF THE REASON FOR THE REJECTION IS A GENUINE LACK OF PARENTAL RESOURCES?

In such cases civil authorities have an interest in providing for the basic care of such a child and supporting the family involved and, indeed, the state has a duty to do so, since the most basic task of civil authority is the protection of the innocent.

CAN THERE BE A DUTY ON MEDICAL STAFF TO PROVIDE MEDICAL CARE AGAINST PARENTS' WISHES?

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. Such an admission would represent a corruption of the medical profession and a cavalier disregard for the child's fundamental human rights.

WHAT RESPONSIBILITIES DO DOCTORS HAVE?

They have a responsibility to take the measures necessary to ensure that children receive the treatment they need, even where parents have rejected their children.

WHAT MEASURES MIGHT BE REQUIRED?

In the UK there are ample statutory and other legal powers available to doctors to enable these measures to be swiftly and effectively applied.

6 SECTION SIX: THE RESPONSIBILITY OF A NURSE WHO IS GIVEN IMMORAL ORDERS BY SENIOR STAFF

WHAT SHOULD A NURSE DO WHEN SHE SEES THAT MEDICAL MANAGEMENT OF A CHILD IS CONTRARY TO THE CHILD'S BASIC RIGHTS?

The nurse should, in the first instance, make his or her position clear to the doctors concerned, seeking if possible to alter their view of what is appropriate in the treatment of the child.

Nurses should certainly not carry out orders which are a gross injustice to the child, such as orders to sedate unnecessarily and give sub-caloric feeds.

If, in the last analysis, hospital authorities will not take rapid steps to remedy wrongful sedation and starvation, 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.

CONCLUSION

This document began with a quotation from Pope John Paul II's letter *The Gospel of Life* which stated: "The Church is close to those married couples who, with great anguish and suffering willingly accept gravely handicapped children."

All people of good will, united by the bonds of common humanity, should share that desire to offer support to families faced with the uncertainties, fears and stress of living with disability. This solidarity should be manifested in a special way by relatives and friends. Parish communities, neighbours and employers should also be sensitive to their responsibilities in this respect.

Finally there is a need for wider society to support those living with disability in the family and to provide every available help to disabled children when parents find themselves unable to care for them.

Society's care for its weakest members is a litmus test of its civilisation.