CATHOLIC BISHOPS' JOINT BIOETHICS COMMITTEE

CARE

of your baby with special needs

CARE OF YOUR BABY WITH SPECIAL NEEDS;

A GUIDE FOR PARENTS AND CARERS

INTRODUCTION

The first few days and weeks following the birth of any new baby can be an emotional period for all concerned. If, however, your baby is suffering from some illness or disability you may feel bewildered and in shock. You have found yourself in a situation not of your own choosing and it can feel as though you are falling headlong into an unknown and frightening future. You may feel like hiding away, perhaps tempted to put the reality of the new situation out of your mind. You may feel angry and bitter, sad and lonely, perhaps even guilty.

At such times it is important to know that all these feelings are perfectly normal.

You will need time to begin to face the new situation. It will take some courage to face whatever difficulties may lie ahead. But it can be done.

Though your own situation is unique, thousands of families each year learn to welcome a new baby with special needs into their lives with love and hope. Mother Teresa of Calcutta reminded us – “Be not afraid in your suffering. God loves you.”

You may find this little leaflet helpful as you consider the decisions that lie ahead.

In his letter *The Gospel of Life (1995) Pope John Paul* II wrote:

“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 the fact that life, even in difficult conditions, is something precious for them and for others.

“The Church is close to those who, with great anguish and suffering, willingly accept gravely handicapped children.”

THE FIRST DAYS

When tests show that your child has abnormalities or special needs you may find considerable difficulty in finding the opportunity to talk over questions and concerns with understanding and knowledgeable experts or others who have faced similar situations.

Sometimes it may seem that there is simply not enough time to understand everything and make the necessary decisions.

Some parents find it impossible to welcome a child with a disability as a gift from God. They may find themselves strongly tempted to deprive the child of the life and care to which he or she is entitled in justice.

If you find yourself in this situation it is important to reflect on the main issues, so as to avoid making a hasty decision you may later regret.

The following paragraphs attempt to clarify some of the main issues confronting parents who have just had a baby with special needs.

WHO IS RESPONSIBLE FOR THE EARLY CARE OF OUR BABY?

Following the birth of your baby, doctors and nurses may take over the immediate care and responsibility. The infant may require intensive care and their special skills are needed. Primary responsibility for the child however belongs to the parents. Your baby needs his or her parents very much at this time. Your baby needs caressing and stroking and will recognise your voice. You will be able to gently care for your baby and to be present more consistently than staff members. Do not neglect this opportunity to bond with your baby.

Close collaboration between yourselves, doctors and nurses is essential at this time. The staff have a serious moral as well as legal obligation to consult with you over the clinical care of your child. It is not sufficient that you as parents and the doctors agree on a policy for the care of your child. What is agreed must respect your child’s rights. It is a mistake to think that a doctor’s primary duty is to agree to the wishes of the parents.

YOUR BABY HAS RIGHTS TOO!

The right you have to speak for your child is similar, in fact, to the right you have to speak for yourself. This means that you will want for your child what you would want for yourself.

On very rare occasions in the past the courts have stepped in because the parents' decision appeared to act against the well-being of the child. Such situations are extremely rare and will not arise when parents and medical staff communicate well. You should ask that doctors and nurses give a truthful and full picture of your child's condition and you should have confidence in the doctors caring for the baby.

This partnership between parents and medical professionals can of course break down where there is no agreement as to how to proceed.

One temptation is to demand treatment which results in prolonging life at all costs, even when extraordinary and burdensome means are necessary and no improvement in condition is possible. Such a request, while completely understandable, fails to respect the dignity of your baby.

For example very premature infants can suffer much pain from repeated heel pricks performed to check blood results for many days and much discomfort from tubes and ventilation before eventually dying. Don't hesitate to ask.

It is important that parents and doctors constantly reflect on whether any proposed treatment takes into account the infant's 'voice'.

Perhaps a more likely scenario occurs when your baby's right to life is threatened by a decision to withhold the basic needs of life: food and fluid. The phrase "his or her life was not worth living" can too easily be applied. It is one thing to spare your child unnecessary suffering. It would be quite wrong, however, to decide to bring about or hasten the passing of your child.

Even in the most severe cases, among very disabled babies without hope of survival, food and fluid should not be withheld, except where the process of feeding itself becomes burdensome and disproportionate to any benefit. Even in these extreme circumstances it is your right as parents to have and to hold; to tend and to nurture your little child until death comes. In addition your infant may require nursing and medical care to prevent discomfort. Do not hesitate to ask for help if you feel your baby is in any way distressed.

THE EARLY DAYS … WORKING WITH HOSPITAL STAFF

It is important for your baby’s psychological development that the normal parental bonding takes place and becomes stronger with time. It is difficult for this to happen if there is uncertainty about whether your baby will survive. In addition it is possible that your initial reaction to your disabled infant might have been one of rejection, of anxiety, of insecurity about coping with a child who will make special demands on you.

In spite of all this, you can help your child enormously by simply holding, talking to and stroking him or her. Staff will help if you feel tempted to reject the baby. Even after “normal” pregnancies the blues can strike shortly after birth!

Another important relationship is that between parents and the nurses. The nurses are there to help you and support you. In these difficult days they are your best friends. Besides their obligations to you and your child, nurses have an obligation to communicate with the consultant in charge of your baby if they have concerns about the treatment your baby is receiving. The nurse also has the responsibility to ensure your baby receives pain relief and sedation. You should let the nurse know if you think your baby has pain or discomfort, or is hungry or thirsty.

It will be helpful for your doctors and nurses to know how you feel. It will be helpful for all concerned if, with the doctors, you can move towards as quick a decision as possible regarding treatment for your child.

HOME FROM HOSPITAL … WHAT NEXT?

The thought of having to cope on your own with the extra demands of a baby with special needs can be overwhelming, indeed frightening. Such fears are understandable, but unnecessary. Support will be available to you and your baby in the months and years ahead.

Following discharge from the newborn nursery your child will have medical follow-up and will be supported by a team of doctors, nurses, social workers and psychologists. The social worker will inform you of allowances available to help with extra materials you may require. You should ask to speak to the social worker at an early stage.

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.

Doctors will make all the arrangements should your child need to be transferred to another hospital and expert teams will be available to care for your baby during transfer.

Again, however, the importance of your affectionate presence cannot be overstated. Your child needs you.

THE FUTURE

Irrespective of your faith or culture, people of good will within the community will seek ways in which to help the parents of children born with disabilities.

Christians will find that the parish will be sensitive to its responsibilities in this respect. The same will be true for believers of other faiths within their own religious communities.

There is also a need for society to recognise the importance of support for parents with children with disabilities and the importance of directly supporting those children when parents find it hard to care for them.

Many voluntary groups exist to help children who are disabled. You could find it helpful to be a member of a parents' group. Ask hospital staff to put you in touch.

Employers, neighbours, relatives and friends will be sensitive to your new situation too. Again do not hesitate to ask for help.

Above all, do not lose heart. Your child needs your care and your love more than you can ever know. As countless families will testify, the decision to welcome into your home a baby with special needs can turn out to be one of the most life-enhancing moments of your life.