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The Reality — A Chain of Decisions

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Parent of a Handicapped Child

One of the greatest decisions a couple take during their lifetime is that of giving birth to a human being. This very important decision is the first in a series of other decisions that parents must take in order to bring up their child in the best way possible.

The number and complexity of the decisions a couple must take increases considerably for a couple, whose child is handicapped. Hence, in order to be able to reach our decisions based on the necessary knowledge, and when we are in a good state of mind and emotionally stable, we parents of handicapped children need to be given, from the very start, the information, help and support which is necessary. The information we are given must be as comprehensive and comprehensible as possible and should reach us in time. Above all information of this sort is ours by right and should therefore not be given to us as a concession, as often happens at present.

We parents need psychological and emotional help in order to pass from the initial shock of losing the ideal baby we'd dreamt of and hence lost because of the handicap, to the maximum acceptance possible. I believe full acceptance can never be achieved as, after all, hope is the last to die. Eventually, we have to get to the stage at which we take positive and constructive action in the name of our handicapped children in order to help them to reach the best quality of life possible.

All parents, on being informed that their child is handicapped may feel various emotions which although perfectly normal, may be unacceptable to them. They may rebel against everything and even against God, wishing their child to die or wishing he was not born at all; they may blame themselves and each other for their child's handicap. These are all normal emotions which it is good for the couple to share, together, with other parents who have experienced them, and where necessary with social worker, psychologist or psychiatrist. Repressing these emotions may cause more harm than good.

At this stage, parents who have little or no information about the handicap, may start shopping from one professional to another. They may ask advise from everybody and in every place whence help may be forthcoming, hoping ultimately that from someone or in some place they may learn that their baby is not handicapped after all. In this regard there exists a very rich sea for 'sharks' who may be found everywhere, (Malta being no exception) who are prepared to do everything for the sake of financial profit.

These are the three principle stages that we parents pass through: initial shock, acceptance and finally action. As parents we will be faced continuously with many decisions which have to be taken, some of them involving delicate principles and for some of which very often, no definite answer exists. Parents, together with professionals, often have to take decisions according to the prevailing circumstances and according to a well-informed conscience. In order to reach certain decisions, parents as well as the family may have to experience periods of tension, periods which may be emotionally and psychologically very stressful, especially since there also exists the burden of caring and attending to the needs of the handicapped person.

A situation which often has to be faced by the parents of a handicapped child, either at birth or possibly, later in life, involves the decision as to whether their handicapped child should or should not undergo medical intervention. Such a decision may have in its balance the life or death of the handicapped person. Other parents may have to decide whether or not to permit irreversable medical intervention to be carried out on their handicapped child - especially when such intervention is still at an experimental stage. Very often it may not be possible for parents to postpone their decision since their children's problems often get more difficult to solve when the children are older.

Some parents may be informed following special tests or because of contact by a pregnant mother with infectious viruses that there is a great possibility of their having a handicapped baby. Such parents may have to decide whether to abort or not. The problem of abortion may also arise in cases where mentally handicapped persons get pregnant.

Genetic counselling is of a great help to parents of handicapped children, to the handicapped persons themselves and also to their siblings in seriously planning their families. Such counselling often presents the parents with a number of important decisions. Can the parent take the great risk of having another handicapped child? If not, what type of contraceptives are available (and are recommended) for use? Is sterilisation an ethical means of contraception in these circumstances?

Siblings too have a right to be informed of the results of such counselling in order to be in a position to plan their lives in the best possible way. When is the opportune time for parents or another person or persons to inform the siblings of certain information, especially if such information includes the fact that they have an above average risk of having a handicapped child?

The mentally handicapped, at least theoretically, have a right to full sexual development and to being able to form a family of their own. Will marriage between such a couple, if it takes place, be legally binding? Can they have children? If the answer is in the negative, can parents ask for these children to be sterilized? What is the legal position in these circumstances of a curator appointed by the court in the absence of the parents? Can such a person take decisions as regards such medical intervention?

These are some of the problems faced by the parents of handicapped children. Other problems which at face value appear to be less complex, in reality cause great emotional and psychological stress on the parents. Very often parents may have to decide on the type of education they want to give their handicapped child whether it is special education or education within the mainstream.

Other parents may have to determine whether to educate their handicapped child in Maltese or in English in the context of a system of education (as well as a culture) which in largely bilingual.

Another delicate decision that nearly all parents may have to face at one time or another is on which occasions to stand up for their handicapped child and when it is more prudent to stay quiet. It often happens that because of too much fear, inferiority-superiority complexes, autocratic and illusive systems, parents give up the fight because they find they cannot quarrel with the professional whom they need, even though, unfortunately, as sometimes happens, these professionals are not up to standard or else not worthy of the parents' trust.

Other important decisions which have to be taken by parents of handicapped persons are those regarding the allocation of resources within the family. The handicapped person requires more attention which obviously will have to be translated into time and/or money. Where are we, as parents, going to draw the lines which are so delicate in such a way as not to neglect or hurt each other, the other siblings and even ourselves?

With the handicapped child, the parents have to strike a delicate balance between the attention and protection really needed by the handicapped person and the independence needed also by the handicapped person to develop his/her potential to the maximum possible. Independence can lead to the handicapped person's getting married, separating himself from his parents and forming a new family. In other cases, the parents may have to take an emotionally difficult decision to separate themselves partially from the handicapped person because in the prevailing circumstances it may be better for the handicapped person to go into a residential home suitable to his/her needs. This decision is by far more difficult and more delicate, if, as is often the case, the parents may have to separate themselves from their offspring, who will be sent into residential hospitals which for various reasons are not suitable for them. Such partial separation may be compared (without stretching the comparison too far) to the greater loss experienced by parents whose handicapped child dies at a tender age.

These are some of the important realities faced by us, the parents of handicapped persons. Often these decisions have two sides to them, one involving the parents and the other involving the professionals working in this field. One decision which can never be taken by the parents but which was taken by the professionals who have chosen to work in this field, is precisely this professional choice. Parents are in this field out of necessity and not through choice. We are faced with this great challenge in our lives where many aspects cannot be changed but can be made better, where the impairment of our children cannot be cured even though its negative effects can be diminished, where often the limitations are great but the possibilities to develop our children's potentialities are also great. Hence there is a great need that together we pray to have the serenity to accept the things we cannot change, the courage to change what we can change and the wisdom to know the difference. And together with serenity, courage and with wisdom, if we add **love** to unify everything, we will have the best recipe for handicapped persons, to have the best quality of life possible.