

Early referral to limb deficiency clinics

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Abstract

Immediate support is needed by parents when a limb deficient child has been delivered, a time when parents' fears and problems are greatest. This support involves special skills not readily available in the community. Thus it is important that these children and their parents are referred to Specialist Clinics by their local doctor immediately after birth. Experienced therapists and medical social workers attached to these clinics are not normally available to obstetric specialists and general practitioners. The doctor-in-charge of the Clinic, the social worker and the therapist visit the parents and child in hospital. This early counselling facilitates the bonding of the parents and child. It also reduces the parents feelings of guilt and distress over having a deformed baby. Appropriate counselling given at this stage on prostheses, daily living activities, parent group discussions and the future prospects for these children, helps ensure a satisfactory life.

Love, indifference and hate experienced in infancy, profoundly affects our development and relationships. Love gives security, warmth and the ability to make close relationships; indifference leads to insecurity and isolation; hate generates guilt or hostility. For most of us there is a delicate balance, in our favour or against us, depending on social pressures and environmental influences. In all but the most exceptional circumstances, to be born with a deformity will swing the balance adversely. Restoration of the balance requires understanding, family support and encouragement, and professional help.

For all of us, birth is a critical period. The outcome depends largely on the acceptance, warmth and care we receive, which in turn is

closely related to the expectations the parents have for the child. A child born with a limb deficiency will be responded to in a variety of ways depending on his parents' background and stability. If these have not been optimal then the presence of disability will place an extra burden on the child. If the parents are not helped to sort out their feelings at the time, then damage will be lasting. The stress resulting from a deficient child can lead to minor differences between parents developing into a major rift.

The presence of a serious handicap in a young infant precipitates a crisis for the whole family. Intervention programmes are essential to save life or to ameliorate the long term effects of the handicapping condition. These programmes require careful and extensive planning if they are to be accepted by the child and his family, rather than being perceived as unacceptable intrusions.

Bettleheim (Klaus & Kennell, 1976) states that "Children can learn to live with a disability but they cannot live well without the conviction that their parents find them utterly loveable . . . If the parents, knowing about his (the child's) defect, love him now, he can believe that others will love him in the future".

The effect of early skin-to-skin contact of infant and mother, following birth, plus the father's presence, helps to bond the infant to both parents. It has been shown (De Chateau, 1976) that mothers having this early contact, give more love, the infants cry less and laugh more, have significantly higher I.Q.'s and develop more advanced scores in language tests. Attachment is crucial to the survival and optimal development of the infant and to the child's bonds with other individuals in the future.

It is now known that the baby sees, hears and moves in rhythm to his mother's voice in the first minutes and hours of life, the linking of the reactions of the two results in a synchronised 'dance' between the mother and baby which is an essential part of the process of attachment. Bonding of the father to his newborn baby

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depends on his attraction to the infant, his perception of the newborn as 'perfect', his elation and increased sense of esteem. Extensive early exposure of the father to the infant in hospital is essential.

Turbulent emotional reactions replace joy and delight where a mother has just given birth to a child with a limb deficiency. The blight of a malformation, particularly where it is visible and hence embarrassing, is a crushing blow to the parents and to everyone else who has shared in the event. What is visually apparent, e.g. a missing limb, is far more distressing to parents than hidden congenital defects or internal disorders—even though these conditions may be far more disabling. The parents' efforts to keep secret the information of the birth of an abnormal child, contrasts strikingly with the usual wish to spread the happy news.

The reactions of parents to the birth will be influenced to a large extent by how effectively their questions are answered and their doubts and problems ameliorated. Sympathetic, realistic advice at the earliest opportunity, from the doctor or therapist experienced in this area, can reduce the long term problems they will have to face. Where no secrets are kept from either one, neither parent has to interpret to the other or feel that he or she has to buffer the shock. Lack of bonding with the child, or rejection by one or both parents is greater when they are not together when they first learn of the birth abnormality.

Mothers, having been told that their baby has a limb deficiency, find that the most traumatic time is when waiting to see the infant. The shock of producing a baby with a visible defect is stunning and overwhelming, but attachment can be facilitated by showing parents their new baby as soon as possible and accentuating the attractions.

Parents also attach great importance in the early stages to the general attitude of the medical and nursing staff, more than to words. Adverse attitudes are never forgotten so that it is important for all staff having contact with the parents to be aware of their own feelings and to guard against over-reaction.

Unresolved guilt, denial, or less than adequate resolutions may cause the child or the family to suffer. Many parents search at length to find a specific cause for the deformity in order to be rid of feelings of guilt, and in some cases the

grandparents may aggravate the feelings of shock, grief, guilt, denial or resentment experienced by the parents.

At the Limb Deficiency Clinic at the Royal Children's Hospital, Melbourne, Australia, when there is a referral after the birth of a limb deficient child, the doctor in charge of the Clinic visits the parents to counsel and to arrange a visit with the medical social worker and occupational therapist, who will give appropriate help and realistic understanding of the future. While visits may be impracticable for a remote country area, as much information as possible is given over the telephone to suffice until such time as the parents and child can travel to the Clinic.

Our best efforts to encourage appropriate referral to local doctors, obstetricians and nursing staff at women's or midwifery hospitals, are often met with apathy and reluctance. This failure highlights the need for appropriate training in the curriculum of the undergraduate medical practitioner. The importance of education being directed to this area cannot be over emphasized.

The security felt by the parents through the knowledge that there is someone who cares and who is readily available for support when needed, helps reduce uncertainties as they arise. It is preferable that the parents develop a rapport and have trust and support with *one* person, one who can handle all situations and be available for the parents' and child's needs as they arise as well as throughout the child's developmental stages, both physical, social and emotional. An occupational therapist may be the ideal person for this role. The occupational therapist is more likely to be experienced in treating and working with limb deficient children and their parents, in dealing with the emotional and physical needs of the child including the training programmes required for a prosthesis, and with activities of daily living should a prosthesis not be worn. It is realised that the emotional responses are more important than anything else. If these are dealt with satisfactorily then the fitting of a prosthesis will be a natural step.

Usually parents welcome the opportunity to meet with another family where there is a child with a similar deficiency. At the Royal Children's Hospital, Melbourne, parents' group discussions are held with the medical social worker and therapist attached to the Clinic. These groups provide the opportunity for



Fig. 1 Help and appropriate early training result in a satisfactory quality of life for a person born with a limb deficiency.

parents to realise that there are other children in the community with similar problems to those of their child. These groups also bring reassurance and an appreciation that the stress of the parents and their disturbed thoughts are not unusual. At the same time emotional support is gained and suggestions for solving physical problems are exchanged.

Not all limb deficient patients attain an optimal result. Some children with a minimum deficiency have difficulty with various skills or in accepting themselves, or in achieving independence. Surprisingly, it seems that these difficulties are largely due to factors within the family rather than to physical limitations of the child. Most girls will discard an upper limb prosthesis with a split hook on reaching adolescence due to its appearance, on the other hand boys tend to continue wearing such a prosthesis, because they depend upon it for function and accept it without hesitation.

The major problems to be overcome are:

1. To ensure that bonding takes place between parents and child.
2. To alert the medical profession and midwifery nurses to the importance of early referral to the Limb Deficiency or Specialist Clinics.
3. To have a named person accept full responsibility for the continuing professional management of the patient.
4. To make the appearance of the prosthesis acceptable to the child and family concerned, without reducing function.
5. To educate professionals working with patients in the prosthetic field to the realization that the amputee child is not a scaled down adult, that for successful rehabilitation it is necessary to know the basic emotional needs of the young child, his physical make-up and the differences between him and an adult.

Help, and appropriate early training result in a satisfactory quality of life for a person born with a limb deficiency (Fig. 1). Successful use of a prosthesis depends on the child seeing himself as loved and accepted as a person in his own right and as he is, rather than as his parents may have wished him to be.

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