

Erb's Palsy



**FAMILY ISSUES
AND
PSYCHOLOGICAL EFFECTS**

Erb's Palsy

Introduction

When a child is diagnosed with a physical disability shortly after birth the response of parents is one of great upset and distress. The perfect child who was expected is suddenly under threat from some unknown condition and this results in a high level of anxiety and fear. The process of coping with these and other distressing reactions is often drawn out over a long period of time and entails contact with a wide range of professionals and a lot of learning.

Over time, as the condition becomes more familiar and the particular form of the condition in a child becomes apparent, parents will gain in skill and confidence. They become more able to deal effectively with the needs of the child and with those around them including their other children, extended family, neighbours and professionals.

The aim of this pamphlet is to outline the psychological issues and the processes of coping which are common in this context and to inform parents as to what to expect so as to minimise pain and confusion.

It is important to note here that the responses of the various individuals involved, while following common patterns, will also show wide individual differences. Some parents for example, may experience extreme levels of distress over significant periods of time while others may learn to cope quite rapidly. Both kinds of response are normal reactions to personal trauma.

Response of parents

After a child is diagnosed with Erb's Palsy both parents are likely to be frightened and confused. It is most unlikely that they will have heard of the condition before and they will be very concerned at the possible extent of the injury and its effects on the child's future functioning. Unfortunately, because of the nature of the condition, they may have to wait some time before the answers to such questions become clear.

There are various ways in which the stresses of the situation may be experienced:

Firstly, very strong emotions are brought to the surface including fear, sadness, hopelessness, helplessness and depression. There may be episodes of acute anxiety or panic and these feelings can seem overwhelming. Intense anger may be felt at what has occurred and this may be directed at medical personnel.

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Secondly, parents may have disturbing thoughts such as they will be unable to cope with the situation, that they will fail as parents, that the child will have a terrible life and some feel so distressed that they fear they are losing their sanity. Concentration and memory may also be adversely affected.

Thirdly, parents may experience disturbing changes in their behaviour. They may have trouble sleeping, may be irritable with those around them, may find their appetite disturbed, either eating too much or too little and may drink or smoke to excess and may abuse drugs whether prescription or of some other type. Fourthly, parents may experience distressing physical sensations such as palpitations or "skipped" heartbeats, nausea, diarrhoea, headaches and chest pains. While it is advisable to have such physical symptoms checked out by a doctor, usually they are due to the psychological demands of the situation.

The above four categories of response are common in stressful situations and there are many strategies that can be used to deal with them. Some of these will be discussed below, but if problems are severe, professional help should be sought.

Over time the acute symptoms of distress dissipate as parents get down to the day to day job of helping their child to progress. It is very important to construct and maintain good channels of communication.

Parents should ask questions of the professionals involved in the case of the child until they have a clear understanding of the issues. This helps them in talking with each other and in explaining the condition to their other children and to others close to them.

Relationships may be strained by the demands placed on parents in taking the child to clinics for various treatment procedures and in trying to care in a balanced way for each other and for other children in the household. It is important that parents make time to be together and that they also pursue individual interests as time goes on so as to normalise the situation as much as possible.

Response of child with Erb's Palsy.

The response of the child to Erb's Palsy will be influenced by a range of factors, the most obvious one being developmental level. The very young child will not be aware of the condition as different from the norm and will be dependent for security on parents. As the child begins to move about independently and to walk, the affected arm becomes more obvious and he or she may become frustrated at diminished function.

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At the toddler stage the child may become temporarily irritated at being unable to perform certain tasks but will be easily distracted from concerns and will move on to other activities fairly quickly.

The child will really begin to notice differences in the preschool and early school context when exposed to other children who are able-bodied and who may ask questions concerning the affected limb. If the child is given as accurate a picture as possible of the condition this can be passed on in their own words to peers in school.

As the child becomes older and team games etc. increase in importance he or she may become more concerned and distressed. Reassurance and a focus on their other strengths is helpful at this time. The concern and assistance of a close friend or sibling is also of great benefit. The tasks faced by all at this time include building the child's sense of competence, confidence and self-esteem in the context of their condition.

In the teenage years the child may be more disturbed at being different. This can be a particularly tough time as the emphasis generally is on being the same as those in the peer group. Personal appearance is experienced as crucial as awareness of sexuality develops and adolescents are often painfully self-conscious. Media emphasis on the attractiveness of particular body shapes and physical attributes can add to such difficulties.

This is a time when earlier investment in open communication will pay dividends as it will make it easier for the child to voice concerns and to receive comfort and support. Adolescent isolation can be very painful for the child and for parents who also feel pain in sympathy with their son or daughter.

Response of siblings.

Siblings will experience a range of responses to disability in a brother or sister. These can range from concern and responsibility through to anger and frustration. As in previously mentioned situations it is very important that siblings understand the disability as far as is possible. While having a good relationship with a brother or sister with Erb's Palsy is of course desirable, it is also important that the able-bodied siblings have their own space and a good independent relationship with parents. In general, siblings can be a source of great support and are more likely to assume such a role if they see the distribution of parental concern and attention as fair. It is up to parents to try to strike the right balance.

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Common concerns.

There are a number of common concerns which parents present around coping with disability in a child. Some of these are outlined below.

1. Behaviour problems.

A range of behaviour problems may arise among children with a disability at a higher frequency than is usual in an able-bodied population. These can include such difficulties as non-compliance, sleep disturbance, eating problems and anger outbursts. Sometimes these result from differential treatment by parents in an attempt to compensate for the disability. Such differential treatment can also result in resentment among siblings. As a general rule the child with the disability should be treated in a normal a manner as the disability allows. Rules and sanctions are of primary importance in building appropriate social skills.

2. Doubts about ability as a parent.

Some parents begin to doubt their own capacity to function in the face of disability. They may feel incompetent or emotionally out of control. Such feelings are generally transient and diminish with experience, just as happens in parents of able-bodied children. If such problems persist it may be helpful to consult with a professional for reassurance and guidance where necessary.

3. Relationship difficulties.

Difficulties may arise between parents for a variety of reasons. They may cope in different ways with the impact of the disability resulting in misunderstandings and consequent tension. Some coping responses may be quite constructive while other may be very destructive. It is important to learn to recognise and change the latter responses so as to facilitate progress.

The key to more harmonious relations once again hinges on open communication. If one partner is having particular difficulties and can be open about this then both can attend for help. This is often best as it facilitates both partners in understanding and resolving issues together.

4. Emotional problems.

Emotional upset is not uncommon and often when it occurs it is helped considerably by a listening ear. If the level of upset is such that everyday functioning is disrupted for an extended period then professional help should be sought. Allowing the appropriate venting of frustration and annoyance by the child in a safe environment i.e. at home, is very helpful.

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General guidelines for coping.

1. Learn as much as possible about Erb's Palsy.
2. Ask questions if you have them. Persist until you understand clearly what you need to know.
3. A particularly important source of support is your local Erb's Palsy Association. As well as providing a wide range of practical information it will arrange for you to meet and talk with other parents of children with Erb's Palsy who will understand first hand the many challenges which face you.
4. Communicate honestly and accurately with the child with Erb's Palsy and with siblings as soon as this is possible. Answer questions as honestly as you can. If this means saying "I don't know", that is fine. If it is feasible to do so you might seek the answer together.
5. Do your best to strike a balance in the treatment of children in the family in terms of attention, rules and sanctions.
6. Utilise supports, whether from family or friends and from professionals as needed.
7. Take care of yourself and your relationship with your partner as your own physical and mental health and a strong and supportive, relationship are among the most important assets in effective coping.

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Hopefully the above information has been useful to you in understanding the psychological response to Erb's Palsy. However, it is a short overview and not intended to be comprehensive. Individuals may differ considerably in the ways in which they deal with the stresses associated with disability. In the majority of cases problems such as those described above resolve and it is also important to note that the high levels of distress felt, particularly in the early stages, are quite normal.

If however, high levels of distress persist over a prolonged period of time and continue to disrupt your day to day functioning, do seek the help of a professional person who is familiar with Erb's Palsy. Appropriate sources can be identified through your local Erb's Palsy association.

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Comments

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Association of Ireland

The Erb's Palsy Association of Ireland was set up by parents of children with Erb's Palsy to provide information and help to other parents whose children have this condition. The Association is run solely by these parents and is striving to achieve a better recognition and understanding of the nature, causes and proper treatment of the condition.

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