

# *Erb's Palsy*

*Association of Ireland*



**FATHERS AND ERB'S PALSY**

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## Introduction

The following document constitutes my thoughts on some of the challenges which face fathers, whose child has been diagnosed with Erb's Palsy. My comments are based in large part on my observations and impressions as a clinician rather than on a reading of the literature which is very sparse in this area. Indeed it is a topic which requires systematic research.

The decision to write a pamphlet which focuses on fathers in particular, arose from comments by a number of men that their difficulties were not being addressed as well as they might. Much more focus is placed on the predicament and the needs of the mother and child. This is not in any way intended to suggest that such attention is inappropriate or even sufficient. It is merely a statement of perceived fact.

The father is often seen as a source of strength and support and may be expected to carry the burden "like a man", with little attention given to his own pain and distress. Some fathers have complained that they have felt excluded and isolated at the early stages. This sense may be added to by their own impression of what is expected of them and they may play out a role which does not reveal their true feelings and level of upset.

## Early Reactions

Fathers will experience a wide range of emotional responses when their son or daughter is diagnosed with Erb's Palsy. Each individual will respond in a somewhat different manner, but common feelings include shock, confusion, numbness and fear. It is very likely that they have not heard the term Erb's Palsy before but the words are sufficient to generate acute distress. Men will also be upset at the distress and confusion experienced by their partner and in not knowing how best to respond. The sense of helplessness which can result may add further to feelings of despair and it may appear that everything is sliding more and more out of control.

Because of the nature of the condition parents may feel extremely angry at what has happened. The expected joy of giving birth to a healthy, perfect baby has been taken away and replaced by indescribable distress. Angry feelings may intrude into day to day functioning, along with all of the other feelings associated with distress and it may be difficult to concentrate, to work, eat and sleep and it may be hard to interact normally with other children in the family.

Some men may immediately slip into a practical, problem-solving mode. "Let's get on with it, stay focused, listen to the professional advice and everything will be ok." Put on a brave face, appear confident and competent and everything will come right. This is not an uncommon strategy to adopt. However, in the quieter moments, with time to reflect, worries will emerge and the seriousness and reality of events will begin to sink in. Nobody is immune to the distress of events such as these.

It is essential that the position of fathers is clearly recognised and acknowledged at an early stage. Coming to terms with the intense emotional vulnerability with which they are faced may be extremely difficult for them. Growing up in a culture which expects men to be always in control and competent, or at least to behave as though they are, can result in immense pressures to hide feelings and appear to be in control at all costs.

## Communication

A central key to coping with the challenges of Erb's Palsy is open and honest communication on all fronts. Many men find communication difficult, particularly around emotional issues. It can be very difficult to cry, no matter how deep the hurt. It can be very hard to find the words to express how they feel, even to their partner and they may be further inhibited because they do not want to add the burden of their own distress to loved ones who are already suffering enough.

Communication is crucial in helping the other people in your life to understand how you feel and to make sense of unusual behaviour which you may exhibit. Uncharacteristic angry outbursts, retreating to your room, going out to the pub more often and so on, may be experienced as abandonment by those close to you, but in reality are common responses to stress. Talking about things will help others to see your particular difficulties in attempting to cope. One of the most important outcomes of good communication is the development of teamwork in looking after the child with Erb's Palsy in the best possible way.

Another important point to remember is that fathers serve as role models for other children in the family. Children learn a lot through observation. A good role model can provide very valuable direction for the future as to how to behave towards partners, children and others and also, how best to deal with challenges and crises. This makes it all the more important that fathers are supported and helped to develop good coping skills.

## Support

Support networks are extremely important for fathers at an early stage. It can be very helpful to meet other men who are further along the path of coping and to hear their stories. Great relief and comfort can be found in realising that others have had similar experiences and are moving forward. The sense of exclusion and isolation which many men feel can be greatly reduced in this way. Because Erb's Palsy can have very different outcomes from one child to another, the uncertainty which follows diagnosis is often very disturbing. There are no immediate answers to many of the questions which may arise and the waiting and watching may feel terrible. Having appropriate supports at this time can help make the task more bearable. Often, the opportunity to talk and offload to someone who has been there, will in itself bring great emotional relief.

### General Suggestions Re : Coping

Communication is essential. Learn all you can about the condition and be sure to question the relevant professionals as often as you need to. It is helpful to write a list of questions to take with you to appointments as it is easy to forget in the midst of a consultation. Listen carefully to your partner's distress, but also be honest about your own.

Utilise whatever supports you can. Relatives, friends, professionals, your partner and members of your local Erb's Palsy association are all potential sources of strength and support.

Expect to feel upset, angry, fearful, tearful and a host of other emotions as a result of your child's condition. These feelings may be painful, confusing, hard to talk about and at times may seem overwhelming, but above all it is important to remember that they are normal. You are not going crazy or failing as a father because you are in turmoil.

It is not a sign of weakness to be upset and tearful. It is an indication of how deeply you care about your loved ones and an expression of your humanity.

If there are other children in the family try to help them to understand the problem as best they are able. They too will be confused and will sense the distress around them. They will need reassurance that they are cared for and will be minded.

Remember that you are human, not superhuman and are just as vulnerable as everybody else. You need personal support every bit as much as you feel you must provide it.

Seek advice as to how best to deal with your distress. Be careful to look after your basic needs and watch for negative signs such as increased alcohol intake, socially isolating yourself and persistent angry outbursts. If you notice such signs seek help from those around you and from relevant professionals if reactions are severe and prolonged.

You may find that you worry about the future of your child with Erb's Palsy. Remember that children are very resilient and most learn to cope very well. Some will require specialist support from time to time, but do well with this in place. It is important that the children learn to cope with their limitations, to develop and take pride in their strengths and develop a strong sense of competence and confidence in the face of their disability. Parents are the most important people in helping the children achieve this.

Mind yourself. Mind your primary relationship with your partner. These two form the cornerstone from which you can build and move forward. Some parents worry that it is selfish to think of themselves when faced with crises such as those described. But a strong relationship and a strong mind and body are essential to effective coping.

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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.

Phone Parent of first contact:

Mary Verbruggen (Gleeson)

Tel: (091) 552623

Secretary: Phillip Murtagh

"L'Abri", Seafield Road, Blackrock, Co. Louth

Tel: (042) 22198

Text by: Paul O'Donoghue.,

Head of Psychology,

Central Remedial Clinic,

Clontarf

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