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"I was delighted when I was asked to be patron of ERBS PALSY FRIENDS & FAMILY Ireland. I first got to know the charity when our friend's daughter Stella began treatment for her birth injury. Her courage really struck a cord with me and I felt I needed to assist to raise awareness, build support and try to prevent this condition. Meeting many with ERBS PALSY - I see this same courage and strength in each and every one. We need to do as much as we can to raise money to build awareness, support and seek to prevent this birth injury.

Please support ERBS PALSY FRIENDS & FAMILY in what ever way you can."

Diarmuid Gavin
Patron

WHAT IS ERB'S PALSY

Erb's Palsy is a term used to cover a number of paralyses to the arm. There are three main categories that this covers.

1. Erb's Palsy

This is a paralysis of the fifth (C5) and sixth (C6) cervical nerves. Outward signs are that the arm is turned towards the body, the elbow does not bend and the hand is in a "waiters tip" (turning backwards) position.

2. Klumpke's Palsy

This is a paralysis of the seventh (C7) and eight (C8) cervical and first thoracic (T1) nerves. Outward signs are that the hand is limp, the fingers do not move and there is often an associated Horner's Syndrome. Horner's Syndrome is when the eyelid droops, the cheek does not sweat and the pupil is smaller than the unaffected eye.

3. Complete Brachial Plexus Paralysis

This is when all five nerves, termed as the brachial plexus, are affected. The entire arm from the shoulder down is paralysed, there is often an associated Horner's Syndrome.

HOW DOES ERB'S PALSY OCCUR?

The cause of Obstetrical Erb's Palsy is mainly due to trauma at birth. Although large (macrosomic) babies are more likely to develop shoulder dystocia because their shoulders become trapped under the pubic bone, most cases of Erb's Palsy do not occur in large babies. The Palsy occurs when there is traction on the shoulder underneath the pubic arch. This can often cause the head to stretch too far away from the shoulder and hence tension is placed on the brachial plexus.

This tension may stretch or even pull apart the fibres within one or more of the nerves. Extreme force on the plexus may rupture nerves entirely or tear them from the spinal cord.

HOW DO I KNOW HOW SEVERE THE INJURY IS?

A high proportion of babies (approx. 80%) recover in the first three months, however there are twenty percent who are left with some residual paralysis. It is believed that recovery can be gauged by the contractions of biceps and deltoid muscles. Recovery may be:

- **Complete:**
Start at one month and are normal by two months.
- **Good:**
Start by three months and are complete by five months
- **Average:**
Start after three months.

However, having said that, recovery largely depends on the extent of injury. The nerves within the brachial plexus can be simply bruised, stretched, or if the injury is severe they can be born away at the spine. Each child is an individual and can have only bruising, a mixture of bruising and tearing, or tearing and total severing of the nerves.

WHAT TREATMENT IS AVAILABLE?

Babies are left untreated for the first 2-3 days of their life so that the nerves are given a chance to recover. Before the baby goes home physiotherapy is commenced.

Once the baby is at home, a complete passive range of movement is started, to keep the joints and muscles healthy. This treatment is provided by the physiotherapist. The affected arm should be moved so that it mimics the normal movement of the good arm.

The baby should be encouraged to feel the arm and maybe suck the fingers, this is done so that the maximum sensation can reach the brain and the baby does not forget it has another arm to use. It is not advised to pin the baby's arm to the cot or to use any kind of splint which restricts the arm's movement.

If after two months the affected arm is showing no sign or recovery it is recommended that the child is seen by a specialist in this form of injury. There are many techniques that can be use to help the arm.

Some of these are:

- *A nerve conduction test to ascertain the state of the nerves.*
- *Nerves are taken from donor sites and are used to graft the nerves that have been either damaged or torn.*
- *Muscle transfers into the shoulder to give the arm a wider range of movement.*
- *Tendon transfers into to the wrist, to give the wrist and fingers more movement.*
- *Neuromuscular stimulators may contribute to the prevention or retardation of dis-use muscle atrophy.*



IN SUMMARY

A large proportion of children fully recover functional use of the arm fairly quickly or certainly within the first three months of their life, but the remainder that do not, depending on the severity of the injury, can have a permanent and lifetime disability.

It is important to ascertain the extent of the injury as soon as possible, the sooner you can get to see a specialist in this field the better. Early treatment particularly in the first year can have a very significant impact on recovery. However, there are other therapies available for older children who improve long term function and posture of the arm.

ABOUT US

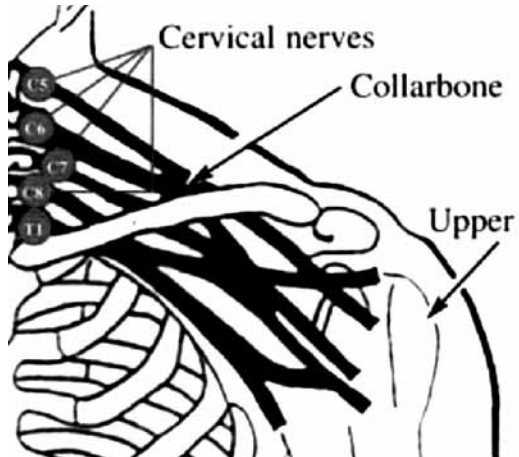
Erbs Palsy Friends & Family is a registered charity, formerly The Erbs Palsy Association of Ireland was set up in 1998 by parents of children with Erbs Palsy to provide information and help to other parents whose children have this condition. The Association is run solely by these parents and is striving to achieve a better recognition and understanding of the nature, causes, proper treatment and prevention of this birth injury condition.

DONATE ONLINE

We appreciate your online donation - enter Erbs Palsy at **www.mycharity.ie** to make a one time donation or to do a fundraiser for us by setting up an event, running a race and sharing with your friends Website: **www.erbspalsy.ie**. E-mail: **info@erbspalsy.ie**

Reference Images

Note: This literature covers the full extent of the injury and some parts may not be relevant to you or your child.



Drawing of Vertebrae, Cervical nerves, Collarbone and Upper arm



A six month old with a total plexus lesion from birth.

Copyright: Howard M. Clarke MD.PHD.FRCS(C), Christine G. Curtis BSc.P.T.



Horner's Syndrome in baby with T1 avulsion.

Copyright: Alain Gilbert MD.

MUSCLE & BONE SURGERY

MUSCLE & BONE SURGERY BRIEF DESCRIPTION

Depending on the amount of nerve recovery, your child may develop good use of the arm. However, even with a thorough exercise programme, some children do have stiffness of the shoulder joint on the affected side. A variety of operations can be suggested to try to improve the range of motion in the shoulder and the use and function of the arm. These operations are mainly on the muscles and ligaments around the shoulder joint. Sometimes the operation can be done on the bones themselves.

MUSCLE SURGERY FOR PATIENTS WITH ERB'S PALSY

WHAT IS THE SUBSCAPULARIS MUSCLE?

The Subscapularis muscle is one of several muscles involved in the movement of the shoulder joint. Unlike the biceps muscle in the upper arm, the Subscapularis is buried deep under other muscles and cannot be felt. In children with Erb's Palsy, the muscle can get too tight and block movement of the shoulder joint. Sometimes the head of the humerus can be pushed backwards out of the shoulder joint – this is called subluxation or dislocation (depending on how much it is pushed back).

The picture in Fig 1. Illustrate the right shoulder looking down from above and from the front. As can be seen, the subscapularis muscle takes root on the front side of the scapula (shoulder blade) and attaches to the upper arm.

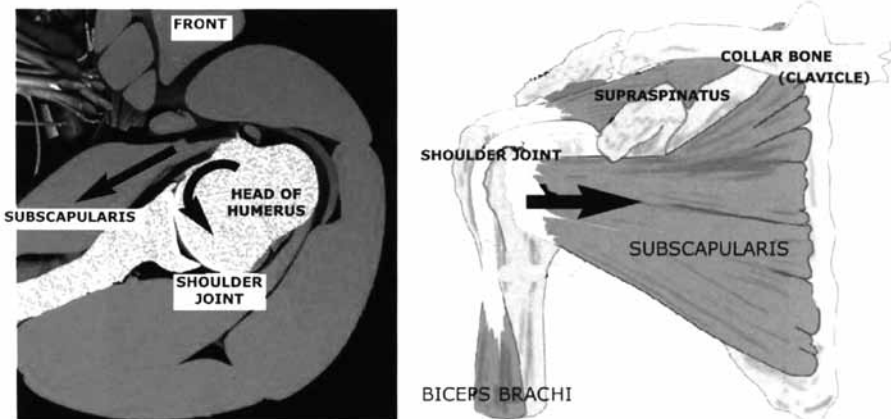


Fig. 1 Looking from above

Looking from the front

(Fig. 1 – drawing of shoulder looking from above and looking from the front)

WHAT IS THE FUNCTION OF THE SUBSCAPULARIS MUSCLE?

The Subscapularis muscle causes the humeral head and the arm on the right hand side to rotate anti-clockwise when looked from above. This is called internal rotation of the arm. When this muscle is too tight, it stops the arm turning outwards and this also restricts elevation of the arm. In the long term, this stiff position can result in abnormal growth of the bones of the shoulder joint. It may benefit the child to have these muscles 'lengthened' or 'released' in an operation, allowing greater movement of the arm.

MUSCLE SURGERY AND WHAT IT ENTAILS

In the operation, the muscle is made longer (the muscle is cut in a "step" and stitched in the lengthened position) or is moved from the shoulder blade to allow for greater movement of the shoulder joint. It will be possible to rotate the arm outwards.



(drawing of the muscle cut in a "step" and stitched in a lengthened position)

The operation takes about 1 hour under general anaesthetic. The scar on the front of the shoulder will measure 2 – 3" or 5 – 6cm. The children have little pain following the operation – and any pain in the first day or two is usually taken care of with simple treatments such as Calpol. Following the operation, the arm is placed in splint for six weeks. Following the removal of the splint, the shoulder will be quite weak initially, but an improved range of motion should be noticeable straightaway.

The worst risks for the child having the operation include reactions to the anaesthetic and infections. The chance of any serious complications (making the child worse) is most unlikely. Fortunately, most children do get a good improvement in function from the operation. For the minority of children with persistent shoulder problems, further surgery may be needed over the following years. This can include muscle transfer or bone operations.

MUSCLE TRANSFER

Depending on the degree of nerve recovery, muscles regain different strength. If a muscle is too weak to do useful movement, it may be possible to transfer a muscle which is working normally to act in its place.

BONE SURGERY AND WHAT IT ENTAILS

Sometimes, surgery to realign the humerus itself is required to improve the position of the arm in front of the child. Generally this is required when muscle surgery is not possible – or after muscle surgery when the arm is still in a poor position for function.

In this operation, the bone is cut and set in a better position. Sometimes wires, plates and screws are used to hold the bone in the best position. As with the other operations, a plaster cast is used to protect the healing bone for 4 – 6 weeks. Even though it is a bone operation, the child will not have any or pain than in the other operations. A scar will be present over the upper arm.

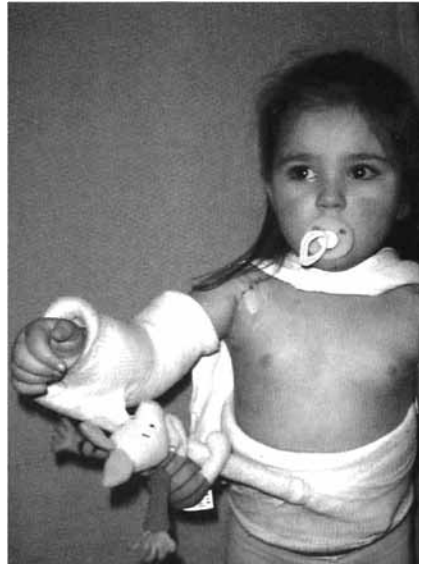
POST SURGERY - WHAT TO EXPECT

After any of the muscle or bone operations, it will be necessary for the child to have a cast on. The cast/splints are designed to hold the shoulder and its muscles in a specific position, holding the correction and ensuring that whilst they are healing they don't return to their pre-operative state. As each child's shoulder will require differing amounts of correction, each cast will look slightly different, however, it will probably look similar to the one in Fig. 2.

The length of time it is required to be kept on may vary, although this is usually between 4-8 weeks. The stitches usually are dissolvable and should fall out around 6-8 weeks. The scar should normally fade – this can take up to one year. It will always be slightly visible.

You, and your child, will need time to adjust to the cumbersome cast and you will probably find that the child will need extra support to adjust to the extra body weight. At first your child may only be able to lie down on his back. It will help to prop the child up with pillows or a bean bag as they are often happier when they can see what is going on. It might take a while before the child is able to turn over and then be able to sit or stand up and become more independent. Breast feeding may be more difficult but not impossible.

Keep the cast as dry and clean as you can. Casts absorb heat very quickly and may make your child uncomfortable, check body temperature regularly to make sure the child isn't overheating, and keep encouraging plenty of fluids in the hot weather, try a fan blowing gently to cool the child down. Baggy clothes that can be layered are best and will be easier to cope with. Using Velcro at the side seams of clothes make them easy to put on and off.



LOOKING AFTER THE CRAWLING CHILD

Your child will need to be supported and watched all the time until the child has become used to the cast as the child will keep trying to crawl and may be quite unstable and lose his/her balance. As the child had not been walking before the operation, he probably won't have the confidence to attempt to walk with the cast unless being supported.

LOOKING AFTER THE MOBILE TODDLER

The day after the operation the child will be encouraged to stand. After a few minutes and some cautious steps there will be no stopping the child walking around as normal. It won't take him very long to get used to the weight of the cast and adjust the balance. Your child will also have to get used to the extra width of the cast.

COMMON PROBLEMS ASSOCIATED WITH SURGERY

Heat rash – there is nothing you can do except to keep the child as cool as possible, it is not advisable to use creams or lotions as this will make the cast even more irritating. If the rash gets really bad, your doctor can prescribe an anti-fungal cream. It's worth trying a fan. Beware of dropping things down inside the cast, this can be messy as well as uncomfortable for the child, and may lead to sores.

If the cast goes soft in places, usually caused by repeated banging into things, your local hospital may patch it up before it becomes necessary to change the whole cast.

Try and keep your child out of the sun as much as possible. Casts absorb heat and even the smallest amount can make your child uncomfortable.

AFTER THE REMOVAL OF THE CASTS

The skin under the cast can get very sore, especially in the folds, i.e. the inside of the elbow. Your child may have dry skin on the arm. After having the arm held up in the air and supported for six weeks, you might expect it to be floppy, but it won't be for long. The child will need to recommence the exercise programme to get the most benefit from the operation.

CONCLUSION

It is always amazing how quickly your child will adjust to the operation and being in a cast - usually more quickly than his parents. If your child does not appear "right" always contact the staff in the hospital, there is always someone there 24 hours to give you advice.

Text in collaboration with: Mr Darragh Hynes, FRCS.ED (Orth)

OSTEOTOMY (BONE) SURGERY

INTRODUCTION

This fact sheet on Osteotomy (Bone) surgery has been written as an attempt to answer some of your questions regarding bone or osteotomy surgery in the event that this is recommended for your child.

WHAT IS AN OSTEOTOMY?

This is an operation in which a bone is cut and reset (usually twisted or rotated) into a different position, in an attempt to improve use of the arm by the patient. This type of operation is used in many different conditions in different bones of the body.

WHEN IS AN OSTEOTOMY DONE?

An Osteotomy is recommended in those children who have persistent loss of function in the arm because of stiffness in the shoulder, elbow or wrist when other treatments options are not available. It is generally not considered until there is little probability of additional improvement of use of the arm with further time, nerve or soft tissue surgery.

RIGHT ARM

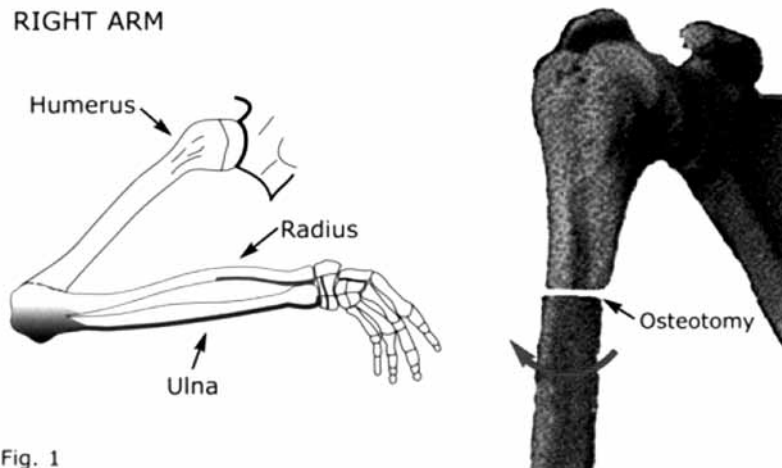


Fig. 1

In Erb's Palsy, an osteotomy can be done on the Humerus or the Radius and Ulna (see Fig. 1)

HUMERAL OSTEOTOMY

An operation is recommended on the humerus (the bone between the elbow and the shoulder see Fig. 2) if the shoulder is stiff and the hand cannot be brought in front of the body where it is most useful. Many children with Erb's Palsy have stiffness in the shoulder resulting in the arm held stiffly across the body.

RADIAL OSTEOTOMY

An operation is recommended on the forearm bones when the forearm is rotated so that the hand is held with the palm facing either upwards or downwards. The most useful position for the hand is when the thumb is pointing upwards and the palm facing the other hand.

AT WHAT AGE IS AN OSTEOTOMY DONE?

There is no specific age for this type of surgery. As stated above, other options of treatment are used before contemplating osteotomy surgery. It is unusual to undertake this type of surgery in the pre-school period. It can be done from 5–6 years of age and has been done in patients over 50 years.

THE OPERATION

The operation takes about 1–2 hours under general anaesthetic. The children generally have little pain following the operation and any pain in the first day or two is usually taken care of with simple painkillers. The child is usually able to go home after a few days. The scar may measure 3–5" on the side of the arm or forearm. A plate and screws or wires will be used to hold the bone together while it heals (see Fig. 3). These are made of rustproof stainless steel. There is no need to remove these in the majority of patients.

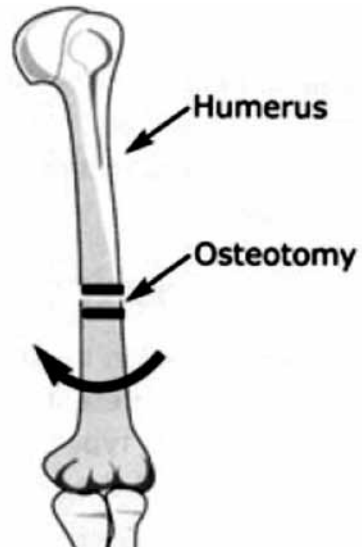


Fig.2 Humerus

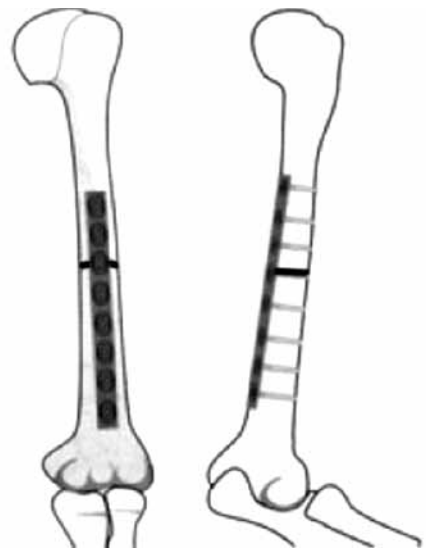


Fig.3

As with all bone surgeries, the risks for the child include reactions to the anaesthetic, wound infections, pain, failure of the bone to heal and persistent loss of function.

Following a bone operation, your child may be placed in a cast or a sling to restrict the movement of the arm, allowing healing of the bone to take place without disturbance. Each surgeon performing an operation will have his or her own preference for the particular type of cast that will be applied. The length of time in cast may also vary, although this is usually about 4-8 weeks depending on the bone and age of the child.

The photograph in Fig. 4 will give you an idea of what the plaster cast may look like in the case of a forearm (radial) osteotomy.

Generally a “fibreglass” cast is used. Keep the cast as dry and clean as you can. It is always amazing how quickly your child will adjust to being in plaster – often more quickly than the parents. The first week is the hardest and the last week the longest, but it does pass. If your child does not appear “right” always contact the staff at the hospital, there is always someone there 24 hours a day to give you advice.



Fig.4

AFTER REMOVAL OF THE PLASTER

The skin under the cast can get very sore, especially in the skin folds, i.e. the inside of the elbow, there might also be a lot of dried skin on the arm.

Because the arm has been held in a cast for a period of time, it can be stiff initially. This usually loosens out quite quickly with an exercise programme under the guidance of the surgeon and physiotherapist. At first, the scars look very red and angry but with time they will fade. If the scars are infected or bleeding in any way, seek medical advice.

The doctor will review your child in the clinic on a number of occasions and order follow-up x-rays to ensure that the osteotomy is healing satisfactorily. As the bone heals, your child will be able to return to full activities and contact sports. Generally, they should stay off contact sports such as football for up to three months following surgery.

In the long term, your child should not have any problems in relation to the osteotomy or the metalwork used to stabilise the bone. There is no necessity to remove the metalwork from the arm. Occasionally some children do have pain in the arm and may benefit from removal of the metalwork.

CONCLUSION

Fortunately, most children do get improved function in their arm following the bone surgery. For those children with persistent loss of use of the arm, further surgery may be suggested over the following years. This could include either tendon transfer or further bone surgery. However, it is possible that further surgical intervention will not be possible or advantageous.

We hope that this fact sheet has answered some of your questions, if you have been advised that your child may benefit from osteotomy surgery. However if there is anything you don't understand, any questions unanswered or you feel you would like to be put in contact with other parents who have experienced this situation before you or just want to share your concerns and worries in a safe environment, please do not hesitate to contact the support group. We see this as one of the main functions of our group and we would hope that you in turn might offer this support to another parent.

BOTOX TREATMENT

Information for parents on the use of botulinum toxin (Botox) in children with an Erbs Palsy Injury.

Botulinum toxin (Botox) works by temporarily weakening a muscle. The drug acts by blocking the pathway from the nerve to the muscle. It is administered by injection directly into the muscle.

Botulinum toxin works best on the muscles that are strong. It blocks their action allowing the weaker muscle to work more effectively. It also enables the strong muscle to become more relaxed so that it can be stretched to its maximum.

The goals for treatment will vary according to the level of disability. For example for some patients the goal may be to increase the length of the strong muscles. For another person the goal may be to help them get their hand to their mouth without lifting their shoulder.

It is important that the parents and the child are clear on what will be realistic goals for them following discussion with the Erbs Palsy Team.

ONSET AND DURATION OF EFFECT

You may expect to start seeing the effect between 3 and 10 days after injection. The effect generally lasts from 3 to 6 months. The link from the nerve to the muscle is gradually re-established and the power returns to the strong muscle, the muscle may also become tight again.

POSSIBLE LOCAL SIDE EFFECTS

Pain at the injection site has been reported but we have found in practice that this is rare.

POSSIBLE SYSTEMIC SIDE EFFECTS

- The risk of side effects is minimal given the dosages that are used in children with Erbs Palsy/ Brachial Plexus Injuries in this centre. Side effects are more common thought still rare when Botulinum Toxin is given to the larger lower limb muscles.

GENERALISED MUSCLE WEAKNESS

- This has been reported where several muscles have been injected. The effect is temporary and usually resolves within two weeks.

EFFECT ON THE BLADDER

There have been occasional incidents of difficulties with loss of bladder control. This is a very temporary effect.

Swallowing difficulties have rarely been reported.

Should there be any concerns regarding the possible side effects following injections, contact the Erbs Palsy/Brachial Plexus Team or local hospital.

WHAT TO EXPECT AFTER INJECTION

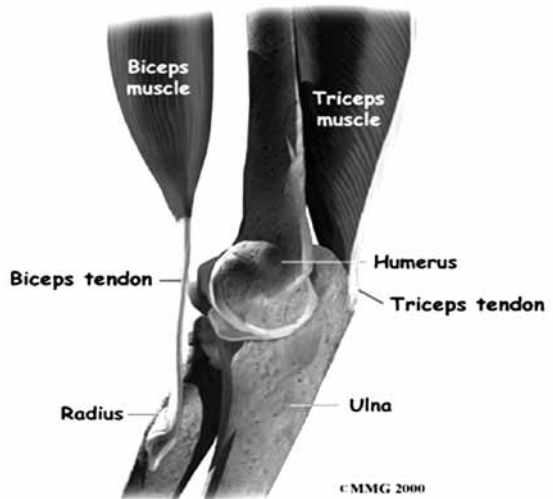
The weakening of the muscle should become apparent in 3 to 10 days. The effect typically lasts for around the three months. However the effects have been known to last up to a year!

If the injection has been beneficial repeat injections may be necessary. The minimum time between injections is three months.

Occasionally the injection has no effect.

Example 1:

If the Triceps muscle is very strong it can be difficult for the child to bring their hand to their mouth. A weak Biceps will be unable to override the power of the Triceps pulling the elbow straight. If the Triceps is injected this may allow the Biceps to work and in the period where the Triceps has been inactivated it is hoped that the Biceps strength will increase. When the Botulinum toxin wears off it is hoped that Biceps will have developed sufficient power to overcome the strong Triceps pull.



Example 2:

Often the Subscapularis muscle is pulling the shoulder into internal rotation. This is most obviously seen by observing the position of the point of the child's elbow. Normally the elbow point is facing backwards when the arm is at rest. In children with a Brachial Plexus Injury the elbow crease is pointing out towards the side because the shoulder is being rotated inwards.

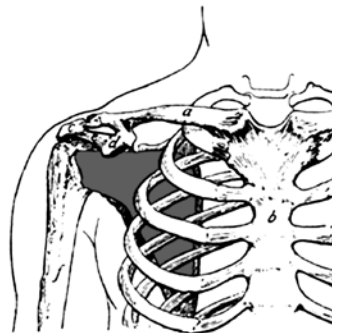


The muscles that externally rotate the Shoulder are always weak and all parents will know that is it a constant battle to try and keep the movement at the Shoulder into external rotation.

Giving Botulinum Toxin (Botox) to Subscapularis decreases the strong internal pull and allows for more effective stretching of the Shoulder into external rotation. If there is any power within the external rotation muscles it is easier for them to work without the strong internal pull.

An injection into Subscapularis requires an anaesthetic due to its deep position.

Botulinum Toxin (Botox) to Subscapularis is only effective in the younger child. In the older child the muscle has become too stiff and surgical release is required.



Treatment technique in Central Remedial Clinic (CRC) Clontarf, Dublin 3:

Twenty minutes before the injection a cream which numbs the skin is applied over the muscle that is going to be injected. The injection takes less than a minute to give.

Treatment technique in Temple Street Hospital, Dublin 1:

Patients may also be scheduled to have their injections in Temple Street Hospital. This will be discussed with you at the clinic. If a general anaesthetic is required, it will be necessary to fast for 12 hours beforehand.

PHYSIOTHERAPY & OCCUPATIONAL THERAPY REVIEW

The after care is as important as the injection. In order to gain the most from the injection it is essential that you follow the Physiotherapy & Occupational Therapy programme for your child. Often it becomes necessary to perform more stretches or strengthening exercises after the injection to try and gain as much strength and range of movement while the opportunity is there.

The child should be monitored by their Physiotherapist & Occupational Therapist and their exercise programme adjusted according to the effect of the injections.

THE DOCTOR'S REVIEW

The child will be reviewed by the Doctor a few months after their injection depending on the dosage and the muscle injected. Their Physiotherapist & Occupational Therapist will regularly update their Doctor of their progress.

Summary:

Botox (Botulinum Toxin) has been a wonderful therapeutic discovery. It provides an opportunity to diminish the muscle imbalance caused by Erbs Palsy injuries and enables the child to increase the strength of their weaker muscles and the length of their stronger muscles.

Our clinical experience with Botox (Botulinum Toxin) and its use in the child with an Erbs Palsy Injury is still in the early stages but is growing all the time. We look forward to further advances as we learn from each child and liaise with our colleagues around the world.

For further information please contact:

Erbs Palsy/Brachial Plexus Team
The Central Remedia Clinic,
Clontarf, Dublin 3
Tel: 01 854 2200
(www.crc.ie)

FAMILY ISSUES AND PSYCHOLOGICAL EFFECTS

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 responses 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.

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 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 their 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.

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. increases 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.

COMMON CONCERNS

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

GENERAL GUIDANCE FOR COPING

- Learn as much as possible about Erb's Palsy.
- Ask questions if you have them. Persist until you understand clearly what you need to know.
- 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 firsthand the many challenges which face you.
- 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.
- Do your best to strike a balance in the treatment of children in the family in terms of attention, rules and sanctions.
- Utilise supports, whether from family or friends and from professionals as needed.
- 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.



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 help of a professional person who is familiar with Erb's Palsy. Appropriate sources can be identified through your local Erb's Palsy Association.

Text by: Mr Paul O'Donoghue, Clinical Psychologist

FATHERS AND ERB'S PALSY

Text by Paul O'Donoghue, Head of Psychology, Central Remedial Clinic, Clontarf

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 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 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.

COMMUNICATIONS

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 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

Text by Paul O'Donoghue, Head of Psychology, Central Remedial Clinic, Clontarf

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 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.

ERBS PALSY ASSOCIATION OF IRELAND

Basic information on where to apply for certain allowances that may be claimed in some Erbs Palsy cases.

It is important to be aware that some allowances will only be granted following individual assessment of the claimant.

Tax allowance for Incapacitated Child

To claim this simply write to your local Tax office outlining the allowance claimed, the nature of the incapacity and the name(s) of the child(ren). If the Tax office requests a medical certificate you should supply it.

Further information is available on form IT 18 which can be obtained from your local Tax office or on the Internet at www.revenue.ie PAYE taxpayers may also telephone the local 1890 number for your part of the country to make your claim.

Domiciliary Care Allowance

This is a monthly allowance paid by your Health Board in respect of children who are so severely physically or mentally handicapped that they require care and attention that is considerably in excess of that normally required by a child of the same age. The allowance is applicable to children from birth up to 16 years of age.

The decision to grant the allowance will be made by the administrative staff of the Health Board following examination of the child by a doctor nominated by the Health Board. For more information contact your local Health Board. Please see Carer's Allowance below which may also be claimed in some cases.

Carer's Allowance

The Carer's Allowance is a payment for carers on low incomes who live with and look after certain people who need fulltime care and attention. Carers who are providing care to more than one person may be entitled to up to 50% extra of the maximum rate of Carer's Allowance each week, depending on the weekly means assessed.

Tel. (043) 45211, ext. 8794/8795 or email to info@welfare.ie. Information is available at www.welfare.ie.

Form E111.

This form covers medical expenses for injuries or sickness contracted while abroad on holiday etc... You simply apply to the local Community Care Office of your Health Board before you travel.

Form E112.

This form covers the cost of medical treatment outside the State. Your local Health Board provides it. Some Health Boards may require convincing that the treatment cannot be carried out in the State and consequently they may require confirmation of this from your consultant.

TEENS & EXAMINATIONS

Children with Erbs Palsy injuries which they believe will significantly impair their performance in examinations may apply to the State Examinations Commissions for a reasonable accommodation(s) to be made to facilitate them taking examinations.

Further information is available at **www.examinations.ie/Candidates**. Applications are made through the school or education provider. The actual application forms, which should be sent in the year preceding the examination year, are to be found at **www.examinations.ie** under Schools / Circulars / Information / Reasonable Accommodations.

FIRST CONTACT

If you have experienced Erbs Palsy and would like to contact someone to help and advise you, please contact us by telephone or e-mail.

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