

a child who only has a cleft lip and/or palate and intellectual ability. In rare instances cleft can occur as part of a syndrome. The cleft team includes a geneticist who can let you know if a syndrome is present and any intellectual implications that might be expected.

Leaflet number 10 in this series is designed especially for teachers and carers. A copy should be given to 'the teacher' at the start of every school year.

### Can my baby be breastfed?

If prior to the birth of your baby, you decided to breastfeed than you should attempt to do so. Success will vary depending on the type of cleft the baby has. Maternity staff and/or your cleft co-ordinator will be able to advise you. If breast feeding is unsuccessful for you, you may wish to try bottle feeding with expressed milk. This can be facilitated by the use of a breast pump which nursing staff can help you with initially.

### What are the implications for bottle feeding?

A baby with a cleft will tend to have difficulty gaining and maintaining suction. There are several types of bottles / teats available that will help overcome this difficulty. In general the bottles work by you squeezing and effectively pumping the milk into the baby's mouth. The Association has a 'Useful Tips' sheet that is available in hospital maternity packs or by contacting the Association.

**It is important to say that many children with a cleft feed without difficulty.**

### Will my child's speech be affected?

Children with cleft lip only rarely have speech problems associated with the cleft. A cleft palate, on the other hand, can affect speech and language development. The problems are generally with articulation or the presence of nasal tones. Speech and language therapy may be required, and regular reviews to monitor the child's speech are essential.

### Will my child's hearing be affected?

When there is a cleft palate, there can be a hearing impairment. This does not always happen, but your child's

hearing should be checked at approximately 12 months of age. Poor hearing can adversely affect your child's speech. Treatment usually involves the insertion of grommets. Continued monitoring of hearing is essential during the developmental years.

### What are the consequences for my child's teeth?

A full orthodontic assessment is carried out when your child is 6 to 7 years old. For some children simple orthodontic treatment involving braces to straighten the teeth may be all that is necessary.

In most cases expansion of the maxilla (upper jaw) and bone grafting is of great advantage. This procedure usually takes place at about 9 to 10 years of age. Full orthodontic alignment can start when all the permanent teeth have erupted, usually by the age of 13 years.

### Will my child have other health problems?

Clefts can be associated with a number of syndromes, but unless your child is diagnosed as having an associated syndrome, there is no reason to believe that he or she will not otherwise be perfectly healthy.

### Are there costs associated with the treatment of cleft lip and palate?

Treatment associated with cleft lip and palate repair can be paid for by the State/Health Insurance. This includes surgery to repair the lip and palate, any revisionary work, associated orthodontic work and any procedures that may be carried out in your child's teenage years. Note: standard inpatient government charges apply. (At time of print these are €75 per night to a max of €750 for 10 nights, in a 12 month period). Contact the hospitals Patient Accounts if you have any queries in relation to in-patient charges.

Speech and language therapy is available through your local Health Board. Dental care is also available through your local Health Board until the age of 16 or 18 depending on your area.

The cost of specialised bottles is not covered, nor are travel costs, parking costs, any overnight costs associated with parents.

#### TITLES IN THE SERIES:

1. *About the Cleft Lip and Palate Association of Ireland*
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3. *Questions and Answers for New Parents*
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Leaflets are available by post from the Association or can be downloaded from [www.cleft.ie](http://www.cleft.ie).

#### ACKNOWLEDGEMENT:

The Association would like to thank the members of the cleft treatment teams and other health professionals for their valuable contributions. See [www.cleft.ie](http://www.cleft.ie) for the full acknowledgement and list of contributors.

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## Cleft Lip and Palate Series

### Questions & Answers for New Parents



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registered charity, is a limited liability company, No. 131497*

## What is cleft lip and palate?

A cleft lip is a separation in the upper lip. A cleft palate is an opening in the roof of the mouth. Clefts result from incomplete development of the lip and/or palate in the early weeks of pregnancy.

Clefts affect approximately 1 in every 700 babies in Ireland.

At time of print, there is no known 'extra care' or preventative measures that a parent can or could have taken to prevent a cleft from occurring.

## Can a cleft be repaired?

A cleft lip and/or palate are birth defects that can be addressed with corrective surgery. So don't despair, your child's appearance will be greatly improved and their quality of life can be as normal as any other child.

## When will the corrective surgery be carried out?

The surgical repair of the cleft lip is carried out at about three to four months of age. The repair of the palate is carried out between six and twelve months of age. Corrective surgery and further refinements to the lip may be required as your child grows and develops.

## For how long will my child remain under the care of the cleft team?

Your child is not finally discharged until he or she reaches the age of 18–20 years, or when the child/parent or individual decides in conjunction with the cleft team that treatment is complete.

## Why was my child born with a cleft?

The cause or causes of your child being born with a cleft are not clearly understood. It is thought that genetic and environmental factors play a significant part in the occurrence of clefts. In some cases there is a hereditary factor but it can appear in a family with no known history of the defect.

## If I have more children, what is the likelihood that they too will have a cleft?

There is a 5% chance of your next baby having a cleft – that is a 1 in 20 chance (remember, the incidence was originally 1 in 700). If a second child is born with a cleft, the likelihood increases further.

## I was born with a cleft. What is the likelihood that my baby will be born with a cleft?

The chances of a parent who was born with a cleft having a baby with a cleft rises to approximately seven in one hundred.

## What am I feeling?

The birth of a child with a cleft represents a crisis for parents. You may experience a range of emotions such as shock, numbness, grief and anger. It takes time for the reality of the situation to sink in. The joy of your child's birth may be overshadowed but it is important to hold onto the positive aspects of your child's birth.

Guilt may hit you, a sense that it is somehow your fault, that there is some hereditary factor involved, or some extra care you could have taken during the pregnancy.

Resolution will be the last stage you will reach, when you come to accept the reality and are ready to face the future.

## How will I cope?

Look at your baby as a beautiful baby first who has a problem second. Leave guilt behind, there is no known cause of cleft and what has happened is beyond your control. On the other hand there are things you can do.

Firstly try not to feel alone. Talk to your partner about how you feel. Listen to what your partner is saying. It is really important to support each other. Recognise that your emotions may vary but by talking and watching out for each other you will not only survive you will thrive as a couple.

Your baby will be treated at one of the cleft centres (see [www.cleft.ie](http://www.cleft.ie) for current centres). Contact your cleft co-ordinator who will be able to give you specific advice and will advise you on your baby's likely treatment plan. It always feels better to have a plan of action in place.

Feeding issues can be quite stressful. Help should be at hand from maternity staff, the cleft co-ordinator and speech language therapists. Persist until you find the right person that can help you and your baby. Feeding can take a bit longer and can be tiring even for parents. Allow other people to help out. Show trusted family and / or friends how to feed your baby so that you can get a break.

The Association can also help. There's lots of information available on the web site. We can also answer some of your queries or direct you to the right person. We can help you to meet or have direct contact with other parents. The discussion forum on the web site allows you to interact with other people who have had similar experiences.

Other coping techniques are

- *To take one day at a time as thinking too far ahead can immobilize you.*
- *Learn about the condition and familiarise yourself with the terminology.*
- *Don't allow your emotional or physical health to suffer.*
- *Talking to a friend or family can help emotionally.*
- *Making time for even a 20 minute walk will help you to maintain your energy levels and physical well being.*

Above all it is important that you hold on to the positive aspects of your child's birth and enjoy all that a new baby brings to a home. Surgical repairs will happen in their own time so try not to allow them overshadow this special time with your new born baby.

## How will I tell family & friends

How your child comes to feel about themselves, their self esteem and emotional and mental well being will stem from you and your positive attitude and outlook. You are the first and greatest influence on your child's life, and that is the greatest responsibility you will ever carry.

When you are telling family and friends about your new baby, concentrate on telling them about your baby, boy or girl, their name, weight and all the other baby things that people like to know. Telling them about the cleft lip and / or palate should be secondary. You will want your baby to be known for the wonderful little person that they are. After all, cleft is not who your baby is, but it is something they were born with and is correctable.

## How will my child cope socially?

Children are very curious people. They ask direct questions, and if given reasonable answers think nothing more about it. If you give your child a reasonable explanation about their condition, their friends will accept this and move on.

Encourage your child to mix with other children from an early age so that your child can learn to handle different situations and also that other children may readily accept your child as they would any other.

If your child is teased, don't assume that it is always cleft related. Ask questions, listen carefully and take time when thinking about how to help your child handle the situation.

## How will my other children react to the new baby?

Because a cleft lip is such an obvious physical condition, your other children may at first be scared and apprehensive. They may also become jealous of the amount of time and attention you are giving to the new arrival. For that reason, you need to reassure them and make certain you give them ample time and affection.

They will naturally be curious, and you ought to answer their questions and make sure that they too learn along with you about the condition. Help your children to have an age appropriate answer ready for when their friends ask questions about the new baby.

Young children often accept news more readily than adults do, and their acceptance and understanding may surprise you. Let them help and praise them for their efforts. Older children can help in more practical ways and take some of the pressure off you, even by way of the small things that need doing.

## Are there implications for my child's intellectual development and schooling?

The presence of a cleft and any associated speech problem should not be interpreted as an indication of a learning disorder or slowness of learning. There is no link between