

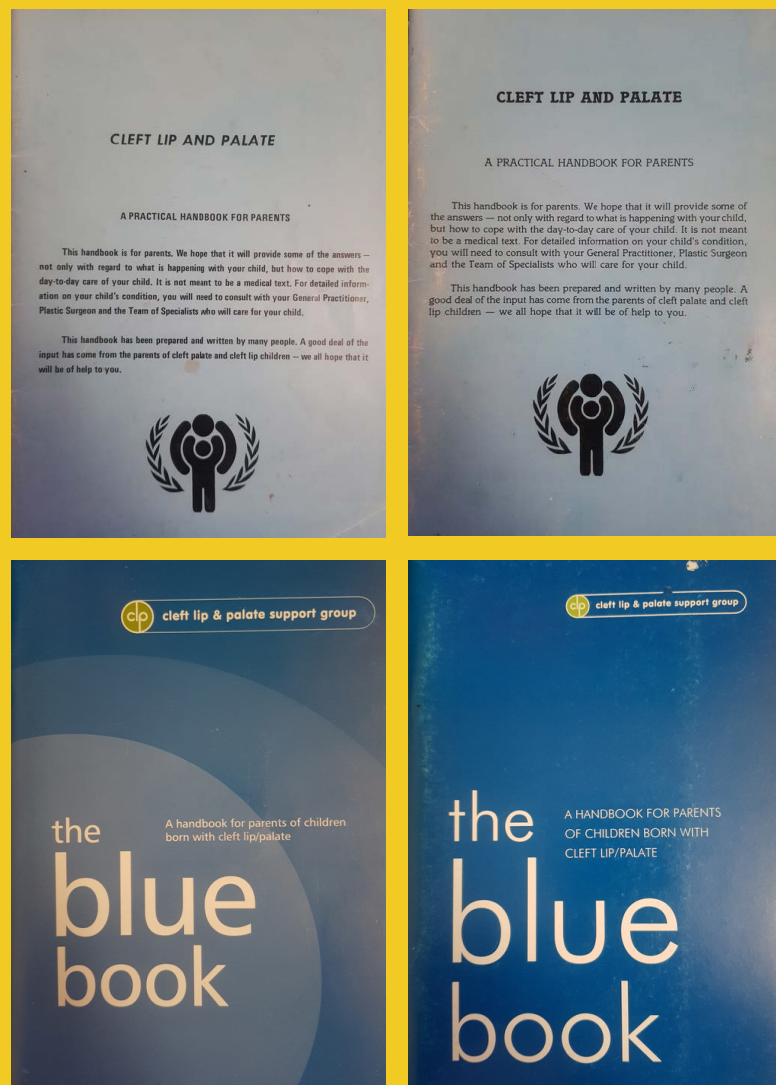
*A handbook for parents of children
born with cleft lip/palate*

the blue book



Blue Book 1 - Antenatal to age one

HISTORY OF THE BLUE BOOK



Cleft New Zealand Incorporated

THE BLUE BOOK VOL 1

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INTRODUCTION

This is the 5th edition of The Blue Book that Cleft New Zealand Inc (Cleft NZ) has published. The Blue Book originated from the vision of one mum, Sharyn Nicholson, in 1979. Sharyn wanted to assist other parents of cleft children to learn about and come to terms with their child's condition. Easing the way for families who are living through this experience is still our motivation for updating the Blue Book. The handbook was printed with a blue cover, and became known as "the Blue Book" – however in this latest edition Cleft NZ have decided to create two books; one for antenatal and the first year, and another to address future surgeries and cleft care up to teens.

We would like to take this opportunity to thank all those who have contributed to each edition of the Blue Book over the years as this has become an invaluable resource for families across New Zealand. These new books have been edited and rewritten by Lisa Kennedy (Cleft NZ) and Megan Sanders (CMDHB), with expert input from other health professionals involved in cleft care (see Acknowledgements, page 38). We would also like to acknowledge the parents and cleft affected young people involved in this project, who have helped with the sharing of photos and stories. It is a generous gift, and one that many new families will benefit from. The information within this book is as accurate as possible at the time of printing. Remember to always consult your health professional for any medical advice and visit www.cleft.org.nz for the latest information from Cleft NZ. Good luck on your journey and remember, your child is a child first, the cleft is secondary.

Andrew Acton-Adams

Chairperson, Cleft New Zealand Incorporated September 2020

MEGAN'S MESSAGE

As a medical professional it is a privilege to be involved with families throughout their child's life, often from the antenatal stage through to adulthood. To meet families when a baby is born and to see them regularly at clinic as they grow to be strong, independent adults has been the best part of my job. Over the years that I have been involved with the cleft service, there have been many changes and improvements in the delivery of health care, surgical techniques and coordination of services, all of which have improved the journey of care for our patients. Each specialist of the cleft team strives to continue to improve the care they provide to their patients by finding new and better ways of treatment.

Over the years there have been numerous parents, with commitment and hard work, contributing their skills to Cleft NZ. Their individual experiences can be drawn upon to help provide the services that parents need. We appreciate the hard work and dedication they have and encourage our families to be part of the group.

Megan Sanders

Cleft/Craniofacial Nurse Specialist, CMDHB, Auckland

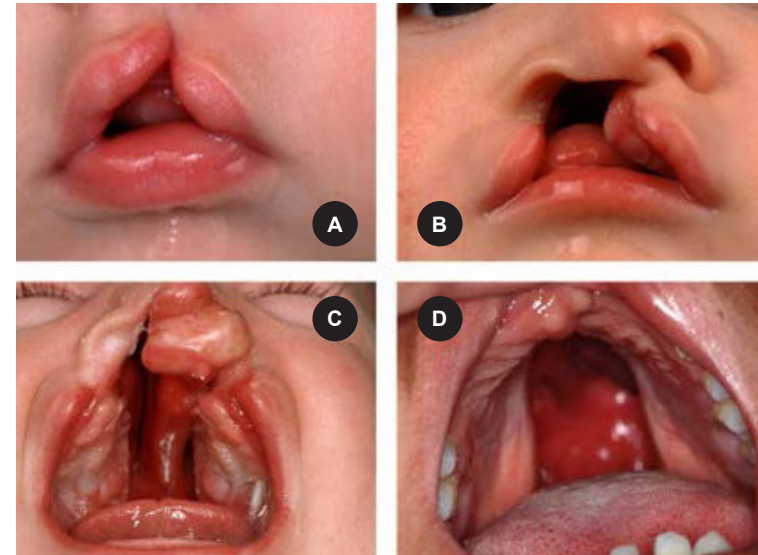
ABOUT CLEFT NEW ZEALAND INC. SUPPORT GROUP

Cleft New Zealand Inc (Cleft NZ) provides support for parents whose baby has been diagnosed with a cleft. We have a website with extensive information on cleft lip and/or palate to inform parents and health professionals, www.cleft.org.nz. Cleft NZ brings together parents of children, teenagers, young people and adults who are cleft affected. It also provides training for health professionals that may need to support cleft affected families. We want to make it easier for your family to cope with and to be involved in your child's or your own care. We also work as an advocate on your behalf for improvements to the services available in New Zealand.

Some babies with a cleft may struggle to fully breastfeed, so Cleft NZ offers a free to loan, breast pump service. We have a closed Facebook group so that parents can support each other and ask questions in a safe space. Talking to other parents who have experienced what you are going through can help ease your anxiety and upset. Cleft NZ holds coffee mornings so you can meet with other parents. To become a member of Cleft NZ, visit our website www.cleft.org.nz. You can also get in touch with us via email (info@cleft.org.nz), phone (0800 425 338), or via our contact forms on the website. We also have an app available, information on how to download our app is available on our website.

WHAT IS A CLEFT?

A cleft means a split or separation of parts. During early pregnancy, four areas of the face develop and then join together. If some parts do not join properly the result is a cleft, the type and severity of which varies. Cleft lip and palate can occur isolated or together.



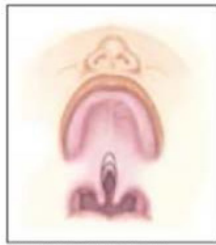
- A** Incomplete unilateral cleft lip
- B** Complete unilateral cleft lip and palate
- C** Bilateral cleft lip and palate
- D** Cleft of hard and soft palate

ANATOMY PICTURES

Illustration by Diane Mercer



Incomplete Cleft Lip



Cleft of the Soft Palate



Cleft of the Soft. & Hard Palate



Complete Cleft Lip



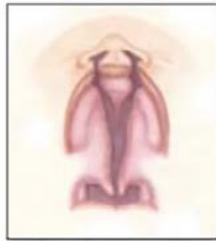
Unilateral Cleft Lip & Palate



Unilateral Cleft Lip & Palate



Bilateral Cleft Lip & Palate



Bilateral Cleft Lip & Palate

A cleft lip (CL) can range from a slight notch in the lip to a complete separation on one or both sides of the lip and extending up into the nose. A cleft on one side is called a unilateral cleft lip and if on both sides it is called a bilateral cleft lip.

A cleft lip and palate (CLP) is when the cleft goes right through from the lip, the gum, the hard palate and to the soft palate. This can be unilateral or bilateral.

A cleft palate (CP) occurs when the roof of the mouth has not joined completely. The back of the palate near the throat is called the soft palate and the front near the gums is known as the hard palate. A cleft palate can range from just an opening at the back of the soft palate to a complete separation of the roof of the mouth (soft and hard palate). This can be unilateral or bilateral.

A submucous cleft palate (SMCP) is a cleft of the soft palate that has been covered by a layer of skin so is not an obvious cleft.

Bilateral Cleft Lip & Palate



Bilateral Cleft Lip



Bilateral Cleft Lip



Unilateral Cleft Lip & Palate



Unilateral Cleft Lip



ANTENATAL DIAGNOSIS

In pregnancy, around the 20 weeks mark, most women have an ultrasound anatomy scan. The majority of babies who have a cleft lip are diagnosed at this scan; however, it is harder to detect a cleft palate.

Antenatal diagnosis of cleft lip is very useful. For the expectant parents, it enables informed preparation before the baby is born, including surgical and feeding issues to be discussed and a more positive delivery experience for the family. The sonographer should communicate results with the parent and also directly to your Lead Maternity Carers (LMC) or obstetrician. Your LMC or obstetrician will refer you to your local fetal medicine team who will see you for a more in-depth scan and also refer you to your local Cleft Team. You may have the opportunity to meet with them prior to the birth.

- You may find it useful to contact Cleft NZ for information, reassurance and support. Details can be found at www.cleft.org.nz.
- Before you leave the fetal medicine appointment or maternity ward, ask for a contact name and number for your Cleft Team/ Cleft Coordinator (this information is also available on the Cleft NZ website).
- Ask about access to a Needs Assessor who can let you know of any financial assistance you may be entitled to. Financial assistance cannot be backdated, so the earlier you apply the better.
- Lactation Consultants are available in most District Health Boards (DHB). See page 15 for further information on feeding.

A parents' story by Aaron and Britt Wright

What's life going to be like as a parent of a cleft affected child?

At first this came as a shock and challenged all our expectations of what we were in for, but we very quickly learnt that this was a minor adjustment to adapt to. Not being able to breastfeed was an emotional hurdle for me, but it also meant that Dad could bottle feed and made us bond deeper as a team and a family. Our family has become so close through it all and our new way of life seems completely normal to us. Now, I wouldn't have it any other way.

Is my child going to be like others'?

The difficulty in breathing for the first 2 weeks was a big challenge as we spent that time in Specialist Care Baby Unit, but as soon as we got our girl home we very quickly began raising her like any other kid. The tests and follow-ups that followed all added to her resilience as she had to overcome a lot of things other kids didn't (breathing, hearing, eating etc.). She is still so full of joy. We have learned that babies are stronger than we give them credit for and they adapt to their situations very quickly. Our girl's little quirks and needs have become a routine for us and seem like a normal part of life.

What will other people say/think?

Everyone has been great with it – she is loved by everyone she meets. People almost see her as more of a strong and resilient little warrior because of the challenges she has had to overcome. She has had an incredible amount of love and support surrounding her since birth, even more than if she had been born without a cleft.

Will they be OK?

This was the question that plagued our mind the most when we first found out. So far she has excelled in everything. Sure there are a few detours you take around the conventional way of doing things but every kid is different regardless. Being a parent is about adapting to them as best as possible. Surrounding your baby with love will help them to happily thrive, regardless of a cleft.

Will they be able to be a "normal" baby/kid?

I truly believe that she will be more than a normal kid as she grows through this. She has had to overcome obstacles that other kids don't face and we get to celebrate more wins and accomplishments than most families. This has definitely given her a little something extra. I think she won't just be normal, she will be extraordinary.

WHAT CAUSES A CLEFT?

This is usually the first question every parent of a baby born with a cleft wants answered. There is unfortunately no simple answer to this question, as a direct cause has never been found. For most babies born with cleft lip and/or palate, the "cause" is termed "multifactorial". This means there may be a small change in a gene, which may interact with some environmental factors, and a cleft may be formed.

Early in the first trimester, events occur that prevent the tissues of the upper lip and/ or palate from developing properly. There may be a family link (hereditary) but in many cases a child will be born without any known previous family history. For a few babies there may be a recognizable pattern of anomalies which denotes a "syndrome". A syndrome may be caused by a chromosomal abnormality where there may be either additional or deleted chromosomal material. A geneticist will provide further testing if this is suspected. Environmental factors may include maternal factors such as diabetes, intake of certain medications such as anticonvulsant drugs, or dietary factors (vitamin levels, alcohol, smoking), etc...

Statistically, around 1 in 700 of all babies born in New Zealand are affected with cleft lip/palate, however the incidence rate for cleft palate in Māori is 1:500. There is no evidence currently to explain why this is so. To discuss the recurrence risk for a cleft in future pregnancies, a referral to a geneticist can be made.

PIERRE ROBIN SEQUENCE

A disorder related to cleft palate is Pierre Robin Sequence (PRS), where the baby presents with a small lower jaw. Around the 7th week of pregnancy, the small lower jaw pushes the tongue upwards, preventing closure of the palate, resulting in a cleft of the hard and/or soft palate. This may be detected on ultrasound.

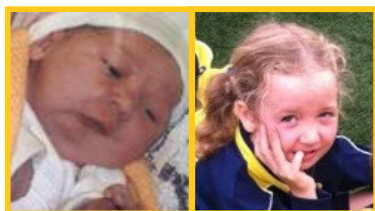
Pierre Robin Sequence varies in severity from child to child. Problems with breathing and feeding in early infancy are the most common issues faced.

Some babies may require partial or full tube feeding for the early weeks or sometimes months until their jaw grows sufficiently. A baby with PRS will use more calories to feed and breathe, so monitoring your baby's growth is important.

Your baby will be reviewed by the Ear, Nose and Throat (ENT) doctors or Paediatric Respiratory team for assessment of their airway. For the more severe cases, Nasopharyngeal airways (NPA) or other surgical options may be required to ensure your baby has a safe airway.

For most babies, the lower jaw grows rapidly during the first 2 years of life, for those babies who do not experience this 'catch up growth', surgery may be required on their jaw when older.

Pierre Robin's and Cleft Palate



THE BIRTH OF YOUR BABY

If you have had a diagnosis in pregnancy you may have concerns around the birth. The diagnosis should not impact on how you choose to give birth. Once your baby is born, the midwife will check your baby and inform the Paediatrician who will review your baby. Skin to skin contact should be initiated as with any newborn infant. You should also have access to a Lactation Consultant via your hospital, to advise on issues relating to breastfeeding and expressing breastmilk. At times, a cleft palate may not have been detected during pregnancy and will be diagnosed shortly after birth.

FEEDING

Feeding your baby need not be a problem and can be just as satisfying and rewarding as with any baby. It should provide nourishment and be a pleasurable experience for both parent and baby.

If your baby has an isolated cleft lip, your baby should manage to breastfeed successfully, if you choose to do so. When breastfeeding, it may help to have the baby positioned so that the cleft is on the side nearest to you. Breast tissue or possibly a finger can help to make a seal so the baby can get good suction. If the baby does not manage to suck from the breast, a standard bottle or specialist cleft bottle may be needed. A Lactation Consultant will be able to support you. Breast milk is the ideal food for babies so breast milk is encouraged for all babies with a cleft.

If feeding from the breast is not possible, colostrum can be given by syringe and when your breast milk 'comes in', you can express and feed from a specialised bottle/teat or store it for

later use. Your Lactation Consultant can provide assistance if you need help with breastfeeding or expressing milk and Cleft NZ can provide free loan breast pumps (www.cleft.org.nz/support/breast-pump-agreement). If breastfeeding or expressing breastmilk is not possible or you choose not to feed your baby breastmilk, then infant formula is an option.

A baby with a cleft palate, or a cleft lip and palate, may experience more problems feeding. To suck adequately, the baby needs to push the tongue and nipple or teat up against the roof of the mouth, then lift the soft palate in order to close off the nose to create suction. With a cleft of the soft palate, it may not be possible to get enough suction. If there is a cleft of the hard palate the baby may be unable to get compression as the surface where the baby is pressing the nipple or teat against may not be intact. It may be helpful to position the teat or nipple to the opposite side from the cleft. A baby with a cleft palate is also more likely to have milk coming out of their nose while feeding. Your baby may also swallow more air than usual so will have to be burped more frequently.

A special cleft feeding bottle/teat may be necessary to overcome these difficulties. The Lactation Consultant and Speech-Language Therapist will assess your baby's feeding to decide on a method that suits you and your baby. Information on the most appropriate method of feeding for each individual baby and on the most suitable feeding equipment should be available in the first few days of life.

Feeding should be relaxed and may take a little extra time at first but generally 30 to 40 minutes should be adequate for each feed. Occasionally, some babies can have difficulties feeding and may need to be fed via a tube from the nose to the stomach. This is often a temporary measure and the baby will usually go on to learn to feed normally.

Introduction of solid foods should occur at the same time and in the same sequence as other infants, at around 6 months. You may find it takes a little longer to establish. Some problems may be experienced with solids such as nasal regurgitation (food coming out the nose via the cleft), coughing and refusing food in the mouth.

If your baby is born prematurely, this age refers to the corrected age. Most babies will grow at the expected rate however it is recommended that your baby is weighed every 4 to 6 weeks to monitor growth at least until the time of surgery. It is important for your baby to be well nourished before surgery to help with the extra stresses in the period after surgery.

Gastric Reflux

Most babies spill some of their feed, so don't immediately assume it is reflux without a professional diagnosis.

Symptoms of reflux may include:

- Difficulty feeding.
- Continuous crying.
- Unable to settle.
- Dramatic change from happy when being carried upright to very grumpy when being laid down due to the pain of gastric acid flowing the wrong way.
- Baby only taking short naps compared to other babies of the same age due to pain and hunger.

Handy tips from parents:

- Hold baby in an upright position after eating for at least 10 minutes.
- Try feeding baby small amounts often.
- Do not be afraid to get medical help for the problem.
- Do not be afraid to try different things, as every baby is different, but do give things a little time to work.
- Do not lie them straight down or sit them on your knee to burp them. Place a towel over your shoulder and gently rest baby so their body is straight with their head on your shoulder and pat them or rub them gently on the back.
- Persevere with tummy time between feeds – protect flooring with a towel or cloth nappy.
- An antacid may be prescribed by your health professionals, to help reduce the burning pain of reflux and make tummy time more bearable.

COPING WITH REACTIONS

Whether you learned about the cleft prenatally or at the birth of your baby, reactions are varied. You may experience feelings of loss, grief, anger, panic, deep sadness or numbness. You may be asking “why us”, or “how did this happen”? These feelings are natural. You need to be able to grieve the loss of the child that you thought you were having, with all the hopes and plans for that child and your family. The process of adjusting to the diagnosis may raise some unexpected feelings. Give yourself time and be understanding of your feelings and those of your whanau.

There may be times when you need to put others at ease with your baby and by demonstrating your love and acceptance, it will

do much to help others relax with them too. They are a baby first – the cleft is secondary, it does not define your baby.

Also remember you have the support of the Cleft NZ community.

THE CLEFT TEAM – HOW DOES IT ALL WORK?

The combined skills of various specialists will be available to treat your child’s condition through their cleft journey.

All of New Zealand's Cleft Centres (contact details on the Cleft NZ website), model their care on a multidisciplinary team approach. This allows all members of the team to jointly discuss your child’s individual needs with you and therefore you do not have to make multiple visits to different specialists at different times. Specific care plans are individualised to your child’s needs.

In some centres, a Cleft Nurse will visit you once the baby is born, to assess your baby and plan care. This nurse is your point of contact for information and support during your child’s journey. In centres without a specialist Cleft Nurse you will be visited by a Speech Language Therapist.

Your first visit to the Cleft Team can seem quite daunting with a room full of people. It is a good idea to come prepared with a written list of questions.

Babies born with a cleft will grow into healthy children and adults able to take their full place in society.

Across New Zealand the Cleft Teams all strive to ensure:

- Development of good speech and hearing.
- There is no difficulty eating/drinking.
- The best possible appearance of the face, lips, and nose.
- The alignment of the teeth, jaw and bite.
- To enable children to be strong, healthy and happy at home and at school.

WHO ARE THE SPECIALISTS?

The cleft team you will see at the cleft clinic appointment may include:

Cleft Specialist Nurse

This is the person coordinating your child's care and is often the point of contact.

Plastic Surgeon

Will repair your baby's cleft and later procedures if required. Other Surgeons specialised in Oral/Maxillofacial surgery may be involved when your child is older. Most commonly, the Plastic Surgeon will be the lead surgeon.

Speech Language Therapist

Will work with you to advise on appropriate feeding methods and oversee speech and language development.

You may meet both a hospital based Speech Language Therapist and also a speech language therapist through Education Services locally when your child is at preschool or school.

Dental Team

This includes an Orthodontist and a Dentist. They monitor tooth and jaw development and either provide or facilitate the provision of routine oral health care. The Dentist offers advice and treatment for tooth decay and gum disease prevention. The Orthodontist specialises in the treatment and correction of teeth positioning and occlusion (bite) and will provide braces for your child in their teenage years.

Ear, Nose and Throat (ENT) (often called Otolaryngology Specialists)

Monitoring of ear function and treating hearing difficulties. They will assist with the diagnosis and treatment of breathing problems, nose and throat infections, voice and resonance issues.

Audiologist

Tests the child's hearing and provides hearing aids if required.

Genetic Counselling Service

They will discuss with you the possible rates of recurrence and the likelihood of passing this on to future family members.

Paediatrician

Looks after the general health needs of your child. A Paediatrician will look at any medical issues facing your child.

Psychologist

They can support your child and family with issues relating to bullying, self-confidence, anxiety and preparing for surgical procedures.

WHAT TREATMENT WILL HELP MY CHILD?

The Specialists on the Cleft Team will work with you to ensure that your baby receives the treatment they need at the appropriate times.

Generally, in New Zealand, a cleft lip is repaired between 3-6 months of age and a cleft palate is repaired between 9-12 months of age. This decision is based on a number of factors including:

- Size and general health of the baby for surgery.
- Repairs to match developmental needs of the baby.
- Individual experience and preference of the surgeon.
- Collective knowledge based on prior experience and international research.

For babies born with cleft lip and palate, where the cleft affects the gum (alveolus), your Cleft Service Centre may begin baby's treatment with presurgical orthodontics. This involves the baby having a dental plate made, which helps keep the shape of your baby's gum line (or dental arch) while they grow and before the cleft lip is repaired.

This dental plate is easy to care for and your orthodontic team will show you how to do this and you will have regular visits to check the plate. After a few weeks, the orthodontist may start taping the baby's lip, to encourage the edges of the lip together. Most Surgeons find this a benefit when it comes to surgery time, but each Centre is different so discuss options with your Surgeon.

Once your baby has had their cleft lip surgery they will no longer need the plate.

Surgical Repair of the Lip

A cleft lip is usually repaired at about 3-6 months. Most babies recover very quickly from this operation and you can expect to stay in hospital with your baby for around 1-2 days. The aim of this surgery is to repair the lip muscles and to achieve as near normal appearance of the upper lip.

If the lip and palate are involved, your surgeon may advocate a two stage repair where the hard palate is repaired at the time of the lip surgery – the surgeon will explain the plan for surgery at your clinic appointment.

Babies with complete clefts of the lip and/or palate nearly always have asymmetric or off-centred noses. The cartilage in the tip of the nose on the side of the cleft is pulled outwards and slumps. During the first operation in which the lip is repaired, the surgeon may also attend to the asymmetry of the nose and try to get this as symmetrical as possible. Again, there are many different ways to approach this and your surgeon will explain at your clinic appointment.

Surgical Repair of the Palate

A cleft palate is usually repaired at about 9-12 months. Most babies recover very quickly from this operation and you can expect to stay in hospital with your baby for around 2-3 days.

The main aim of palate surgery is to repair the soft palate so that the muscle sling is reconstructed and the palate is long enough to touch the back wall of the throat so that when a child talks, air comes out their mouth with speech, not out of their nose.

There are a variety of techniques the surgeon could use to mobilise the muscle tissue from the sides to the midline of the palate to achieve closure which then separates the nose from the mouth - your surgeon will be happy to explain the procedure to you.

Going in on the day of the surgery

You would have had a pre-op check over the phone with one of the nurses a few days before the surgery.

During this call they will check that your baby is fit and healthy and advise you what time to be at the hospital and where to go. They will also let you know when to stop giving them food and fluids.

Make sure you have things to entertain your child with while waiting and bring their favourite toy or blanket with you.

It's also a good idea to pack an overnight bag for yourself and your child, but leave this in the car and only get it after they are settled into the children's ward. Sometimes it pays to pack food for the parent as the hospital only supplies breakfast.

What to expect after surgery

Immediately after the operation your baby will go to the recovery area. One of the nurses will give you a call once they are awake and then you will be able to go in and see them.

They may appear pale and sleepy at first and often there is some blood around their mouth and nose. They may also be crying and disoriented but all of these reactions are normal and the recovery nurses will be there to help you.

Your baby will have an I.V. tube inserted in either their hand or foot, which will be protected by a splint or bandage. The tube is used to administer any pain relief or to rehydrate your baby if necessary.

A temperature and pulse probe may also be attached to their toe and will continue to be used when you get to the ward.

Once your baby is stable you will be moved to the Children's ward.

Instructions around feeding your baby post operatively will be documented. Each surgeon will have specific post operative instructions for the nursing staff depending on the type of surgery. Always ask if you are unsure of what to do.

Often babies reduce the amount of fluid they take after the palate repair and often prefer puree food.

This is quite normal and it may take some time to get back up to levels they were having before surgery. Persevere, as it is important that they get enough fluids. Nursing staff will want to be assured that feeding is re-established before you will be discharged.

Your child may also have to wear arm splints for 3 weeks post surgery to prevent fingers or other objects going in their mouth, which could damage the delicate stitches of the repair in the first few weeks.

For lip repairs, there is often a nose stent (small tube) inserted in their nostrils. This is to help keep the shape of the nostril. Your surgeon will arrange for this to be removed, usually one or two weeks after surgery.

Your baby will be given regular pain relief and antibiotics to keep them comfortable. The amount is worked out by their weight so it is safe to give to the baby.

If you are worried about anything, at any stage, just ask. The staff are there to help you and your baby.

Sometimes a small hole (fistula) will remain in the palate after repair. Fistulas are generally repaired if they are affecting your child's development. There needs to be at least 6-9 months between repairs to enable the scar tissue to fully heal.

Things to be aware of

Surgeries can be postponed. This can be due to a range of factors, including your baby's health, the success of the taping and positioning of the lip, and/or hospital occupancy pressures. It may be postponed before the surgery, that morning or even after you get to the hospital.

Do not worry, there is a window of opportunity to do this repair, and whilst it is very stressful to have a surgery postponed it won't affect the quality of the outcome for your child.

Surgery is a stressful time for the whole family. No matter how much information you have, preparation you have made, and people you have talked to, you will still feel some anxiety. This is normal, but it helps to talk about it.

Even though this may be your second experience of surgery and hospital admission, do not be surprised if you have many of the feelings you experienced the first time around.

Babies can look different after the lip repair, and you may be surprised by your reaction to this. Remember they may look a little different but they are still the same precious baby that you know and love. It can be nice to have photos taken of your baby before the lip repair to record this time of their life.

Scars have a life cycle. At the beginning, the scar can look very clean and minor. As time progresses the scar shortens and thickens up, appearing more obvious, redder and more prominent. This will change again as the tissue around the scar relaxes over time. You can try a moisturiser on the suture line when it is healed (6 weeks post operation) to help with scarring. Ask your surgeon for advice.

Think about how your family, friends and Cleft NZ can help you during this time. You may need some food, cleaning, other children taken care of, breaks, or just a listening ear. Let them know how they can support you.

Be open minded about what the outcome of the surgery might be, focus on the positive outcomes of surgery. It is hard but worthwhile and remember, your child is a child first, the cleft is secondary.

Phoebe's Story

Dear Parents, my name is Phoebe, I'm 15 years old and I have a cleft lip and palate. Having a cleft is really not all that hard. I don't really remember most of it because I was just a baby when I was having my first big surgeries. For me it wasn't all that scary because I didn't really know what was happening. I think it was a lot scarier for my parents seeing me go into surgery and then be in pain afterwards. I definitely feel like it would be a hard thing to see your child go through but I think for all of us it's definitely worth it in the end.

The first surgery I can actually remember was my bone graft which I had when I was around 10 years old, this was one of the biggest surgeries that I needed to have. If you don't know about it, it's where they took bone from my hip and put it in my jaw so that it had more structure. This is when I first felt the physical pain of having a cleft. I was in the hospital overnight and I was out of school for about two weeks. Since some of the operation was on my hip I had to have crutches but, since I had the surgery when I was about 10 having crutches was kind of a fun thing and I was pretty cool when I went back to school - not gonna lie.

At school I never really felt any different to the other kids; no one has ever really treated me differently so maybe I am one of the lucky ones. All the teachers knew about my cleft because me and my parents gave them a copy of the blue book and we talked to them at parent teacher interviews. They were very understanding and supportive when I had to go out to my hospital appointments. The only comments I would get about my cleft have been from other kids who would say things like "what happened to your face?", or "did you get in a car accident?", but I kind of learned how to deal with these questions after a while because it just became normal to me. I occasionally ask my friends about what they think and they just say they don't really notice anything different because I've been like this the whole time that they have known me and it's just me, you know.

The only person who has really bullied me about my differences is myself. Being a 15 year old girl I have to say I do care what I look like. I like to tell myself having a cleft lip and palate isn't really a big deal but it does affect me, I don't really like public speaking and I don't like people looking at me because I feel like I'm different. I'm not as confident as I want to be because I feel like people are always just looking at my face and thinking to themselves what's wrong with it. But hey that probably goes for most 15 year old girls right? And as a whole it hasn't really affected my life dramatically, it's just another little bump in the road. I still get to do all the things that I love to do, there's really no limitation. I'm a horse rider, I'm out competing every two weeks, I ride three times a week and I am an instructor at Auckland Equestrian Centre. If your child has a cleft I reckon there's not much to worry about, everything will be OK.

ENCOURAGING YOUR BABY'S SPEECH AND COMMUNICATION DEVELOPMENT

Most children born with a cleft will develop normal speech, however, some need more help than others to achieve this. It is important to encourage your baby's interest in speech, language and communication in the normal way.

How does a cleft palate affect speech

Children born with a cleft palate will vary in their speech development. The severity of the cleft does not always indicate how a baby's speech will develop. Many will have no problems, whilst others find some sounds more difficult to make.

The palate works to separate the nose from the mouth for feeding and for speech. By closing off the nose, it allows pressure to build up in the mouth for sounds such as 'p,b,t,d,k,g,s,z,f,v'. It also stops liquid and food going up into the nose.

For some children, even after the palate has been repaired, the muscles are not quite long enough or stretchy enough to reach the back of the throat to block off the nose from the mouth during speech. This can allow air to leak into the nose when speaking. Sometimes the air can be heard coming down the nose or you may hear a slight snort noise. Often the tone of the voice can sound nasal. It is important that you try to understand the words they are saying, even if they are nasal.

Children who have had a cleft palate may develop a tendency to use the back of their tongue and the back of their mouth more often than normal to make sounds. They might replace 'front sounds' such as "p, b, t, d" with 'back' sounds such as "k, g". So 'daddy' may sound like "gaggy".

How can speech language therapists help

The speech language therapist can:

- Check if your baby's soft palate is working properly for speech.
- Provide you with advice to prevent your child from developing abnormal speech sounds.
- When older, if your child starts to produce abnormal sounds, they can give you ways to try to eliminate the abnormal sounds and encourage the production of more typical sounds.

How can I help my baby's speech and language development?

By the time babies are six months old they are beginning to 'babble' – (make speech like sounds). These sounds continue to develop throughout the first year of life and beyond and you will gradually begin to recognise them as your baby's first words.

There are many ways you can help your baby during this important time. Some ideas of ways to encourage their speech and language development are listed below.

Listening

It is important for your baby to look, listen and experience sounds before he/she can produce them.

- Cut down background noise (such as a TV or radio) when talking to or playing with your baby. This will enable them to hear your voice and the quieter speech sounds such as p, t and k.
- Try to sit close to your baby and preferably facing him/her so he/she can clearly see your face and mouth.

- Draw your baby's attention to everyday noises such as aeroplanes/cars going by, the telephone, vacuum cleaner etc by asking 'what's that noise?' – then show them what made the noise, where possible.
- Play with musical toys and instruments (including banging saucepans!). This also develops listening skills.

Language

- Talk to your baby. By doing this, you will be providing your baby with models of clear speech. They may not copy you straight away but they will take in what your face and mouth are doing and the sounds that you are making. It is not necessary to teach your baby to make sounds or to prompt them to copy you.
- It is important to vary the loudness and pitch of your voice and to use lots of facial expression. You may find you are doing this automatically when you are having fun.
- Copy your baby's sounds and noises. Children need to learn early on how to take turns in a conversation. Copy their noise/sound, then wait for them to make another. This is the beginning of turn taking.
- When you are playing with your baby (for example, in the park or the bath) and when you are doing everyday things (for example, shopping) name familiar objects/toys and talk about what you are doing. If your baby makes a noise whilst looking at or playing with a familiar toy, interpret their noise as a word, praise them and repeat back the real word for the object.
- Repetitive games such as 'peek-a-boo', nursery rhymes and songs are useful for teaching your baby language.



Developing your child's awareness of your lips and mouth. (encouraging sounds like p,b,m,f,s,sh, th,l.)

- When talking to your child, if you are focusing on a sound, take care not to stress the sound or say it with any extra force. If you do, your child may also say it with extra stress or force (which uses the back of the throat). Do not say the sounds any louder than normal.
- Babies have a tendency to stick their tongue out a lot early in life. It is important to positively reinforce/encourage this early on by copying and praising your baby when they do this. The idea is that they will then be used to using their tongue when they begin to make sounds later on.
- Imitating tongue/lip movements, puffing out cheeks, blowing kisses, wiggling your tongue etc will all encourage babies and children to use their mouth and tongue.
- Do not copy or encourage throaty, growly sounds as we want your child to use their mouth for speech sounds rather than their throat.
- Eye contact and close proximity is essential but do not tell or try to make your child look at your face. If they are not interested, just try again another time.
- Say the sound p,p,p then 'pop' bubbles from a tube or in the bath or when washing up.
- Use words that contain front sounds such as 'up', 'more', 'woosh', 'push' and 'wee' as you play games, go down slides etc.
- Make animal noises and environmental noises such as 'brmm', 'beep', 'miow', 'baaa'.
- Play 'peek a-boo' games.
- If your child likes looking at books, you could make a scrapbook with your child of familiar toys or objects beginning with 'front sounds'. Talk about the pictures together.

Most importantly, have fun with your child and enjoy!

Hi everyone, my name is Sophie and I am 18 years old.

Last year, I graduated high school at St Paul's Collegiate with Honours and am currently at the University of Canterbury studying towards a Bachelor of Commerce in Accounting and Finance. My hobbies include playing tennis, hanging out with my friends, and tutoring younger students.

Being born with a cleft palate saw me go through many years of speech therapy and checkups at the hospital. However, I can confidently say that being born with a cleft palate hasn't stopped me from anything. Through out primary and high school, I often made the finals in speech competitions, and today am a confident public speaker. I've taken an interest in languages and have studied Spanish for over 5 years. The past year of my life has seen me be fortunate enough to be granted the PwC School Scholarship and University of Canterbury Emerging Leaders and Excellence Scholarships. I cannot emphasize enough, how being born with a cleft palate does not hinder you or your child's ability to succeed, rather, shapes you into the unique person we all are.

I would love to see every cleft child become as confident and happy in their lives as I am. Anything is possible, if you have the desire to achieve it.

BENEFITS AND ENTITLEMENTS

In New Zealand, we are very fortunate that the public health authorities fund the treatment and repair of cleft lip/palate. You should not have to pay for any outpatient fees, time spent in hospital, orthodontic equipment, or (in most cases) feeding equipment. However, having a child with a cleft lip and/or palate will still mean you do have some extra expenses.

To receive public health funding you must be a permanent resident or citizen of New Zealand. You will need to provide proof of this prior to receiving treatment.

Parents of children born with cleft lip and/or palate have compiled this information as a rough guide to the benefits you may be entitled to. It is as accurate as we can make it at the time of printing but you must speak to either a Social Worker or Needs Assessor for current details of entitlements in your local area. You can also contact Work and Income (WINZ).

There are various benefits, both financial and practical, which you may be entitled to as the parent of a child born with cleft lip and/or palate.

High Frequency Health User Card

This can be obtained through your GP and can sometimes be utilised to get extra subsidies on prescriptions.

Child Disability Allowance

A Child Disability Allowance is available to people looking after a child with a serious physical or mental disability at home. This allowance is not means tested and babies with cleft lip/palate are classed as having a physical disability. This is periodically reassessed and you may only be eligible for 1-2 years.

Disability Allowance

The Disability Allowance is a supplementary allowance for people with a disability on a low income or receiving a benefit.

Carer Support / Respite Care

This is an allowance paid to an alternative caregiver, at the family's request. A Needs Assessment is required to access Carer Support by your Social Worker or Needs Assessor.

Don't allow the names of these benefits to shock you -the words "handicapped" or "disabled" are simply used to describe a wide range of conditions. In the vast majority of cases, a cleft lip and/or palate is a purely "cosmetic" condition. Your baby will be otherwise healthy and develop normally.

Before applying for these benefits you need your child's birth certificate. Payment generally does not commence until the Needs Assessor receives the completed forms and cannot be backdated. Members of your cleft team can assist you to complete the required forms.

FINAL WORDS FROM THE EDITOR

It is a privilege to be a board member of Cleft NZ and lead the rewrite and creation of the Blue Book 1, Antenatal to age one. As a cleft affected person myself, with three cleft affected children, I am fully invested in improving the experience for you and your baby. I hope the information contained within this book and the personal stories shared will inform and support you and your baby in their own cleft story. Although your journey with your baby who is cleft affected, may seem daunting at times, Cleft NZ is here for you. Our website has lots of information, so please join as a member to benefit from our experience and resources. Blue Book 2 is also available from Cleft NZ, containing invaluable information on cleft care for the older child. My gratitude and thanks goes to the creators of all the editions of the Blue Book and especially to Megan Sanders for all her expertise and dedication with these new editions.

Kindest regards,

Lisa Kennedy

Cleft affected family, Board CleftNZ

Websites:

For up to date information on website links, resources and support available please go to the Cleft New Zealand website:

www.cleft.org.nz/support/information-links

DONATIONS

Cleft NZ inc is a charitable trust and registered as an Incorporated Society. As such, we rely on fundraising and donations to keep us going.

If you have found this book useful, found an answer to your questions on our website or are looking to the future for you and your child, then you may want to help us financially.

Your donation will make a difference. Your help will ensure the group continues to support all those going through the cleft journey, and help us to expand the services we can offer you and your child into the future. Every donation to Cleft NZ makes an enormous difference. As a registered charity, we depend on the generosity of our supporters to finance our work.

Through our website you will find different options on how to donate and if this is not possible here are some suggestions on how to help support us:

- Join our Facebook page. It is a great way to promote Cleft NZ to your networks.
- Volunteer your time and expertise.
- Help us spread the word & raise public awareness of cleft.
- One off gifts.
- Ongoing monthly contributions.
- Bequests.

With your help we continue to support families, children and adults, with realistic information and positivity and with a real sense of hope for the future. Because we think the future looks great.

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NOTES

This edition

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Previous Editions

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Ian Esson (Special Needs Dentist)

Lesley Salkeld, Anthony Cecire (Otolaryngology (ENT) Surgeons)

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