

### *Antenatal*

You may not be aware of your baby's condition as it is difficult to pick up a cleft of the palate, but some parents will know before the birth and be able to prepare.

### *Birth*

Congratulations – make sure you celebrate the birth of your much loved baby. Of course you will feel shocked if you weren't prepared, take a deep breath, give yourself time out, and look to family and friends for their support.

Cleft NZ can also help right from day one. Remember, your baby is totally unaware of any difference and just looks to mum & dad for love!

### *Neonatal - Newborn*

Important steps will be taken as soon as possible to ensure both baby and parents make excellent progress over the next few weeks

#### **Diagnosis**

A Paediatrician will check your baby's overall health.

#### **Clear airway**

Ensuring your baby has a clear airway is number one priority.

#### **Sleep apnoea monitor - may be needed**

As your baby grows, breathing and swallowing challenges become less -time and growth is a huge help for your baby.

#### **Feeding**

A Speech Language Therapist will help you to establish feeding. It is unlikely that you will be able to breastfeed your baby and if you need specialised equipment your SLT will organise it for you.

#### **Expressing milk**

Give yourself time to become relaxed and you'll find it gets easier. A electric breast pump is recommended.

## Assessment and the Plan

You will visit the Cleft team at a combined clinic and they will discuss with you the Care Plan for your baby.

## Financial help

You are eligible for money through WINZ and one of our Cleft Team members will sign the forms for you ready for you to take in.

## Call Cleft NZ

We are here to help all parents and their children so make contact as soon as possible for advice and support. You are not alone.

## 6 months

### Dental health

Start cleaning your baby's teeth as soon as they appear, enrol them in a dental service (school dental nurse or family dentist) and ask for 6 monthly check ups.

### Hearing

Your baby's first hearing check will be at around 6 months of age. Earlier tests can be arranged if you have concerns about your baby's hearing. Grommets may be needed from this time for recurrent glue ear.

## Palate Repair - 9-12 months

Palate repair is carried out which may mean 2-3 days hospital stay. Armsplints are usual for 3 weeks after the surgery. Your baby may prefer solids – it is necessary to make them soft and runny and a non suck method of feeding is usual for 3 weeks after the surgery. Post surgical followup appointment is at 6-8 weeks

## Checkups

### 12 MONTHS

- Hearing and audiology checks to continue
- First Speech assessments through your Child Development Services , SLT, is usually done approximately 3-6 months after the palate repair.

### 2-3 YEARS

- Speech Therapy If your child continues to need Speech therapy you will be referred from the hospital system to the education system around now. (Group Special Education). Speech Therapy can be delivered at your early childhood centre.
- Yearly cleft team clinic appointments continue.

### 3 – 5 YEARS

- Nasal speech may require further investigation with either a review by your Cleft Team SLT and possibly a Videofluoroscopy. Further palate surgery could be needed to improve speech and sound production.

- Fistula (hole) repair – sometimes there may be a small gap remaining in the palate and if this is affecting speech, surgery may be required.
- 1-2 yearly cleft team appointments continue.

## *School Starts*

### 5 YEARS

- What a great milestone – party time!
- If you have any concerns at all just talk to us at Cleft NZ about starting school as we have some resource available to parents and kids.(Clancy has a Cleft)
- Speech therapy may continue at school.
- Be prepared and prepare your child. Children are curious about difference so prepare some answers and always look for any changes in your child's behaviour to alert you to what is happening at school.

### 10 YEARS +

- You may need orthodontics just like other kids of your age. If so you will be under the oral health unit's care till dental work is complete.

### 16 YEARS +

- Some young people require Maxillofacial work. This adjusts the position of the jaw and needs to wait until growth has stopped.

### 16 - 20 YEARS +

- This is the age when young adults are discharged from the medical system and take on their own care and decisions for their future.

## *What Now?*

Young adults can still contact the Cleft Clinic for extra information they want to know about such as, further plastic surgery, speech issues, genetic information, starting a family, or psychological support.