

your baby's a Star!

Milestone Chart | For babies born with cleft lip & palate

Antenatal

A 20 week scan can identify the condition of cleft and it is a good idea to prepare for the birth and afterwards by talking to Cleft NZ. You can share your concerns, get answers to any questions and importantly visit your Cleft Team before baby is born.

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

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. An electric breastpump is usually recommended.

Assessment and the Plan

You will visit the Cleft team at a combined clinic and they will give you the Care Plan outline 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.

Pre-surgery - from I week

Pre surgical dental plate (sits on the roof of the mouth behind the gum line) is used to narrow the cleft in preparation for surgery. A 'bonnet' or taping may also help to reposition the lip.

The orthodontist will guide you through this process and you will be visiting regularly (up to fortnightly) to check on progress and the fit of the plate.

Lip repair - 3-5 months

Surgical repair of the lip and hard palate and some work on the nose may be done at this time as well. If you have been using a plate you won't need it from now on. This involves a stay in hospital for 1-2 days and baby will need to wear arm splints to protect the surgical site for 3 weeks.

Your surgeon will advise you on the recommended feeding method post surgically – it is often a non suck method of feeding for 3 weeks.

Post-surgical recovery

This will be an adjustment time to how different your baby now looks, and there may also be a temporary behaviour change in your baby. Any behaviour changes are always temporary and it may help to talk to us about your concerns at this time.

Post surgery followup appointment at 6-8 weeks

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.

Audiology

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 YEARS

- Nasal speech may require further investigation with a review by your Cleft Team SLT and possibly a Videofluroscopy.
- 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

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.

8-12 YEARS

x-rays to find out how adult teeth are growing

- Pre-surgical orthodontic treatment (6 months prior to bone graft surgery)
- Bone graft surgery.

12-16 YEARS

• Orthodontic treatment to straighten teeth and improve occlusion (bite).

16-18 YEARS

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

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.

We will also talk about any plate breakages, but if it has been lost a new one will have to be paid for. Ongoing dental health & hygiene is also each person's responsibility.

