



Cleft lip and palate information for parents



Compassion

Accountability

Excellence

Equity

Collaboration

Respect

Table of contents

Introduction	3
Feeding my baby	3
Common feeding problems	3
Breastfeeding	3
Bottles and teats.....	4
Post-surgery	6
Swallowing difficulties.....	7
Problem solving some common cleft feeding issues	7
Introducing solids	9
Bonding with my baby	10
Language and speech development	10
Ear health	10
Grommets	11
PCH cleft team timeline	11
Helpful contacts.....	13
Useful websites	13

Introduction

- Congratulations on the birth of your baby!
- We hope this information helps you in the first few months.
- Babies can be born with an isolated cleft palate, an isolated cleft lip or a cleft lip and palate.
- This information is for babies with a cleft palate or cleft lip and palate.

Feeding my baby

- Our goal is for feeding to be a positive experience for you and your baby.
- With the right support, most babies with a cleft palate can feed effectively and safely.
- This can be challenging at first until you have worked out what works for you and your baby. Every baby is unique.
- Please contact your Universal Plus child health nurse, child health nurse or your speech pathologist if your baby is having feeding issues.

Common feeding problems

- Feeding is important for all babies to grow, develop, bond with their caregiver and learn about eating and drinking.
- There are three main parts to effective feeding: attachment, compression and suction.
- Babies with a cleft palate cannot separate the nasal and oral spaces and hence cannot create a strong suck.
- Babies may have:
 - a weak suck so they have to work harder to extract milk. They can become fatigued with feeds, take inadequate volumes, have difficulty gaining weight and take a long time to feed.
 - excessive air intake.
 - milk coming out of the nose (nasal regurgitation).

Breastfeeding


- It is often difficult for babies with a cleft palate to create enough suction for breastfeeding. Success depends on the size and location of the cleft.
- Breastmilk may be expressed using a pump and given to your baby using a bottle.
- Please speak with your medical team, nurse and a lactation consultant if you wish to pursue breastfeeding or need support with expressing milk.

Bottles and teats

- Most babies with a cleft palate feed well with a bottle once the most appropriate method for them is established.
- There are a range of bottles and teats that can help your baby feed well.
- You may find different teats or bottles that work for your baby. Every baby is unique.




Most babies with a cleft palate feed well with a **MAM squeezey bottle** and **fast flow teat**. These will be provided to you at PCH.



Table 1: Bottles and teats

What	Information	Where can I get it?
<p>Mam squeezey bottle</p> 	<ul style="list-style-type: none"> • You squeeze the bottle so your baby does not need to suck. • Can be used with most narrow/standard neck teats. • Most parents prefer this squeezey bottle. 	<ul style="list-style-type: none"> • You will be given 2 MAM squeezey bottles as an inpatient at PCH. If your inpatient stay was elsewhere these will be provided by the PCH cleft palate clinic coordinator. • CleftPALS WA. https://www.cleftpalswa.org.au/shop • Online pharmacies e.g. www.thepharmacy.com.au
<ul style="list-style-type: none"> • Fast flow teat. • Many brands are available e.g. PCH ward teat. • Pigeon L teat. • Tommee Tippee fast flow teat 6+ months. 	<ul style="list-style-type: none"> • Helps to extract milk more easily. 	<ul style="list-style-type: none"> • You will be given 2 fast flow ward teats at PCH. • A range of brands sell fast flow teats. These are readily available at supermarkets, baby shops and chemists.

You do **not** need to try all of these options. They can be considered if your baby does not feed well with a squeezey bottle and fast flow teat.

Table 2: Other bottle and teat options



	What	Information	Where can I get it?
Squeezy bottles	<p>Pigeon cleft palate bottle</p> 	<ul style="list-style-type: none"> Works the same way as the MAM squeezy bottle. 	<ul style="list-style-type: none"> CleftPALS WA. https://www.cleftpalswa.org.au/shop
Special feeders	<p>Dr Brown's Medical Specialty Feeding System</p> 	<ul style="list-style-type: none"> A special valve enables your baby to compress the teat to extract milk, reduces air intake and allows your baby to self-pace the feed. 	<ul style="list-style-type: none"> Some online stores. <ul style="list-style-type: none"> Cleft Connect Australia. https://cleftconnect.org.au/store/Dr-Brown-bottles-Specialty-Feeding-System-designed-for-cleft-babies-p98681666 Baby Kingdom. https://www.babykingdom.com.au/dr-brown-s-250-ml-bottle-with-infant-paced-feeding-valve-level-1-teat-extra-valve.html
	<p>Medela Special Needs Feeder (also known as a Haberman bottle)</p> 	<ul style="list-style-type: none"> Your baby can extract milk by compressing rather than sucking. A one-way valve stops air from entering the teat. You can help your baby feed by squeezing the teat (as needed). Variable flow teat. 	<ul style="list-style-type: none"> CleftPALS WA. Online pharmacies e.g. Chemist Warehouse.

	What	Information	Where can I get it?
Teats	Pigeon cleft palate teat (9) 	<ul style="list-style-type: none"> • Has a Y-cut allowing your baby to chomp (rather than suck) to extract milk. • Has a valve to reduce excessive air intake. 	<ul style="list-style-type: none"> • http://cleftconnect.org.au/store/ • Online pharmacies e.g. www.thepharmacy.com.au • Some interstate CleftPALS websites (e.g. CleftPALS QLD and CleftPALS Vic).
	Chu chu easy feed teat 	<ul style="list-style-type: none"> • Place the flat side upwards. • The cross cut will not leak when your baby stops sucking. • The underside of the teat is soft making it easier for your baby to extract milk. 	<ul style="list-style-type: none"> • CleftPALS NSW, Vic, QLD. • www.thepharmacy.com.au

Post-surgery

- After surgery your baby **must avoid placing anything in their mouth** while the suture site heals including teats, dummy, fingers and toys.
- Post-surgery, **babies wear arm splints** to prevent them from putting anything near their mouth.
- A spoon attachment or open cup is used instead of a teat for feeding for about three weeks post-surgery. You will be given specific recommendations during your inpatient stay.
- Practice using the spoon attachment for feeding and remove their dummy before surgery to help your baby during the post-surgical period.

Table 4: Post-surgery spoon attachment

What	Information	Where can I get it?
<p>Boon spoon</p> 	<ul style="list-style-type: none"> Your baby drinks from the spoon. You squeeze the bottle to get the milk out. 	<ul style="list-style-type: none"> CleftPALS WA. Baby shops and pharmacies.
<p>Pigeon bottle with spoon attachment</p> 		<ul style="list-style-type: none"> CleftPALS WA. You will be given one of these during your inpatient stay at PCH.

Swallowing difficulties

- A cleft palate affects your baby's ability to compress and suck effectively. It does not effect swallowing.
- However, some babies have additional medical issues that may impact on feeding in other ways (e.g. difficulty swallowing). This is not covered here. Please speak with your baby's medical team (and feeding team if involved) regarding the specific needs of your baby.

Problem solving some common cleft feeding issues

My baby becomes distressed by milk coming out of his/her nose.

- This is common before your baby's cleft palate repair.
- Position your baby in a **semi-upright position** for feeds.
- Slowing the pace can help reduce milk coming out of the nose (nasal regurgitation).
- Sneezing is a good way to clear the nose.



My baby is showing discomfort e.g. crying or arching back during feed.

- Your baby may need more **frequent burping**. It is common for babies with a cleft palate to take in more air when feeding.
- Some babies also experience reflux. Position your baby semi-upright during feeds and 20 minutes following feeds.
- Speak with your nurse or family doctor (GP).

My baby seems to suck and suck but does not get much milk out (2).

- Your baby may need to **try a bottle/teat that is easier for them** (e.g. faster flow teat, cross-cut teat, squeezey bottle).

My baby frequently falls asleep before finishing the feed.

- Your baby may need more time and practice to build endurance with feeds.
- You can try changing them mid-feed.
- Or they may need to try a bottle/teat that is easier for them (e.g. faster flow teat, cross-cut teat, squeezey bottle). Be sure to allow them enough time to practice a new teat.

My baby spits the teat out, turns away, spills, coughs, gags or appears disinterested in the bottle.

- The flow of milk may be too fast for your baby to manage. You can help slow the feed down or give your baby little breaks. You can also try a slower teat.
- Squeeze the bottle at the pace your baby sets (the pace that matches their suck, swallow, breathe rhythm).
- **Follow your baby's cues** – they will tell you what is or is not working. Some cues can be clear (e.g. crying, arching back, coughing). Some may be more subtle (e.g. your baby may be very sleepy for feeds, not gaining weight as expected). Give your baby more time to accept the teat.
- Have some gentle, positive experiences around your babies mouth (e.g. soft kisses and touch).
- **Offer the bottle gently and when your baby is ready.** Do not force the teat into your baby's mouth. Do not force your baby to take more milk than they want to. This can be difficult if you are concerned about the volume of milk your baby takes or their growth. Please speak to your child health nurse or speech pathologist for support with this.

My baby spits the teat out, turns away, gags or appears disinterested in the bottle.

- Babies need to feel safe and comfortable to feed well. It is important that your baby knows what to expect at each feed.

- **Be consistent** – offer the same bottle, teat, milk and feed in the same position. This will help your baby feel safe and comfortable.
- If you need to try something new (if things are not working or as your baby grows and becomes more efficient); try to change one thing at a time and give your baby a chance to learn the new way of feeding.

My baby always takes more than 40 minutes to feed.

- All new babies work hard to feed. This is especially true for a baby with a cleft palate. They can get very tired, especially if feeds take a long time.
- As a general rule, **feeds should take no more than 30 minutes**. A baby can use too much energy if feeds take too long.

My baby is not growing as expected.

- Please contact your child health nurse. There may be ways to make feeding easier and more efficient for your baby to help support their growth.

I feel stressed about my baby's feeding.

- If you are worried about your baby's feeding please speak to someone.
- Refer to the contacts on page 13.

Feeding in a nutshell...

- Position semi-upright
- Burp them a lot
- Find the bottle and teat that is the best fit for your baby
- Be consistent
- Follow your baby's cues
- Do not force your baby to take more milk
- Keep feeds to 30 minutes or less
- Get help if you need it.

Introducing solids

- Follow normal recommendations given to you by your child health nurse.
- A baby with a cleft palate should be offered solids at the same time and same types of foods and textures as a baby without a cleft. There will be specific recommendations for the post-surgical period (provided to you during your pre-surgery visit).
- As with milk, nasal regurgitation on solids is common before palate repair. You can encourage an upright position, smaller mouthfuls and slowing down eating.
- Sneezing after eating is common and a good way to clear the nose.

Bonding with my baby

- Your new little person is getting to know you and their world.
- Relationships and interactions with special people helps your baby feel loved, secure and primes their brain for learning.

Language and speech development

- Language can refer to understanding and expression.
- A cleft palate does not directly affect your child's language development.
- Most children with a cleft palate will develop normal language. Some will have language delay (like a child without a cleft).
- Speech refers to the production of sounds.
- Speech sound development is affected before palate repair.
- Your baby may start babbling before their palate is repaired using /m/ and sometimes /n/ (e.g. 'mamama' or 'nanana'). They will have difficulty producing other sounds in babble (such as 'dadada', 'gagaga', 'bababa') until after their palate repair.
- Encourage your baby to be vocal and explore their voice. Listen to their sounds, respond with warmth and interest and copy their sounds back to them.
- Some children will need ongoing help with speech sounds after palate repair. Your speech pathologist will monitor this closely.

Ear health

- Babies with a cleft palate may experience ear infections or glue ear.
- Glue ear is a thick fluid (like glue) in the middle ear. This can lead to varying degrees of hearing loss.
- What are the symptoms of glue ear?
 - Sometimes there are no obvious symptoms.
 - Fever, runny nose, irritability, loss of appetite.
 - Babies may cry a lot and sometimes pull at their ear, especially when lying down at night.
 - Intense pain in the ear.
- All new babies have 'Universal Hearing Screening' just after birth. If needed, a referral will be made to an ear, nose and throat (ENT) specialist then.
- All babies born with a cleft palate see an ENT at around six months of age.
- Prolonged hearing loss can affect speech and language development.
- It is important to monitor your baby's ear health and see your GP if you suspect an ear infection or glue ear.

- If middle ear issues are persistent, grommets may be recommended by your ENT.

Grommets

- What are grommets?
 - Grommets are tiny ventilation tubes that are inserted into the middle ear.
 - They allow air into the middle ear and prevent a build-up of fluid.
 - They usually fall out by themselves within 6-12 months.
 - Some children will need multiple sets of grommets.

PCH cleft team timeline

- The PCH cleft team will support your child from birth to growth completion.
- The following timeline is approximate and may vary depending on other factors (e.g. your child's other medical needs and growth).
- The following is a standard pathway. Some children will need more or less involvement depending on their needs (e.g. some children will need speech therapy, others will not). The team will respond to the needs of your child.

Table 5: PCH cleft team timeline

Antenatal (pre-birth)	<ul style="list-style-type: none"> • Initial plastics consult.
Newborn	<ul style="list-style-type: none"> • Plastics review. • Pre-surgical orthopaedics if needed with frequent reviews. • Meet speech pathologist.
4-6 weeks	<ul style="list-style-type: none"> • Phone call/video teleconference with speech pathologist.
3 months	<ul style="list-style-type: none"> • Repair lip, nose and anterior palate.
3-6 months	<ul style="list-style-type: none"> • Speech parent counselling.
6 months	<ul style="list-style-type: none"> • First ENT appointment.
9 months	<ul style="list-style-type: none"> • Repair hard and soft palate (and grommets if needed).
12 months	<ul style="list-style-type: none"> • Plastics review. • Speech pathology assessment. • Dental assessment. • ENT as needed.
12-18 months	<ul style="list-style-type: none"> • Reviews as needed.
3 years	<ul style="list-style-type: none"> • Plastics review.
5, 7.5, 10, 15 years	<ul style="list-style-type: none"> • Cleft palate clinic (with plastics, dental, speech pathology and sometimes ENT). • Speech pathology reviews.
2 years–15+ years	<ul style="list-style-type: none"> • Plastics, ENT, dental and speech reviews as needed. • Bone graft (if needed) 8-12 years. • Dental management as needed including orthodontics. • Orthognathic surgery (if needed) at growth completion.

Helpful contacts

At PCH

- Speech pathology – (08) 6456 4766
- Cleft Lip and Palate Team Clinic Coordinator – (08) 6456 4380
- Plastics Registrar: contact PCH switchboard – (08) 6456 2222

Outside of PCH

- Metro Perth – your local child health nurse
- Country WA – your local child health nurse
- CleftPALS WA <https://www.cleftpalswa.org.au/> (voluntary support group)

Useful websites

- https://www.rch.org.au/kidsinfo/fact_sheets/Cleft_lip_and_palate_infant_feeding/
- https://www.rch.org.au/kidsinfo/fact_sheets/Cleft_lip_and_cleft_palate/
- <https://www.cleftpalswa.org.au/>
- <https://raisingchildren.net.au/>
- <https://www.zerotothree.org/>
- <https://acpa-cpf.org/>
- <https://www.clapa.com/>

Supporting my baby's speech and language development

- <https://www.zerotothree.org/resources/80-birth-to-3-months-your-baby-s-development>
- <https://www.zerotothree.org/resources/81-3-6-months-your-baby-s-development>

Introducing solids

- https://www.health.wa.gov.au/docreg/Education/Population/Child_Health/Feeding/HP003055_babys_first_foods.pdf
- <https://raisingchildren.net.au/babies/breastfeeding-bottle-feeding-solids/solids-drinks/introducing-solids>

Useful websites to support attachment with your baby:

- <https://raisingchildren.net.au/newborns/connecting-communicating>
- <https://raisingchildren.net.au/babies/connecting-communicating>
- <https://vimeo.com/122770192>

Feeding video

- <https://cleftline.org/family-resources/feeding-your-baby/feeding-your-baby-videos/>



Government of **Western Australia**
Child and Adolescent Health Service

This document can be made available in alternative formats on request for a person with a disability.

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