

CHILDREN BORN WITH CLEFT LIP & PALATE



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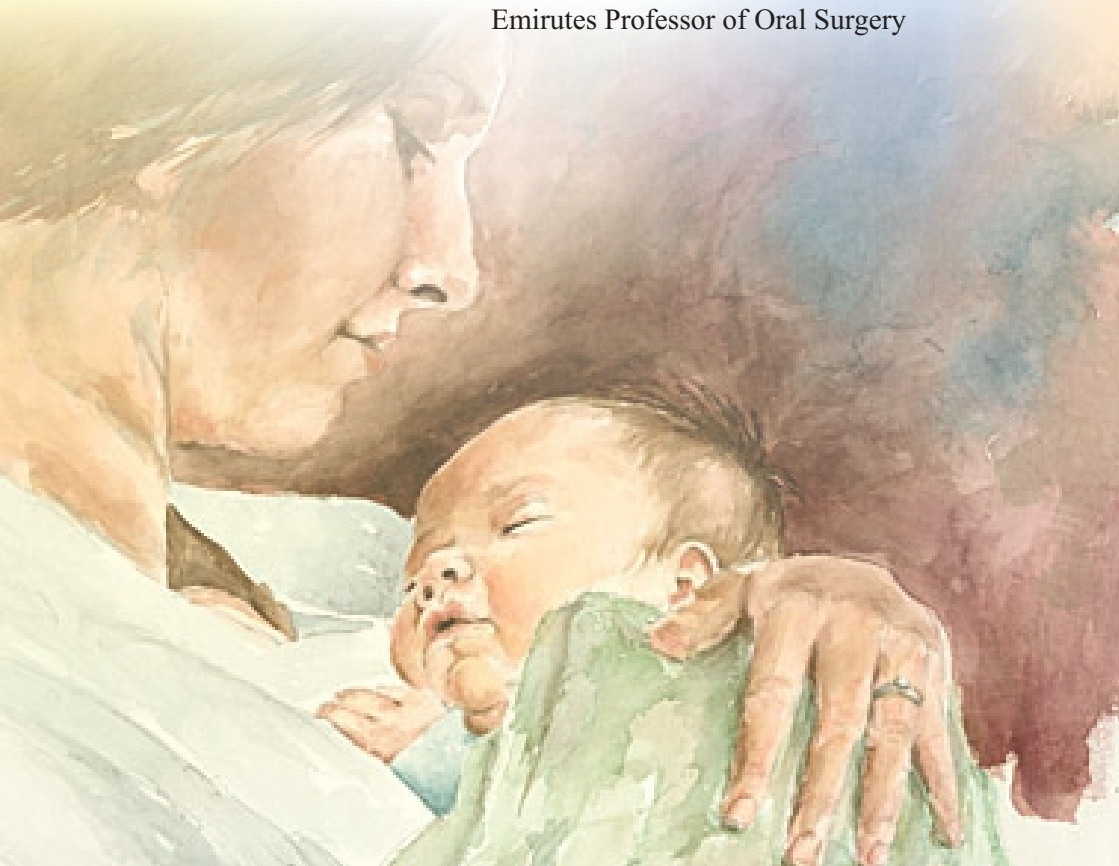
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Preface

It is a pleasure to give this little message in this booklet. Though it is a little booklet it has very valuable essential information written succinctly and in simple language which could easily be understood by the mother of the child born with a cleft lip and palate. Management of a cleft child becomes extremely difficult if not impossible if the mother is not well informed. Hence this booklet serves a very important purpose and fills a vacuum as there are no such literatures written in all three languages spoken in this country.

Professor N.A.de.S.Amaratunga

Emirates Professor of Oral Surgery



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Cleft Lip and Palate

Introduction:

This booklet is for parents of children born with cleft lip and palate and for anyone caring for such children. It is usual for parents to be distressed and worried about the future when they first see their child with a cleft. But it is always advantages to think that your baby is absolutely normal.

You will be relieved when you come to know that there is a group of specialists to care for your baby born with a cleft.

We hope that this booklet will help you to be more confident in caring for your baby and will explain and guide you through the management of the child. We also hope that this will assist you in getting the best for your child.



Normal lip



Normal Palate

What is Cleft Lip and Palate?

During early pregnancy different areas of the face develop separately and later join together. Failure to join properly results in a “cleft” which means a split or separation, in the lip palate or both. The exact cause or the reason for this defect is not known although several factors are thought to be contributing. About one in seven hundred (1: 700) children born in this country is born with a cleft.

Cleft Lip

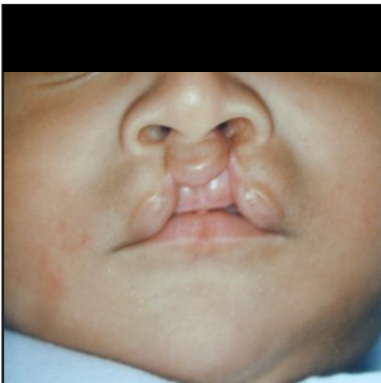
Cleft lip is a split in the upper lip below the nose. It may range from a slight dimple or notch in the upper lip to a complete separation up to the nose either on one side or on both sides.



Incomplete cleft lip



complete cleft lip



Incomplete
bilateral cleft lip



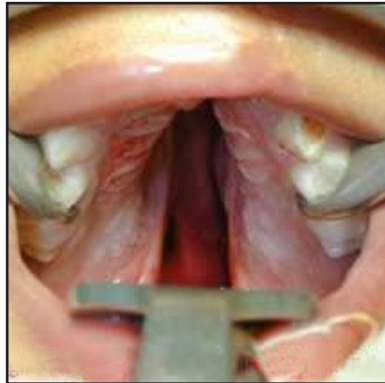
complete
bilateral cleft lip

Cleft Palate

Cleft palate is a split in the “palate” or roof of the mouth. It may range from a slight separation of the soft palate to complete separation either on one side or on both sides up to the hard palate.



Cleft palate roof



separation of the
soft palate and hard palate

Possible Problems associated with cleft lip & palate

01. Nutritional Problem
02. Growth Problem
03. Speech Problem
04. Healing Problem
05. Mental Problem
06. Social Problem
07. Respiratory Problem

Management and the treatment of the baby born with a cleft starts soon after birth and extends for about 20 years into adulthood. It includes repair of the cleft and dealing with the associated problems mentioned above by a “Specialist team”

Specialist Team

Cleft Team consists of specialists who deal with different conditions or different problems caused by the cleft. One specialist may deal with one problem or several. All these specialists work together in one team as the problems are inter related.

At Dental Hospital, Peradeniya and Lady Ridgeway Hospital Colombo have two such cleft teams .

Specialist Team

Specialist	Task
Pediatrician	Detection and management of problems in growth and development, abnormalities of heart, lungs etc and infections.
Nutritionist	Dietary alterations and advice
Surgeons	Surgical correction of the cleft, bone and jaws
Speech & language Therapist	Speech and language training
ENT Specialist	Assessment and treatment of hearing problems
Dental Surgeon	Dental care and oral health
Orthodontist	Correction of malpositioned teeth
Psychiatrist	Psychological assessment and treatment of cleft children and parents
Counselor	Psychological support

Treatment Protocol

1. Meeting the cleft team soon after the birth of the baby.
2. Screen for abnormalities, monitoring of nutrition and growth.
3. Correction of the cleft lip by a surgery at the age of three months.
4. Correction of the cleft palate by surgery around 10-12 months
5. Assessment of hearing
6. Speech and language training
7. Dental and oral care
8. Alveolar bone grafting depending at the age of 9-10 years.
9. Orthodontic treatment – correcting the position of the teeth at 11-13 years. Short course of orthodontic treatment will be carried out before alveolar bone graft if necessary.
10. Correction of jaw position and shape of the nose – (orthognathic surgery and Rhinoplasty) at 20-25 years.

Nutrition of the baby

Milk is the only food for the new born baby. Muscles around the baby's mouth and the throat have to work in co-ordination to create a negative pressure inside the mouth for the baby to suck. It is essential to have a good seal of the lips holding the nipple or the teat of a feeding bottle to suck executively

Children born with clefts can find it difficult to suck because, the lips do not seal around the nipple adequately to create a negative pressure in the mouth.

Associated conditions with clefts although rare may make sucking less effective eg. Heart problems , respiratory problems , muscle weakness etc.

Facts about feeding

- ❖ The ideal milk for your baby is breast milk. You should try your best to give breast milk to the new born baby.
- ❖ giving any other milk should be on prescription by a doctor.
- ❖ cause for crying may be hunger.
- ❖ adequate burping - improves the feeding.
- ❖ feeding the baby on demand satisfies the child and improves milk production.
- ❖ It improves the bond between the mother and the baby.
- ❖ If you think the quantity of your milk is not adequate a close healthy relative can breast feed your baby after feeding her own.
- ❖ Always empty the breast after feeding the child by expressing the milk to improve milk production.



- ❖ The quality of breast milk improves when you add milk eggs, fish, meat, fresh fruits and vegetables to the mother's diet.
- ❖ Physical and mental well being of the mother improves the quality and quantity of breast milk.

Breast feeding the babies with the cleft

Babies with only cleft lip

These babies can be breast fed very well although some may need little help. It depends on how effectively the breast could be moulded into the cleft – to seal the gap.

Hissing sound indicates air entering into the mouth. It is necessary to readjust the position of the baby till the sound disappears.



Holding the baby in fairly upright position will prevent choking.

Babies with cleft lip and palate

Babies with tiny cleft in the palate can suck normally. The breast should be held well against the area where there is no palate so that the baby could well using the tongue movement.

Breast feeding becomes difficult when the breast engorges. Good flow of milk helps the baby suck well. Milk flow can be encouraged by massaging breast or by using a breast pump. The team will help with information.



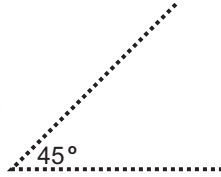
breast pump

If the baby cannot suck well it is necessary to express the breast milk and feed using a bottle or cup. Some babies may need a small tube passed through the nose into stomach to feed them.

Formula milk may be needed on the doctor's recommendation.

Burping every 10 minutes will enable you to expel the air and fill the baby's stomach with adequate amount of milk per each feed.

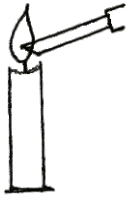
Feeding with the bottle



- * hold the baby in breast feeding position when you feed.
- * Expressed breast milk or formula milk can be fed by the bottle.
- * The number of feeds per day should be equal to that of a normal baby.
- * Baby with cleft lip and palate taking a long time to feed indicates that sucking is ineffective.
- * It will be necessary to use a modified normal teat , a special teat or spoon to feed the baby if the feeding time is more than 30-40 minutes.

Modifying the normal teat

Make a hole in following manner using a red hot needle or a knife to increase the milk flow.



(i)

sterilize the needle /
knife by holding
against a flame



(ii)

enlarge the hole
by putting an 'X'
shaped nick



(iii)

ensure adequate
flow of milk

Feeding technique

Insert the teat through the cleft in the gum and press against the hard palate. It will help the child to suck with the help of the tongue.

Special bottles and teats

These are necessary for children who are unable to suck with a modified normal teat due to cleft palate on both sides. The feeding becomes more effective when you press the squeezable bottle in co-ordination with baby's sucking attempt.



Special 'teats'



Special - soft bottles



Burping/Winding

Babies with the cleft may take in more air than usual due to incomplete seal on the nipple or the teat.

It is important to hold the baby more upright during feeding and burp him regularly during and after feeding.

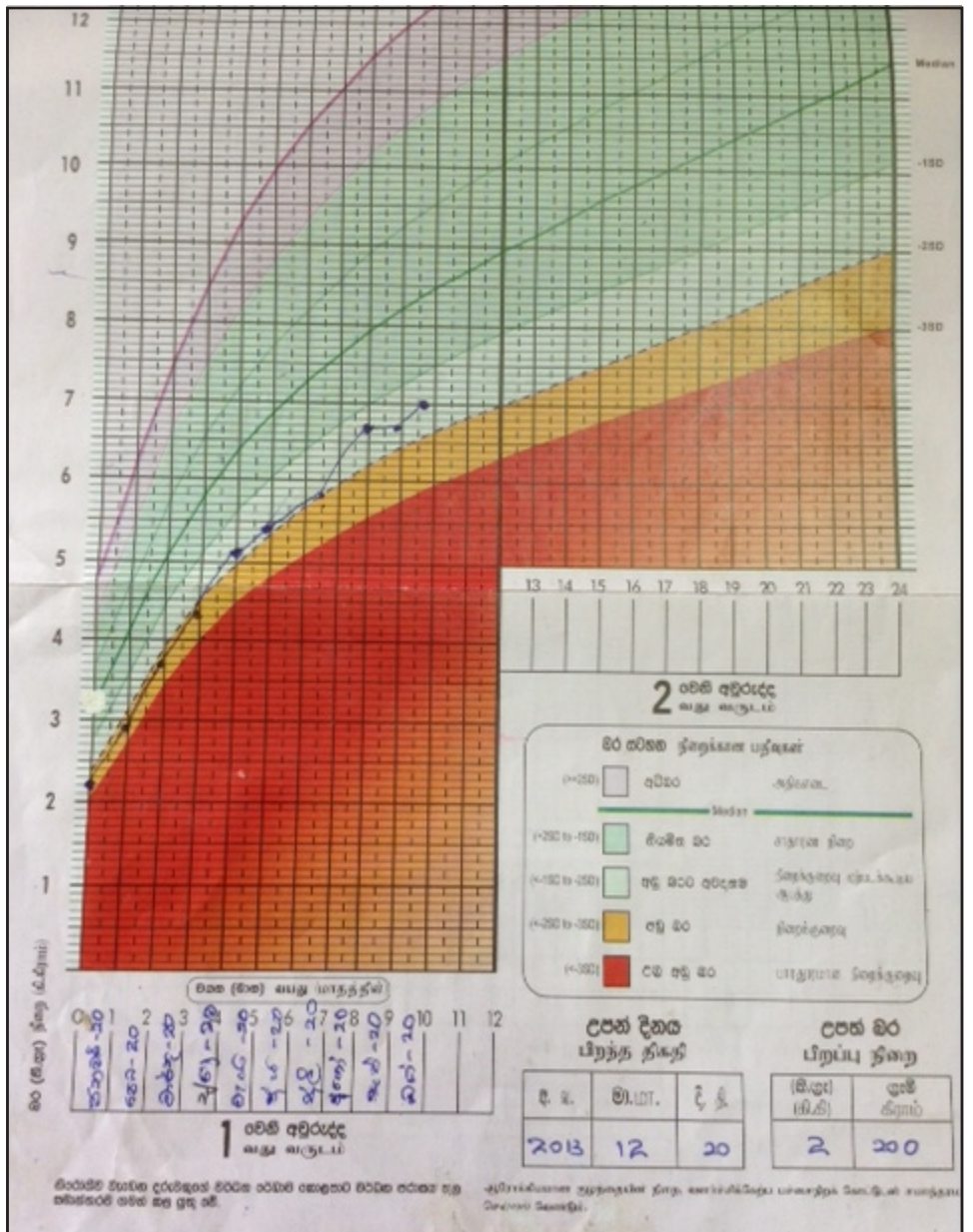
Is feeding adequate?

All babies loose about 10% of their birth weight over the first few days after birth and gain it during the next two-three weeks.

Six to seven wet nappies per day and regular bowel motions, satisfaction and comfortable sleep of about 3 hours after feed and steady weight gain indicate that the child is getting adequate feeds. A child with cleft may not gain weight at the rate of a normal child. But it is necessary to seek medical advise if the weight gain is very low.

It is necessary to check the weight of the baby regularly, to make sure that the baby gains 100-150 Gms per week steadily.





- ❖ Recurrent fevers, infections and associated rare problems like heart problems can slow down the weight gain. These conditions need investigations and treatment.
- ❖ Mother or care giver should be able to identify early features of dehydration.
- ❖ Thirst, dry mouth, and reduced urine output indicate dehydration.
- ❖ Feeding after operations should always be discussed with the cleft team.

Weaning -

Weaning is gradual introduction of other food items while milk is withdrawn. Weaning is usually started around 6 months in a normal baby who is exclusively breast fed. The children with clefts also should be weaned similarly although it depends on the condition of the baby. The time, type of weaning food and the technique should be discussed with the team.



Weaning could be started around 4 ½ - 5 months if the baby is not exclusively breast fed. Usually weaning is done by introducing rice based preparation to which gradually mashed vegetables- yams, other cereal pulses and animal food are added one at a time.

Example : - To 2-3 table spoons of rice flour add 3 cups of water. Boil it like rice and cook stirring until it becomes a thick liquid. To a little of it add breast milk/ formula milk – so that it could be fed via bottle. Gradually add vegetable extracts- powdered roasted sprats, powdered other cereals – and natural flavors like curry leaves etc. The quantities could be increased according to the baby's requirement. The mixture can be thickened in to “yoghurt” like preparation to be replaced with mashed rice after 6 months.

Other facts you must know

1. Always wash your hands thoroughly with soap and water before you prepare or handle baby's food.
2. Every feed should be given in a sterilized bottle if you are not breast feeding.

Cleaning and sterilizing bottles

Special Bottles

4. Some times you may have to use special bottles. You will be instructed about sterilization of these bottles by the doctor or nursing officer.

Sterilization of normal bottles



Use a brush and Clean the bottle
In warm water

Place the bottle and other
Parts in a pan fully
covered With water and
boil



Correction of cleft lip

Surgical repair is the only way to correct cleft lip.

Usually this is done when the baby is around three months old

The surgery consists of repositioning of the muscle, mucous membrane and the skin.



Correction of Unilateral Cleft Lip



Before Surgery



After Surgery



After 4 years

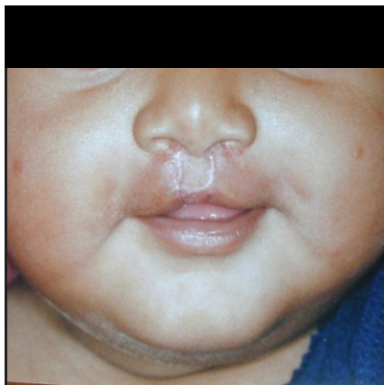


After 8 years

Correction of Bilateral Cleft Lip



Before Surgery



After Surgery



Before Surgery



After Surgery



4 years after the surgery

Correction of cleft palate



Before Surgery



After Surgery

The surgical repair of the cleft palate is done around 10th to 12th months of age.

It has been shown by research that the correction of cleft palate before development of initial speech leads to normal speech.

Speech and Language development

Normal speech development

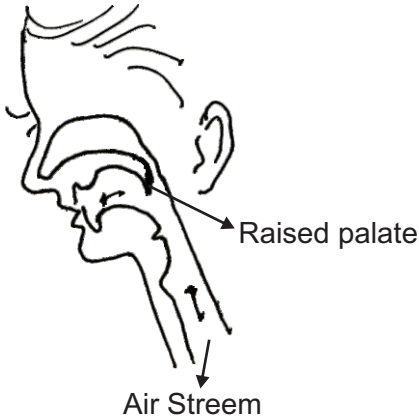
Age / Months

3 – 4	Laughs aloud Plays with own sounds
5	Creates and imitates sounds
5 – 7	
6 – 7	Understands few words babbling sounds
10 – 12	Understand 20 -30 words with meaning Amma, Baba , Thaththa
12 – 18	More words with meaning, Two word sentences
24 -	Understand 100 to 150 words , Forms A Simple Sentence

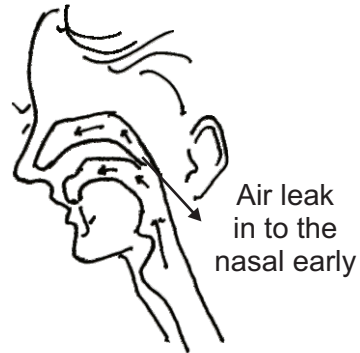
The roof of the mouth is the palate which consists of non-movable hard palate in front and the soft movable part behind which ends at the uvular.

Correction of speech

1. Mouth and the nasal cavity should be separated correctly, by correct functioning of the soft palate and the muscles of the throat. Which is essential for correct speech.



Normal Child with Complete separation of Nasal and oral cavities By the soft palate



Child with a cleft with Leakage of air from Oral Cavity in to nasal cavity due to incomplete soft palate

2. Closure of the lips should be adequate.
3. The tongue should move freely to touch different parts of the palate and teeth.

Children born with cleft can have problems with speech due to lack of fulfillment of above factors.

Speech Therapist in the team will help your child to develop speech along with the rest of the treatment.

How do you prepare your child for speech?

It is important to develop the child's ability to observe, watch and listen. It is very effective when you do this training in the form of play and games.



Play

Select a quiet place to play with the child so that the child could hear the soft sounds like ' p ' . ' k ' ' t ' clearly, Sit in front of the child for him to see the movements of your lips and mouth. Speech the rapist will help you to select activities Suitable for your child.

Improve listening Skills

Train the child to listen to the sounds of day to day life e.g. Sound of running water, sounds of animals and vehicles.

Imitate the sounds and get the child to repeat it.

Talking with the child

Talk to the child. Change your voice and expressions of the face. Change the volume to make it interesting to the child. Do not talk fast. His vocabulary will increase and will be encouraged to talk.

Alternative speech

Give the child a turn to talk in the form of dialogue. It is an important step in developing speech. E.g.:- talking through (Toy) telephone.

Blowing

Blowing soap bubbles whistling and blowing to hot food are few exercises to lip muscles will improve movements of the lip and air flow through mouth.

Breathing exercises (eg: Yoga) will help the child to regulate breathing for speech.



Hearing

Children with clefts can have hearing problems due to collection of secretions in the middle ear (secretary otitis media). This can occur in normal children too.

The ENT specialists in the cleft team will monitor the hearing on a regular basis.

Most of the hearing problems will last only for the first few years of life. Rarely the hearing problems may be permanent due to developmental defects of the ear.

Games of improving mindfulness will improve the child's ability to listen and pick up the language.

Dental Health

It is very important to protect your child from dental decay and gum disease. For good oral health it is necessary to

1. Practice correct brushing techniques
2. Have some control over consuming sweetened food and drinks.

You should obtain necessary treatment and instructions regularly from your dental surgeon.



Alveolar bone grafting

When the upper jaw bone is affected by the cleft the gap beneath the gum should be bridged by a bone graft. It is important for the correct shape of the nose and the development and eruption of teeth. The operation is carried out at the age of 9-10 years after a course of orthodontic treatment. The graft is obtained from the child's hip bone.

Orthodontic treatment

Orthodontic treatment is Correcting the position of the teeth

When the upper jaw bone is affected by the cleft it causes some of the front teeth to erupt twisted and in a wrong position. Some teeth may be absent and there may be small extra teeth in these children. The treatment will be started by the orthodontic specialist in the team at the age of 11-12 years.

Short term orthodontic treatment may be necessary before alveolar bone grafting.

Future

- ❖ The Psychologist and the rest of the team will help you to adjust to the situation, and also to cope up with the treatment.
- ❖ Explain the condition to the child in simple terms when he / she starts questioning about the lip. Both you and the child will be psychologically benefited by seeing photographs of the babies with corrected clefts.
- ❖ The intelligence is not affected by the cleft. Encourage and train the child to get mixed up with other children and be independent. Keep regular contacts with the school teachers to help assess the progress of the child.
- ❖ It is very important to have a close relationship with the child, express your love and share his/her experience to create a good self-image in the child.
- ❖ Inculcating good manners etiquette ; and encouraging to be a helpful child will enable him to become a lovable child in the society.

Talking to parents of children with clefts

You may find it useful to share the experience with the parents of other children with cleft.

Always be positive and make the child think positively regarding the outcome of the treatment, his/her appearance and the future.



For your child born with cleft lip and palate

There is a special team dedicated only for this condition at the Dental (Teaching) Hospital- Peradeniya. All the necessary treatments for your child could be obtained free of charge.

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From Editors.

This booklet is presented introduced with the intention of educating the parents and care takers of children born with cleft lip and palate. Further information pertaining to this condition could be obtained by contacting us by person, visiting our web site, through email, telephone or fax. We gratefully acknowledge the guidance given to us by Professor N.A.de.S.Amaratunga, Senior Professor of Oral and Maxillofacial Surgery.

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