

Cleft Lip *and* *Palate*



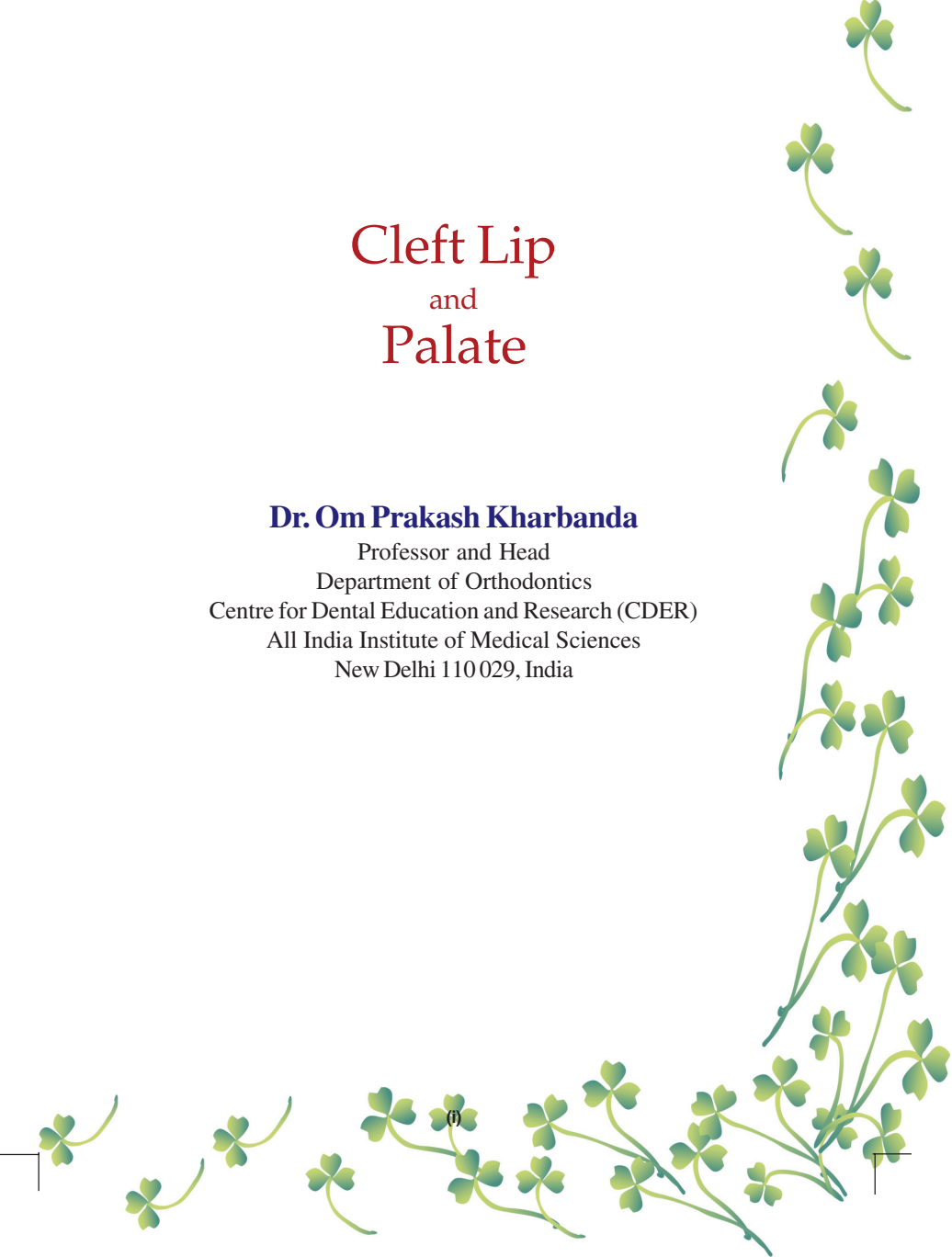
Om Prakash Kharbanda



Cleft Lip and Palate

Dr. Om Prakash Kharbanda

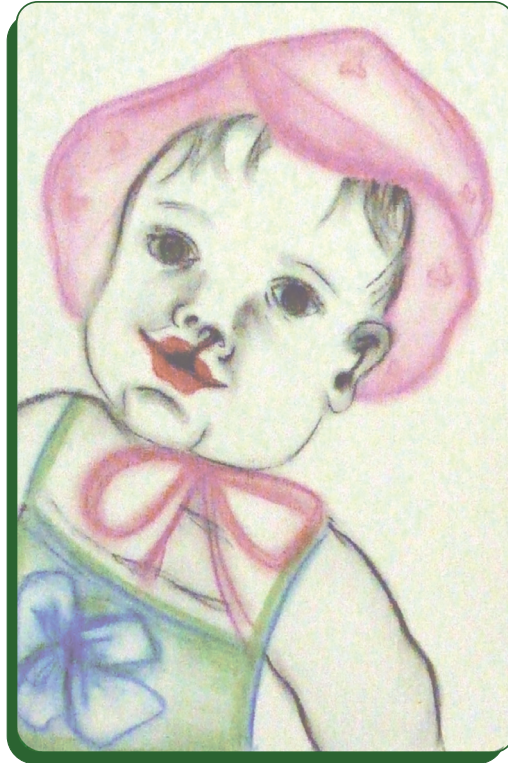
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Cleft Lip and Palate

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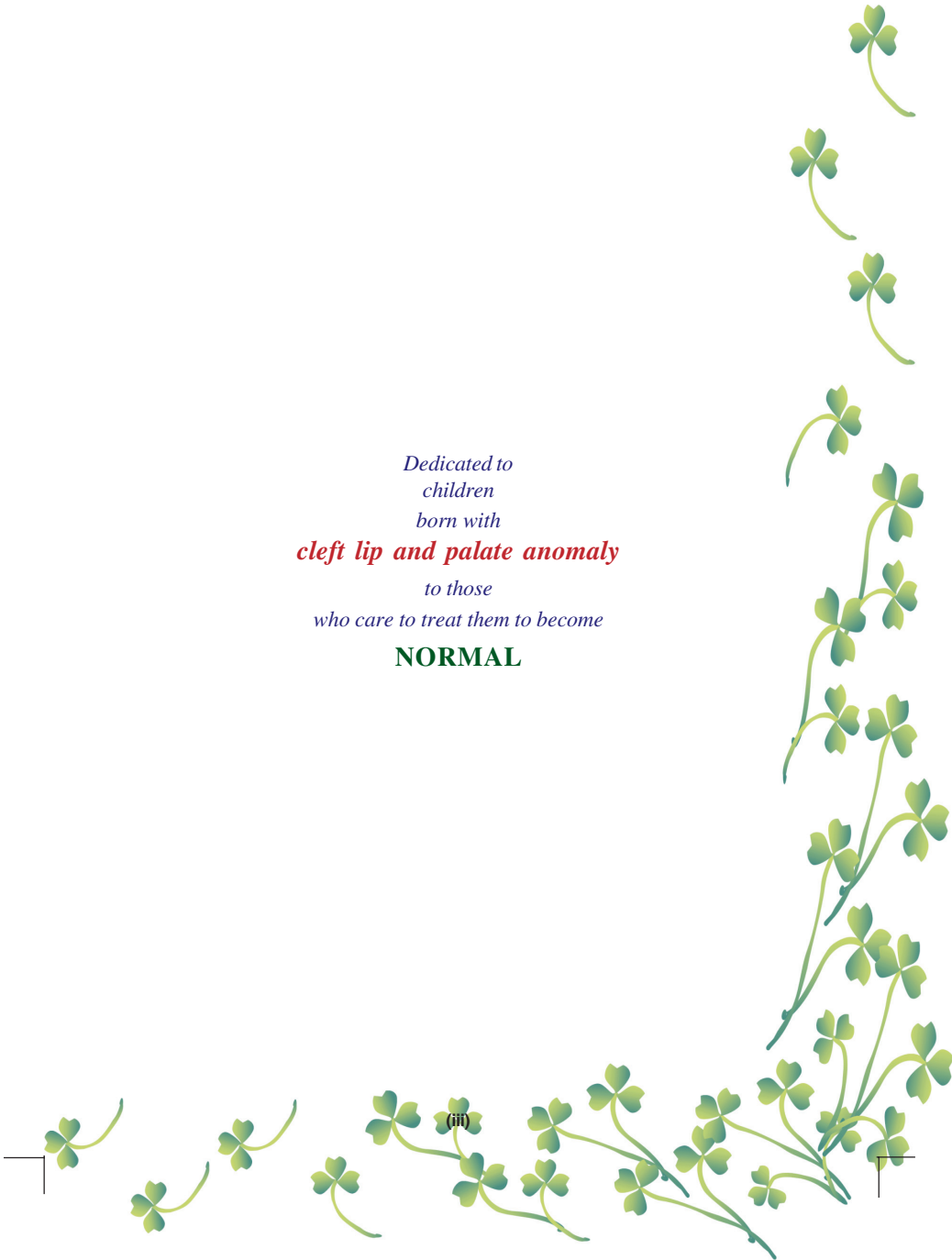


Created by Priyanka Chowdhury

Disclaimer: Medical information, technology and concepts are on a constant change. This booklet provides the fundamentals of treatment and protocols as these are practiced. The treatment steps and stages may vary in individual case/cases depending upon type and severity of the deformity, social needs, socioeconomic status, availability of infrastructure, expertise and many more. Author is in no way responsible for any untoward or unexpected outcome following the suggestions given in the book.

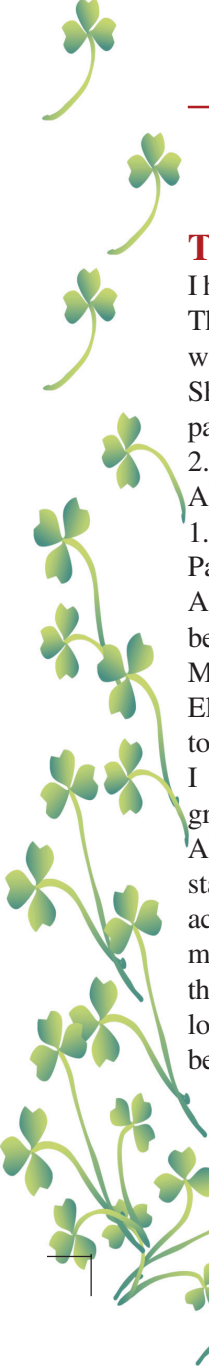
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*Dedicated to
children
born with*
cleft lip and palate anomaly
*to those
who care to treat them to become*
NORMAL

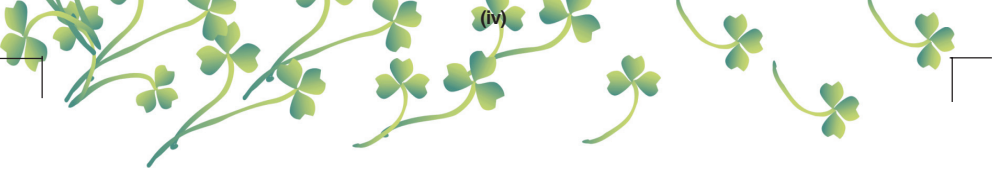




Acknowledgement



This book is a culmination of efforts of all those with whom I had the opportunity to learn, work and share my experiences. This book, has been written and rewritten several times. It was finally put into a brief set up by Dr. Priyanka Chowdhury. She has also contributed significantly in this book by her paintings. The figures contributed by her are nos 1.2b, 2.2b, c, 2.4b and 2.6. Dr. R.K. Khazanchi, my former colleague at AIIMS has as well contributed to several pictures, nos 1.1, 1.2a, 2.1, 2.2, 2.4a, 7.3c, d and 7.10. Pictures on feeding with Paladi (Fig. 7.2 in part) are courtesy of Dr. Ashok Deorari AIIMS, New Delhi. Many of the figures in this book, have been cited from my text book of Orthodontics Diagnosis and Management of Malocclusion and Dentofacial Deformities, Elsevier First Edition 2009 pages 491–516. My sincere thanks to Elsevier for allowing me to reproduce these figures here. I would also like to thank my Faculty Colleagues, Post-graduates, Senior Residents and Professional colleagues at AIIMS for their contribution in various forms and different stages. My sincere thanks to Mr. Mahesh Ramanathan for his act of kindness in bearing cost of printing of this booklet. My most sincere thanks goes to cleft lip and palate patients and their parents who have given me the opportunity to serve during long years of my journey with them, many of whom have become a part of our extended family.



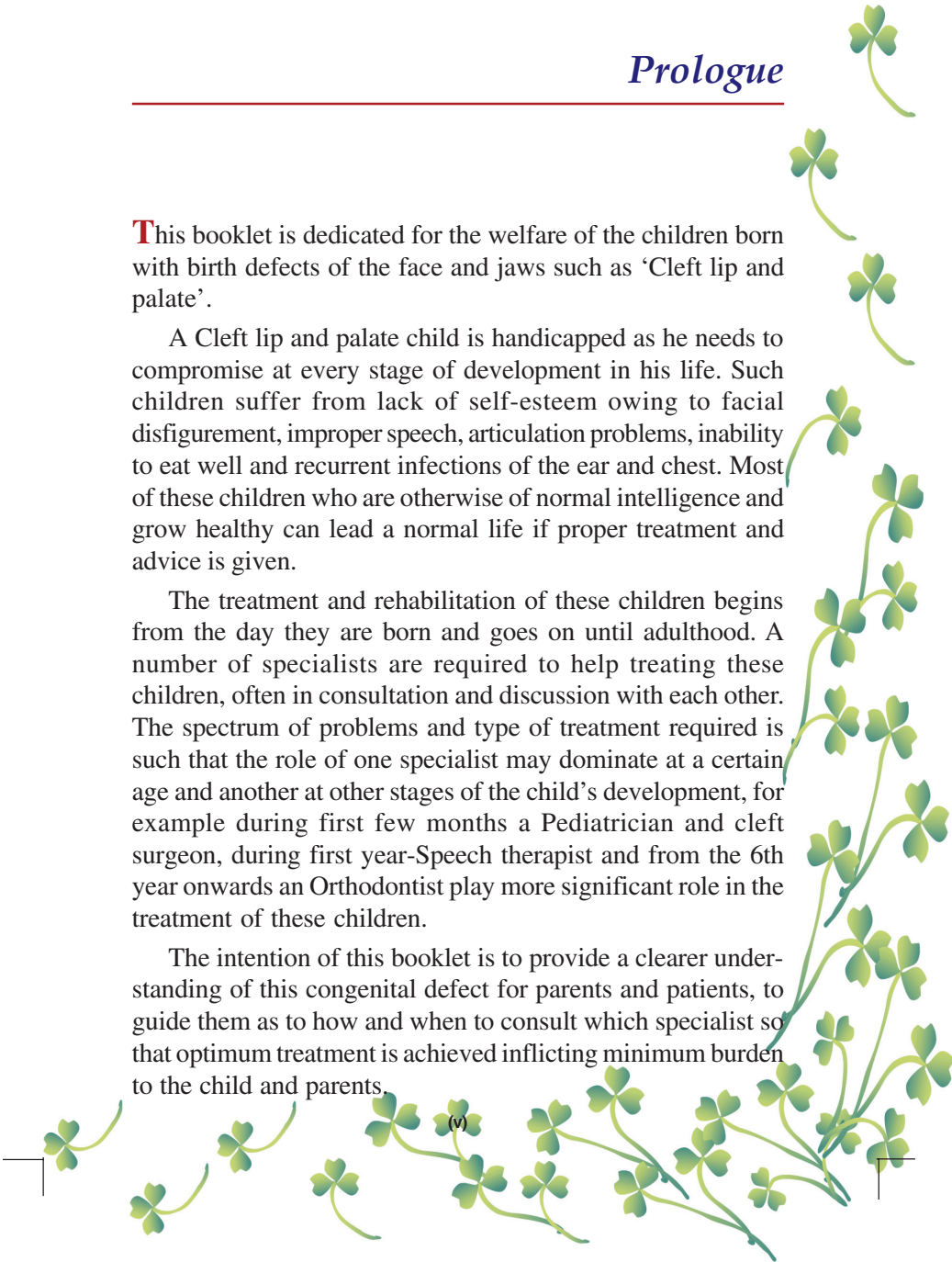
Prologue

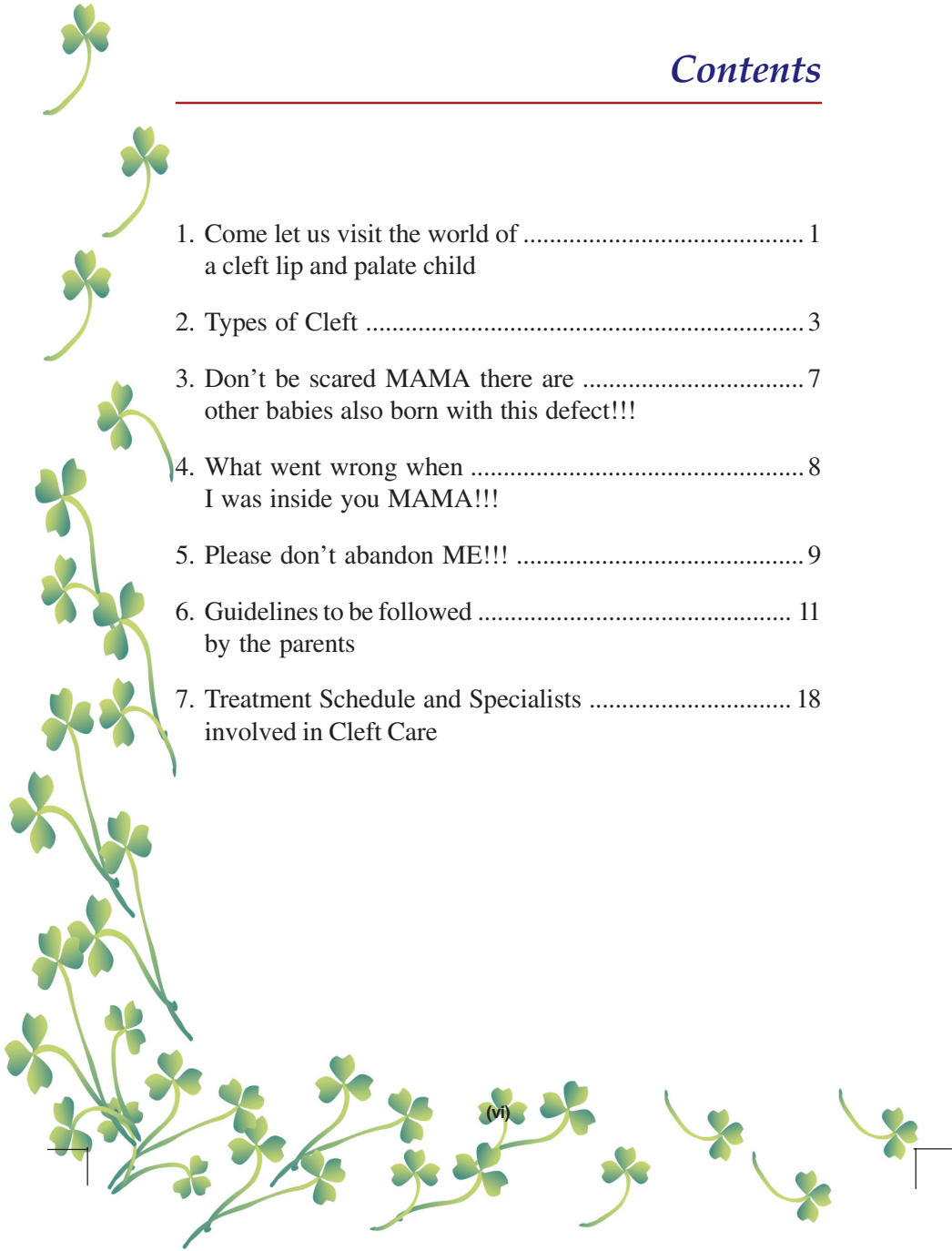
This booklet is dedicated for the welfare of the children born with birth defects of the face and jaws such as ‘Cleft lip and palate’.

A Cleft lip and palate child is handicapped as he needs to compromise at every stage of development in his life. Such children suffer from lack of self-esteem owing to facial disfigurement, improper speech, articulation problems, inability to eat well and recurrent infections of the ear and chest. Most of these children who are otherwise of normal intelligence and grow healthy can lead a normal life if proper treatment and advice is given.

The treatment and rehabilitation of these children begins from the day they are born and goes on until adulthood. A number of specialists are required to help treating these children, often in consultation and discussion with each other. The spectrum of problems and type of treatment required is such that the role of one specialist may dominate at a certain age and another at other stages of the child’s development, for example during first few months a Pediatrician and cleft surgeon, during first year-Speech therapist and from the 6th year onwards an Orthodontist play more significant role in the treatment of these children.

The intention of this booklet is to provide a clearer understanding of this congenital defect for parents and patients, to guide them as to how and when to consult which specialist so that optimum treatment is achieved inflicting minimum burden to the child and parents.





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Come let us visit the world of a cleft lip and palate child

What is cleft lip and palate?

CLEFT MEANS GAP

A cleft lip is a separation of the two sides of the lip. The separation often includes the bones of the upper jaw and/or upper gum. A cleft palate is an opening in the roof of the mouth. Cleft lip and palate is a condition, which occurs when the two sides of the lip or roof of the mouth (palate) does not completely fuse together, as the unborn baby was developing. The lip and palate develop separately so it is possible for a child to have a cleft lip, a cleft palate or both. The size of the cleft lip may range from a small notch in the upper lip (Fig. 1.1) to an opening



Fig. 1.1 Microform of cleft lip.



that extends into the base of the nostril (Fig. 1.2). The cleft may be single sided or may occur on both sides.



Fig. 1.2a and b A baby with cleft lip, extending into tooth bearing part of upper jaw.

○○○



Types of Cleft

1. **Cleft lip:** At times parts of the face do not grow fully and meet each other in the midline, leaving a gap (Fig. 2.1).

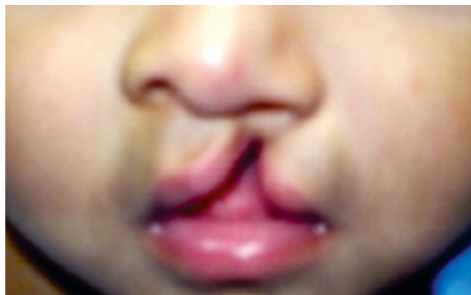


Fig. 2.1 Cleft of lip.

2. **Complete cleft:** When the deformity spreads back across from the jaw bones where tooth buds are hidden to hard palate and even soft palate it is called complete cleft (Figs 2.2 and 2.3).



(a)



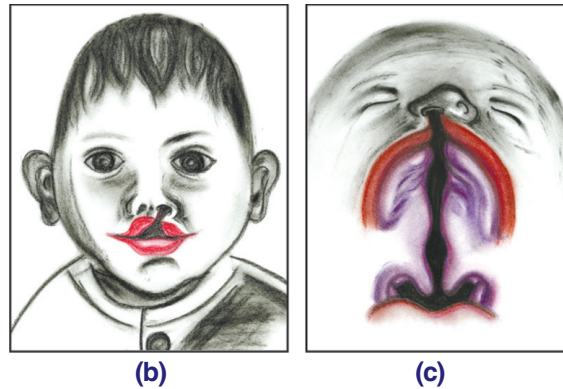


Fig. 2.2a, b, and c Cleft of lip extending into hard palate and soft palate.



Fig. 2.3 Cleft of lip extending into hard palate and soft palate.

3. **Bilateral/Unilateral cleft:** If the upper lip that is formed in three parts, the middle, and the two halves on the sides do not attach to each other, and if the defect is on both the sides called bilateral or at times it may be on either side then it is called unilateral cleft lip (Figs 2.3, 2.4 and 2.5).





(a)



(b)

Fig. 2.4a and b Cleft of lip on both sides.



Fig. 2.5 Cleft of lip on both sides extending into hard and soft palate.



4. **Cleft of soft palate:** At times the cleft may be limited only to the soft palate while the rest of the palate and lip/face may be normal (Fig. 2.6).



Fig. 2.6 Cleft of soft palate extending into hard palate.

5. **Problems associated with cleft:**

- Feeding problems, baby cannot suck milk
- Flow of milk through nasal passages during feeding causing recurrent chest infections
- Failures to gain weight
- Speech difficulties
- Recurrent ear infection
- Missing teeth or extra teeth, poorly formed front teeth
- Malaligned teeth
- Change in nose shape

○○○



3

CHAPTER

Don't be scared MAMA there are other babies also born with this defect!!!

How often is Cleft Lip and Palate?

REMEMBER: You are not the only parent to have such a child.

Approximately one child out of 1000 live births in India is born with this facial deformity. The majority of children born with cleft lip and palate are otherwise normal with no associated syndromes. However a few may have associated disease affecting several systems called syndromic clefts. Cleft lip and palate occurs more frequently in males and cleft palate alone occurs more frequently in females. The incidence of cleft palate has some racial predictions.

Why am I the chosen one???

Why did God choose me???

WHY MY CHILD HAS CLEFT LIP/PALATE?

While your baby is growing in the mothers womb, parts of the skull, face and head gradually grow together. Cleft lip and palate occur when some of these areas do not join up fully before birth. These defects do occur during first few weeks of life.



What went wrong when I was inside you MAMA???

Why some children have this deformity?

The real cause of this problem is usually unknown. Cleft deformity can be familial. Probably it's causes involve a combination of genetic and environmental factors. Environmental factors, which may increase the risk of clefting are:

- ❑ Smoking and alcohol use during pregnancy,
- ❑ Poor maternal nutrition,
- ❑ Vitamin B deficiency,
- ❑ Excessive exposure to radiation,
- ❑ Anti-abortificant drugs, and
- ❑ Certain medications such as those used to control nausea

**Please take care of yourself when we are inside—
it's a safer world out there!!!**

Cleft lip and palate has familial tendency too.

○○○



Please don't abandon ME!!!

INDIAN SOCIAL SCENARIO

India is said to be a land of religious beliefs, superstitions and myths associated with all kinds of diseases. In such a social scenario a child born with a birth defect of the face maybe considered bad omen.

The mother is blamed and the problems become compound if it's a baby girl. The rural scenario is sad due to the lack of knowledge regarding cleft lip and palate.

Many parents may not disclose the child born with cleft lip or palate however the urban scenario is a little better. This may not be the case with the educated and affluent families. They start consulting doctors, surgeons and others collecting information about the health, safety and longevity of their child. Yet they need guidance, to follow the correct course of treatment for better outcome.

Unfortunately, little information is available in India in print or media and there are no cleft palate help lines or trained social workers or specialist nurses to handle such a family and child. In Indian medical setting perhaps, we need to educate people and bring awareness among medical, paramedical and all health professionals about:

- ❑ What are the problems of a child born with cleft?
- ❑ How soon can we have his/her surgery to repair the lip and palate?



- ❑ Can he/she grow like other normal children?
- ❑ Will he/she be able to speak and eat normally?

Treatment of such a child is required from the day a child is born till adulthood. Several specialists have an important role in the management. Let us meet them and see what they are supposed to do for you.

Do not forget that for better results of the treatment to make child look and grow like normal with minimum physical and financial burden, it is recommended to follow treatment at cleft specialized centres which follow “interdisciplinary team approach”. That means that all the important specialists should see the child together whenever needed and plan the treatment in consultation with each other. They may carry on the treatment independently thereafter, but must at some point meet to evaluate treatment outcome and discuss further treatment whenever the need be there.



Guidelines to be followed by the parents !!!

Interaction with the right professionals regarding awareness of long term treatment and guidance with various other specialists is needed from time to time. Choose a team of specialists which works closely and has also the availability or referral to supportive specialists as and when required (Figs 6.1 and 6.2).

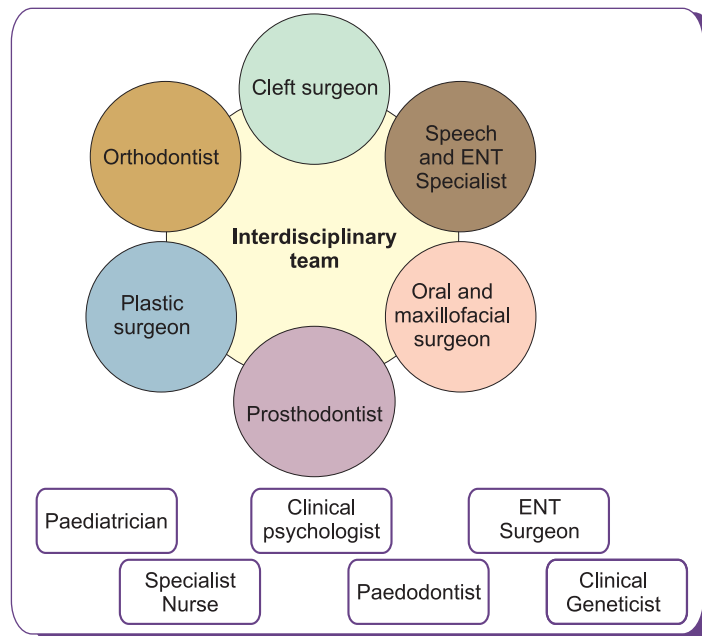
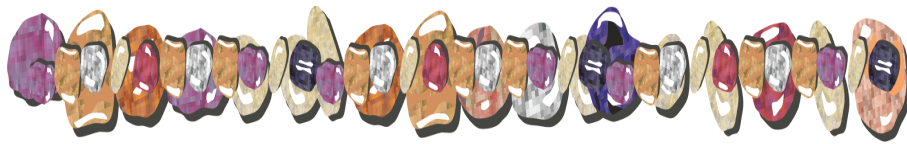


Fig. 6.1 The interdisciplinary cleft team.





Schedule and timing protocol of cleft care

Age	Months				Years																		
	0	3	6	9	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
Palatal obturator/ Feeding appliance	Grey	Grey	Grey	Grey	Grey																		
Primary cleft lip surgery	Blue																						
Palate repair				Grey	Grey																		
Tympanostomy tube				Blue	Blue																		
Speech therapy/ Pharyngoplasty					Orange	Orange	Orange	Orange	Orange	Orange													
Bone the grafting jaw													Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue	Blue
Orthodontics																				Orange	Orange	Orange	Orange
Orthognathic surgery and Rhinoplasty																							

Fig. 6.2 Schedule and timing protocol of cleft care.

THE INTERDISCIPLINARY TEAM

Interdisciplinary treatment approach works best for the cleft child. There could be a large number of experts in the team with the best of expertise and knowledge. What is really needed is understanding and cooperation among them in order to provide best care for the child.

PAEDIATRICIAN

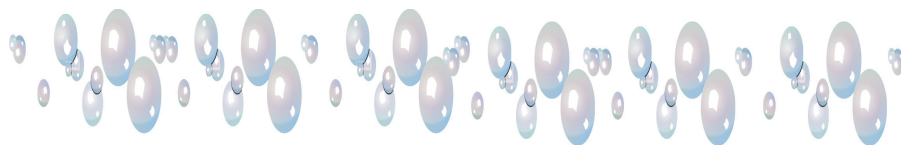
The person who specializes in the care of new born children is called neonatologist. However, in many cities, towns and villages a paediatrician may perform the duties of a neonatologist. He is usually the first person to notice the defect as soon as a child is born and would be the in charge of new born baby's health and medical problems. He would also monitor heart, lungs and other systems of the body to rule out if cleft lip and palate are the only defects or they are associated with other anomalies. He may seek expert opinion from a heart specialist or a geneticist. Your doctor will also monitor regular feeding and weight gain and health of the baby.

SPECIALIST NURSE

Many cleft centers have a specialist nurse trained to handle new born with congenital defects of face and cleft lip and palate. A nurse educates parents of the cleft child to feed and use of devices required to feed a child with cleft lip and palate. She will also communicate with surgeons during and after surgery of the cleft child.

CLEFT SURGEON

The cleft surgeon handles surgery of small children born with cleft of the lip and palate. He is either a Plastic surgeon or an



Oral surgeon who has special expertise in surgery of this defect of face.

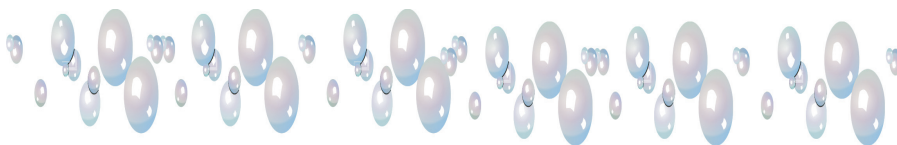
- ❑ If the surgery involves both, lip and the palate then extra care is required in handling the lip, which is yet to grow to the full size of an adult. First surgery is often restricted to repair of lip and front part of jaw, done usually around 10 weeks.
- ❑ The cleft lip and palate surgery is extremely delicate and a good surgery is one which brings about good esthetics and in the long run speech is not severely affected and so there is least inhibition in the growth of upper jaw.
- ❑ The cleft surgeon will also undertake surgery later in life to close the remaining gap in the palate. The surgery on palate is done around 12 months to 18 months of age.
- ❑ Surgery to undertake a bone graft at about 9 to 11 years is necessary followed by another surgery of the lip and nose to give them a better shape in adulthood.
- ❑ The above may also involve operations on the soft palate to make it longer for better speech.

CLINICAL PSYCHOLOGIST

A clinical psychologist counsels parents to overcome and deal with psychological issues consequent to a baby with a defect of face. He also helps the child to overcome any difficulties in social behavior, low self esteem and social adjustment in life. Do not avoid consulting him if you feel the need for it would be a benefit for you and your child.

SPEECH AND LANGUAGE THERAPIST

A speech and language therapist helps the child overcome speaking and language problem. He/She would assess the



nature and severity of speech and communication problems of the child asking you to undertake several tests to analyze the severity of the problem. The therapist may like to give you certain speech and articulation advice and exercise.

Audiologist and ENT Surgeon

The audiologist and/or ENT surgeon helps you to assess the hearing problems in the child.

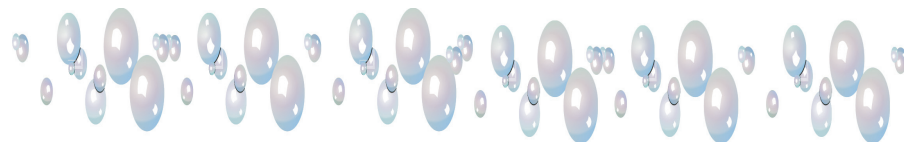
- ❑ Take the child for testing hearing ability with audiologist and consult with ENT surgeon.
- ❑ Recurrent middle ear infection/blockage of the tube connecting throat with the middle ear causes inadequate hearing capacity of the child.
- ❑ Consequences are delayed/improper speech: *The development of speech is in response to hearing.*

DENTAL SURGEON OR CHILD DENTAL SPECIALIST: PAEDODONTIST

The dentist takes care of dental health and gives you advice on hygiene and how to prevent dental decay. He/She will also be watchful of the developing dentition and any dental irregularities and refer you accordingly to an orthodontist.

ORTHODONTIST

The orthodontist is the specialist dental surgeon who will take care of the dental irregularities and will work as a watch dog to see how the jaws are growing as the face grows big towards adult size. He may in some cleft teams be a team leader and service coordinator for your child's problems with all other specialist. The following features are watched out by the orthodontist:

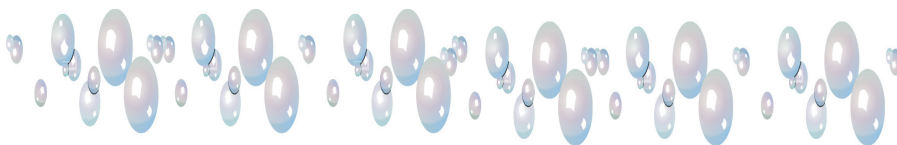


- ❑ Normal and abnormal eruption pattern of teeth
- ❑ Irregularities in the teeth
- ❑ Extra teeth
- ❑ Missing teeth
- ❑ Shape and health of teeth
- ❑ Assess the growth of the face and jaws
- ❑ Any rehabilitation required
 - e.g.:* Plate to cover post surgical defect/measures to expand upper jaw if it is narrow in proportion to the lower jaw. It is called Obturator.
- ❑ Alignment of crooked teeth/malaligned teeth with the orthodontic braces (removable and fixed braces).
- ❑ Co-ordination with the oral surgeon regarding bone grafting and institution of comprehensive orthodontic care.
- ❑ To make a periodic review to prevent any relapse of corrections from occurring.
- ❑ Coordinate and prepare teeth and jaws with Oral and maxillofacial surgeon in case the child needs secondary surgery of jaws.
- ❑ Coordinate with plastic surgeon when patient needs secondary surgery/ies of lip nose or other such cosmetic surgeries.

ORAL AND MAXILLOFACIAL SURGEON

An oral surgeon is the one who undertakes surgical procedures on the face or mouth particularly on the jaws and associated structures.

- ❑ In cases with severe growth deficiency harmonising jaw relation is not possible alone with orthodontic treatment. Here the oral surgeon has to undertake surgery to achieve good



balance of the face. Such procedures are carried inside the mouth to avoid scar formation on face.

- ❑ **Orthognatic Surgery:** It is done mostly after growth is complete say during early adulthood. These are called Orthognatic Surgery which is preceded and followed by orthodontic treatment for final settlement of dentition. Such surgeries are usually done after puberty is complete.

PROSTHODONTIST

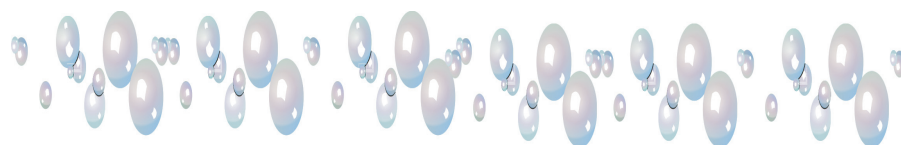
The Prosthodontist is the specialist dental surgeon who deals with rehabilitation of teeth by making artificial teeth and prosthesis.

The followings procedures are often done by a Prosthodontist or a Dental Specialist:

- ❑ Rehabilitate cleft defect by making a plate for those patients where it is not possible to repair by surgery or failed due to surgery.
- ❑ Replace missing teeth with implants or such options
- ❑ Restoration of malformed teeth with crowns, or laminates or esthetic fillings or such procedures.
- ❑ Make special appliances called speech bulb to help and improve speech.

CLINICAL GENETICIST

The clinical geneticist helps parents making them aware of the chances of having another baby with cleft or not.



Treatment Schedule and Specialists Involved in Cleft Care

First Few Weeks (Primary concern of the parent) Feeding!!!

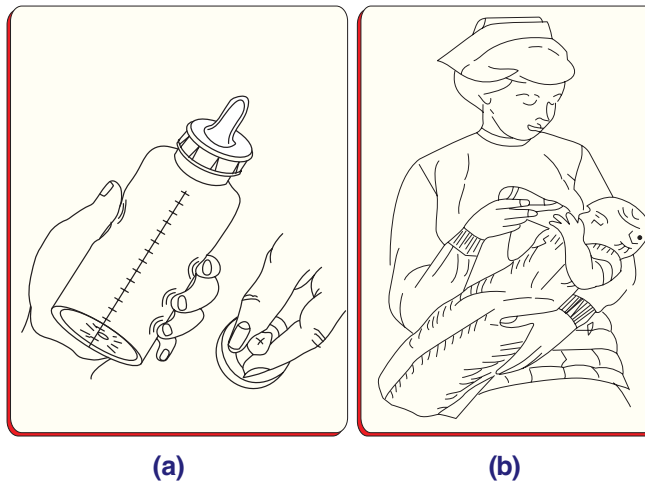


Fig. 7.1* (a) A soft squeeze bottle for feeding, nipple of which can be modified. The hole is made bigger which helps to drip the milk in baby's mouth, (b) Feeding position for cleft baby.

How to make feeding easy for a child with a cleft palate?

- ❑ Use a *Squeeze soft bottle*
- ❑ Conventional nipple can be modified by making the hole big enough so that milk drips down drop by drop without much effort.

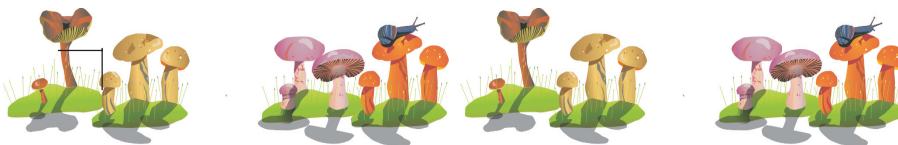




Fig. 7.2* (a) Feeding position for cleft baby, (b) Use of Paladi for feeding, (c) A baby with extensive cleft, (d) Feeding plate, (e) Feeding with plate in mouth which covers the gap.

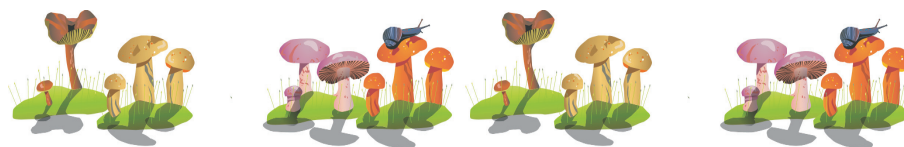
How to feed such a child?

FEEDING POSITION

- ❑ Mother should hold the baby in the lap at about 45°, keeping his head high so that milk/feed does not get in to lungs.
- ❑ Use small feeds at each time
- ❑ Frequent *Burping* should be initiated following feed
- ❑ Use of deep spoon called *Paladi* can be useful

How does this help the child?

- ❑ Child is unable to create negative pressure because of the defect in the palate and hence cannot suck the milk from nipple.



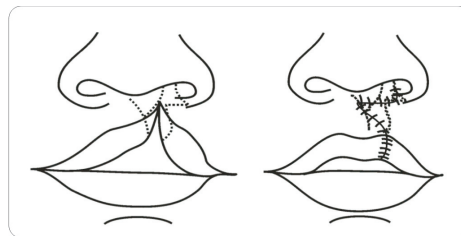
- ❑ Big hole in the nipple helps drip the milk effortlessly
- ❑ Drip the milk in the area of intact palate, watch for milk getting down for the child to swallow. It should not get into breathing tube or come out of nose.

Whom to consult at this stage?

1. A specialist nurses helps you to understand how to feed the cleft baby
2. To watch out for weight gain; chest infection and such things get in touch with pediatrician
3. For recurrent ear infections ENT surgeon may be consulted. It is a good idea to get hearing tested.

3 Months

Primary cleft lip surgery!!!



(a)

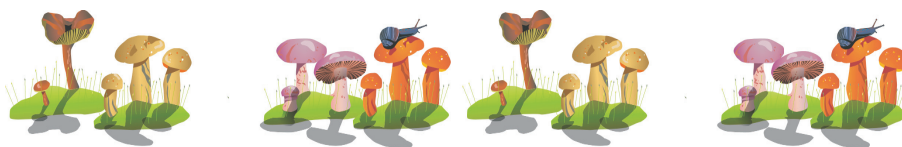
(b)



c

d

Fig. 7.3* (a, b) Plastic surgery for repair of lip, (c) pre surgery, (d) repaired lip.



What is the purpose of surgery?

- ❑ To close gap in lip and also front part of the palate

Who does the surgery?

- ❑ Cleft palate surgeon

6 months–1 year

Can the child hear properly??

Can the child start speech??

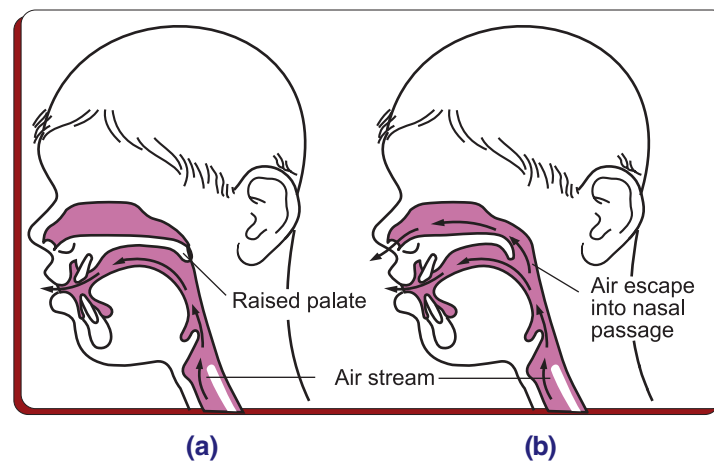
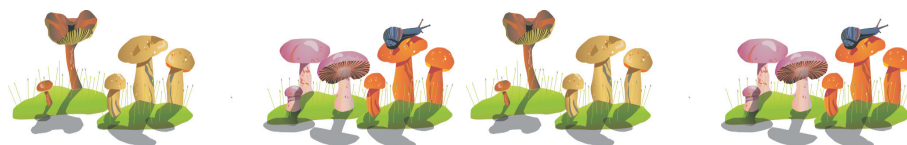


Fig. 7.4* (a) Normal palate is mobile and separates nose cavity from throat during speech, (b) Short palate allows air to escape in nose therefore causes high pitched nose sound during speaking.

Whom to consult?

- ❑ ENT Surgeon
- ❑ Speech Therapist



What to watch out for?

- Throat infection
- Chest infection
- Ear infection with hearing loss

9 months – 1 year***Palate Repair!!!*****What is the purpose of second surgery?**

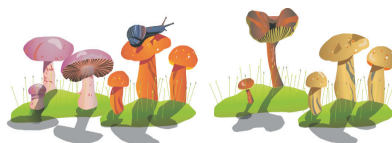
- To close back part of palate down up to the soft palate
- Revision of lip and deepening of sulcus when upper lip is not very mobile
- To develop good speech both upper and lower lip should meet

1 year – 6 years***Can the child talk properly??*****Whom to consult?**

- Speech Therapist

What to watch out for?

- Nasality of voice
- Speech and language problem



Who else to consult?

- Dentist
- Orthodontist

What else to watch out for?

- Erupting milk teeth
- Oral hygiene, dental caries
- Tooth erupting in the palate or at site of operation
- Articulation problems
- Irregular permanent teeth
- Escape of fluids from nose

6 years – 9 years

To check for irregularities of teeth!!!

To check quality of speech development!!!

Review by the cleft surgeon!!!

Whom to consult?

- To be under constant review with the following people:
 1. Speech therapist
 2. Cleft surgeon
 3. Orthodontist



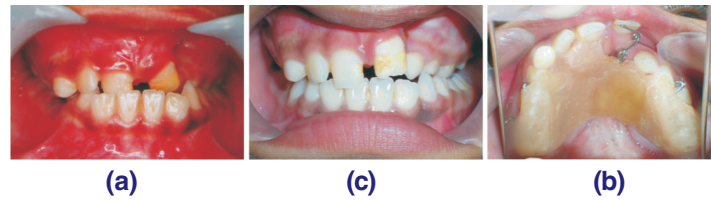


Fig. 7.5* (a) Front teeth may grow inwards then normal position, (b) Orthodontic plate with spring is used to push the tooth towards lip, (c) Corrected tooth.

What to watch out for at this stage?

Development of teeth in the cleft region



Evaluation of effects of surgery on growth of upper jaw



Rotation of teeth/Absence of permanent teeth



Abnormal Jaw movement/Facial asymmetry



Anterior/posterior placement of teeth



Escape of fluid from mouth to nose

9 years – 12 years

Speech improvement has taken place or not!!!

Does fluid escape from mouth to nose!!!





Fig. 7.6* (a) Scarring in palate due to surgery causes narrow upper jaw which is expanded with orthodontic appliance, (b) After expansion, (c, d) The malaligned teeth are corrected with fixed orthodontic appliances. The big hole seen in the palate is filled with bone through secondary alveolar bone graft (SABG). Afterwards the missing teeth are replaced with artificial teeth.

IF YES!

Whom to consult?

- Plastic surgeon/Oral surgeon

What is the purpose?

- Prepare child for bone grafting
- Secondary bone graft is done to fill the bony defect underneath the skin of lip and mucosa
- Purpose is to make two halves of the upper jaw one and provide bone support for upper adult canine to erupt normally.
- Also helps to close communication between mouth and nose.



7 years – 14 years

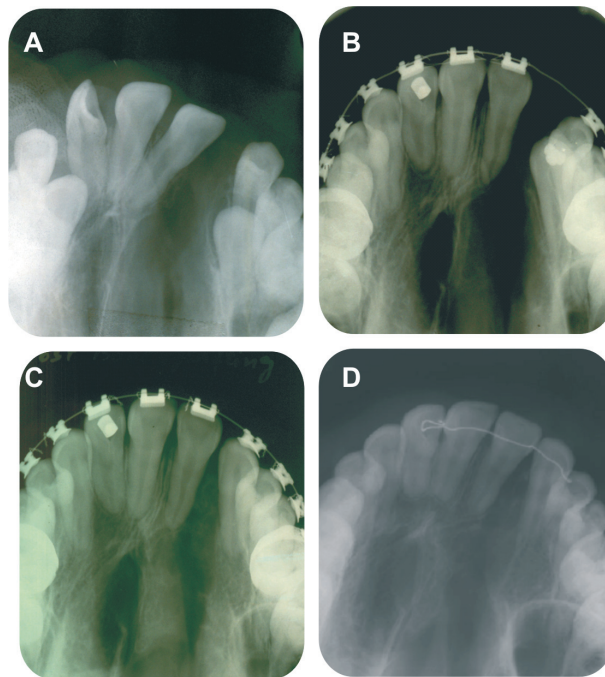


Fig. 7.7* (a) X-ray shows big bony defect in upper jaw, (b) After orthodontic treatment, ready for bone graft, (c) The defect has been filled with bone, (d) After removal of braces and completion of orthodontic treatment.

- (a) *Wrong position of teeth erupting in the mouth*
- (b) *Extra teeth or missing teeth in the mouth*
- (c) *Narrow upper jaw*
- (d) *Interlocking of upper and lower teeth—cross bite*

Whom to consult?

- Orthodontist



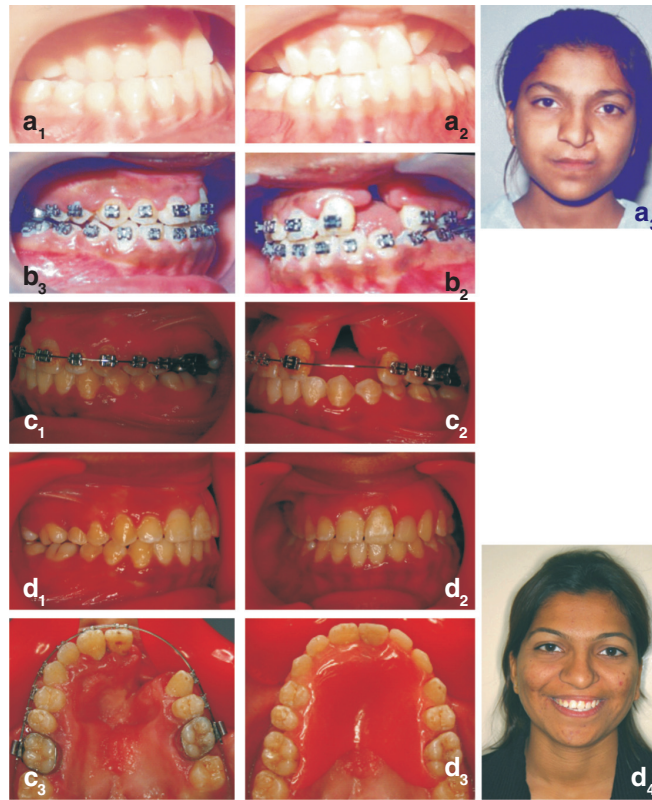


Fig. 7.8* (a₁,a₂,a₃) Pretreatment: Young girl developed small upper jaw has missing teeth, (b₁,b₂) During orthodontic treatment, (c₁,c₂,c₃) At completion of orthodontic treatment, (d₁,d₂,d₃,d₄) After removal of braces and replacement of missing teeth with a removable partial denture. A happy patient.

What is the purpose?

- To correct irregularities of teeth
- To harmonize jaw bones
- To create good smile and balanced face



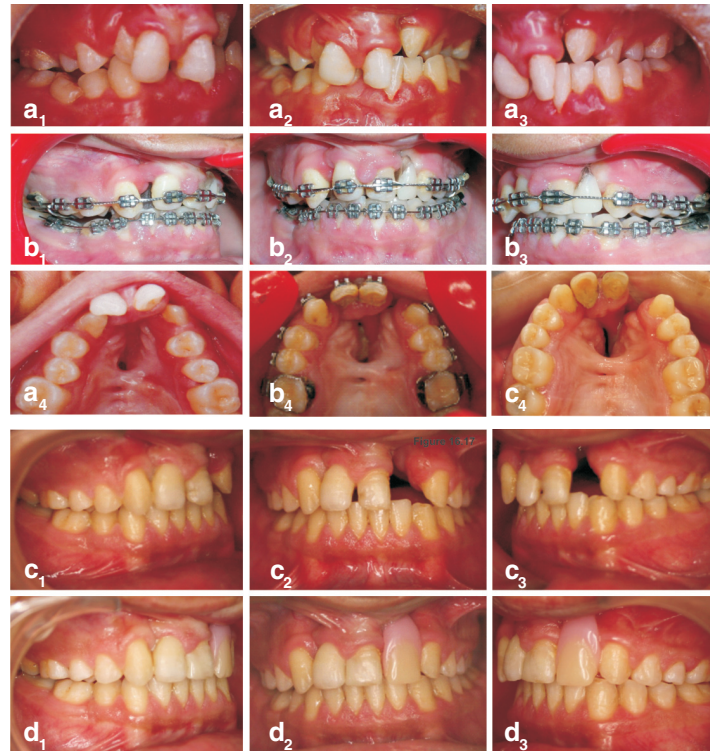


Fig. 7.9* (a₁,a₂,a₃,a₄) A young boy of bilateral cleft lip and palate has bad teeth. (b₁,b₂,b₃,b₄) During orthodontic treatment. (c₁,c₂,c₃,c₄) At completion of orthodontic treatment and removal of braces. (d₁,d₂,d₃) After replacement of missing tooth with plate which also serves as a obturator that covers hole in the palate and therefore helps in improvement in speech and prevents food from escaping through nose.

18 years and above

Scar revision or rhinoplasty
Rehabilitation of missing teeth



Whom to consult?

- Orthodontist
- Prosthodontist
- Plastic Surgeon

To check if facial balance can be managed with braces alone or child needs a surgery. If surgery is needed, it may require joint consultation with an Orthodontist, an Oral Surgeon and a Plastic surgeon.

What is the purpose?

- Harmonize upper and lower jaw** Orthognathic surgery by Orthodontist
- Rehabilitation of missing teeth** implant denture by Prothodontist
- Rhinoplasty** to improve shape of the nose by Plastic Surgeon



Fig. 7.10* An adult patient of cleft lip has been treated for lip revision and nose surgery (a) Pre treatment, (b) Post treatment.



Adulthood and Marriage

Whom to consult?

- Clinical geneticist

MILESTONES TO GOOD OUTCOME

- Cleft children are not different from other kids.
 - They can grow and live normally.
- Cleft Surgeon is your friend
 - Do not forget to see him at regular intervals
 - Do not see him only when you need surgery
- Consult Speech Therapist
 - He may guide you for speech and hearing problems
 - Follow timings of treatment 6 months to 2 years are critical for speech
- Consult orthodontist
 - 6 years and above orthodontic consultation is important

It is our responsibility to make the life of a cleft baby a blessing!



*Cited from Orthodontics Diagnosis and Treatment of Malocclusion and Dentofacial Deformities by Om P. Kharbanda, Elsevier, First Edition 2009. Holistic treatment approach in the interdisciplinary management of cleft lip and palate 491–516. These pictures are copyright of Elsevier and restricted for further use.

