ORAL HEALTH IN COMPREHENSIVE CLEFT CARE
Guidelines for oral health professionals and the wider cleft care team
EXECUTIVE SUMMARY

Introduction

Clefts of the lip and palate (clefts) are the most common birth defects of the face and mouth. Clefts occur when parts of the lip and/or palate and nose do not fuse together during embryonic development. Clefts can be associated with missing or extra teeth, and malformed teeth and facial structures. Even children who undergo cleft surgery are often at an increased risk for caries, periodontal disease, and other oral health and wellbeing issues as they grow and develop. These children require regular dental care to ensure adequate monitoring, education, support, and treatment to prevent oral disease and achieve the highest possible quality of life.

Key Messages

• All of the providers involved in the care of people born with a cleft have a role to play in maintaining a person’s oral health and wellbeing.

• It is essential that agreed protocols are developed and adopted for providers to ensure good interdisciplinary communication.

• Providers should support caregivers, as caregivers may worry about their children’s oral health and how their teeth may appear after eruption.

• The objectives of interdisciplinary collaboration are to optimize cleft patients’ oral health and wellbeing including the ability to eat, speak, breathe and swallow.

• Caretakers may need support and encouragement to learn how to clean the cleft area and around the mouth. It’s important for them to understand what causes oral disease and how to prevent it.

Continuum of Care

Many providers are involved in the care of people who are born with clefts. Everyone has a role to play in reducing oral disease in people who are born with clefts. This resource has been developed to assist providers in their decision making during the oral health care continuum.

Classification of Clefts

An anatomical based classification known as LAHSAL uses the lip (L), alveolus (A), hard (H) and soft (S) palate to describe the characteristics of the cleft. The first character is for the patient’s right lip and the last character for the patient’s left lip.

• LAHSAL code indicates a complete cleft with a capital letter and an incomplete cleft with a small letter.

• No cleft is represented with a dash.

EXAMPLES

1. Bilateral complete cleft lip and palate: The condition is bilateral cleft lip and palate, so there will be no dash and all letters of the LAHSAL code will be written as capitals and thus this will be represented as LAHSAL.

2. Left complete cleft lip: A complete cleft lip will be represented with the capital letter “L”, as it is left, so this “L” will be written at the end. A patient with a left cleft lip will be represented as _ _ _ _ _ L
### Oral Health Professionals

**Cleft Oral Health Guidelines (by age group in years)**

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<td><strong>Routine Care</strong></td>
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<td>• Age appropriate oral hygiene - toothbrushing, mouth cleansing</td>
<td>• Age appropriate oral hygiene - toothbrushing, interdental cleaning, and tongue cleansing</td>
<td>• Discuss adverse habits - bruxing, nail biting, and smoking - and injury prevention</td>
<td>• Discuss adverse habits - thumb sucking/pacifiers/clenching, bruxing, and nail biting - and injury prevention</td>
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<td>• Professional fluoride application</td>
<td>• Dietary advice - avoid fizzy drinks, cariogenic snacks</td>
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<td>• Fissure sealants as molars/premolars erupt</td>
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<td>• Scar management should be explained to caregivers and patients</td>
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<td>• Identification and monitoring of white/brown spot lesions</td>
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<td>• Discuss adverse habits - thumb sucking/pacifiers/clenching, bruxing, and nail biting - and injury prevention</td>
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<td>• Atraumatic Restorative Treatment (ART) using adhesive materials such as glass-ionomer</td>
<td>• Interceptive orthodontics if required</td>
<td>• Interceptive orthodontics/orthopedics</td>
<td>• Assess the need for jaw surgery and specific orthodontics to correct severe malocclusion</td>
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<td>• Stainless steel or zirconia crowns</td>
<td>• Consider space maintainers if any primary teeth are lost</td>
<td>• Assess need for alveolar bone graft (ABG), maxillary and/or palatal expanders</td>
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<td>• Direct bonding</td>
<td>• Consider space maintainers if any primary teeth are lost</td>
<td>• Maxillary orthopedic protraction if required</td>
<td>• Assess the need for jaw surgery and specific orthodontics to correct severe malocclusion</td>
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<td><strong>Orthopedic and Orthodontic Tips</strong></td>
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<td>• Brief oral hygiene intervention (page 17)</td>
<td>• Consider space maintainers if any primary teeth are lost</td>
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<td>• Maxillary orthopedic protraction if required</td>
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<td>• Rhinoplasty if required</td>
<td>• Speech language assessment and treatment if required</td>
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**Oral Health Professionals**

- It is essential to achieve minimally invasive dentistry and maintain primary dentition.
### Risk Assessment for Non-Oral Health Professionals

**Applies to all age groups**

Use this quick reference guide to assess the level of risk for oral disease.

Each factor below — whether occurring on its own or in combination with other factors — increases patients’ risk of caries (tooth decay), periodontis (gum disease), and other oral diseases.

- Active or previous caries lesions
- Low socio-economic status
- Frequent consumption of dietary sugars
- Reduced salivary flow or salivary pH
- Poor oral hygiene
- Suboptimal fluoride exposure
- Familial risk factors (educational level of parents'/sibling's oral health status)

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<td>• Referral to dental team if required</td>
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<td>• Scar management should be explained to caregivers and patients</td>
<td>• Discuss stopping adverse habits - thumb sucking/pacifiers/clenching, bruxing and nail biting - and injury prevention</td>
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<td>• Coordinate with the dental team for extractions and orthodontics as required</td>
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**Non-Oral Health Professionals**

**Cleft Oral Health Guidelines**

(by age group in years)

At each appointment the care provider should refer to these guidelines.

- Coordinate with the dental team for extractions and orthodontics as required.
0-2 YEARS

ORAL HEALTH PROFESSIONALS

Routine Care

It is essential to achieve minimally invasive dentistry and maintain primary dentition.

- At this age, appropriate oral hygiene measures should begin and be taught to the caregivers (defined as parent or guardian) to establish a good routine of mouth cleaning and gum wiping before the eruption of primary teeth and gentle toothbrushing as the primary dentition erupts.
- Explain to the caregiver the causes of tooth decay and gum disease, by describing the role of plaque and sugars and the effect on the oral tissues.
- At this age, nighttime feedings and baby bottles can contribute to high rates of early childhood caries. Discourage caregivers from putting honey or sweetened beverages in the bottle and ensure that the child’s mouth is fully cleansed after the final nighttime feed.
- Discuss adverse habits with the caregiver—thumb sucking, nail-biting and pacifiers should be actively discouraged. There may be concerns about the child clenching and bruxing their teeth, especially at night. Caregivers should be reassured that their child will usually outgrow this habit, but referral to a general practitioner for sleep analysis may be required in severe cases.
- A smear of fluoridated toothpaste should be used, and children should spit out, but not rinse away, the toothpaste residue. Fluoride supplements can be considered if the local water supply is not fluoridated.
- Early identification and monitoring of white/brown spot lesions are essential to prevent and manage caries. Professional fluoride application can be carried out twice per year from six months of age.
- Scar management can be carried out when the surgical site is fully healed, and sutures have been removed. Caregivers should be encouraged to massage downwards from the columella end of the scar to the vermilion, three times per day for 8-10 minutes.
- Proper cleaning of the obturator and appliance should be taught to maintain a healthy mouth. See guidelines on page 17.

Restorative Tips

- Silver diamine fluoride (if available) should be utilized to treat and manage caries.
- Minimally invasive techniques such as Atraumatic Restorative Treatment (ART) should be carried out using adhesive materials such as glass-ionomer.
- Stainless steel or zirconia crowns should be used on teeth with extensive caries or following a pulpotomy.
- Direct bonding can be used when required (strip crowns/composite restorations/pit and fissure sealants).

Orthopedic and Orthodontic Tips

- The orthodontist should monitor the child’s oral health and refer to the dental team if they identify any issues such as white spots or early caries.
- At each appointment, the orthodontic team should provide brief oral hygiene, advice and educate the caregiver about the care of presurgical infant orthopaedics (PSIO) or obturators.
- The orthodontist may be involved with providing the PSIO or palatal obturators before surgery.

Other Specialty Tips

- At this age, the child will be undergoing treatment with the comprehensive cleft care team:
  - Prenatal-birth: Genetic & feeding counseling
  - 0-3 months: Feeding counselling; hearing screening & ENT services if required
  - 3-6 months: Lip repair
  - 6-18 months: Early speech & language stimulation
  - 6-18 months: Palate repair
  - Ongoing: Psychological support and counselling should be provided to the patient and their support network

NON-ORAL HEALTH PROFESSIONALS

Care and Tips: Key Points

- All members of the comprehensive cleft care team can take part in monitoring and maintaining the child’s oral health.
- Assess the child’s level of risk for oral disease using the quick reference guide. Refer to risk assessment on page 5.
- ’Lift the lip’ is a quick and easy way to check the child’s oral health status, as shown on page 10.
- Referral to the dental team if any white or brown spots are noticed on the teeth.
- Thumb sucking and pacifier use should be discouraged.
- A brief oral hygiene intervention should be provided at each visit.
- Scar management should be explained to caregivers.
- Cleaning of the obturator and orthodontic oral appliances by following the obturator cleansing guidelines on page 17.
- Any prescribed medicines should be sugar free.
2-6 YEARS

ORAL HEALTH PROFESSIONALS

Routine Care

- At this age, appropriate oral hygiene measures should be reinforced to the caregivers to maintain a good routine of gentle toothbrushing as the primary dentition continues to erupt. If possible, interdental cleaning should be carried out.
- Explain to caregivers the causes of tooth decay and gum disease, by describing the role of plaque and sugars and their effect on tooth enamel.
- At this age, nighttime feedings and baby bottles can contribute to high rates of early childhood caries. Discourage parents or guardians from putting honey or sweetened beverages in the bottle and ensure that the child’s mouth is fully cleansed after the final nighttime feed.
- A smear of fluoridated toothpaste should be used, and children should spit out, but not rinse away, the toothpaste residue. Fluoride supplements can be considered if the local water supply is not fluoridated.
- Early identification and monitoring of white/brown spot lesions are essential to prevent and manage caries. Professional fluoride application should be carried out every six months.
- Scar management can be carried out when the surgical site is fully healed, and sutures have been removed. Caregivers should be encouraged to massage downwards from the columella end of the scar to the vermilion, three times per day for 8-10 minutes.
- Discuss adverse habits with the caregiver—thumb sucking, nail-biting and pacifiers should be actively discouraged. There may be concerns about the child clenching and bruxing their teeth, especially at night. Caregivers should be reassured that their child will usually outgrow this habit, but referral to a general practitioner for sleep analysis may be required in severe cases.

Restorative Tips

- Silver diamine fluoride (if available) should be utilized to treat and manage caries.
- Minimally invasive techniques such as Atraumatic Restorative Treatment (ART) should be carried out using adhesive materials such as glass-ionomer.
- Stainless steel or zirconia crowns should be used on teeth with extensive caries or following a pulpotomy.
- Direct bonding can be used when required (strip crowns/ composite restorations/pit and fissure sealants).

Orthopedic and Orthodontic Tips

- The orthodontist should monitor the child’s oral health and refer to the dental team if they identify any issues such as white spots or early caries.
- At each appointment, the orthodontic team should provide brief oral hygiene advice and educate the caregiver about the care of obturators or orthodontic appliances.

2-6 years only

- As the child grows the primary dentition should be maintained. Space maintainers should be used as appropriate if primary teeth are lost.
- As the permanent dentition begins to erupt, interceptive orthodontics should be used if required.

Other Specialty Tips

- During this phase of growth, the child will require monitoring by the surgical team in case any surgery revision is required. As the child develops speech and language skills, they may need a referral to a speech therapist for assessment and treatment.
- Psychological support and counselling should be provided to the child and their support network.
- Interdisciplinary team clinic appointments should be offered to all children and their parents or guardians annually.

NON-ORAL HEALTH PROFESSIONALS

Care and Tips: Key Points

- All members of the comprehensive cleft care team can take part in monitoring and maintaining the child’s oral health.
  » Assess the child’s level of risk for oral disease using the quick reference guide. Refer to risk assessment on page 5.
  » ‘Lift the lip’ is a quick and easy way to check the child’s oral health status, as shown on page 10.
  » Referral to the dental team if any white or brown spots are noticed on the teeth.
  » Thumb sucking and pacifier use should be discouraged.
  » A brief oral hygiene intervention should be provided at each visit.
  » Scar management should be explained to caregivers.
  » Cleaning of the obturator and orthodontic oral appliances by following the obturator cleansing guidelines on page 17.
  » Any prescribed medicines should be sugar free.

ILLUSTRATION

Teach caregivers to support the child when brushing their teeth

1 2

‘Lift the lip’ is a quick and easy way to check the child’s oral health status.
6-12 YEARS

ORAL HEALTH PROFESSIONALS

Routine Care
It is essential to achieve minimally invasive dentistry and maintain primary dentition

- At this age, appropriate oral hygiene measures should be taught to the caregivers and child to continue a good routine of toothbrushing and introduce interdental cleaning and use of an inter space brush in the cleft area. Children should be supported in their oral hygiene routine until at least the age of 8.
- Explain to caregivers and the child the causes of tooth decay and gum disease, by describing the role of plaque and sugars and their effect on the oral tissues.
- Dietary advice should be provided to the caregiver and child with instructions to avoid fizzy drinks and reduce the consumption and frequency of cariogenic snacks.
- A pea-size of fluoridated toothpaste should be used. Children should spit out, but not rinse away, the toothpaste residue. Fluoride supplements can be considered if the local water supply is not fluoridated.
- Early identification and monitoring of white/brown spot lesions are essential to prevent and manage caries. Professional fluoride application should be carried out every six months.
- Scar management can be carried out when the surgical site is fully healed, and sutures have been removed. Caregivers should be encouraged to massage downwards from the columnella end of the scar to the vermillion, three times per day for 8-10 minutes.
- Discuss adverse habits with the caregiver—thumb sucking, nail-biting and pacifiers should be actively discouraged. There may be concerns about the child clenching and bruxing their teeth, especially at night. Caregivers should be reassured that their child will usually outgrow this habit, but referral to a general practitioner for sleep analysis may be required in severe cases.
- Fissure sealants should be placed as molars/premolars erupt to prevent caries.
- A periodontal examination should be carried out every six months to monitor for inflammation.
- Radiographic assessments should begin to monitor the eruption of the permanent dentition.

Restorative Tips
- Silver diamine fluoride (if available) should be utilized to treat and manage caries.
- Minimally invasive techniques such as Atraumatic Restorative Treatment (ART) should be carried out using adhesive materials such as glass-ionomer.
- Stainless steel or zirconia crowns should be used on teeth with extensive caries or following a pulpotomy.
- Direct bonding can be used when required (strip crowns/composite restorations/pit and fissure sealants).

6-12 years only

- At this age, the child will begin to develop self-awareness and start attending school. Clinicians should provide partial dentures for missing teeth, and the fit of the denture should be reviewed regularly as the child grows.

Orthodontic and Orthodontic Tips

6-12 years only

- The orthodontist should monitor the child’s oral health and refer to the dental team if they identify any issues such as white spots or early caries.
- At each appointment, the orthodontic team should provide a brief oral hygiene advice

Other Specialty Tips

6-12 years only

- The child will continue to grow rapidly and may require further surgery such as a bone graft to the alveolar cleft(s) and closure of the oro-nasal fistula and rhinoplasty.
- Speech-language therapy will be ongoing if required.
- Psychological support and counselling should be provided to the patient and their support network.
- Interdisciplinary team clinic appointments should be offered to patients and parents or guardians annually until about ten years old, then biannually until they complete care.

NON-ORAL HEALTH PROFESSIONALS

Care and Tips: Key Points

- All members of the comprehensive cleft care team can take part in monitoring and maintaining the child’s oral health.
  » Assess the child’s level of risk for oral disease using the quick reference guide. Refer to risk assessment on page 5.
  » Referral to the dental team if any white or brown spots are noticed on the teeth.
  » Thumb sucking and pacifier use should be discouraged.
  » A brief oral hygiene intervention should be provided at each visit.
  » Scar management should be explained to caregivers and children.
  » Coordinate with the dental team for extractions and orthodontics as required.
  » Any prescribed medicines should be sugar free.

ILLUSTRATION

Children should be supported in their oral hygiene routine until at least the age of 8
12-18 YEARS

**ORAL HEALTH PROFESSIONALS**

**Routine Care**

- Essential to achieve minimally invasive dentistry and maintain primary dentition.
- Appropriate oral hygiene measures should be reinforced at every appointment to continue a good routine of toothbrushing, interdental cleaning and use of an interspace brush in the cleft area. Specific oral hygiene measures will be needed for patients undergoing orthodontic treatment to clean around the brackets and underneath the archwire.
- Explain to caregiver and patient the causes of tooth decay and gum disease, by describing the role of plaque and sugars and their effect on the oral tissues.
- Dietary advice should be provided to the patient with instructions to avoid fizzy drinks and reduce the consumption and frequency of cariogenic snacks.
- A bean-size of fluoridated toothpaste should be used. Patients should spit out, but not rinse away, the toothpaste residue.
- Professional fluoride application should be carried out every six months.
- Scar management can be carried out when the surgical site is fully healed, and sutures have been removed. Caregivers should be encouraged to massage downwards from the columella end of the scar to the vermilion, three times per day for 8-10 minutes.
- Fissure sealants should be placed as molars/premolars erupt to prevent caries.
- A periodontal examination should be carried out every six months to monitor for inflammation.
- Radiographic assessments should continue to monitor for caries and the periodontal condition.
- Information on behaviour modification, including smoking cessation and the reduction of alcohol consumption, should be provided as needed.
- Injury prevention should be discussed as well as the importance of using a fitted mouthguard during sports.

**Restorative Tips**

- Silver diamine fluoride (if available) should be utilized to treat and manage caries.
- Minimally invasive techniques such as Atraumatic Restorative Treatment (ART) should be carried out using adhesive materials such as glass-ionomer.
- Stainless steel or zirconia crowns should be used on teeth with extensive caries or following a pulpotomy.
- Direct bonding can be used when required to improve aesthetics with a minimally invasive approach (strip crowns/composite restorations/pit and fissure sealants).
- Clinicians should provide partial dentures for missing teeth, the fit of the denture should be reviewed regularly.
- Begin to consider cosmetic requirements: for example, resin-bonded bridges, crowns or veneers.

**Orthopedic and Orthodontic Tips**

- Specific care instructions for orthodontic appliances should be given to the patient. The oral hygiene regime should be carried out after each meal, in addition to in the morning and at night. The patient should avoid sticky foods and sweets.
- The orthodontist should monitor the patient’s oral health and refer to the dental team if they identify any issues such as white spots or early caries.
- If jaw surgery is needed to correct severe malocclusion, orthodontics will be required to prepare the patient for surgery.

**Other Specialty Tips**

- Monitor for sleep apnea by questioning the patient if they feel unusually sleepy during the day or if they have heavy snoring. Patients should be referred to a sleep specialist if they have concerns.
- Psychological support and counselling should be provided to the patient and their support network.
- If the patient receives jaw surgery to correct severe malocclusion, speech should be assessed after surgery to rule out any issues with velopharyngeal dysfunction (VPD).
- Interdisciplinary team clinic appointments should be offered to patients and parents or guardians at least biannually.

**NON-ORAL HEALTH PROFESSIONALS**

**Care and Tips: Key Points**

- All members of the comprehensive cleft care team can take part in monitoring and maintaining the patient’s oral health.
  » Assess patient’s level of risk for oral disease using the quick reference guide on page 5.
  » Referral to the dental team if required.
  » A brief oral hygiene intervention should be provided at each appointment.
  » Scar management should be explained to patients.
  » Coordinate with the dental team for extractions and orthodontics as required.
  » Coordinate with the facial surgeon and orthodontist if jaw surgery is required to correct severe malocclusion.

**ILLUSTRATION**

Specific oral hygiene measures will be needed for patients undergoing orthodontic treatment
ORAL HEALTH PROFESSIONALS

Routine Care

It is essential to achieve minimally invasive dentistry and maintain primary dentition.

- Appropriate oral hygiene measures should be reinforced at every appointment to continue a good routine of toothbrushing, interdental cleaning and use of an interspace brush in the cleft area. Specific oral hygiene instructions will be needed for patients with orthodontics, implants and bridges.
- Explain to the patient at every appointment the causes of tooth decay and gum disease by describing the role of plaque, inflammation and sugars and their effect on the oral tissues.
- Dietary advice should be provided to the patient with instructions to avoid fizzy drinks and reduce the consumption and frequency of cariogenic snacks.
- A bean-size of fluoridated toothpaste should be used, and patients should spit out, but not rinse away, the toothpaste residue.
- Professional fluoride application should be carried out every six months.
- Following surgical revisions, scar management can be carried out when the surgical site is fully healed and sutures have been removed. The patient should be encouraged to massage downwards from the columella end of the scar to the vermilion, three times per day for 8-10 minutes.
- A periodontal examination should be carried out every six months to monitor for inflammation.
- Radiographic assessments should continue to monitor for caries and the periodontal condition.
- Information on behaviour modification, including smoking cessation and the reduction of alcohol consumption, should be provided as needed.
- Injury prevention should be discussed as well as the importance of using a fitted mouthguard during sports.

Restorative Tips

- Silver diamine fluoride (if available) should be utilized to treat and manage caries.
- Minimally invasive techniques such as Atraumatic Restorative Treatment (ART) should be carried out using adhesive materials such as glass-ionomer.
- Stainless steel or zirconia crowns should be used on teeth with extensive caries.
- Direct bonding can be used when required (strip crowns/composite restorations/pit and fissure sealants).
- Clinicians should provide partial dentures for missing teeth and the fit of the denture should be reviewed regularly.
- Begin to consider cosmetic requirements: for example, resin-bonded bridges, crowns or veneers.
- Tooth whitening, if required, can be carried out.

18+ years only

Orthopedic and Orthodontic Tips

- Specific care instructions for orthodontic appliances should be given to the patient. The oral hygiene regime should be carried out after each meal, in addition to in the morning and at night. The patient should avoid sticky foods and sweets.
- The orthodontist should monitor the patient’s oral health and refer to the dental team if they identify any issues such as white spots or early caries.
- If jaw surgery is needed to correct severe malocclusion, orthodontics will be required to prepare the patient for surgery.

Other Specialty Tips

- Psychological support and counselling should be provided to the patient and their support network.
- If the patient receives jaw surgery to correct severe malocclusion, speech should be assessed after surgery to rule out any issues with velopharyngeal dysfunction (VPD).
- Interdisciplinary team clinic appointments should be offered to patients and parents or guardians at least biannually.

NON-ORAL HEALTH PROFESSIONALS

Care and Tips: Key Points

- All members of the comprehensive cleft care team can take part in monitoring and maintaining the patient’s oral health.
  » Assess patient’s level of risk for oral disease using the quick reference guide on page 5.
  » Referral to the dental team if required.
  » A brief oral hygiene intervention should be provided at each visit.
  » Coordinate with the facial surgeon and orthodontist if jaw surgery is required to correct severe malocclusion.

ILLUSTRATION

Specific oral hygiene instructions will be needed for patients with orthodontics, implants, and bridges.
Instructions for Cleaning of the Obturator/Appliance (OA)
Applies to age groups 0-2 and 2-6 only

Performed after each feed for the first 48 hours after the OA is fitted; then twice daily thereafter.

1. Remove the OA and wash in cooled boiled water.
2. The mouth should be inspected for any areas of ulceration, bleeding and tooth eruption. The OA may need to be adjusted by the dentist.
3. Using a moist swab stick clean under the flattened nostril.
4. Carefully insert the OA slightly sideward for a unilateral cleft and straight for a bilateral cleft.
5. Apply soft white paraffin to all lip areas and the premaxilla as needed and at each feed time.

Brief Intervention of Oral Hygiene for Non-Oral Health Professionals
Applies to all age groups

1. Brush twice per day for 2 minutes.
2. Use a fluoride toothpaste. (Spit, but don’t rinse!)
3. Try not to snack between meals.
4. Snacks should be non-cariogenic—plain yoghurt, cheese, whole fruits.
5. Only water or milk should be given for drinks between meals.
6. Visit the dentist regularly.