



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## The Challenges of Dental Care

*by Richard Mungo, D.D.S. (January/February 1996)*

Many parents and caregivers have written to the Foundation with concerns about proper dental care and oral hygiene for children with CdLS. They have also asked for help in making the examination and cleaning of the teeth an easier experience for both the child and the caregiver. Dr. Richard Mungo, a pediatric dentist and a member of the Foundation's Scientific Advisory Council, offers the following suggestions.

Children with CdLS present many challenges to the professionals, parents and caregivers who provide their oral hygiene care. The oral abnormalities associated with CdLS can complicate efforts to maintain a healthy oral environment.

Teeth may be poorly shaped, missing, over-retained or delayed in erupting into the mouth. A high palate or common clefting can contribute to a very narrow upper jaw. These factors can make oral hygiene practices seemingly impossible. Limited access to the mouth because of the small opening and short jaws, makes just getting into the mouth an overwhelming exercise. Special approaches to good brushing and preventive practices are necessary to keep our children from experiencing dental infection, discomfort and eventually the loss of teeth.

Attempting to examine the ears, teeth or eyes of children with CdLS can be extremely difficult. Children do not take well to this "invasion" of their space and may resist strongly. Pulling away and pushing away our hands are their only "defenses" from our misunderstood advances in providing health care. Examinations must be performed with gentleness and good control to ease their fears. Our challenges can be minimized and overcome if we consider the following areas:

- Child positioning and access to the mouth
- Proper equipment and medications
- Appropriate monitoring and professional care

### **Child Positioning and Access to the Mouth**

Gaining access to the mouth or other head and neck areas can be accomplished in many different ways. Each child will respond according to his likes and dislikes.

First, the head must be controlled before attempting to gain access to the mouth. Control is important and if your child is comfortable, then head control becomes easier. Try brushing your child's teeth while he or she is sitting in a wheelchair, a regular chair, or on a bean bag chair. With your child securely seated, you can control head movements and overcome any



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resistance with care and safety. Approach your child from behind, gently cradle the head in your arms and begin brushing.

You can also try placing your child in bed, using the covers to swaddle or wrap the child in a secure position. This will allow you to concentrate on head control for access to the teeth. One parent or caregiver can lean over the child and sing to him, maintaining the child's arms and legs within the covers, while an assistant brushes the teeth and controls the head.

A simpler technique for body and head control is to place the child on your lap, facing you. An assistant sits opposite you, accepting the child's head upon his or her lap as the child is gently laid back. The two caregivers become a "chair" and the child is well positioned for brushing, and evaluation, with the arms and legs controlled by one person and the head by the other. Your child is held securely and he or she can see both people who are trying to help.

## **Helpful Addresses:**

First Teeth Toothpaste  
Nu-Tec Health Products  
Carlsbad, CA 92008  
Tel: 1-800-868-8338

Collis Curve Toothbrush  
313 West 48th Street  
Minneapolis, MN 55409  
Tel: 800-945-6665

American Academy of Pediatric Dentists  
211 East Chicago Avenue  
Chicago, IL 60611-2616  
Tel: 312-337-2169

## **Proper Equipment and Medications**

Now that we have the body and head under control, we must think of how we are to gain access to the mouth. Human bites can be very serious. If one is inadvertently bitten by the child, the level of discomfort is not the only alarming complication. Infections from human bites can be extremely difficult to deal with and must be avoided if possible. An intraoral device that will help the child keep her mouth open for inspection and brushing will also help protect the caregiver from harm.

Stack together two or three tongue depressors and roll gauze around one end to make a soft cushion for biting upon. Tape the gauze securely to the sticks. You can make many of these devices ahead of time and use them when needed.



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Similar devices made of a sponge-like cushion on a stick are sold in some drug stores. Anything can be used, as long as it allows good access to the oral structures, does not have the potential of harming the child, and cannot be broken and possibly swallowed.

By placing one of the instruments into the mouth and holding it off to one side, you will have access to the opposite side for brushing or inspecting the teeth and gums.

Toothpaste is recommended for good cleansing of the teeth and breath freshening. However, most of our children cannot expectorate or spit out toothpaste in the usual fashion, and most toothpastes are not ingestible and may release excessive fluoride if swallowed on a daily basis. We recommend First Teeth, an ingestible toothpaste without fluoride, used for infant care. Ask your pharmacist for assistance.

There are many different kinds of toothbrushes and you may question which one is best for your child. Some are designed very simply, others are very sophisticated and offer better efficiency and maneuverability. In general, you need a brush that offers good control and good access to the hard-to-reach areas of the mouth. Above all, brushes should have soft bristles with rounded ends. When they show signs of fraying, throw them away.

Electric brushes are efficient choices for brushing teeth in a limited amount of time. However, your child might be afraid of the noise and rapid movement of the brush, and you must experiment to see what works best. The Braun electric toothbrush is very good for small mouths and offers the rotary motion that is excellent for cleaning the teeth and gums. The Collis Curve toothbrush is good for brushing the top, inside and outside surfaces of the teeth all at once. Ask your pharmacist for help in finding these brushes.

Flossing is another challenge that might appear beyond the level of care we can offer our children. With guidance from your dentist and special floss aids and devices, you can achieve a flossing routine that will help prevent cavities and gum disease that are so prevalent in children with CdLS.

## **Appropriate Monitoring and Professional Care**

The American Academy of Pediatric Dentists recommends that the first dental visit take place within the first year of a child's life. This may seem extremely early, but good preventive care will keep problems from arising later on. Talking with a pediatric dentist and staff can be very helpful in planning for your child's specific needs.

During that first visit, the dentist will make a good inspection of the mouth and evaluate the gums, palate, cheeks, tongue, lips, and teeth. Brushing techniques and approaches to gaining access to the mouth can be discussed and demonstrated.

Caregivers should inspect and monitor the mouth on a daily basis. Schedule a routine dental check-up every six months. A lot of changes can occur in six months and little problems can be taken care of easily before they become big problems.



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Preventing disease and promoting good growth and development can be achieved with a little guidance and help. Parents and caregivers can carry out home oral hygiene exercises with a great deal of success. Gentleness, control, and efficiency will ease your child's fears and bring about a healthy and happy smile.