

The Cleft Palate Team

Depending on its extent, a cleft of the lip and/or palate usually affects other functional areas in your child's development. Problems may arise pertaining to feeding, facial appearance, speech, hearing, dental functioning, and psychosocial development. All of these problems can be managed best by bringing together many specialists in related disciplines to review the physical and psychological changes involving the cleft and to coordinate treatment to the best advantage of the patient and parents. Your newborn's attending obstetrician, pediatrician, nurse, or social worker may—if they are involved with a cleft palate team—be sufficiently well-informed to outline the general problems for you and provide guidance.

The best time for the first team evaluation is within the first few days or weeks of your baby's life. However, referral for team evaluation and treatment is appropriate for patients of any age. Treatment teams will give you information about recommended treatment procedures, options, risk factors, benefits, and costs to help you make decisions on the child's behalf and prepare the child and yourselves for all recommended procedures.

Often the family is referred directly to a plastic

surgeon, who recommends that the child be examined by other cleft palate team specialists. The team then meets periodically for a cross-specialty discussion of your child in order to exchange information and decide on the appropriate treatment plan. As a parent, you should be given the opportunity to ask questions and to discuss the child's proposed treatment with all of the specialists after your child has undergone a number of diagnostic tests. (A special breakdown of diagnostic tests and procedures can be found at the end of this chapter.)

Who Is on the Team?

The ACPCA (American Cleft Palate Craniofacial Association) states that a cleft palate team should consist, at minimum, of a plastic surgeon, a speech pathologist, and an orthodontist. However, the team may also include a prosthodontist, pediatric dentist, oral and maxillofacial surgeon, general dentist, psychiatrist, audiologist, geneticist, neurologist, neurosurgeon, radiologist, psychologist, otorhinolaryngologist (ear, nose, and throat doctor), social worker, public health nurse, and pediatrician. The team leader can be any one of these professionals, and all team members should possess appropriate credentials and experience in the evaluation and treatment of patients with cleft palate and other craniofacial anomalies.

Each specialist has an important function in assisting both you and your child. For example, the psychologist can, through evaluation of family dynamics, assess the psychological effects the cleft is having on your youngster as well as on your family and friends. Subsequently, appropriate help and support can be offered on a short-term basis or on

through your child's development.

Care should be coordinated by the team but should be provided at the local level whenever possible; complex diagnostic and surgical procedures, however, should be restricted to major centers that have appropriate facilities and experienced care providers.

A Partnership—Parents and the Cleft Palate Team

A university/hospital cleft palate team can help you understand and manage the problems that your child will have. Such team guidance can help you arrive at realistic expectations about your child's facial growth and development and about what the team can accomplish during each stage of treatment. Through good communication with the team, a bond can be established that will help both you and the team carry out your individual roles, to the benefit of your child.

In many or most cases, parents and cleft palate team members work together for several years as the infant grows into childhood and adolescence. During that time, you as parents will play many roles, including that of unofficial but important members of the team. You will act as a two-way communications conduit, providing a continuing flow of information about your child to the health-care providers, while, at the same time, helping your child understand and accept the medical treatment. You will also make decisions for your child when he or she is too young to do so. At times, you may be asked to agree to various treatment plans, the technical details of which you don't completely understand; or, alternatively,

the technical details are clear, but the necessity or advantages of the proposed treatment are not. It is essential to ask questions of your child's health-care providers at times like these, not only to alleviate your own anxiety but also to enable you to offer reassurance and support to your child.

An excellent source-book for parents and team members alike, entitled *Family-Centered Care for Children with Special Health Care Needs**, eloquently spells out the philosophy behind parent-team collaboration:

- This philosophy recognizes that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
- The professional must share unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
- This new philosophy recognizes family strengths and individuality and respect for different methods of coping. It also encourages parent-to-parent support groups.

The role of the psychologist and social worker

Your child's habilitation process clearly involves more than medical and dental procedures. The involvement of psychologists and social workers is extremely valuable, and the earlier they become involved, the better. Discussing your feelings as a

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parent is important because the team's understanding of family dynamics plays a significant role in developing the most appropriate treatment plan for your child. Discussing your feelings will also be useful for you because you will almost certainly come to understand that the full spectrum of your feelings is normal.

In addition to your family, other factors influence your child's life. For example, the psychologist and social worker will consider the resources or facilities available to him or her in school, in the neighborhood, and in the community. In other words, the child's treatment plan will depend in part on the resources and support available.

Once these professionals have spent time with your child, they will communicate with the team of medical specialists what they have learned. In this way, your child will be seen as an individual throughout treatment. In addressing your family's concerns, these professionals truly facilitate the best outlook for your child and for the family as a whole.

Parents Want the Professionals to Know . . .

Listen to my ideas. I have spent many days and nights with my child and am closely attuned to any changes in his condition. I have observations and a perspective worth listening to. Keep me informed when my child is in surgery. Knowing the worst is better than what I might imagine. Give progress reports on how the surgery is proceeding.

Don't give medical advice or opinions unless you are my primary physician or I request it. Your information may be incorrect, incomplete, and disturbing.

Be careful to give accurate information and take the time to answer all of my questions. It takes time to absorb and understand what you have to say.

Do *not* move my child's bed while I am away without telling me before I return to the room. It is very hard to leave my child at any time, for fear of what might happen, and finding my child gone terrifies me.

Tell me as soon as possible if my child's condition significantly changes. Hearing about this ahead of time helps prepare me for seeing my child in his new state.

Give me an explanation if I can't see my child in the Intensive Care Unit or be with him during a procedure. It is easy to imagine all kinds of scary possibilities.

Give me information I need to care for my child at home as early as possible. Instructions in writing, like a booklet with medication schedules, nutrition advice, recommendations from specialists, and so forth, would be very helpful.

Discharge summary sheets are often too brief for the information I need. I need time to review the materials and get my questions answered before going home with my child. Last-minute changes/additions can be made at discharge.

Understand if I am not at the hospital as much as usual as my child nears discharge. This is a time I need to be elsewhere to prepare for my child's return home.

Let me use the equipment I will be using at home with my child while we are still at the hospital. I need to practice with my child where there is backup while I am learning.

Be cautious with your casual comments about my child. You may be sharing new information, and your words carry more weight than you realize. Think about my child as a child first and not as a child with a handicapping condition.

Think about ways my child may be able to participate in research without interfering with his or her normal routines. It is very important that my child experience the activities and rhythms of daily life as other children do.

Don't treat every parent or child you meet as the same. We are different, with different needs, abilities, styles, personalities, and values. Remember that with time we will be able to absorb and understand more.

Don't judge my ability to parent based upon my child's behavior during the stress of a long hospital visit. My child will behave differently here than at home.

See my child as a whole child and not just a diagnosis or an interesting case. Respect my child's dignity.

Assign my child to the floor he/she was on during previous stays. My child will be less frightened, and we will not have to start over with developing relationships with staff or figure out how things work on a new floor.

Look beyond my child's medical needs and remember developmental needs as well. Don't put off attending to my child's overall development. The illness may continue for a long time, and I want my child to develop as normally as possible in spite of it.

Pay attention to the environment my child is in and plan to coordinate the care so as to reduce excessive medical interventions, light, noise, and other unnecessary stressors.

Consider a variety of approaches and resources to help my child. Be open to other people's practices and routines even though they may be new or unfamiliar, and may require a change in the way you do things.

Thank you for treating me as an equal in our partnership for my child's care.

Diagnostic Procedures and Instruments

Following are some of the more common procedures, tests, and instruments used by cleft palate teams to assess the overall condition and development of children with clefts.

Casts. Casts of the palate and the lower jaw are made from impression material that is placed on a tray and in the mouth for thirty seconds. Plaster is put in the impression to make a mold (also called a cast). It is used to study palatal growth and the bite relationship (*occlusion*) between the upper and lower teeth.

Facial and intraoral photographs. These photographs of the face and the inside of the mouth help in evaluating facial form and contour; they also assist in evaluating dental arch relationships.

Cephaloroentgenographs. These lateral and frontal head x-rays, used for studying facial and skull growth, help assess the form of the passage above and below the oral cavity. The views disclosed include the throat (pharyngeal space) and the size of the adenoids relative to the size and shape of the passage above the soft palate leading to the nasal airways (nasal-pharyngeal airway space). They also help determine the form of the cervical spine as well as the size and length of the soft palate. Cephaloroentgenographs provide information about air flow, not muscle movement.

Multiview videofluoroscopy. This procedure yields x-ray images of the upper and lower jaws (from the front, side, and underneath) on videotape. These three views are used to evaluate velopharyngeal function (eg, swallowing and speech).

Nasopharyngoscope. This instrument contains a fiber-optic lens, which is placed in the nose and directed toward the back and top of the throat. It is used to view the larynx, the soft palate, and the movement of the lateral and posterior pharyngeal wall muscles during speech.

Aeromechanical instruments. These are used for measuring air flow during speech, and, from it, the size of the space between the mouth and nose.

Panographic or panorex images. These x-ray images of the upper and lower jaws reveal the presence and form of the crowns of the teeth and their roots, and the relationship of the teeth to each other. They also reveal the size and symmetry of the vertical portion of the lower jaw that hinges to the skull (ramus) and the body of the lower jaw (mandible).

Otoscope. An otoscope is used to visualize the tympanic membrane, which separates the middle ear chamber from the outer ear canal.

Other audiologic (hearing) evaluation instruments. These aid in the detection of hearing disabilities. The detection of such a disability by the physician marks the beginning of a diagnostic process that varies in duration and complexity with the child's age and the nature of the auditory problem.

Articulation tests. A speech/language pathologist systematically evaluates both correct and incorrect formation and production of the sounds of speech. This includes omissions, distortions, and substitutions of normal sounds or compensatory error sounds. Systematic evaluation of the articulation of speech helps ensure complete and consistent analysis of the problems so that effective and efficient treatment can be planned.

Rating scales of speech intelligibility and acceptability. Rating scales are often used by speech/language pathologists and other members of the cleft palate team to score the overall severity of the communication impairment in several categories. Ratings of intelligibility describe how well an individual's speech can be understood by others, whereas ratings of acceptability describe the pleasantness of both the sound and the appearance of speech.