

What You Need to Know

It's natural for parents to feel that because their child's face is slightly unusual, everything about their child must be different. But that's not so. The child's cleft is only a small part of who he or she is. Instead of focusing on the problem, parents need to focus on the many more things—the countless things—that make their child a wonderful and miraculous gift.

It's a good idea for you as parents to encourage your child to talk about his or her feelings and to be willing to just listen. As the child grows and begins to ask questions, be truthful about the scars; don't blame them on an accident. Even with support and understanding, the older the child becomes, the more "different" he or she will feel, and the youngster may retreat socially. You can help prevent this by providing your child with continuing social and psychological support and by encouraging him or her to not be afraid to enter social situations. Children with visible differences are often ignored, which is one reason that teaching them communication skills is so important.

Psychosocial counseling for you and your child can be most helpful, and you should feel comfortable

pursuing it if you feel that it would be beneficial. Remember also that cleft palate team members are ready to answer questions at any stage of your child's treatment; it is important that you understand what is being attempted to reach the goals of good speech, hearing, dental function, and facial appearance. Much will be done to help your child attain these goals, but the process takes time and requires patience and cooperation.

Most of all, keep in mind that a healthy, giving attitude toward your child and toward your spouse—along with realistic expectations about what the cleft palate team can achieve—are of vital importance in rearing a well-adjusted child who just happens to have a cleft.

Bill of Rights and Responsibilities for Patients and Parents

It is important for you to know what your child's rights are as a patient and what your rights and obligations are as a parent and client of the hospital. Some hospitals have adopted a set of written principles to help ensure that your child receives appropriate medical care. Talk with those involved in your child's care. What follows are the guiding principles of patient care adopted by Miami Children's Hospital.

You and your child have the right

1. To considerate, respectful care and to privacy consistent with the care prescribed. This includes consideration of the psychosocial, spiritual, and cultural variables that influence the perceptions of illness.
2. To know by name the physicians, nurses and staff members responsible for your child's care; to receive responses to questions and requests; and, to receive information regarding your child's diagnosis, the treatment prescribed, the prognosis of the illness, and any instruction required for follow-up care, in language you understand.
3. To know what patient support services are available to you and your child.
4. To request a consultation or second opinion from another physician; to change physicians; to change hospitals.
5. To participate in decisions regarding the medical care of your child. To the extent permitted by law, this includes the right to refuse consent for treatment; to cross out and initial any part of a consent form that you do not want applied to your child's care; to withdraw consent, and to be informed of the consequences of these actions.
6. To participate in the consideration of ethical issues arising in the care of your child through the Hospital Bioethics Committee.
7. To expect all communications and other records pertaining to your child's care, including the source of payment for treatment, to be kept confidential except as needed for proper treatment and hospital administration, or as authorized by appropriate consent, or otherwise provided by law or third-party payment contract.

8. To be informed of the hospital's policies regarding payment; to request, prior to treatment, an estimate of charges for medical care; and to request information and counseling on the availability of known financial resources for your child's care.
9. To receive an itemized bill, and to request an explanation of the charges.
10. To have access to the medical resources of the hospital indicated for your child's care without regard to race, national origin, religion, handicap, or source of payment.
11. To treatment for emergency medical conditions that will deteriorate from failure to receive treatment.
12. To information about medical treatment given for the purpose of research, or research being conducted in addition to medical treatment; and, to refuse to participate in research, with the assurance that care will not be adversely affected by such a refusal.
13. To express concerns or complaints regarding these rights or the quality of care and service provided by the hospital to the Department of Patient/Family Relations.

You have the responsibility

1. To know and follow the rules and regulations of the hospital and the particular unit. Parents or other responsible adults should accompany minor children on any hospital visit and observe all hospital rules.
2. To provide, to the best of your knowledge, accurate and complete information about present complaints, past illnesses, hospitalizations and other matters relating to your child's health; and, to report unexpected changes in your child's condition.
3. To notify your child's physician or nurse if you do not

understand a diagnosis, treatment or prognosis; and, to ask for clarification if you do not understand papers you are asked to sign.

4. To cooperate and to follow the care prescribed or recommended for your child by the physician, nurses or allied health personnel.
5. To keep your appointments and to be on time. When an appointment cannot be kept, the hospital or the clinic should be notified as soon as possible to cancel the appointment and arrange for a new one.
6. For your actions and their consequences if you refuse treatment for your child, or do not follow the physician's instructions.
7. To assure that the financial obligations associated with your child's care are fulfilled as promptly as possible.
8. To be considerate of the rights of other patients and hospital personnel by assisting in the control of noise, the number of visitors your child receives, and by observing the no-smoking policy. Note: you are welcome to stay in your child's room provided the rules and regulations are adhered to. Exception: Parents of patients in the intensive care units and in the psychiatric inpatient unit are not permitted to stay in the room with their child.
9. To advise your nurse, physician, or any members of your health care team of any dissatisfaction you may have with your child's care.

The Department of Patient/Family Relations is responsible for pursuing any questions, concerns, or formal complaints you may have about your rights or the quality of care and service provided by your hospital. You may contact the departmental staff directly, or ask any staff member to contact them on your behalf. Your complaint will not adversely affect your child's care and the staff will welcome the opportunity to address your concerns and be of assistance.