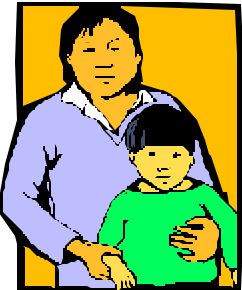


Does Your Child Have Special Health Care Needs?



Special health needs may be physical, developmental, behavioral or emotional, and may first become evident in a child of any age. With or without a specific diagnosis, children with special health needs often require health and other related services beyond those needed by other children, due to the complexity and chronic nature of their conditions.

Some genetic conditions and birth defects can be diagnosed before a baby is born. Other conditions are diagnosed at birth, or with additional testing, soon after the baby is born. Sometimes children develop special health needs due to an accident or illness. However, many families have nothing more than a "gut feeling" that something is not quite right with their child. Their child's development and behaviors, like puzzle parts, are slowly pieced together over time before the whole picture emerges and special health needs are determined.

As a parent, you know your child best and it is important to follow your instincts. If you think your child has special health needs, speak with your pediatrician. This primary care physician is your professional partner in caring for your child's health and well being. It is important to share your concerns and get his/her input. It may take several visits with the doctor to sort out your child's symptoms. When you make the appointment, be sure to request enough time for more thorough discussion with the doctor. Many pediatricians offer consultation appointments for parents so they can meet without their child, and/or telephone times for discussion. Before the appointment or phone call, write down your questions and concerns, so you don't forget the issues you want to discuss.

Does your child have a special health need?

Consider the following questions:

- Are you concerned about your child's eating, weight gain or loss, and sleeping patterns?
- How does your baby respond to light, touch and sound?
- Has your young child been learning new skills (walking, talking, playing) about the same time as other children his/her age?
- Has your child stopped learning new skills or regressed (lost skills s/he had previously learned)?
- Is your child treated for on-going health issues that are unique for a child his/her age (for example: chronic ear infections, asthma, allergies, joint pain, or frequent stomach aches)?
- Has there been a distinct change in your adolescent's eating and sleeping patterns, hygiene, general attitudes and emotional health?

Write down your observations, and be as specific as possible. For example, if your baby seems overly sleepy, instead of saying the baby sleeps all the time, include information such as, 'I need to wake my baby for all her/his feedings, and then s/he falls asleep again.' If your child frequently complains of headaches, do the headaches coincide with medication times, if they occur at school, during which activity? This additional information will help the doctor work with you to figure out what is going on with your child.

This is not an exhaustive list. These questions are only intended as a starting point for further discussion with your child's physician. You and the doctor will work together to "solve" the puzzle and develop a course of treatment, which may include a referral to a physician who specializes in a particular area of medicine. For example a cardiologist will provide consultation about suspected heart defects; for problems with the stomach, colon and intestines, your primary care physician may refer you to a gastroenterologist.

What does it mean to have a child with special health needs?

Having a child with special needs means you have entered a world that most of us hoped we never would have to explore. You are still the parent of a wonderful and unique child, and you will still have hopes and dreams. However, those hopes and dreams may be interrupted or altered by medical tests and procedures, hospitalizations, unique feeding routines, and other demands that are different from most families' parenting experiences.

Give yourself time to learn as much as you can and to understand, accept, and cope this change. You are not alone. Your medical team will be there to explain treatment options and help guide you in the many decisions you will now be making. They will teach you how to administer medications and provide any other special care your child may need. This team will also refer you to community resources and networks of parents who also have children with special needs. Many families find that connecting with other families of children with special health needs provides an important source of support as well as help in finding useful information and resources. These families can share their experiences and guide you in the discovery of the world of parenting a child with special health needs.



Massachusetts Family Voices is a state chapter of Family Voices, a national grassroots network of families and friends speaking on behalf of children and youth with special health needs. Funding for this article was provided by The Center for Health Care strategies (CHCS), in Lawrenceville, NJ, through the project, Building Capacity for Family Partnerships with Managed Care Organizations. This Grant was made possible through a separate Grant to CHCS by The Robert Wood Johnson Foundation.