

Parenting Challenges (This page updated 04/17/08)

No job is more challenging or more rewarding than parenthood. The challenges and often the rewards too are even greater when your child has special needs.

Some Problems You May Face When Your Child Has a Trach and/or Other Medical and Long-Term Issues

Feeling a multitude of uncomfortable emotions such as helplessness, anger, fear, guilt, depression, confusion, sadness, jealousy and shame. These are all normal reactions to the loss of a “normal” child. Some may last a few weeks, while others can linger for years. All parents go through a grieving process when they learn their child needs a tracheostomy. But the process itself is very individualized.

- Overall increased STRESS
- Difficulty learning to care for your child and feelings of inadequacy
- Financial burdens
- Problems and red tape with insurance companies, equipment vendors, medical staff, nursing agencies, government agencies and community organizations.
- Home accessibility problems and limited space for equipment and supplies

- Marital problems
- Sibling anger, jealousy and resentment
- Danger of over-protecting the child with a trach
- Your child may be teased or feel different because of the trach
- Loss of privacy
- Loss of sleep
- Social isolation
- Overwhelming number of doctor's appointments, therapies and surgeries
- Problems obtaining services through special education
- Family and friends may not understand how much extra work, time and stress is involved in raising a child with a trach.
- Job issues: needing more time off and flexibility
- Discrimination toward people with disabilities

Some Suggested Techniques to Help Minimize These Problems

- When your child has a new trach, spend time caring for your child in the hospital before discharge, so that you will be more comfortable with homecare.
- Train other family members or friends to care for your child in case of an emergency or if you need a babysitter.
- Take care of yourself and arrange regular breaks (respite). Your rest is very important. Your child may suffer if you are overwhelmed with stress and responsibility.
 - [National Respite Locator Service](#)
- Take time for hobbies.
- Network and talk to other parents dealing with similar issues.
 - [Trach-ties](#)
 - [Tracheostomy Message Boards](#)
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- Get on-line access, if possible, for research, information and networking.
 - [Tracheostomy Resources](#)
- Join a local support group.
- Choose your battles wisely and prioritize. This is especially true when dealing with special education problems.
- Bring someone with you to take notes at Individual Education Plan (IEP) meetings. If this is not possible, ask if you can tape record the meeting (this may be uncomfortable for some).
- Allow and encourage siblings to express their feelings.
 - [The Sibling Support Project](#)
- Treat your child as normally as possible. Set limits and discipline your child as you would if the child did not have a trach.
- When in doubt or for any major medical procedure, get a second opinion.

- Understand that your child has a legal right to an appropriate public education. In order for your child to be safe at school, he/she must have a person trained in tracheostomy care (preferably an RN or LPN) with him/her at all times. Work with your school to assure that your child is safe at school and during transport.
 - [School Nursing Services for Special Children](#) Legal information by By Phil Stinson, Esq.
 - [Medical Services: The Disputed Related Service](#) Journal of Special Education, Winter, 2000, by Larry Bartlett
 - [Policy for Tracheostomy Care and Suctioning in the School Health Setting](#), Courtesy of Escambia County Health Department-school
 - [Macon boy, 3, collapses at school, dies at hospital](#)
- Do your own homework regarding your child's condition. Do not assume that the medical professionals know what is best for your child or that they have all the answers.
- You are the most important person in your child's life, and you are an equal part of your child's medical team. Be your child's advocate.
- Find a pediatrician experienced with children with special needs who will work with you in coordinating your child's care and other medical specialists.
- You have the right to approve or disapprove of a nurse or nursing agency. Having nurses in your home is a difficult adjustment, try to have reasonable expectations.
- There is a huge discrepancy in the amount of skilled nursing care that a child with a tracheostomy should receive. In the U.S., children with tracheostomies average 8 hours per day of home nursing. This amount increases to 16 hours if the child is also on a ventilator. These are very general guidelines and vary depending on the individual child's needs. Some families would rather not have nurses in their home; others cannot manage without home nursing. The important issue is safety. If you feel that you cannot safely care for your child 24 hours a day, then it is reasonable to insist on home nursing for a child with a tracheostomy.
- SPEAK UP: do not be afraid or embarrassed about asking questions or asking for help.
- There is nothing wrong with asking for help. To quote parent of a child with a trach, "Children with special needs have parents with special needs."
- Keep organized with a "Things-To-Do" list.
- Keep an updated calendar for appointments, doctors appointments, therapies, start dates of medications, when to order supplies, etc.
- Make a checklist of critical items to take with you when traveling away from home.
- Do a weekly inventory and keep back-up supplies to avoid running short of equipment.
- [Financial Assistance for Kids with Tracheostomies](#) by Kathy Rowe
- Call government agencies such as the Department of Public Health and the Department of Public Welfare to find out what programs are available in your state.
 - [SSI](#)
 - [Medicaid](#)
 - [Medicaid Waiver Programs](#)
- Contact local charitable organizations such as Lions, Knights of Columbus, Kiwanis, and Church groups for help with items not covered by insurance (such as ramps, lifts and other home adaptations).
- Contact groups such as [United Cerebral Palsy Association](#), [Easter Seals](#), and the [March of Dimes](#) for special programs that might benefit your child.
- Take advantage of opportunities to educate the public about the value of children with special needs to help lessen ignorance and discrimination.
- Communicate with your spouse, listen to each other and make a date with your spouse!
- Plan special activities and private times with siblings.
- Keep a sense of humor:-)
- Seek outside professional help if needed for emotional support.

Tips when Working with Doctors

- Find a doctor you are comfortable working with
- Find a doctor with a "Family Center" approach
- Work together as a team
- Recognizing each others expertise
- Realize that doctors are human
- Get a second opinion when needed
- Be organized for appointment