A Guide To Pediatric Tracheotomy Care

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A Guide To Pediatric Tracheotomy Care

Second Edition

By

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DEDICATION

This book is dedicated to my children,
Anthony, Frank and Lena,
who taught me that, with love,
wonderful things can happen.
I also want to dedicate it to
all God's "special" little children,
who deserve the very best of care and love
that we can give them.

Foreword

Almost 12 years have passed since I was privileged to comment on the value of the First Edition of this publication. Since that time, many things have changed in the diagnosis and management of disorders of the respiratory system. However, the anxiety and tension that accompanies the parental responsibility for caring for a child with a tracheotomy remains the same. In addition, the tremendous social impact such a child makes on the entire family structure continues to be formidable.

Until Mrs. Adamo-Tumminelli published her First Edition, there had never been a comprehensive guide for the care of pediatric tracheotomies prepared by a parent who had lived with the anxiety and frustrations that are part of the every day experience of those individuals charged with the care of such children. Only a parent who has lived this experience can relate to the most intimate problems that occur on a day-to-day basis.

Mrs. Adamo-Tumminelli felt compelled to update her original work and she and her family should be congratulated for continuing to make this significant contribution to other patients and their families.

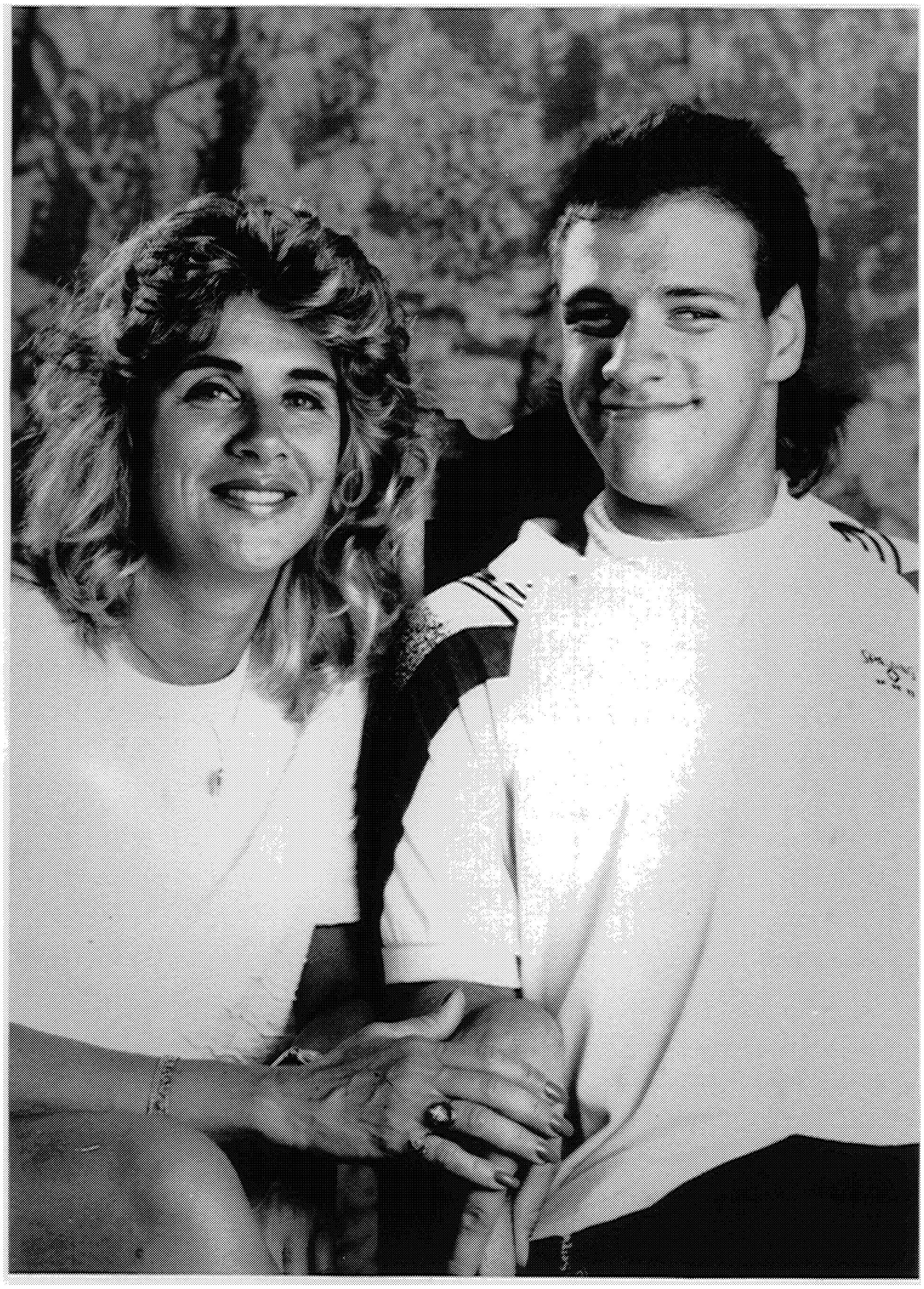
It was a pleasure for me to care for her son, Anthony, and to be involved with such a loving and caring family for so long a period of time. I sincerely hope that the information available in this publication will insure that both patients and their families receive the same appropriate and loving care.

Gerald B. Healy, M.D.

Foreword

Pat Tuminelli, R.N., has written a comprehensive tracheotomy care book which highlights her sincerity, honesty and love of her family. She was the original "first" in many categories concerning her son, Anthony, and now enjoys a very special relationship with him which would have not occurred had she given up at any of the innumerable obstacles she faced. This book teaches the subject of tracheostomy care but expresses her advocacy of improving conditions for children with special needs. I admire Pat for all she has done and continues to do for children with special needs and am grateful for having had the chance to become involved with such an exceptional person.

Mark N. Goldstein, M.D.
F.A.C.S., F.A.A.P.



Pat Adamo-Tumminelli and son, Anthony.

Preface

My son, Anthony, received a tracheotomy (trach) on his first birthday. It was performed to bypass the complications of croup and mechanical damage sustained to the trachea at birth. From that day forward, my life, and that of my family members, was never the same again. Life became an emotional roller coaster, laden with numerous medical happenings and hospitalizations. With time, work, growth and perseverance eventually our lives calmed down, but it took a tremendous effort to keep family life intact.

Sixteen years ago the medical scene was not what it is today. Home care for infants and children with trachs was virtually non-existent and DRGs (diagnostically related groups) had not yet been developed. No one put a time limit on a child's stay in a hospital the way they do today. Children with trachs lived in hospitals and families were outside observers. Parents did not feel that they had control over their own children's lives. Professionals cared for them and the family took a back seat. In my son's case, I was even advised to institutionalize him due to his multi-handicapping conditions. Anthony lives with the inconveniences of cerebral palsy, profound deafness, hyperactivity with attention deficit disorder and a permanent tracheostomy. Although I was given this advice from numerous professionals at various times in Anthony's life, I never considered it an option for myself and my son. Looking back, I'm glad I made the decision I did as Anthony has grown and developed with the love and nurturing that only comes from family life. But, of course, this is an individual decision for each family.

Today the medical attitude and atmosphere has changed. The pediatric philosophy now in vogue encourages parent participation and home care for all children capable of living at home. The most disabled child can be maintained at home and even attend school with the proper medical, nursing and social supports. With the passage of P.L. 94-142 in 1975 all handicapped children must be provided with a free, appropriate public education. Services have improved, but involved parents must be advocates for their children. They must support the intricate system which helps their child and push for continuing legislation so services may continue.

Sixteen years ago, when my son was trached, most trach information was written for medical professionals and geared to clinical situations. There was no written information or guide for parents to use so they could more easily care for their children at home. In an attempt to satisfy this need, I have written this book in layman's language with simple graphic illustrations for ease of comprehension.

The responsibility of caring for a child with a trach may seem overwhelming initially. Oftentimes a tracheotomy is performed in an emergency situation with little or no time given to explore the facts and ramifications. When parents first see their child post operatively, attached to monitors, intravenous lines, ventilators and the like, this sight alone can be very overwhelming. Parents will experience a vast gamut of emotions in a very short time. This, linked with many questions and doubts, can be very upsetting. Fear of the unknown and awe of medical procedures is difficult for parents who have no medical background. Parents cannot believe that this little child so encompassed by technology will ever return home to them again. Believe me. He will.

I wrote this book to enable any parent who wants to bring his child back home again to be able to do so. But, remember, this is only a guide and is not intended to substitute for the expert advice of your child's doctor or home care program. Each doctor has his own personal preferences and you should follow his advice as it pertains specifically to your child. Remember, each child is an individual and each airway problem is unique.

My goal is to provide you with a broad base of information on trach care, respiratory equipment and emergency measures. Social, emotional and psychological issues are also discussed as our children's growth and development are very important to us. We can be the best technicians, but if we do not deal with psychological issues, our children will be shortchanged and they will not adapt well to this great change in their lives. The psychological impact of having a "special" family member must be explored. Over the years I have visited many children's hospitals around the country and shared information and feelings with many parents. I have tried to provide you with a synopsis of their many excellent ideas.

At the end of the book there is a section called "Checking Your Progress" which covers the most important information and most commonly asked questions. This serves as a good review for parents and caregivers.

Twelve years have passed since I wrote the First Edition of this book. Much has changed in my life since then and I would like to share my knowledge and experience with you. I am a nurse today, but what I have to say comes from the heart, as parent to parent. In the fifteen years since Anthony was trached, I have had the good fortune to meet many extraordinary people. In the world of "special" children, there are an abundance of "special" people. I refer, of course, to teachers, parents, grandparents, friends, siblings, doctors, nurses, therapists and volunteers. The list goes on and on. Our special children inspire many people to dedicate their lives to selfless giving. They bring out the best in people. Many of us aspire to heights we would never have thought possible. Families and friends rally to our aid to help us survive and make it through the day. With time and commitment we carry on, survive, and thrive.

I became a pediatric nurse so that I could provide my son with the best possible care and help other children like him. My profession enabled me to support my children as a single parent and it provided me with a great sense of fulfillment. I learned the intricacies of the medical system, worked with it, sometimes fought against it and ultimately emerged victorious. Today I smile when I look at Anthony—I see a teenage boy who enjoys life—a life filled with love, dignity and wonderful good times. He has a contagious smile which radiates inner peace and happiness. He has friends, family and acquaintances who love him dearly. He has grown to be an engaging young man who has touched the lives and hearts of many. A number of young people whom we know have entered into the healing, helping professions as a result of their friendships with him.

This year Anthony won four gold and one bronze medals at the New York State Games for the Physically Challenged. He is an active member of the special Boy Scouts troop 900. He has gone on overnight camping trips and even slept in a tent with an electrical hook-up for his compressor and nebulizer. Yes, the human spirit prevails and inspires others. I have learned so much from the years I spent raising my son.

I want to thank my parents, Jackie and Al Milusich, for their constant support and encouragement. Their help and constant love made this book a reality. Their dedication enabled me to give my children a happy, secure life.

My special thanks go to Millie Rosenfeld, CSW of Long Island Jewish Medical Center, New Hyde Park, New York for planting the seed that grew into this book. Millie encouraged me to gather my thoughts first into a pamphlet, and eventually into a published work. And, most especially, she supported me in my plans to bring my son home. She gave me hope and never gave up on me.

I also want to remember a very special lady, Blanche Stern, CSW, whose kind and gentle understanding and support helped me complete this revised edition.

I want to thank Dr. Allan Abramson, Chief of Otolaryngology of Long Island Jewish Medical Center for saving Anthony's life on his first birthday. He was the person who asked me "Mom, what do you want me to do?" as my baby lay struggling for his life. "Save my son," I replied. And he did. He believed in me and helped me achieve my goals.

My fondest thanks to Dr. Gerald Healy, Chief of Otolaryngology, of Childrens Hospital Medical Center of Boston for his review and foreword, but most especially for the expert, tender medical care he gave to my son. He always treated Anthony with reverence and respect, despite his handicapping conditions.

Dr. Mark Goldstein has cared for Anthony over the years and has always been there for both Anthony and myself. His devotion to all our special children has earned him a special place in my heart. He is affiliated with Schneider Children's Hospital of New Hyde Park, New York. My sincere thanks for his review and foreword.

Joan Sheeron, M.A., R.N., has been a special person in our family's life. She, too, is a mother and nurse who has dedicated herself to caring for special children. She helped Anthony achieve some of his goals and contributed the very informative chapter on ventilator dependent children.

I will always be grateful to Eric Nelson for transforming my ideas into many clear, beautiful graphics. He also lived with the struggle of raising a cardiac baby with a trach and suffered through many serious hospitalizations and life threatening experiences with his son, Danny.

And last but most importantly, I thank my sons, Frank and Anthony, for being there, every day, as I typed and edited. They patiently awaited many late dinners as I finished "just this page." But, most of all, they helped "make it work." They showed that, with love, anything can happen.

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A Guide To Pediatric Tracheotomy Care

Function of a Tracheotomy and Indications

A tracheotomy is an incision into the trachea (windpipe) and the insertion of a tracheostomy tube below the larynx (vocal chords or voice box) in order to establish and maintain a patent (open) airway. (see Fig. 1.)

Tracheostomy tubes vary in type and size. Neonatal tubes come in sizes 00, 0 and 1. Pediatric tubes come in sizes 00, 0, 1, 2, 3 and 4. The difference between neonatal and pediatric tubes is the length—pediatric tubes are longer. There are both metal and synthetic tubes. Originally, metal tubes (Fig. 2) were the only type made, but now a large variety of synthetic tubes are manufactured. Metal tubes are rigid and are made of silver or stainless steel; synthetic tubes (Fig. 3) are more flexible, made of PVC (polyvinyl chloride),* silastic or rubber. The type of tube is decided by the physician, depending upon the needs of the patient and the reason for the tracheotomy.

Pediatric tracheostomy tubes are commonly made of synthetic materials which are flexible. They tend to minimize irritation, which reduces complications. Metal tubes are often used during surgical procedures, such as in laser surgery. Later on, they can be changed to softer, synthetic types. Metal tubes can be boiled or autoclaved and reused.

Smaller trach tubes, such as those used for children, are usually either of a one-piece construction (trach tube alone) or a two-piece construction (trach tube plus obturator). Larger ones used for adults are generally a three-piece construction (trach tube, inner cannula and obturator). (Fig. 2.) The obturator, supplied with many trach tubes, serves as an insertion guide, facilitating proper

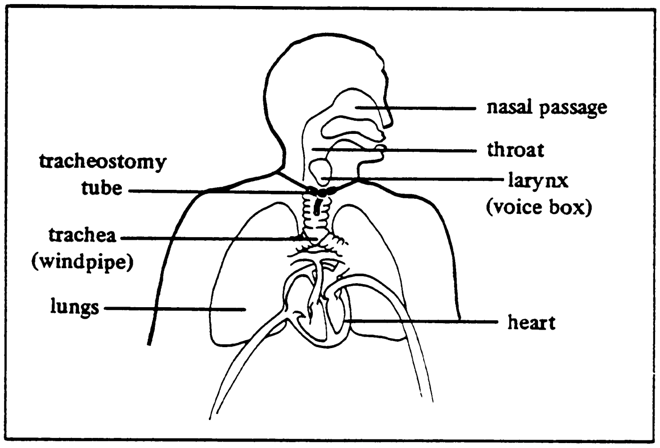

Figure 1. Tracheostomy tube in position in the trachea.

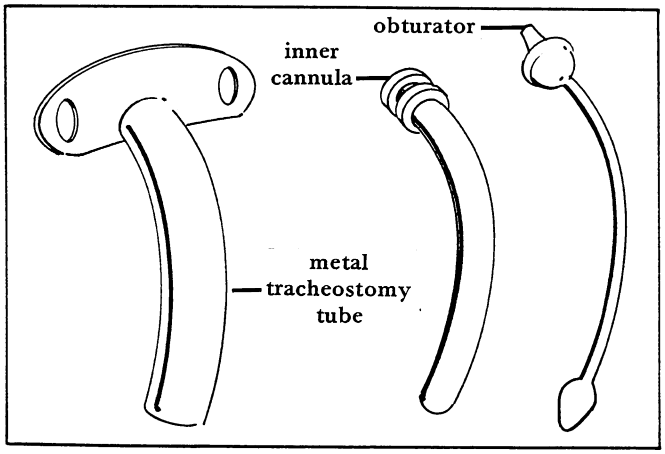

Figure 2. Metal tracheostomy tube. (Courtesy Pilling Co., Phila., Pa.)

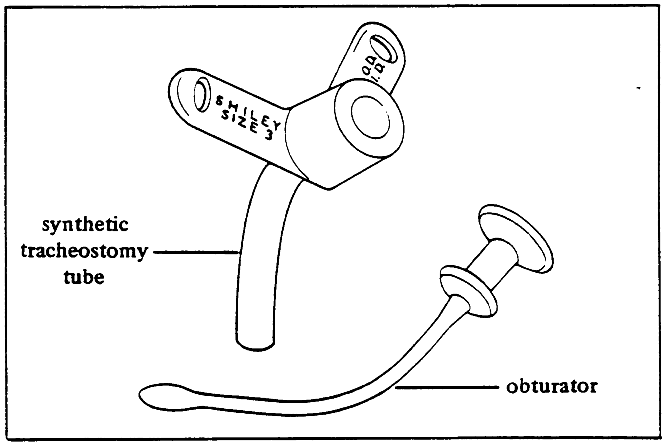

Figure 3. Synthetic tracheostomy tube. (Courtesy Shiley Inc., Irvine, Calif.)

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*By Dow Corning, Midland, Mi.

placement. In larger tubes an inner cannula (inside sleeve) may be removed for cleaning. Cotton twill tapes are included with all trach tubes and are used for fastening around the neck.

Reasons for an individual's requiring a tracheotomy vary from patient to patient and many patients have other conditions which may or may not have an effect on the tracheotomy. It is important that the reasons the child requires the trach are explained in detail by the physician. This enables the family to give comprehensive care to their child. In times of illness or complication they can troubleshoot and work with the medical team to solve problems or new situations and restore their child to wellness.

Today, as we save more and more premature babies (preemies), the indications for tracheotomy have increased. More infants present with diagnoses of subglottic stenosis, tracheomalacia and laryngeal webs. Preemies who were placed on ventilators for long periods of time may later suffer from bronchopulmonary displasia (BPD) and live with trachs and/or ventilators for years. Some of these conditions are parts of syndromes; others are isolated congenital problems. Some children develop recurrent respiratory papillomas and need long-term therapy and/or laser surgery and so require tracheotomies. Vocal chord paralysis and tracheo-esophageal burns are also indications for trachs. Children suffer damage to their airways from prolonged and/or repeated intubation with the subsequent growth of scar tissue. There are also neuro-muscular disorders which require tracheotomy and ventilation.

Whatever the cause, the commonalities of care are basically the same. Make sure your physician and medical team explain your child's care in detail and that you are comfortable with it. Any idiosyncrasies peculiar to your child should be explored. Any questions you may have are good questions. Ask them. Don't feel silly because you don't understand something. You did not enter parenthood planning to care for a child with an intricate medical condition. Your medical team is there to help you give your child optimal care.

In 1993 we have many infants and children with tracheotomies living at home and attending school and special programs. This is a condition which was unheard of twenty years ago. Previously children either outgrew their airway problems or had the airway corrected by reconstructive surgery, but they did not attend school or live at home.

You may meet other families with children with trachs. Your hospital may have a network or parents' group so you can share information, common experiences, and support one another. This is definitely an asset, but, remember, your child is an individual and his case may be different from someone else's. In the end, your physician is the authority in your child's case. Freely avail yourself of the opportunity to discuss changes in your child's condition and his changing needs. In nursing, care plans are frequently changed. At home, you are the expert and you will know best when things need changing for your child.

Chapter 2

Role of the Hospital Nurse Clinician

After the surgery is over and the child stabilizes, you will begin to feel more at ease with the tracheotomy. As days go by and you observe routine care of the trach as carried out by nurses, you can begin, under their supervision, to take an active role in your child's care.

The long term goal for many families will be to bring their child home again.

A successful home care program requires the following elements:

1. The child must be medically stable.
2. There must be family involvement.
3. You need a supportive home/community environment.
4. You need the appropriate equipment.
5. The child needs financial support and/or good insurance coverage.
6. He must have an individualized, coordinated care plan.

In hospitals which specialize in parent-training programs, a nurse clinician or nurse practitioner will take you on a step-by-step course of instruction. Her role is three-fold: teaching, coordination of services and follow-up care.

1. TEACHING. She will be the person mainly responsible for teaching you on a one-to-one basis. She will explain how and why she has to perform certain procedures and she will demonstrate while you observe her. During this process, you should ask questions so that you will be ready to repeat each procedure, one at a time, under her guidance. Her instruction will be augmented by staff nurses, who will provide you the opportunity to practice the skills you are learning under their guidance. The actual procedures will be repeated many times until you become comfortable with them.

It is optimum for children to be discharged into a home where at least two family members are proficient in trach care. Back-up personnel, such as grandparents or close friends can learn trach care and should be encouraged to do so. This is done so that parents can have respite from daily chronic care and can "refresh their spirits." Home care can be tiring and resentment and frustration can build up among family members. It is very important for everyone to get a break from this routine.

You, as a parent, may decide to train others in trach care to help you at home. This can be very helpful to you and your family. Remember to teach them all the items that you learned. Have them take a CPR course at a local hospital, the Red Cross or the American Heart Association.

Teach them trach care and have them demonstrate back to you until they reach a competency level that you are comfortable with. Solicit feedback and have them summarize explanations in their own words so that you know they understand.

2. COORDINATION OF SERVICES. The nurse clinician will coordinate the assistance of other departments which will enable you to bring your child home. The Social Services, Respiratory, and Home Care Departments will be called in for consults. There will be supplies and equipment to order and sometimes environmental modifications to be made. Visiting Nurse Service and/or Home Care nursing must also be ordered. These departments will work together to accomplish this goal.

3. FOLLOW–UP CARE. After your child is home, the nurse clinician will provide follow-up care to make sure that all is going smoothly for your child and family. She will help you with problems or questions you may have. If your child is hospitalized at any time in the future, she will be available to you as a support person and also to provide necessary information.

Chapter 3

Home Care Overview—Emotional Aspects

Most children need emotional support immediately after a tracheotomy. At first the child needs his nurse almost constantly for medical care and reassurance. Later, this need will be shifted to his parents or the person who will care for him. With a trach, many children cannot cry or call for help and therefore may fear being left alone. There is also the frustration of not being able to talk. Some children who previously could talk, now cannot; others might still be able to talk but have reduced volume or may experience difficulty coordinating breathing and talking. Alternate communication systems can be implemented to help the child express himself. Initially, eating may be difficult, but usually children resume eating with time.

Routine suctioning to clear the tube of mucus may frighten and upset the child. As time goes by, he will learn that this provides relief and will make him more comfortable. An extra trach tube can be fastened to a doll or teddy so the child can play with him and practice suctioning and trach care. This therapeutic play will help him work out his own feelings towards his new self-image. During this time, the child needs much understanding and reassurance from his parents and nurse to dispel his fears. However young your child may be, he will soon know that his trach is his lifeline and he will have respect for it and for its care.

The importance of the tracheostomy should be stressed and explained within the child's ability to understand. A young child should be instructed not to pull on the tube and also not to insert anything into the tube. The parent should develop a keen eye and ear to detect potentially dangerous situations for the child while he has the trach.

Once the child is home, it is important to treat him as normally as possible. He should be loved, as well as guided and disciplined, just as he was before the trach. Many parents encounter difficulty in this area. They are often afraid to tell the child "no" when it is necessary. If this happens, the child becomes "in charge" and all family members cater to him. This can ultimately be unsettling to the normal life of the family. The sooner parents treat the trached child as if he were a normal child, the sooner the family will settle into a comfortable way of life.

If there are brothers and sisters, the new needs of the child who now has a trach should be explained to them. It can be startling to hear coughing through a trach tube for the first time or to see mucus expelled. These children also need much reassurance that their brother or sister will be all right, and also that this is not necessarily going to happen to them.

In some cases, siblings feel that they are somehow responsible for the illness. Their fears may be exhibited indirectly, either by difficulty in school, in peer relationships, or in some other way. Parents should watch for signs that their other children are having difficulty accepting what has happened to their brother or sister. The services of a social worker or psychologist may prove helpful to assist the children to verbalize their feelings and gain a fuller understanding of the situation. Some hospitals and special education settings have sibling programs which help children explore and deal with their feelings in these situations. It is very important that the entire family be comfortable with the situation, so the family unit can function well. Hidden anger and resentment can fester and later destroy healthy family life. Be alert for problems among siblings.

In the case of the child who will be attending school, the specifics of his case should be explained in depth to the school nurse, teacher and any other professionals who will be in contact with the child. Routine trach care, as well as the warning signs of dangerous situations, must be reviewed to insure a safe environment for the child to learn and grow. CPR must be taught or reviewed with the school personnel who deal with this child.

School mates must receive instruction on the seriousness of the situation and have to realize that they may never touch or pull on the trach tube. If the classmate with a tracheotomy is unable to speak and appears to be in trouble, classmates should know enough to alert the teacher to his needs.

A child who cannot communicate effectively often develops behavior problems. Professional help may be necessary to help the child and parents cope with the situation.

In some school districts, a nurse may be assigned to the child on a one to one basis, depending on the acuity of the situation. Parents should familiarize themselves with their entitlements under the law and be prepared to petition their local Committee on Special Education for related services. Each school district must, by law, provide parents with copies of Federal Law 94-142 which spells out the law for special education children.

Speech therapy is often needed. Sign language, communication boards