

Home Care of the Child with a Tracheotomy Tube

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Over the past decade, the number of children being discharged from the Children's Hospital of Pittsburgh with a tracheotomy tube in place has risen sharply. The home care of the child with a tracheotomy tube, once believed to be an impossible task, has now become almost routine. The excellent survival rate of these children at home results from the motivation of parents and the extensive training that they receive before the discharge of their child from the hospital. Table 1 lists the diagnoses most frequently encountered in children in whom long-term tracheotomy tubes are placed.

Table 1. *Diagnoses Made in 136 Children with Long-Term Tracheotomy Tubes (Children's Hospital of Pittsburgh, 1968 to 1980)*

Diagnosis	No	Total (%)
Vocal cord paralysis	19	14
Croup	17	12.5
Hemangioma	12	8.8
Subglottic stenosis	11	8
Surgical procedure*	8	5.9
Brain damage**	8	5.9
Down's syndrome***	7	5.2
Brain tumor	6	4.4
Stridor	3	2.2
Juvenile papilloma	3	2.2
Prematurity****	3	2.2
Pierre Robin syndrome	2	1.5
Guillain-Barré syndrome	1	0.7
Cystic fibrosis	1	0.7
Miscellaneous*****	35	25.7

* Includes such procedures as cardiac surgery and tracheoesophageal fistula.

** Includes brain damage received from such sources as battered child syndrome and near drowning.

*** Patients underwent cardiac surgery.

**** Premature infants had long intubations for lung disease, and other surgical conditions.

***** Remaining diagnoses include automobile accidents, tumors, muscular dystrophy, accidents at home, and so forth.

The role of the home care coordinator begins once the family has been informed by the physician that a tracheotomy will be necessary. Support is offered to the family, and the groundwork is laid for future teaching. The age of the child, the capabilities of the parents, the social situation and lifestyle of the family, and fears and concerns that family members may have about home care should all be considered in planning an approach to parent

teaching. Parents will be apprehensive and question their ability to care for the child. They may have questions about the length of time the tube will be in place and the possibility of unwittingly doing something to harm their child.

The home care coordinator should also be sensitive to complications or other medical conditions that may present special problems in care, especially of infants. The baby who must undergo a tracheotomy is often separated from the mother soon after birth and may require a long stay in the hospital. Mothers may experience feelings of guilt or mourning in giving birth to a baby with a defect. If this is the mother's first child, she will need to learn routine baby care in addition to the special tracheotomy care. As soon as she is physically able to do so, the mother should be encouraged to become involved in the baby's care.

A tracheotomy tube in an older child, who can make his needs known to others and who has achieved some independence, is usually not as stressful to parents, especially after the child resumes normal play and daily activities. Sometimes stress can be relieved by introducing parents to other parents who have children with tracheotomy tubes. The parents who are experienced in home care can offer support and encouragement as well as, perhaps, helpful suggestions for care.

After the first 48 hours post-tracheotomy, and if there are no complicating factors, parents can begin to become involved in the care of the child. Holding and feeding the child helps to reestablish parental bonds. Under the supervision of hospital personnel, parents learn to care for the child and his new way of breathing. Knowing when to suction the child is a concern of parents. This judgment is developed as the parent spends time caring for the child in the hospital under our supervision. We encourage parents to spend at least one night with the child before discharge from the hospital. A diagram is used to explain to parents the alteration in the child's breathing and the temporary inability of the child to talk or make noise. However, in all other respects, including eating, the child is normal.

When the tract in the neck is well formed, parents can be taught to change the tube. The tube should be changed at least weekly to avoid occlusion by dried mucus or mucous plug, or whenever there is any sign of respiratory distress. Although initially this task produces the most anxiety in parents, once they have accomplished it successfully they are much more at ease.

A practical, clean rather than sterile procedure has been developed at the Children's Hospital of Pittsburgh for suctioning in the home, and no infections resulting from this procedure have been reported. The home care coordinator should explain the necessary equipment and technique to the parents. The equipment includes: a suction machine, tracheotomy tubes and suction catheters which are washed with soap and water and reused, a cool mist humidifier to be used especially when the child sleeps, cotton twill tape for ties, a dropper bottle to instill saline, and DeLee traps for suctioning when away from home. The suction machine can be rented or purchased at a medical supply store; humidifiers are available in most drugstores; and tracheotomy tubes, catheters, and twill tape are available through the hospital. The cannula of the tube is often shortened for small infants, and the outer cuff on the Shiley tube is sometimes shortened to allow forward movement of the head, especially for infants with neuromuscular problems. The end of the cannula is then smoothed with an acrylic bur drill in the dental department.

Parents are encouraged to treat their child as normally as possible in order to allow normal growth and development, and to use discipline appropriate to the level of the child. Playing with such toys as swings and bicycles should not be forbidden if the child is at an age to enjoy them. Talking to and playing with the child just as for any other child will stimulate normal lingual development; as the child grows, and if no other complications develop, he will follow the usual pattern: first babbling, making noises, then learning to say words. Three of our children go to school and several babies have been camping!

However, developmental delays may occur in infants with vocal cord paralysis or other neurologic problems. Home care planning for these infants should include referral to an infant stimulation program. Because such children often stay in hospital for longer periods of time, the program usually begins in the hospital and involves the parents, who learn a variety of techniques to help their child.

Infants with bronchopulmonary dysplasia and a tracheotomy require extra moisture to the trachea (which is supplied by a nebulizer setup), frequent chest physical therapy and suctioning, and possibly oxygen, an apnea monitor, and an Ambu bag. With diligent care, parents can accomplish satisfying results with these infants at home. These infants also require continued involvement with an infant stimulation/OT, PT program at home.

Some parents quickly learn home care techniques and are anxious to take their child home, whereas others require a longer learning period. The particular situation of the family may require the help of a social worker, and the home care coordinator should make arrangements for this supplemental assistance. Parents should be taught to prevent or manage emergencies at home, such as occlusion caused by a mucous plug, accidental extubation, bleeding, or excessive dryness in the trachea.

Home care of the child with a tracheotomy tube shortens the hospital stay, allowing the child to return to his home environment and a normal lifestyle sooner. The intensive teaching provided by the home care coordinator makes this possible. Until a repeat endoscopy determines that the tracheotomy tube can be safely removed, the home care coordinator provides continuity of care for the family and joins with them in solving problems that may arise in home care. Often practical solutions are found that can then be passed on to other families with similar problems. Home care of the child with a tracheotomy tube has proved to be a valuable and a viable alternative to prolonged hospitalization.