Growing & Thriving with a Tracheostomy

A Complete Guide for Anyone Caring for an Infant, Child,
or Teenager with a Tracheostomy

Kristi Vander Hyde MS, APRN, FNP, BC

GROWING & THRIVING WITH A TRACHEOSTOMY

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AUTHOR
Kristi Vander Hyde MS, APRN, FNP, BC
Family Nurse Practitioner
University of Michigan Health System
Division of Pediatric Otolaryngology

CONTRIBUTORS
Diane Kemp, MS, RN, APRN, BC
Pediatric Nurse Practitioner
University of Michigan Health System
Division of Pediatric Otolaryngology

Kerri and Chris Bowen
Katrina and Domenic DiMassa
Melissa Gallagher
Kurtis and Lindsay Halstead
Jennifer Hefner and Dave Tessier

CONSULTANTS/EDITORS
Diane Kemp, MS, RN, APRN, BC
Pediatric Nurse Practitioner
University of Michigan Health System
Division of Pediatric Otolaryngology

Marci Lesperance, MD, MS
Professor, Department of Otolaryngology - Head and Neck Surgery
Division Chief, Division of Pediatric Otolarynogology
University of Michigan Health System
Division of Pediatric Otolaryngology

PARENT REVIEWERS & EDITORS
Kerri and Chris Bowen
Katrina and Domenic DiMassa
Sylvia Driscoll
Melissa Gallagher
Danisha Green
Lindsay Halstead
Jennifer Hefner and Dave Tessier
Lucy's Parents

GRAPHIC DESIGN & LAYOUT
Kimberly Lennex

ILLUSTRATIONS
Ubin Li

PHOTOGRAPHY
Steven Christian Upton, PA-C

Families of Angel, Caleb, Carson, Courtland, Destiny,
Jackson, Kloe, Laura, Lucy, Mary, Nakaila, Olivia,
and Tyler

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Inquiries (734) 936-5730

Compiled by Kristi Vander Hyde MS, APRN, FNP, BC
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>
> Special recognition goes to the parents who shared their feelings and experiences with their own children at a meaningful and difficult time in their childrens' lives. The parent letters and tips section offers "new" parents hope and helps ease the fear and anxiety that comes with learning that your child will need a tracheostomy.

Finally, to the sweet children and families from whom we have learned so much and who touch us every day.

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INTRODUCTION

MESSAGE TO PARENTS

"From caring comes courage." - Lao Tzu

Welcome. We look forward to sharing in your upcoming adventure of caring for a child with a tracheostomy. We think of this experience as an "adventure" because, while tracheostomy often makes life easier for your child, it can present many challenges for parents and caregivers.

By working with parents and caregivers of children with a tracheostomy, we have learned what families need to face the challenges of caring for a child with a tracheostomy, and develop the abilities, comfort, and confidence necessary to provide safe care.

Knowledge Heals…

We designed this book to be easy to use and to serve as a constant source of information for parents, families, friends and anyone who has an interest in learning more about tracheostomy.

The intent of this book is to:

- ensure the highest quality of care for children with tracheostomies in the home and school setting
- provide complete and up-to-date information about caring for a child with a tracheostomy
- offer a complete look at all aspects of caring for a child with a tracheostomy
- allow parents to customize the binder and include information specific to their child and to make changes over time
- help ease the anxiety and fear that often comes with learning to care for a child with tracheostomy

Diane Kemp, MS, RN, APRN, BC
Pediatric Nurse Practitioner

Zander with his mother and nursing coordinator, Trina

THE CARE TEAM

Your child will be cared for by a number of professionals. With their help and support, you will gain the skills and confidence needed to safely care for your child at home.

Members of the care team for all children undergoing tracheostomy include:

- Surgeon
- Nurse Practitioner or Physician's Assistant
- Staff Nurses
- Speech Therapist
- Respiratory Therapist
- Discharge Planner

In addition to your child's pediatrician, depending on you and your child's needs, other professionals who may be involved in caring for your child.
These include:

- Pulmonary doctors and/or Ventilator Team
- Other medical specialists, surgeons
- Dietitian
- Occupational Therapist
- Child Life Therapist
- Physical Therapist
- Social Worker
- Chaplain

TRACHEOSTOMY TEACHING

You will be working closely with staff who are experts in childhood tracheostomy care.

At least two adults must learn your child's care. You and the second adult ("co-caregiver") will practice all skills before your child can go home.

The co-caregiver must live with you or live very close by. The co-caregiver should be a person you feel you can count on.

- Please invite older siblings, other family members, friends and/or neighbors to receive this training with you.

Parents feel supported and less alone when other family members have some understanding about their child's tracheostomy.

When there are other people in your life who are trained to safely care for your child, you can take breaks and will have help if you become sick or injured.

- Older children and teenagers with a tracheostomy may want to learn their own care. Some kids feel that attending teaching sessions is "too much too soon"; these children can be taught by their parents when they feel ready.

Sooner or later, some older children may be able to assist or perform most of their own tracheostomy care.

Parents have many different feelings when they learn their child needs a tracheostomy. We know this is a stressful time. At any time, please let the person teaching you or your child's nurse know if things are going too fast for you or if you are worried about being able to learn your child's care.

We want you and your co-caregiver to feel comfortable and skilled with tracheostomy care before it is time to take your child home.

On the next page you will find a learning list of the topics and skills that you and your co-caregiver must learn and practice before taking your child home.

You or the person teaching you will check off each learning area or skill as you successfully complete it.

You and your co-caregiver will need to practice the hands-on skills at least 3 times before you take your child home. You can practice a skill as many times as you wish to feel confident.

It is normal to feel scared and nervous at first. You will be surprised at how quickly you adjust.

LEARNING CHECKLIST

LEARNING AREA OR SKILL	PRIMARY CAREGIVER	SECONDARY CAREGIVER
The Basics		
Basic Understanding of Normal Airway, Breathing, & Airflow		
What is a Tracheostomy & Reasons for Tracheostomy		
Why My Child Needs a Tracheostomy		
Types & Parts of Tracheostomy Tube, Trach Tube Ties		
Changes in the Airway Associated with Tracheostomy & Management (Humidification, Air Filtering, Respiratory Secretions, Voice, Swallow, Access to Lungs)		
Risks & Precautions Related to Tracheostomy		
Safely Going Out, Playing, Child Care/School		
Go-Bag Contents & Use		
Use of Humidification (Nose, Mist Mask, Saline Lavage)		
Going Home; Preparing the Home, Family & Friends		
Infection Control, Clean Storage of Supplies		
Preparation, Use, & Handling of Solutions		
Tracheostomy Skills		
Type & Size of Your Child's Trach Tube		
Type & Size of Your Child's Emergency Trach Tube		
Purpose of Suctioning & Signs of Need to Suction		
Reason for Suction Depth		
Suction Depth for My Child's Trach Tube		
Demonstrate Suction Technique		
Proper Use of Saline Lavage		
Managing Possible Mucus Plugs when Child is Breathing		
Managing Possible Mucus Plugs when Child is Not Breathing		
Evaluation of Respiratory Secretions		
Skin Care: Solutions, Monitoring, Evaluation & Treatment		
Demonstrate Stoma Care		
Tracheostomy Tie Change: When, Checking Tightness		
Demonstrate Tracheostomy Tie Change		
Inner Cannula: When to Change, Cleaning		
Demonstrate Inner Cannula Change		
Routine & Unplanned Trach Tube Change: When & Why		
Demonstrate Tracheostomy Tube Insertion		
Demonstrate Tube Removal		
Reuse, Cleaning, & Storage of Trach Tubes		
Potential Emergencies		
CPR		

HOW TO USE THIS BOOK

This book is designed to reinforce and complement the face-to-face teaching you will receive.

- Read about a topic before and after you receive teaching on that topic. This will strengthen your understanding.
- Tell the person teaching you if you have any trouble reading or understanding this book.
- Have a paper and pen when you go through the book. Write down any questions or concerns you have. This will help you to remember to talk about questions with your teacher or child's nurse.
- You can use the book to find answers for any questions that might pop up when you are not with the person who is doing your teaching.

At the back of the book, there are definitions for most of the medical words and uncommon words used in this book.

You will find that certain words in the book are bolded. This means there is a definition for these words in the Glossary.

The "Pull-Out" section in PART V contains pages that you may want to remove and hang close to where you will care for your child at home. Some of the sheets in the "Pull-Out" section have blank lines that you will fill in with details about your child.

Use this book as a guide to teach others to how to care for your child's tracheostomy.

The "mini-training manual" in PART V can be removed or copied to give to people who will be caring for your child.

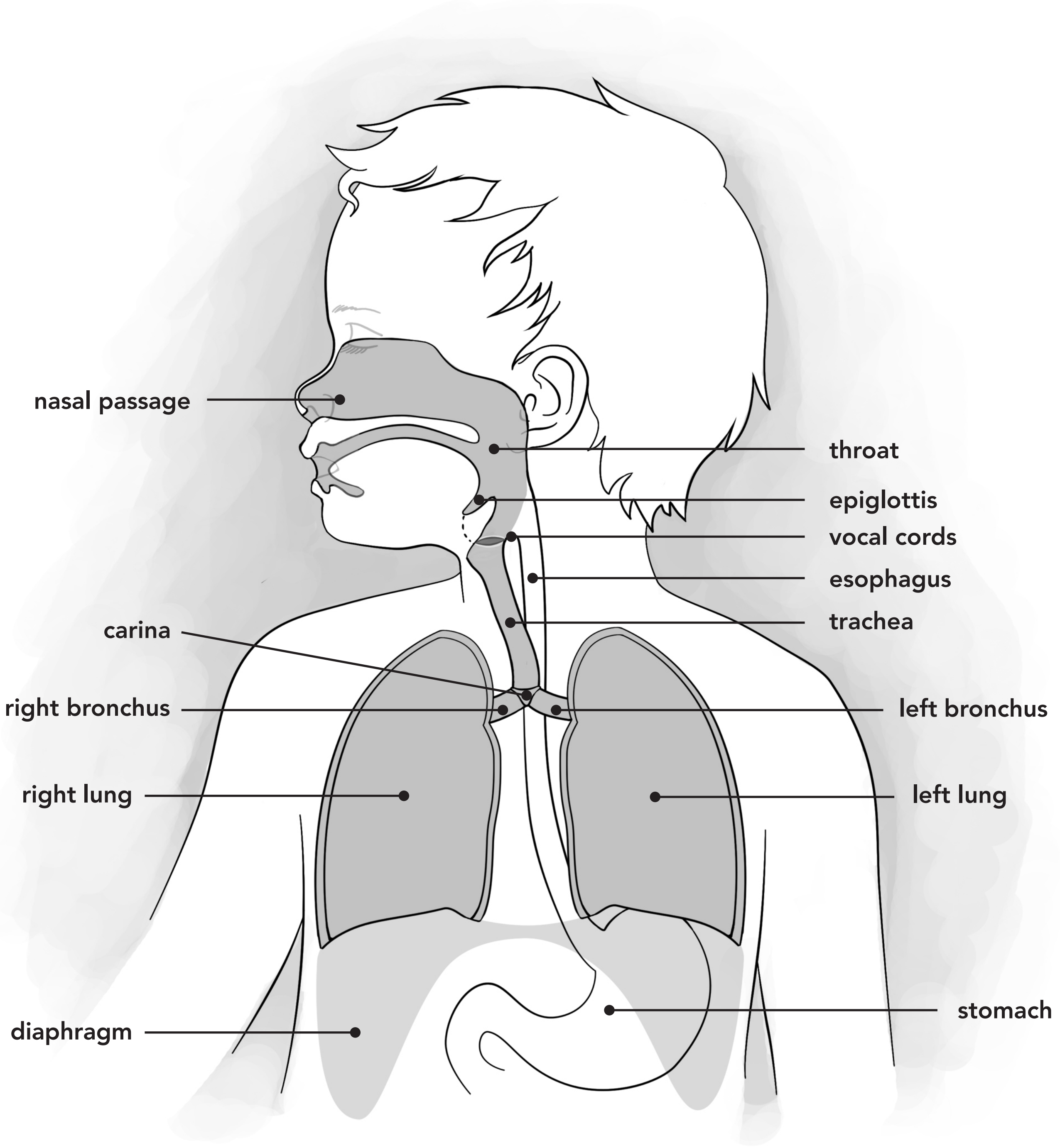
Once you are home with your child, it will help to go through this book every now and then. You may find things in this book that you missed while in the hospital.

Feel free to use this book how you choose. The binder allows you to add what you wish. For example, you may want to add a section for immunization records, appointment slips, business cards, notes from doctor's visits or teaching materials related to other care or treatments your child receives.

We welcome any suggestions you may have about tracheostomy teaching or this book. We are always trying to improve.

PART I: The Basics

The airway is the pathway through which air enters and leaves the body. It is important to have a basic understanding of the normal airway (respiratory system) before we talk about tracheostomy.



PARTS OF THE NORMAL AIRWAY

The normal airway is divided into the upper airway and the lower airway.

Parts & Functions of the Upper Airway

Nose and Mouth
Cleans, warms, and moistens (humidifies) the air we breathe in.

Larynx
A protected passage between the base of the tongue and the lower airway. The opening to the tube that delivers food to the stomach (**esophagus**) is behind the larynx. Two important structures are part of the larynx:

Epiglottis
A flap of tissue which closes off the opening to the lower airway to prevent food from entering the lower airway. Food is then directed into the esophagus.

Vocal Cords (Voice Box)
Made of tissue stretched cross the larynx. The vocal cords open and close. The main purpose is voice. The vocal cords close to keep food and liquid from entering the lower airway.

If food or liquid get past the epiglottis and the vocal cords, a strong cough is triggered to expel the matter and prevent food and liquid from entering the lower airways.

Trachea
An airway passage between larynx and bronchi. The trachea is lined with mucus glands which help moisten the air as it passes through and catch small particles before they reach the lower airways.

Coughing helps keep the trachea clean and free of excess mucus.

The wall of the trachea is composed of stiff but flexible cartilage rings that support the trachea and prevent walls from collapsing to allow for clear passage of air.

The trachea splits into the right and left bronchus. This split is called the **carina**.

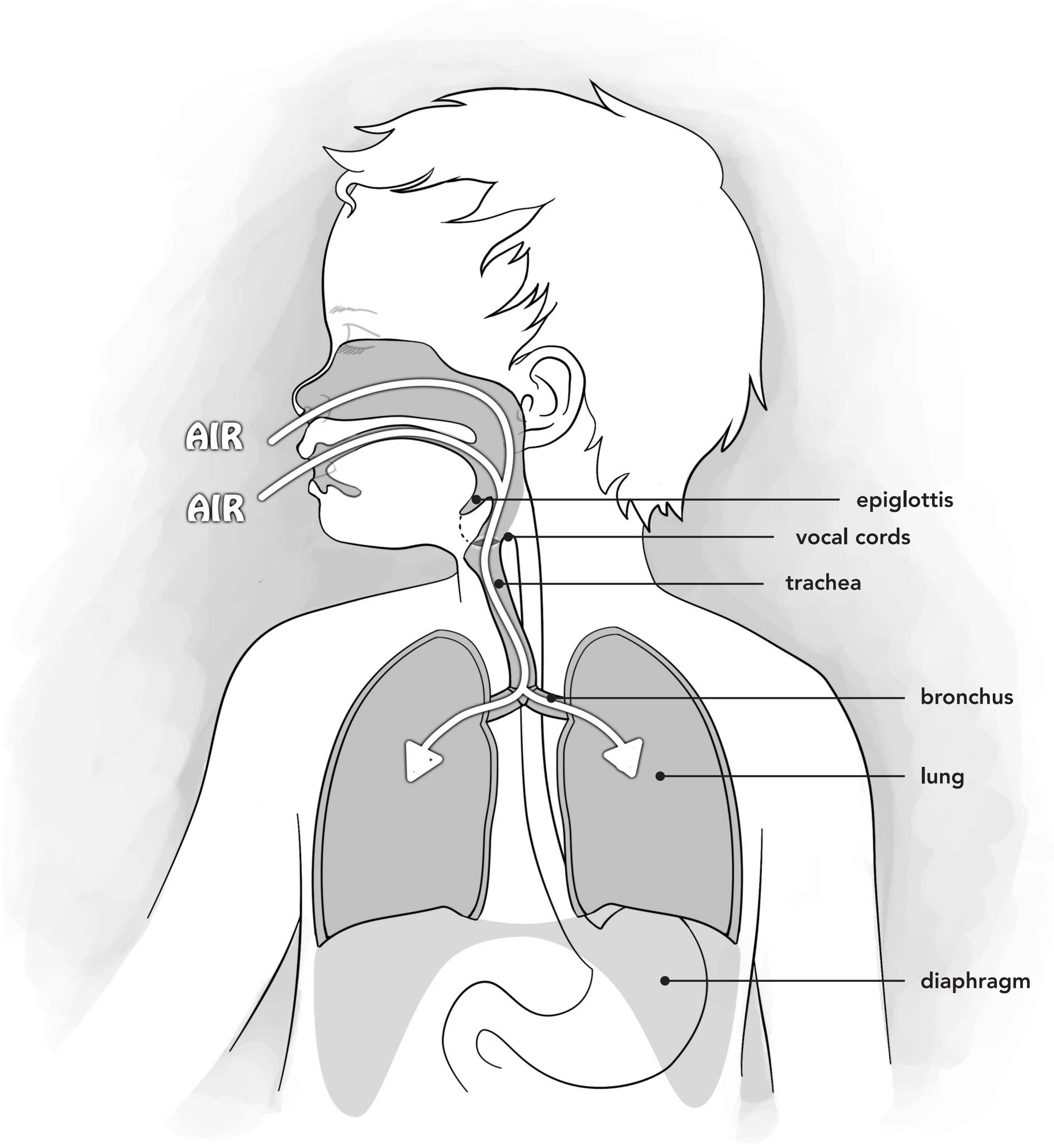
Parts & Functions of the Lower Airway

Right and Left Bronchus
Deliver air to the lungs. Split into smaller and smaller branches.

Lungs
Absorb oxygen from the air and deliver it to the bloodstream. The lungs also absorb carbon dioxide from the blood and release it as waste.

Diaphragm
Large muscle below the lungs involved in breathing

The upper airway and parts of the lower airway normally contain some bacteria and other germs. The lungs normally do not have germs and are considered sterile. Keeping germs out of the lungs is an important function of both the upper airway and parts of the lower airway.


AIR
AIR
epiglottis
vocal cords
trachea
bronchus
lung
diaphragm

NORMAL BREATHING & PATH OF AIRFLOW

The **diaphragm** is a large muscle located below the lungs. The brain and nerves from the spinal cord control the diaphragm.

We are forced to take a breath in (**inspiration** or inhale) when the diaphragm tightens (contracts).

On inspiration, air flows into the nose and mouth, past the larynx and vocal cords, and into the trachea.

The trachea splits into the right and left main bronchus which then branch into the lungs.

The airway ends at the lungs.

The lungs are lined with tiny blood vessels which soak up (absorb) oxygen from the air. Blood delivers oxygen to the rest of the body.

We automatically breathe out (**expiration** or exhale) when the lungs are full.

When we exhale, air follows a reverse path from the lungs, through the bronchus, trachea, past the vocal cords, larynx and out the mouth and nose.

The air we breathe out contains carbon dioxide. Carbon dioxide is a breathing waste product.

A problem at any point in the airway can prevent the body from getting enough air and the oxygen it needs to keep going and support life.

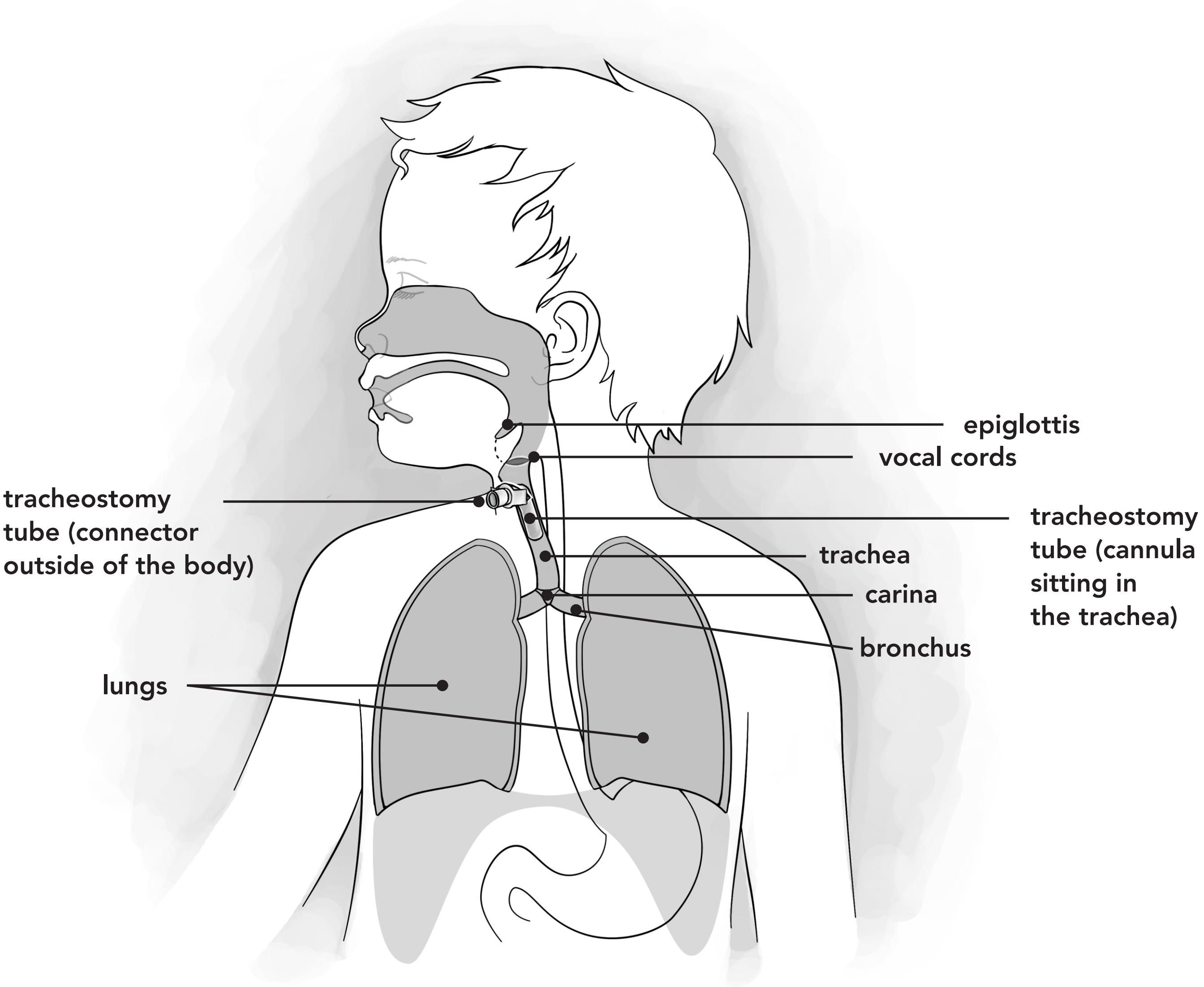
A problem in the airway can also keep the body from getting rid of carbon dioxide which can build up and cause severe problems.

NORMAL AIRWAY STRUCTURE & VOICE

The larynx is a major source of sound in speech. Sound is made by the rhythmic opening and closing of the vocal cords. The vocal cords are open during inspiration and expiration and closed when holding one's breath. When speaking and singing, the vocal cords quickly vibrate open and closed.

A tracheostomy is a procedure that is performed by your child's surgeon in an operating room under general anesthesia.

The actual procedure takes about 30 minutes. However, your child may be in the operating area for a longer period of time to prepare for surgery and to recover.



In a tracheostomy, your child's surgeon makes an opening (incision) in the front of the neck and trachea.

- The opening is made below the vocal cords. The opening in the skin is called a stoma and the opening into the trachea is called a tracheotomy.

You may hear the terms, tracheostomy, tracheotomy and trach used interchangeably.

A tube, called a tracheostomy tube or commonly called a trach tube, is placed into the trachea through the stoma (see illustration above). There are many kinds of tracheostomy tubes. Your child's surgeon will chose a tube that best meets your child's needs.

Once the tracheostomy is made, your child will breathe in and out through the tracheostomy tube (instead of breathing through the nose and mouth; see illustration on next page).

- If your child is unable to breathe effectively on his or her own, a breathing machine (ventilator) can be attached to the tracheostomy tube.

After surgery, your child will stay in the intensive care unit or special care unit. Your child will be kept quiet to allow the tracheostomy to heal.

- Some children need to be sedated to keep them comfortable and help them stay quiet.

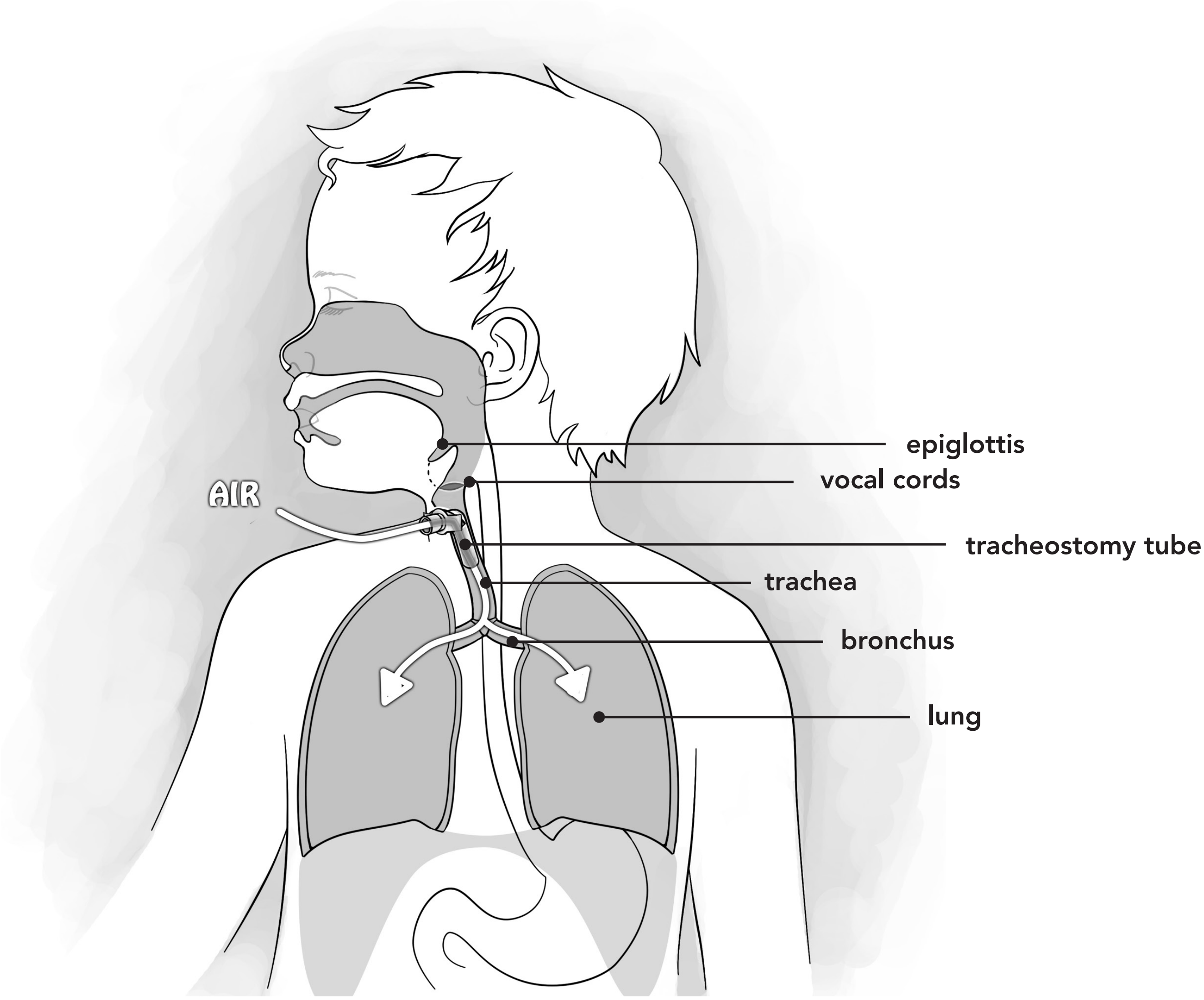
You may not be able to hold your child for a while to keep movement to a minimum.

Some surgeons stitch (suture) the tracheostomy tube in place to keep the tube from accidentally falling out during the healing period.

Three to seven days after surgery, the surgeon will remove sutures and change the tracheostomy tube.

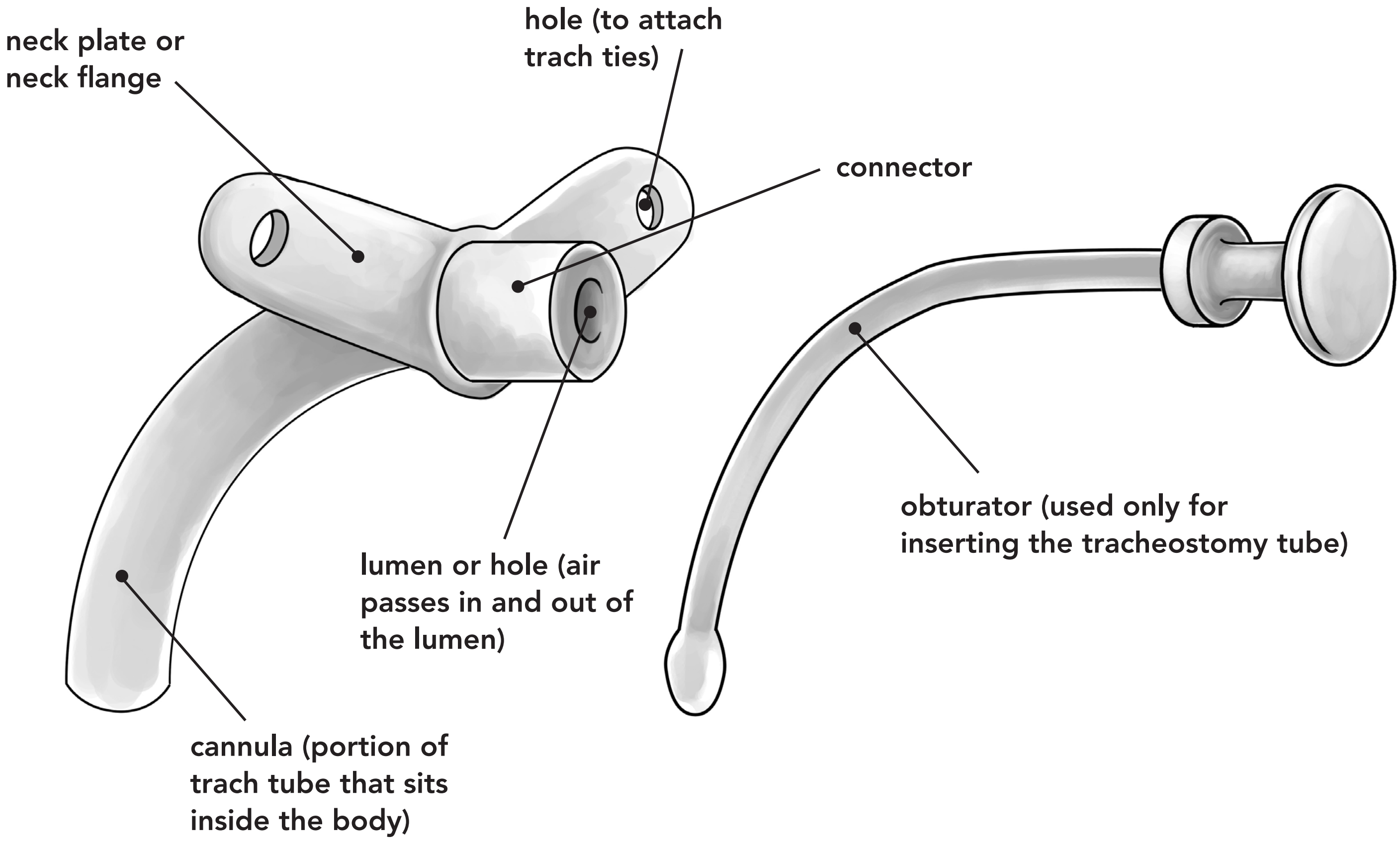
- After the first trach change, your child may be moved to a general care unit. Your child will be allowed to move around and play as much as he or she feels up to it.

Typically, pain or tenderness is greatly decreased about 10 days after surgery, and most children feel no tenderness after 2-3 weeks.



TYPES & PARTS OF THE TRACHEOSTOMY TUBE

Your child's surgeon will determine the size and length of the tracheostomy tube to give the best airway fit and to meet the needs of your child.

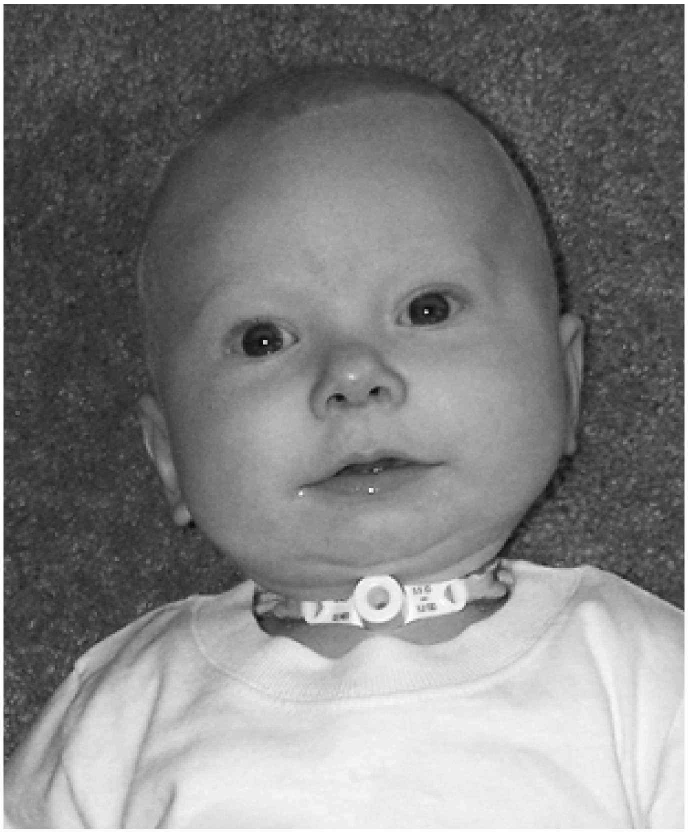


Once your child is feeling better and is moving around, other members of the team will look at your child when he or she is in different positions. They will decide if a different shaped tube is needed to give the best airflow and comfort.

The trach tube does not fit tightly in the airway. There needs to be some airflow (sometimes called an "air leak") around the tube.

- In some cases, there may be too much airflow around the tube. Too much airflow may cause problems for children who are on a breathing machine (ventilator).

If the lungs are not getting enough air because there is too much air leaking around the trach tube, the surgeon may decide that the child needs a larger tube or a cuffed tube to help lower the amount of air leaking around the tube.



Jackson wearing a 3.5 Neonatal Shiley tracheostomy tube.

Inner Cannula

Some brands of adult size tracheostomy tubes have an inner cannula.

- An inner cannula is a small tube that fits inside the tracheostomy tube.

Custom Trach Tubes

For some children, regular trach tube sizes or designs do not work well with their body shapes or airways. These children may need a specially designed tube. Members of your child's tracheostomy team will determine if your child needs a custom trach tube.

Tracheostomy Ties

Tracheostomy tubes are held in place with tracheostomy ties.

The ties are threaded through holes in the tracheostomy tube neckplate and are kept in place around your child's neck with Velcro**.**

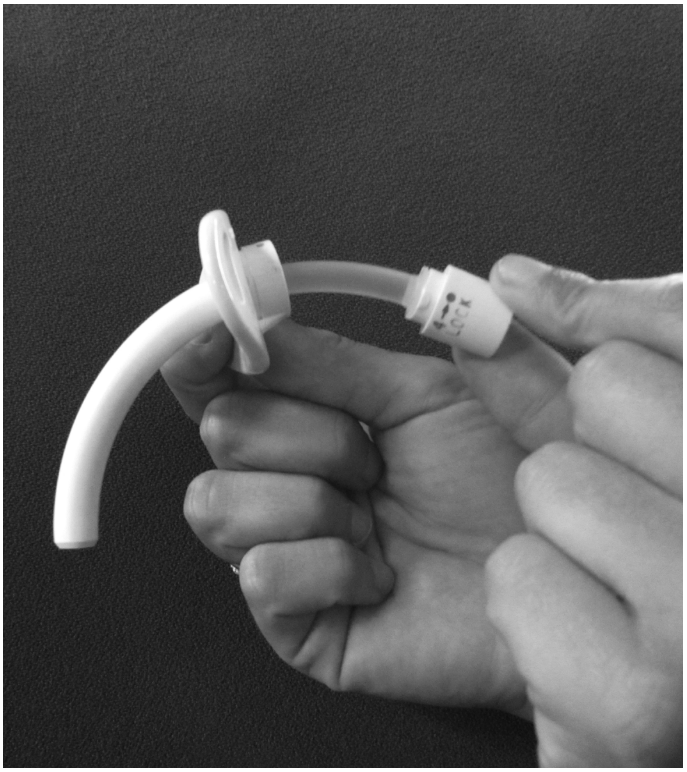
Tracheostomy Tube Measurements

Trach tube measurements that are important are:

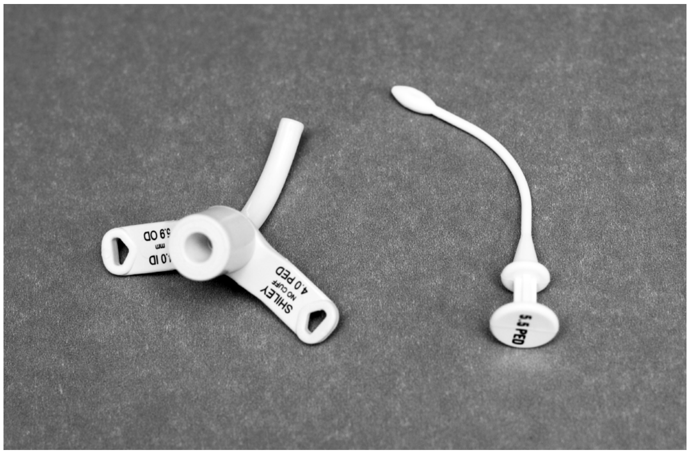
- inner diameter of the cannula (size of the opening)
- outer diameter of the cannula (thickness of the tube)
- length of the cannula (neonatal length, pediatric length, and adult length)

Trach tubes are usually described by the inner diameter, length and brand. For example, if your child has a 3.5 Neonatal Bivona, this means the inner diameter (ID) of the tube is 3.5 millimeters, the length is the neonatal length (that corresponds to 3.5 ID), and the brand of the tube is Bivona.

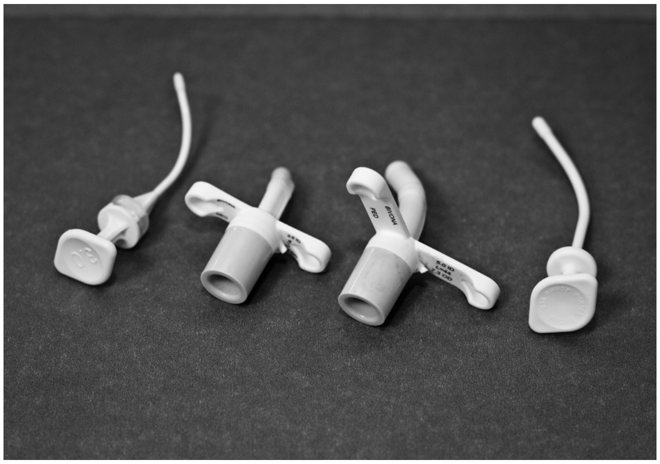
Most often, the trach tube brand, ID, OD and either "NEO" or "PED" are printed on the neck plate of the trach tube.



Removing the inner cannula from an Adult Shiley tracheostomy tube.



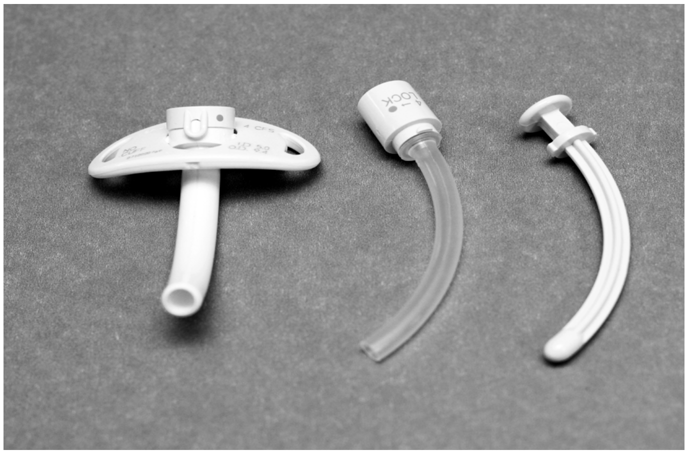
4.0 Pediatric Shiley with obturator



(Left) 3.0 Neonatal Bivona with straight neck plate
(Right) 3.0 Neonatal Bivona with a V-neck plate;
Obturators shown on either side of tubes

(Left) 5.0 Pediatric Bivona Flextend with straight neck plate
(Right) 4.5 Pediatric Bivona Flextend with V-neck plate

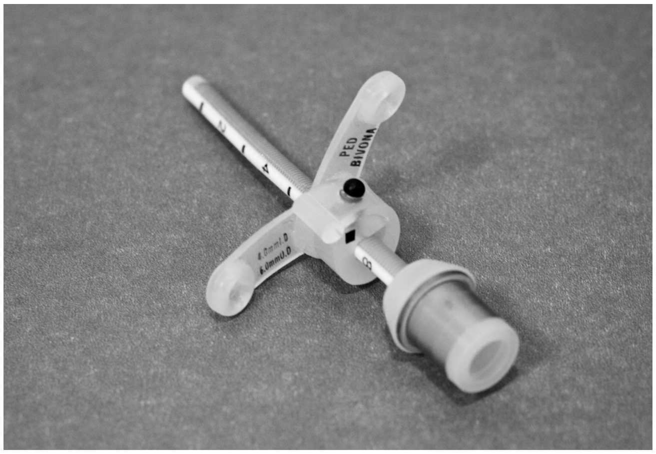
3.0 Neonatal Bivona with tight-to-shaft cuff and V-neck plate



Adult 4.0 Shiley with inner cannula and obturator

5.0 Adult Bivona

Metal trach tube (adult sizes only)



Bivona Hyperflex (specialized tube)

REASONS FOR TRACHEOSTOMY

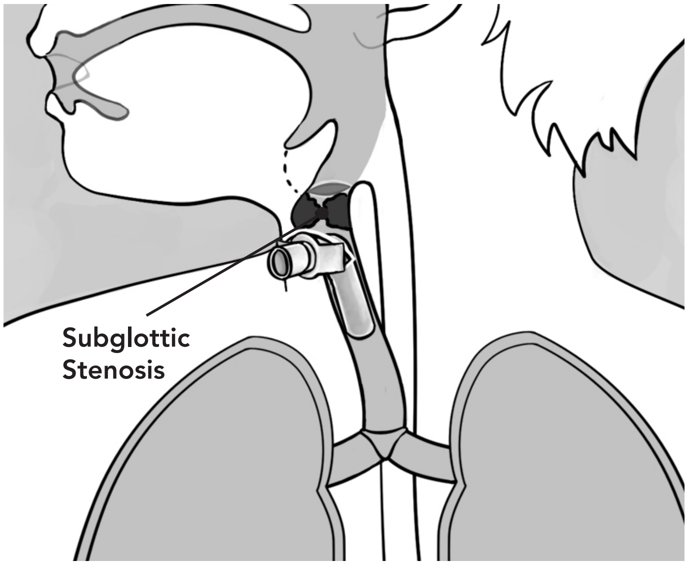
Children need a tracheostomy for many different reasons. Your surgeon will help you understand why your child needs a tracheostomy. Below are some common reasons a child may need a tracheostomy:

Airway Problems

Some children have an abnormality that prevents or reduces the flow of air through the airway passages.

There are a number of abnormalities and conditions that cause these obstructions in the airway. Some examples include:

Subglottic Stenosis
The airway is narrow below the vocal cords. Some children are born with a narrow airway. Narrowing can also be caused by scar tissue or swelling after intubation, trauma or infection. (See illustration at right.)



Laryngomalacia and Tracheomalacia
The tissues supporting the voice box or trachea are immature and floppy and may collapse during inspiration. Air cannot flow well through the collapsed portions of the airway.

This condition can be very mild and not need treatment at all, or it can be very severe and require tracheostomy.

Micrognathia
If the lower jaw bone is unusually small, there is a decrease in the size of the opening to the airway at the back of the mouth. When the lower jaw is small there is less room for the tongue. The tongue may be pushed back into the throat, further blocking the opening to the airway.

Vocal Cord Paresis/Paralysis
One or both vocal cords are not moving or opening to allow enough air flow to and from the lungs.

Masses of the throat
Growths such as cysts or tumors in or near the airway may block airflow. This is an uncommon reason for tracheostomy in children.

Lung Problems

Children who have unhealthy or immature lungs may need mechanical ventilation (breathing machine or ventilator) until their lungs heal and mature.

These children need a tracheostomy tube to make an opening in the airway for ventilated air to reach the lungs. Example:

Bronchopulmonary dysplasia

BPD is a lung disease due to premature birth. The lungs are inflamed and scarred.

Damaged lungs do not absorb oxygen and cannot handle even mild colds.

There is no cure for BPD. With time and breathing support, new lung tissue will grow to make up for the damaged lungs.

Bronchomalacia (floppiness of the bronchi)
Often occurs as part of BPD due to incomplete building of airway support tissues. Air has a hard time flowing through floppy airways.

Courtland with ventilator attached to his tracheostomy tube

Musculoskeletal or Neurological Problems

The diaphragm may work poorly or not at all in children who have had a spinal cord injury, or who have a neurological or muscular condition. These children often need a tracheostomy for long term mechanical ventilation.

Some children have a neurological disorder where the respiratory control center in the brain is affected. The control center does not "alert" the body to breathe during sleep, and in some children, at other times. This is called Congenital Central Hypoventilation or Central Apnea. These children need a tracheostomy so they can use mechanical ventilation when they sleep.

Some children have poor muscle tone which affects their swallow. These children may have trouble keeping saliva out of their airway. Saliva tends to pool around the larynx and then seep into the lower airways and lungs. This can lead to **aspiration pneumonia**.

A tracheostomy tube allows saliva and oral secretions to be suctioned from the airway before the saliva and secretions reach the lungs.

- Several spine deformities such as scoliosis can restrict the ability of the lungs to fully inflate. If the lungs cannot inflate properly, the body does not get enough oxygen.

Some children who have severe spine deformities need a tracheostomy so they can use mechanical ventilation to help inflate their lungs.

Laura wearing a customized 8.0 Adult Bivona. Laura wears her trach tube capped during the day and is on a ventilator at night.

FOLLOW-UP AFTER TRACHEOSTOMY & DISCHARGE FROM THE HOSPITAL

The surgeon who placed your child's tracheostomy tube will want to see your child in the doctor's office a few weeks after your child has gone home.

- After the first visit, your child will see the surgeon, a nurse practitioner, or a physician's assistant every 3-12 months.

- Depending on the reason for your child's tracheostomy and your child's surgeon's usual practice, your child may be taken to the operating room every 6-12 months for a **direct laryngoscopy and bronchoscopy**.

Direct laryngoscopy and bronchoscopy allows the surgeon to look closely at your child's airway to check for improvement and possible problems.

HOW LONG WILL MY CHILD HAVE A TRACHEOSTOMY?

Tracheostomy is temporary for most children. Some children outgrow the problem. Some children need surgery to correct their airway problem.

- Airway surgeries are usually performed after a child has reached a certain age and/or weight.

Children with conditions that do not improve with growth or cannot be corrected by surgery may need their tracheostomy forever.

It is important that you understand how long your child will likely need his or her trach tube.

Discuss how long your child may need the tracheostomy with the surgeon who performed your child's tracheostomy.

Discuss the medical goals your child will need to reach to no longer need the tracheostomy tube. Ask your child's doctor how your child will be checked along the way to find out if your child has reached those goals.

DECANNULATION

Children who no longer need their tracheostomy are eventually "decannulated." Decannulated means the trach tube is taken out. (You will also hear about "accidental decannulation." Accidental decannulation is when the trach tube falls out unexpectedly.)

The doctor who placed the trach tube will decide when your child is ready for decannulation. The pulmonary team will also be part of this decision if your child has had lung problems or has been on a ventilator.

When it looks like a child is ready for decannulation, most doctors teach parents to gradually start capping the tracheostomy tube. This helps the child get used to breathing through his or her nose and mouth.

Once the child is comfortably capping the trach tube during all waking hours, the surgeon will take one last look at the airway to make sure it is healthy.

The trach tube is NEVER capped during sleep while at home.

After making sure the airway is healthy, the child will stay in the hospital to make sure he or she can breathe through his or her nose and mouth with the trach tube capped while sleeping. If this goes well, the trach tube is removed the next day.

After decannulation, some stomas close on their own. Other children may need surgery to close the stoma.

Not all doctors use the capping method. Ask your doctor about the process for decannulation.

Carson wearing a cap on his 3.0 Neonatal Shiley tracheostomy tube

After tracheostomy, your child will breathe through the tracheostomy tube. There may be some, but usually very little airflow through the mouth and nose (or above the level of the tracheostomy tube). There are changes when air is taken in through the trach tube rather than the nose and mouth.

HUMIDIFICATION & WARMTH

With a tracheostomy, air flow bypasses the nose and mouth. This means there is less chance for the air to get warmed and moistened before it reaches the lower airway.

Moisture (**humidification**) and warmth help keep the lungs and airway healthy. The airway and the lungs can become irritated if constantly exposed to cold or dry air.

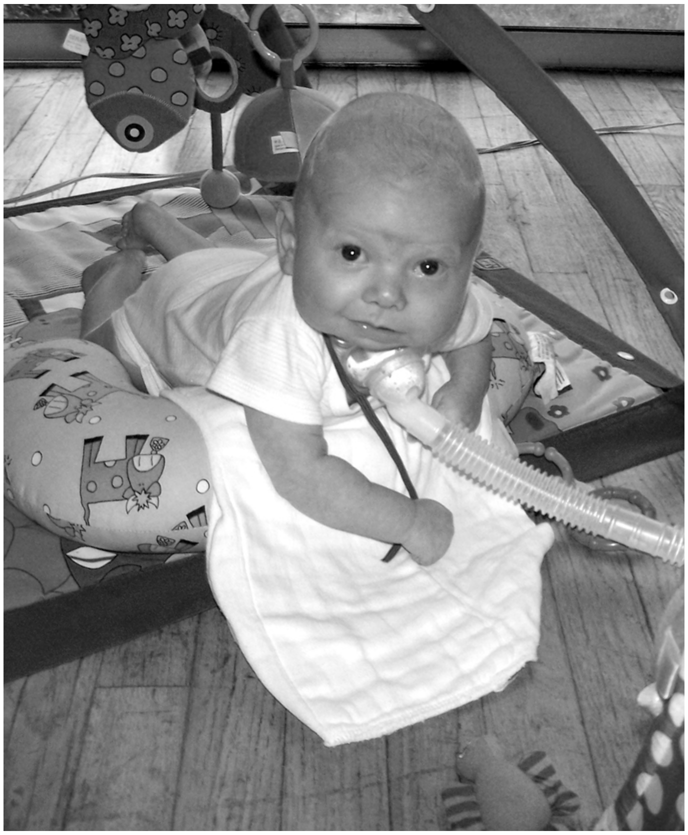
Humidification also helps keep mucus thin to reduce coughing and to make it easier to keep the tracheostomy tube free of mucus build-up.

Mist Mask

When resting or sleeping, your child will wear a mist mask (also called a trach mask) over the tracheostomy tube. Infants will wear the mist mask most hours of the day.

The mist mask is connected to a machine (compressor) which gives off humidified air.

Infants and children under 2 years of age usually get warmed, humidified air. Children older than 2 years of age often do not need warmed air, only humidified air.



Jackson wearing mist mask to help humidify the air entering his tracheostomy tube

Artificial Nose

When your child is active and not wearing the mist mask, he or she will wear an artificial nose. The artificial nose fits over the opening of the tracheostomy tube.

It is possible for the artificial nose to get plugged with mucus. So, your child must NEVER wear the artificial nose when not being observed or when sleeping.

Infants can get too dry if they wear the artificial nose for more than a couple of hours at a time.

- There may be times when you have to be away from home and your infant has to wear the artificial nose for a long time. If this happens, we suggest putting a few drops of sterile, normal saline into your child's trach tube every hour or so to help keep the airway moist.

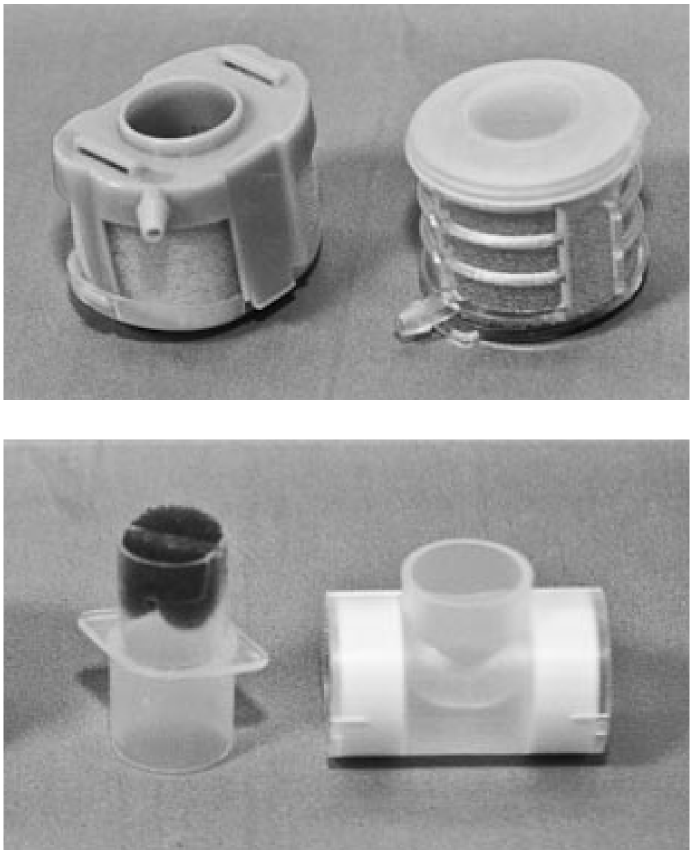
Other Ways to Keep Air Warm & Moist

Try not to use wood stoves and fireplaces. These dry out the air.

In very cold weather, put on artificial nose and loosely place a blanket or cotton scarf over the tracheostomy tube to prevent cold air from entering the airway.

Children who are on ventilators get warmed, humidified air through the ventilator. Some portable ventilators do not give humidified air.

The ventilator team will teach you how to give humidification when your child is using a ventilator that does not supply humidified air.



Various artificial noses

Olivia wearing her artificial nose at the beach

INCREASED COUGH & MUCUS

The tracheostomy tube may irritate the airway. Airway irritation can cause some children to cough more and produce more mucus, particularly during the first few weeks after tracheostomy tube surgery.

Also, mucus tends to build up in the trachea because the trach tube prevents the normal flow of mucus.

Trach ties that are properly snug (see CHAPTER 11) will help keep the tracheostomy tube from wiggling in the airway too much. This will help reduce cough in some children.

Keeping the airway humidified will help reduce cough and keep mucus thin and flowing.

VOICE

The tracheostomy tube blocks some of the airflow to the vocal cords.

Airflow may be further blocked:

- *in children who have swelling after tracheostomy or have a narrowed airway in the space above the tracheostomy tube and below the vocal cords*
- *if a child needs to wear larger size trach tube to supply enough air to the lungs*
- *if a child has a cuffed trach tube*

In addition, most of the air returning from the lungs escapes through the tracheostomy tube.

A child's ability to make sound depends on the child's age, lung health, development, health of the vocal cords, the type of trach tube the child is wearing, or other health problems.

- Your child may have a hard time speaking if the vocal cords are scarred and weak.
- Infants often cannot breathe out forcefully enough to push air past the tracheostomy tube in order to reach and vibrate the vocal cords. Some infants make no sound while others will make sound only when breathing out is forceful, such as when crying, coughing, or when excited.
- Most older babies and children can make sound as long as they do not have a severe blockage around the vocal cords or other health conditions that may cause a problem with speech.
- Some children discover they can make sound if they cover their trach tube with a finger or chin.

Tyler wearing a Bivona Flextend and artificial nose

Speaking Valve

In some cases, a speaking valve can be attached to the trach tube to help children make sound or speak. The speaking valve allows a child to breathe in through the trach tube but does not allow air to escape out the trach tube when the child breathes out. Air is forced to travel around the trach tube and up through the vocal cords.

Your surgeon will decide when your child is ready to try a speaking valve. A speech pathologist will check if your child can manage a speaking valve and will teach you and your child how to use the speaking valve.

Developing & Encouraging Speech

Children who cannot speak may learn sign language. They can also be taught to use pictures or symbol boards to communicate. Sign language can help children who have some speech or are expected to be able to talk at some point.

- A speech pathologist will follow your child closely.

- Parents and family members can help their children develop speech by talking to their infants and children as much as possible. Point out objects to your child and name them. Singing and reading to your infant and children are also important in helping build speech.

Nakaila trying her speaking valve for the first time

SWALLOWING

The esophagus (food tube) is a separate tube from the airway. It is located behind the trachea. The opening of the esophagus is next to the larynx. Normally, when we swallow, the epiglottis closes off the larynx so food and liquid cannot enter the airway.

Carson enjoying a snack

Sometimes, the tracheostomy tube affects the ability of the epiglottis to make a tight seal. If this happens, food and liquids may leak into the airway. When food or liquids leak into the airway, this is called **aspiration**. Aspiration can cause aspiration pneumonia.

Most children do not have trouble with aspiration after tracheostomy, especially if they did not have swallowing problems before surgery.

Some children only have trouble with thin liquids. For these children, parents are taught to thicken the liquids they give to their child.

To be safe, after tracheostomy and before your child is allowed to take any food or liquids by mouth, the speech pathologist will check your child's swallow.

- The swallow test may be as simple as giving your child a small amount of liquid with blue dye and then suctioning the tracheostomy tube to see if any blue dye got past the epiglottis and entered the airway.

Your child's surgeon may ask for a formal swallow study if there is a suspicion of swallowing problems or if there is a question of aspiration after the blue dye test.

The swallow study uses an X-ray to get a closer look at your child's swallow to determine the cause of aspiration.

REDUCED ABILITY TO CLEAN OR FILTER AIR ENTERING THE AIRWAY

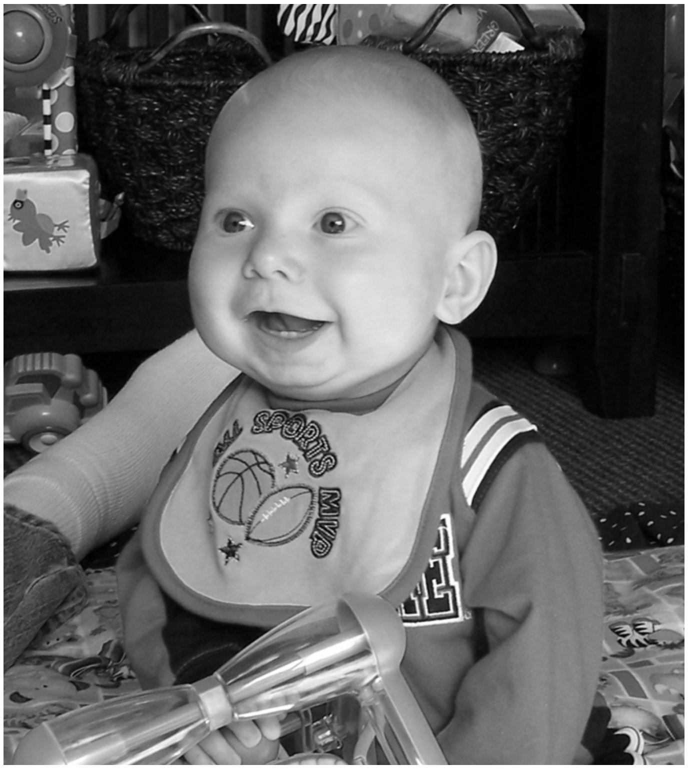
One of the primary jobs of the nose and mouth is to clean or filter the air before it reaches the trachea. With a tracheostomy, air, and anything in the air, bypasses the nose and mouth and goes directly into the trachea and then the lungs. It is important to protect your child from germs, dust and droplets that float in the air, smoke, strong fumes, and other small particles.

The following safety measures are necessary:

- Use good infection control, including handwashing and clean handling and storage of supplies. This helps keep germs away from your child. (See CHAPTER 8 for additional recommendations for preventing infection).
- Do not use powders on or around your child.
- Do not use spray cans (aerosol sprays).

If you must use an aerosol spray, close the door to the room where you are using the spray. Keep the door to that room closed, and keep your child out of the room for 20 minutes after spraying.

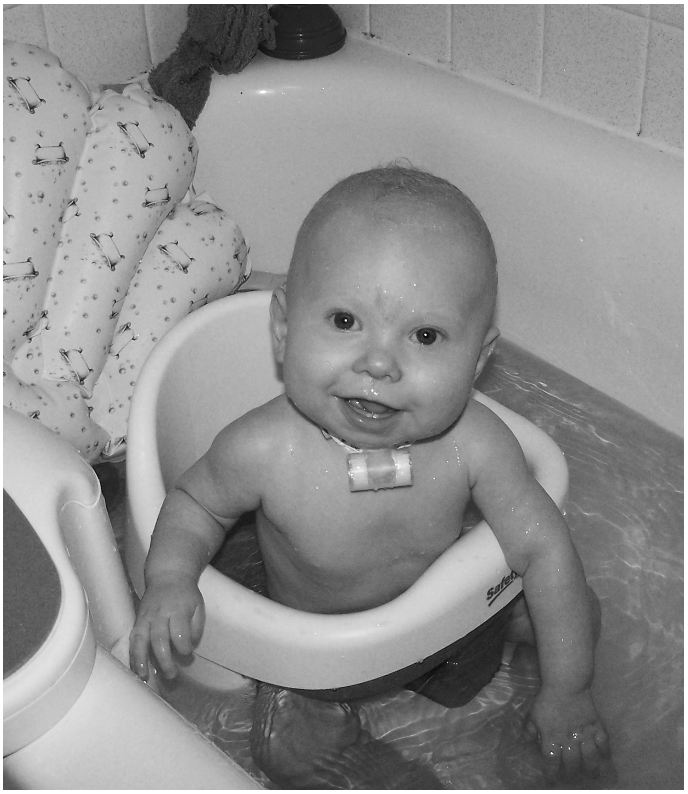
- You may use pump sprays in the same room with your child as long as the sprayer is not pointed at your child and your child is at least 3 feet away from the spray.
- Do not use chlorine bleach, ammonia or other strong cleaning products near your child.
- Do not use plug-in room fresheners, especially those with fans that blow the scent out into the room. Do not use scented candles or incense in the house.
- Do not use anything around your child's trach tube that might shred or shed. This includes tissues or cloths that are not lint-free. Do not use store-bought products such as Q-tips around the trach tube.
- Keep your child away from fuzzy or fur clothing and stuffed animals.
- Do not allow your child to play in a sandbox.
- Do not allow your child to be near cigarette smoke.
- Keep your child away from dusty areas. Keep your home as free from lint, dust and mold as realistic.
- Keep your child away from pet hair. You will need to keep your pets away from your child's supplies, your child's bed and wherever you do tracheostomy care such as suctioning and tracheostomy tube changes.
- Use the artificial nose, loose cotton scarf, loosely tied cotton bib (no plastic backing) or a surgical mask over your child's tracheostomy tube in smoky, smoggy or dusty places that you cannot avoid.



Jackson wearing a cotton bib over his trach tube

DIRECT ACCESS TO LUNGS

The tracheostomy bypasses some of the normal body systems that work to protect the lungs from water and larger objects. Precautions are necessary.



Jackson taking a bath, sitting in a chair that gives good support. Wearing artificial nose to keep splashes out.

- Do not put your child in the shower and use caution with baths.

Use shallow water in the bathtub. Keep water from splashing into the tracheostomy tube. A trach mask or artificial nose can be worn during baths for added protection.

When washing your child's hair, carefully pour water over the head with a cup as your child lies back with head supported.

Never leave your child alone in the bathtub. Always have a hand on or near your child.

- No swimming.
- No wading for small child. The risk of falling is too great.
- Keep your child away from small toy parts or other objects that are small enough to pass through the tracheostomy tube.

Parents and caregivers must be aware of the risks of tracheostomy.

RISK FOR TRACHEOSTOMY TUBE OBSTRUCTION OR BLOCKAGE

Obstruction or blockage of the tracheostomy tube is the most serious risk to children with a tracheostomy tube. The tracheostomy tube must stay open and free of blockage so your child can breathe.

Mucus that builds up in the trach tube can block the tube. Mucus that is thick from lack of moisture is also more likely to block airflow through the tracheostomy tube.

Airflow through the tracheostomy can also be blocked by objects that accidentally fall into the tube or by materials that cover the opening of the tube.

To lower the risk of the tracheostomy tube becoming blocked or obstructed:

- Keep the trach tube free of mucus by suctioning excess mucus from the trach tube.

You will learn how to suction to keep mucus from building up, drying out, and plugging the tracheostomy tube.

- Keep mucus thin with proper humidification.
- Do not cover the tube with anything that does not allow air flow.
- Small children may be interested by the tracheostomy tube and will see you put the suction catheter into the tube. It might be tempting for small children to put their fingers, food or other objects into the tube.

Do not allow small children to be with your child without close supervision.

- Keep small toy parts away from your child.
- Do not let your child wear necklaces.
- Do not dress your child in clothing that tightly covers the tracheostomy tube. Clothing and fabrics that allow air to flow through, such as loose fitting cotton-backed bibs and lint-free clothing and scarves are fine.

Do not use plastic-backed bibs directly over the tracheostomy tube.

In CHAPTER 12 and in PART III, you will learn how to tell if your child's tracheostomy tube may be blocked or plugged.

You will learn to change the tracheostomy right away if you think the tube may be blocked.

THE TRACHEOSTOMY TUBE ACCIDENTALLY FALLING OUT (DECANNULATION)

The tracheostomy tube may fall out of your child's stoma for many reasons. Perhaps the ties were too loose, or the child was tugging on the tube. If a child is on a ventilator, the breathing tubing may catch on something and then pull on the tube.

In some children, it is not always clear that the tube has fallen out.

The stoma may stay open for a period of time so the child does not look like they are having trouble right away.

Also, sometimes the tube may slip out of the stoma and stay tied to the neck so you may not see that the tube is actually out.

- The stoma will eventually begin to close. Then, it may be hard to re-insert the tube.

The trach tube must be inserted immediately after it is found to be out, even if your child looks like he or she is breathing okay. Things can change VERY quickly. You will learn how to insert the tube urgently in CHAPTER 12.

Properly secure the tracheostomy tube with tracheostomy ties, and check snugness of ties throughout the day to help prevent accidental decannulation. (In CHAPTER 11, you will learn how to secure tracheostomy ties.)

There are steps you can take to keep ventilator tubing from pulling on the trach tube and to keep your child from pulling on the tracheostomy tube.

In PART III, you will learn these measures and others for preventing accidental decannulation.

CONSTANT SUPERVISION

The risks of tracheostomy tube blockage and decannulation are two important reasons for making sure that your child is constantly and directly being watched.

Your child must NEVER be out of the sight of an adult for more than a minute or two.

Your child MUST have a sound monitor when asleep.

There must always be an adult within shouting distance, who is trained and competent in providing both every-day and emergency tracheostomy care, including CPR.

Constant and direct supervision is especially important with infants and small children who may not know when they are in trouble and are unable to seek out or call for help.

INCREASED RISK OF INFECTION

Bacteria and viruses (commonly known as germs) must get inside the body in order to cause illness. These germs can get into the body through the eyes, nose, mouth, and other body openings.

The tracheostomy tube is another entry point for germs. The tracheostomy bypasses a large portion of the upper airway, which usually helps keep germs from entering the lower airway.

The following practices are necessary to prevent infection:

The number one and best way to keep your child away from germs that cause illness is to wash your hands before having contact with your child, your child's supplies, and before doing any tracheostomy care.

Ask/teach brothers and sisters, family, and visitors to get into the habit of washing their hands after nose blowing, using the bathroom, and after any contact with body fluids.

Ask/teach brothers and sisters, family, and visitors to get into the habit of washing their hands when entering your home and before touching or holding your child.

If your child is older, teach your child good handwashing practices.

- Cover your mouth when you cough or sneeze. This will keep germs from flying through the air and from soiling surfaces. Be sure to immediately wash your hands after covering your mouth for a cough or a sneeze.
- Keep your child's tracheostomy tube and surrounding skin clean and dry to help prevent infection causing germs from growing around the trach tube and stoma.
- Keep your supplies clean. Only use clean supplies with tracheostomy care.
- Do not expose your child to people who have colds or other contagious illnesses. If this is not possible, ask people with cough, runny nose, sneezing and/or fever to wear a mask when in the same room with your child.
- Consider limiting close contact with non-family members during the cold and flu season.
- Use a sanitizer to clean public surfaces your child may have contact with, such as grocery cart handles or restaurant high chair trays. (Make sure sanitizer is dry before allowing your child to go near a freshly sanitized surface.)
- Make sure immunizations are up-to-date as recommended by your child's pediatrician.

See CHAPTER 8 for additional infection prevention measures.

Taking Your Child Out /Go-Bag

You will be able to take your child shopping, to the playground, or to visit friends and family like any other child. Your child should be able to enjoy the world outside of home. When you go out, you need to be prepared and have all of the equipment you need to perform usual tracheostomy care as well as emergent care.

Be able to get help if you need it. If you have a cell phone, always have it fully charged and always bring it with you. If you do not have a cell phone, be sure to have a plan for how you will get help if you need it.

GO-BAG

The "Go-Bag" is a bag or container that holds all of the supplies you will ever need to perform usual or emergency care of your child's tracheostomy. You can choose any kind of bag or container that works for you. It is critical that you have these supplies close at hand at all times (even when you are at home).

GO-BAG CONTENTS

The Go-Bag includes the Portable Suction Machine and the following supplies:

A. **Spare tracheostomy tube**
The same size your child is wearing with the ties attached; to use if your child's tube falls out (including spare inner cannula if your child's tube has an inner cannula)

B. **Tracheostomy tube that is one size smaller than your child's usual tube with ties attached (Cuffless unless instructed otherwise)**
To use in case you are unable to insert the same-size spare tracheostomy tube

C. **Obturator of the tracheostomy tube your child is wearing**
To use for trach tube insertion

D. **Water soluble lubricant**
To use when inserting the tube

E. **Resuscitation bag (sometimes called an "AMBU-Bag") with face mask and trach adapter**
For giving your child breaths

F. **Pair of Scissors**
For cutting/trimming ties

G. **Extra set of trach ties cut to fit your child**

H. **Pair of Hemostats**
For pulling ties through trach tube holes if needed

I. **5 Vials of Normal Saline**
For suctioning and moisture

J. **2 Suction catheters of appropriate size of your child's trach tube**
For suctioning

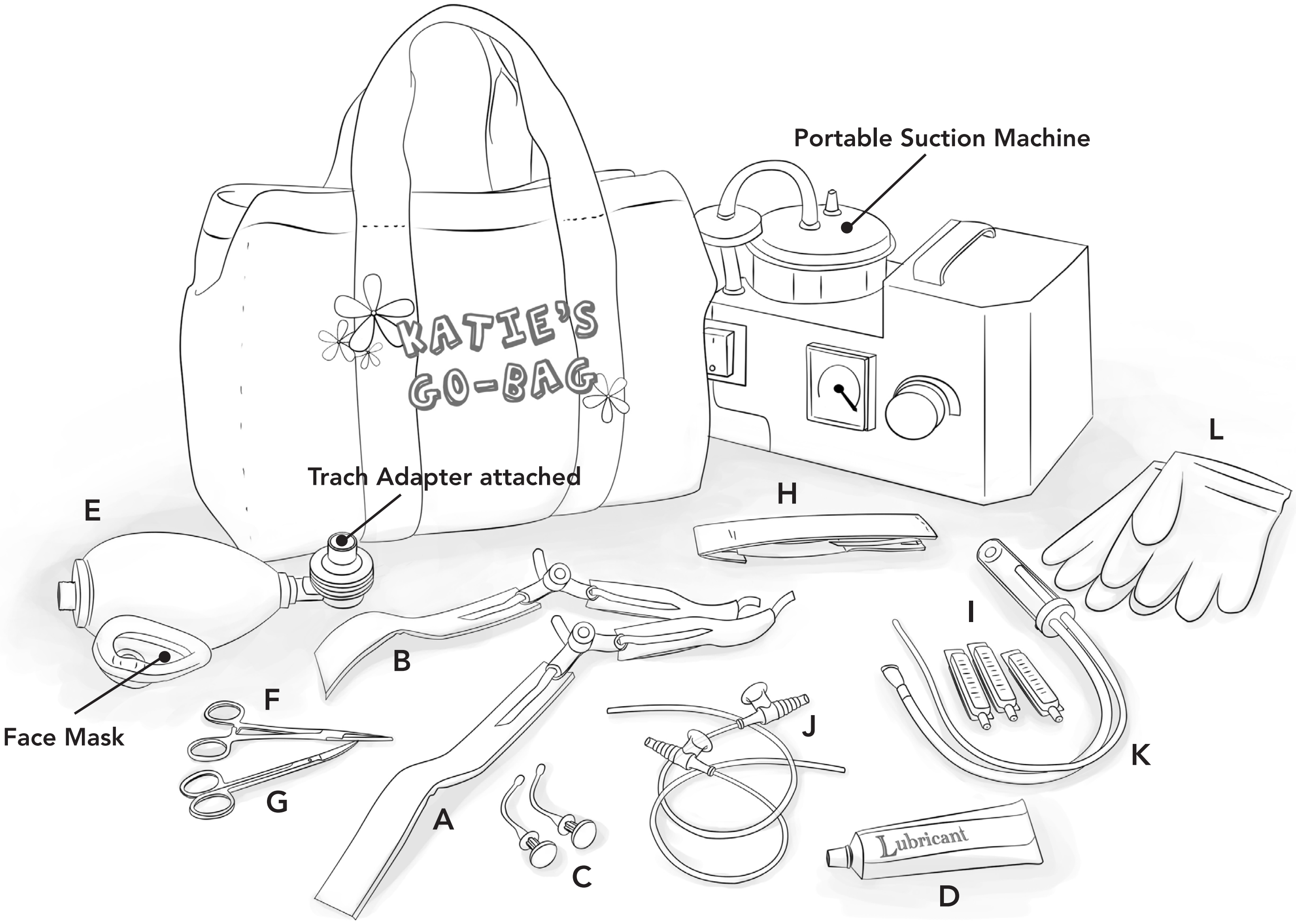
K. **Delee Suction unit**
To use if suction machine is not working or if the battery runs out

L. **Gloves**

M. **Syringe for Deflating Cuff (not pictured)**
If your child has a cuffed tracheostomy tube

N. **2 Suction catheters of appropriate size for the emergency tube (not pictured)**
If the size is different from usual suction catheters

- ALWAYS check the Go-Bag before going out to make sure it contains all of the supplies listed above.
- ALWAYS keep your portable suction machine plugged in at home so it is fully charged when you are ready to go out. Make sure suction machine works properly on the battery before you go out. Bring cord with you.
- You will learn more about these supplies and how to use them in the "Tracheostomy Care" chapters.



OTHER SUPPLIES PARENTS HAVE FOUND HELPFUL TO KEEP AT HAND OR STORED IN THE GO-BAG

Locking type plastic bags
To store and organize supplies; place used and dirty supplies in a plastic bag until you have a chance to clean them. This way, the dirty supply cannot contaminate the bag or other clean supplies.

A small flashlight
To use, for example, if you need to suction in the dark

Alcohol hand sanitizer

Sanitizer wipes
For cleaning public surfaces

Three-prong plug adapter
For plugging in equipment that requires a 3-prong socket

Car Lighter Adapter
For charging/plugging in equipment in the car

Extra Artificial Noses

It will be helpful to look for a stroller that will carry all supplies. Here is an example of a good stroller. There is a baby in there!

HUMIDIFICATION

Use artificial nose and normal saline to help keep airway moist when away from home. See CHAPTER 3 for additional information on humidification.

PROTECTING THE AIRWAY FROM COLD OR WINDY WEATHER & DUST

Have your child wear an artificial nose or speaking valve when going out to help filter and warm the air.

- If it is very cold out, you may want to use a non-shedding scarf or kerchief tied loosely over the tracheostomy tube (along with the artificial nose or speaking valve).

PLAYING WITH OTHER CHILDREN

It is important that your child plays with other children.

- Play must be supervised.
- Children under the age of 5 must never be left alone with your child.
- Do not allow your child to play rough games. Ask your child's surgeon about participating in sports.

Carson in the snow

Olivia playing in leaves

Tyler having fun

CHILD CARE & SCHOOL

Children who have a tracheostomy can attend school. Children can also attend child care, as long as the child care has the staff and resources to safely care for your child.

- Your child must take his or her Go-Bag and portable suction machine to school or child care.
- There must be a person in the school or child care setting who is immediately available and has been trained in tracheostomy care and emergency measures, including CPR with a tracheostomy.

Once you have received training and are comfortable and confident with your child's care, you can train school staff. CPR must be taught by someone who is certified to teach CPR, such as a Red Cross teacher.

The individual who will care for your child must have inserted a tracheostomy tube in the past or practiced at least one tracheostomy tube insertion on your child while you observe.

- See letter to schools in the PART V, "Pull-Out" section. This letter tells schools and daycares what must be in place before your child is safe to attend school.
- Public Law states that all children are entitled to free and appropriate public education.

Your child is entitled to any services that are necessary for such attendance.

Most states require a 90-day notification period so they can prepare employees to assure your child will be safe at school.

TRAVELING WITH YOUR CHILD

Your child can travel with you whether by car, plane, boat, bus or train as long as you have your Go-Bag supplies, suction machine, and a place where you can charge the battery if needed.

- Check with the ventilator team about travel if your child is on a ventilator.
- Carefully plan all travel.

1. Figure out how long you will be gone and how much of your supplies you will need to take with you.

Always take more than you need in case your return home is unexpectedly delayed.

2. Call your supply company and check if they have a branch near your destination in case you need additional supplies.

Ask about being able to get a humidification machine from a local supply company so you do not have to pack yours.

3. Get a plug adapter for the car so you can plug suction machine into the car lighter.
4. Make sure the place you are staying has grounded (3-prong) outlets and that the electricity service can handle your child's equipment.
5. Call the emergency department of the local hospital near your destination. Make sure they can manage a child with a tracheostomy and any other health problems your child has.

If they are unable to treat your child, ask how far away the nearest hospital is that can.

6. Call the local ambulance company and ask how long it will take them to get to where you will be staying in case your child needs emergency medical attention.
7. If traveling by plane, check with the airline before buying your tickets to make sure you can travel on that particular airline with the equipment your child requires.
8. Pack a copy or two of the Emergency Contacts and Information sheet from PART V. Put sheet in a place where you will be able to access it quickly.

Caleb on vacation, ventilator and all.

While your child is still in the hospital, there are things you can think about and do to get your home ready.

Family members are often looking for ways to be helpful and supportive. They may welcome the opportunity to look into some of these things for you—don't be afraid to ask.

NOTIFYING FIRST RESPONDERS

In most communities, the fire department is the first to respond to a 9-1-1 call. In other communities, it may be the police or other emergency medically trained personnel.

It is a good idea to find out who first responds to 9-1-1 calls in your community. Contact that responder to let them know you have a child who has a tracheostomy and is at risk for requiring emergency attention.

Give the first responder precise directions to your home. Many first responders will make a "dry run" to your home to make sure they are prepared.

- Make sure your home address is easily seen, even in the dark.

PHONE

You must have a working phone at all times. You need to be able to make emergency calls and your doctor needs to be able to reach you if needed.

Ask to speak to the social worker about help in obtaining a phone if you do not have a phone.

- Have a back-up plan for mobile phones that may lose their charge and for portable phones that will not work when the power is out. It is a good idea to have a corded phone that can be used if the power goes out.

ELECTRICITY

If you live in a home with unreliable electricity, contact your landlord or an electrician about updating your electric service. The social worker can help you with this if you have concerns.

- It is a good idea to contact the electric company to let them know that your child is medically dependent on electricity. Ask if your residence can be prioritized for getting power back on in the event of an outage.

PEDIATRICIAN

Have a discussion with your child's pediatrician to make sure he or she is comfortable caring for a child with a tracheostomy. The pediatrician must also be willing to work with you in coordinating your child's care with other medical specialties as needed.

- Once home, you will need your pediatrician to evaluate your child if you are concerned about respiratory infections or skin problems around the tracheostomy tube.
- When your child is discharged from the hospital, your pediatrician will receive a letter that summarizes your child's hospitalization, including the reasons your child required a tracheostomy.

SOUND MONITORS

You must have a good sound monitor so you can hear your child at night and during the day when you are in another room.

WHERE YOUR CHILD WILL SLEEP

Think about where you will want your child to sleep. Your child's crib or bed can be placed in the same room with you or your child can sleep in his or her own room with a sound monitor. It depends on your family situation and your comfort.

- Some parents have their child sleep in the parents' room indefinitely.
- Other parents start out with the child sleeping with them, and as they gain comfort, they move the child into his or her own room with a sound monitor.
- Most children can go at least 5 hours without the need for suctioning when they are asleep.
- Some parents choose to set an alarm to wake up every 2 hours to suction their child until they learn exactly what their child's suction needs are during the night.
- Think about bed placement. It is best to put the bed near an electrical outlet for plugging in equipment.

If possible, it is helpful to have both sides of the bed away from the wall to allow easy access from either side of the bed.

If your child is in a crib, it is best if the crib has rails that lower on both sides.

- It is helpful to have a table next to your child's bed for easy access to supplies.
- Keep in mind that equipment will create additional noise and possibly warmth in the room where your child is sleeping.

Jackson's room setup. Crib away from walls. Humidifier (compressor) on left. Sound monitor on right. Optional video monitor attached to bed.

SUPPLIES

The surgical service that placed your child's tracheostomy will prepare a list of the tracheostomy supplies you will need at home. They will give this list to the discharge planner. The discharge planner will meet with you and help you choose a medical supply company.

Typically, supplies will be delivered to your home a couple of days before your child is ready to go home.

Someone from the supply company will meet with you at your home or in the hospital to teach you how to use the suction machine and humidification machine.

You will be surprised at the amount of supplies you will receive each month.

Before you go home, start thinking about how and where you will store these supplies. Some families clear out a bookcase, dresser drawers, or changing table drawers for supplies.

- Think about where you will spend most of your daytime hours when at home. You will want to store supplies wherever you will be spending most of your day, as well as in your child's bedroom.
- You may want to set up some type of portable supply container that you can easily move around with your child.
- Some parents store a few days worth of supplies in an easy-to-reach area.
- The bulk of the supplies can be stored in an out-of-the-way area, such as a shelf in a closet or a large plastic container that can be stored under a bed or in a closet.

Try to not make any drastic or expensive changes or purchases for supplies until you are actually home and caring for your child for awhile.

- Once you are home, you may learn that what you thought would be perfect does not work as well as you imagined.

After the first supply delivery, supplies are usually delivered monthly and as needed.

The supply company will either deliver supplies automatically, or will teach you how to use a monthly checklist to mark the supplies you need each month (occasionally you will have an excess of some supplies and may not need certain items every month).

Make sure you understand what your supply company expects you to do so you will get the supplies you need each month.

The Bowen Family's storage pantry. Supplies are stored by type in covered plastic bins.

Sophie with her mother and aunt

BROTHERS & SISTERS & OTHER FAMILY

Talk about your child's tracheostomy with your other children and family. Speak about the tracheostomy in a matter-of-fact manner.

Showing your acceptance and comfort with the tracheostomy helps others become comfortable with the tracheostomy.

- Encourage other family members to visit while you are still in the hospital, observe tracheostomy care, and play with your child.

Seeing that the tracheostomy tube has not "changed" your child will help them become comfortable and give you the support you need.

- You may have spent a lot of time away from home caring for your child in the hospital. Allow and encourage your other children to express their feelings.
- Plan for special activities and private time with other children when they visit the hospital.
- Bring your other children into the hospital to visit as much as possible. Show them how you care for their brother or sister. They will feel a part of things if you allow them to help. Younger brothers and sisters can do simple tasks, such as handing you a piece of equipment. Older children may be able to participate in tracheostomy training.
- Think about activities you can give to brothers and sisters to prepare for your child's homecoming.
- Think about how you might be able to plan for breaks from the hospital so you can spend time nurturing other important relationships in your life.

YOU

It is also important to think about how you may be able to get some time for yourself.

- You need time to meet with friends, have private or quiet time, or keep up with any hobbies or activities that are important to you.
- If you work, take this time to make arrangements with your employer and complete any paperwork that might be needed to allow you to spend time with your child in the hospital to learn their care.
- If you are going to return to work, think about childcare and who can be trained to properly and safely care for your child.
- Ask if there are any other parents you can talk to who have cared for a child with a tracheostomy at home.
- Consider checking out websites or online parent support groups for parents of children with tracheostomy or for parents of children with the same medical condition your child has.

It is not unusual to feel grief over your child's illness. If you feel you are not coping with your sadness, if you are having trouble moving forward, or are feeling alone and panicked, ask to speak to the social worker.

PREPARING FOR DISCHARGE DAY

Think about whether you will want visitors the day you get home. Some parents like to have one or two people meet them at home to help them settle.

- Before you go home, speak honestly to family and friends about what will make you most comfortable in terms of their help.
- If you planned for visitors, once home, you may decide that you are ready for them to leave sooner than you expected or you may want them to stay longer than planned.

Warn visitors ahead of time that you don't know what you will feel like or how long you will want to have company.

- If you planned on being on your own the first day, you may suddenly decide you want somebody around.

Make arrangements with supportive family or friends to be "on-call" during your first day home.

- Think about the first week home. You may want to schedule visitors for certain days to spread out company and help.
- Consider going home a day or two before discharge to clean the house, do laundry, or go grocery shopping, so you will not need to think about these things for a week or so.
- If you have been sleeping at the hospital, make arrangements to sleep at home the night before discharge day to assure a good night's sleep.

Angel and her brother

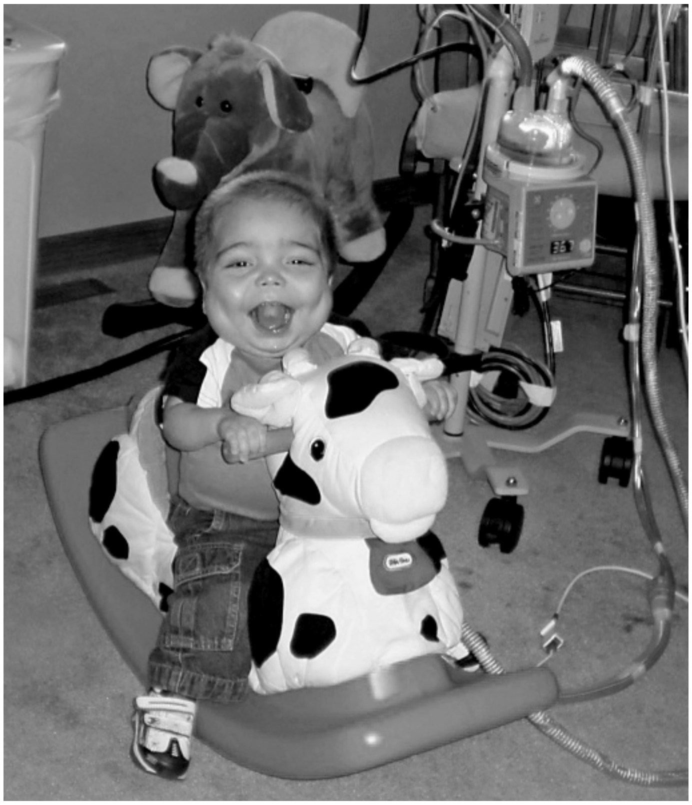
You have been setting your sights on home since the first day of your child's hospitalization. All of those involved in your child's care while in the hospital have made sure that you are properly trained, are confident, and have the knowledge, equipment, and support to safely and expertly care for your child on your own.

Despite all of the preparation and assurance and, even though the idea that being home may sound like the most wonderful thing in the world, the reality often feels a little scary. This is normal.

- Parents who are bringing their first baby home may feel particularly nervous at first. So much is new.
- Be patient with yourself. It will take time to settle into a routine and prove to yourself that you can do it.
- Take your days slowly at first. Don't expect too much of yourself.
- If you have a friend or family member with a flexible schedule, arrange for that friend or family member to be "on-call" for a while so you can contact him or her if you want help, company, or are simply feeling overwhelmed.
- It is important that you find ways to get out of the house or take breaks from being the sole caregiver for your child.
- It is especially important that you spend good amounts of uninterrupted time with the other important people in your life, such as other children, spouses, significant others, and family.
- If there is someone who is available and trained to care for your child's tracheostomy, plan for that person to babysit so you can spend special, uninterrupted time with brothers and sisters.

TRAINING OTHERS TO CARE FOR YOUR CHILD

Keep in mind, once you are actively and comfortably caring for your child at home, you will be the expert in your child's care. This means you will be able to train others to care for your child. In PART V, "Pull-Out" section, there is a Mini Tracheostomy Teaching Manual. You can use this "Babysitter Manual" to help teach others.



Happy Caleb

Courtland enjoying his swing set

Training Others To Care For Your Child On Their Own

Consider training a trusted friend or family member to *independently* care for your child so you can safely leave your child alone with him or her.

Watch him or her practice all skills, particularly suctioning and a tracheostomy tube change. Make sure he or she performs these skills correctly before you leave your child in his or her care.

Those who care for your child on their own need to be trained to perform all care including recognition and management of emergencies.

They will need to learn CPR from a certified instructor, such as the Red Cross.

Prior to leaving your child alone with a friend or family member, he or she must practice caring for your child for a few hours on his or her own while you are around.

Training Others To Care For Your Child While You Are Nearby

If you do not have a friend or family member who can care for your child on his or her own, consider training a friend or family member in just a few key skills.

This will allow you to work on a project, take a nap, or plan special play time with your other children, yet remain within shouting distance to attend to any problems.

Those who care for your child while you are nearby should:

1) Be familiar with your child and be able to recognize when he or she is acting differently

2) Practice selected skills and know the following:

- *» Operation of suction machine and suction technique*
- *» How to recognize signs of respiratory distress*
- *» Specifically, when they need to call for your help*

HOME NURSING

Typically, the hospital discharge planner will arrange for a home health care nurse to come by within 24 hours of your first day home and on the day of your first trach tube change at home.

After the initial visits, the home health care nurse will plan visits around your needs.

Some families and children require daily visits for awhile. Some children and families are fine with just one or two visits.

Some children require private duty nursing. Private duty nurses usually spend several hours per day, a few days per week, caring for your child on their own or with you around, at your home.

- The discharge planner will work with you and your child's doctor to determine if your child needs private duty nursing and if your insurance covers this service.

The discharge planner will work with you and the nursing agency to decide on a schedule that works with your needs and the availability of nurses in your area.

- If you have private duty nursing, remember that you are still the expert in your child's care. Nurses will have a variety of backgrounds and will need to know specifically how to care for your child.
- Sit down with nurses who are new to the home and go over your child's care. The nurse should care for your child the same way you have been taught to.

You can use the "AT - A - GLANCE Tracheostomy Care" sheet in PART V to review your child's care with nurses. At a minimum, private duty nurses must know:

» how to perform all skills in the same manner described in this book

» the content, use and location of the Go-Bag

» your child's name, date of birth, your home address and phone number in case they need to call 9-1-1

» how to reach you, and they must have a list of emergency numbers close at hand.

Infection Control, Storage of Supplies, Solutions

Remember, the tracheostomy tube serves as an entry point for germs. Therefore, it is important that you adhere to infection control practice to help prevent infections.

HANDWASHING

Hands must be washed or sanitized prior to any activity involving the tracheostomy or tracheostomy supplies.

- Soap and water work by removing dirt and germs from your skin.

If your hands are wet or visibly soiled with dirt or body fluids, then you must use soap and water to clean your hands. Wash your hands for at least 30 seconds.

- Hand sanitizers work by killing the germs on your hands. Hand sanitizers are unable to get to germs that are embedded in any dirt or body fluids that may be soiling the hands.

If your hands are not visibly soiled with dirt or body fluids, you can use an alcohol hand sanitizer to clean your hands.

PRINCIPLES OF CLEAN TECHNIQUE

"Clean technique" is a way of doing everything to make sure the tracheostomy tube, site, and tracheostomy supplies remain as free of germs as possible.

- Clean technique is used whenever handling the tracheostomy tube, stoma, or tracheostomy supplies.

Examples of Clean Technique

- Using clean hands (freshly washed) before touching the skin around the stoma or before handling any tracheostomy supplies.
- Throwing away a suction catheter that has accidentally fallen on the floor or has touched anything that may not be clean.
- Using containers that are freshly washed and dry for all solutions.
- Using "No-touch Technique." No-touch technique is a clean technique method to help keep an item clean and free of contamination. It involves not touching any part of a device or supply that will have direct contact with the inside of your child's body.

For example, learn to not touch the part of the suction catheter that will enter the trach tube, even if your hands are freshly washed.

The same is true for the part of the trach tube that has contact with and sits inside the stoma (the cannula); do not touch the cannula when handling the tracheostomy tube.

CLEAN STORAGE OF SUPPLIES

Store all tracheostomy supplies in a way to protect them from possible contamination. It is best to store supplies away from high-traffic areas in your home.

Store items that will have contact with the inside of your child's body, such as suction catheters and trach tubes, in covered, breathable containers to assure they are kept free of contamination.

HOW LONG TO KEEP VARIOUS SUPPLIES

Tracheostomy Tubes
In general, tracheostomy tubes may be used for 4 one-week intervals.

Shiley brand manufacturer recommends that trach tube usage not exceed 29 days.

Bivona brand manufacturer recommends that the trach tube be thrown away after 5 cleanings.

Artificial noses
Throw out after one day of use. Throw away sooner if the filter portion of the nose (paper or sponge) gets wet, contaminated, or saturated with mucus.

Suction catheters
Reuse for 24 hours as long as you flush the catheter with a disinfectant after each use.

Throw away suction catheter after one use if you do not flush with a disinfectant, or if you have not been able to flush promptly after use and secretions have dried on the catheter.

Speaking valve
Clean daily in soap and water. The manufacturer guarantees that the speaking valve will last for a minimum of two months with proper handling.

The valve can continue to be used beyond two months as long as it does not exhibit stickiness, noise, vibration, increased resistance to inspiration, or any other difficulties.

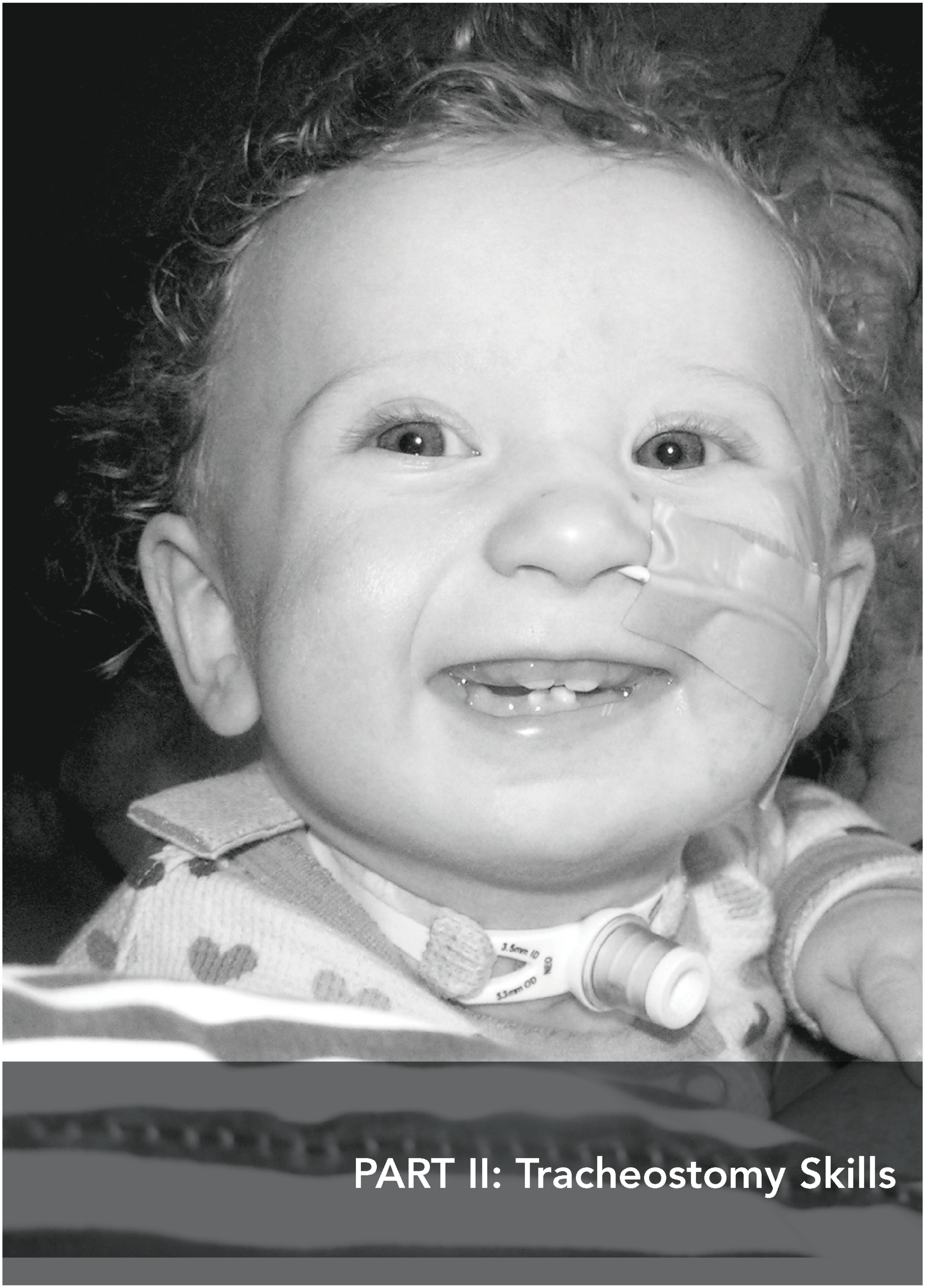
SOLUTIONS USED IN TRACHEOSTOMY CARE

You will be making solutions to use for skin care, flushing the suction catheter between uses, and to clean your child's tracheostomy tube. Recipes for these solutions are found in PART V, "Pull-Out" section, page 107.

- When preparing solutions, make sure that your work area, pots, pans, and the containers you will be using for solutions are clean.
- Do not use solution containers for any other purpose.
- If you are able, try to reserve pots and pans specifically for tracheostomy cleaning and solutions.
- All solutions that are actively being used are good for 24 hours. After 24 hours, the solution must be thrown out and containers must be cleaned and dried. Containers can be cleaned in hot, soapy water and air-dried or may be washed and dried in a dishwasher.

You may choose to prepare a large container or pitcher of a solution, keep it covered in the refrigerator, and pour what you need to use for the day into a second "in-use" container.

Solutions stored in the refrigerator and used as a source for solutions (only poured from and not entered into), are good for 72 hours.



PART II: Tracheostomy Skills

A NOTE ABOUT BEING PREPARED

You must always be able to provide care the moment your child needs it. It is important that supplies are looked over, organized, and set up in a manner that allows for immediate use.

- The day you receive a supply delivery, sit down and carefully go through all supplies. Make sure that sizes and brands are correct. Check that all supplies are in working order.

Look carefully at tracheostomy tubes and make sure you have the correct brand and size.

Check the tube carefully for any defects or irregularities.

Put the obturator in and out to make sure it works.

If your child's trach tube has an inner cannula, put the inner cannula in the trach tube to check that it fits properly. Make sure the latching device works properly.

Throw out any extra supplies that come with the trach tube that you do not need or use.

Do not use a trach tube that is a different size, looks different, or is damaged.

» If the tube is the wrong size, looks different to you or is damaged, promptly call the equipment company and ask them to replace the tube as soon as possible.

- If your child wears a cuffed tracheostomy tube, prime the cuffs of new tubes according to the manufacturer's instructions. (Depending on the brand, cuffs are primed or inflated with air, normal saline, or sterile water.)

For example: If your child has a Bivona brand pediatric trach tube with a tight-to-shaft cuff, the manufacturer recommends that you inflate the cuff with 5 cc of sterile water before using it.

If the cuff leaks or does not inflate properly, call the equipment company and ask them to replace the defective tube.

- Look at tracheostomy ties. Check that you have correct brand and size. Cut all tracheostomy ties down to size as needed for your child.

- Attach tracheostomy ties to all tracheostomy tubes in the house. Every tube in the house must have ties attached so the tube is ready to be used when needed.

- Check suction catheters to make sure you have received the correct type and size.

- Regularly check the places where you store tracheostomy supplies (drawers, shelves, bag, etc.). Make sure they are fully stocked so you are not out of a supply that you may need in a hurry.

Whenever you use the second-to-last item, immediately re-stock.

- Have the Go-Bag or at least the following supplies within reach of your child AT ALL TIMES.

» Obturator from the trach tube your child is wearing

» Spare tracheostomy tube the same size your child is wearing with the ties attached

» A tracheostomy tube that is one size smaller than your child's usual tube with ties attached (emergency tube)

» Water soluble lubricant

» Resuscitation bag with face mask and trach adapter

» Pair of Scissors

» Vials of Normal Saline

» Suction machine and suction catheters (for both spare tube and emergency tube)

Angel

- Keep your suction machine plugged into the wall while you are home. Before you leave your home, check to make sure the battery is fully charged, and test your suction machine to make sure it runs on the battery.
- Always check your Go-Bag before leaving the house. It must have all supplies listed on page 38.

THE PURPOSE OF SUCTIONING

The purpose of suctioning is to clean the inside of the tracheostomy tube and keep it free of mucus so your child can breathe easily through the tube.

- The trachea is lined with mucus. Mucus filters the air we breathe and protects the lungs by trapping particles and germs. Mucus also helps keeps the trachea lining moist.
- Normally, excess mucus moves up the trachea until it can be swallowed. The trach tube blocks some of this upward movement.
- Mucus can collect in and around the tracheostomy tube, making it harder for your child to breathe.

Most infants and small children cannot produce a cough that is strong enough to completely clear the tracheostomy tube of mucus build-up.

Older children can clear most of their mucus by coughing it out of the tracheostomy tube. Occasionally, especially if the mucus is thick or if there is a lot of mucus, older children may be unable to clear out all mucus with coughing alone.

WHEN TO SUCTION

Suction your child whenever it sounds or looks like there is mucus build-up in the tracheostomy tube and/or if your child has any signs of respiratory distress.

- Older children require less frequent suctioning. To assure the tracheostomy tube is open, suction older children at least twice a day.
- As long as you are not suctioning too deep, you do not need to worry about suctioning "too much."
- Common signs that your child needs to be suctioned:

  - *Rattling mucus that you can hear and that your child does not clear with coughing*
  - *Bubbling mucus at the opening of the tracheostomy tube*

- Signs of respiratory distress signaling the need to suction immediately:

  - *Flared nostrils*
  - *Chest retractions*
  - *Fast breathing or increased work of breathing*
  - *Dry, whistling sound*
  - *Clammy skin*
  - *Agitated behavior or restlessness*
  - *Frightened or anxious expression on face*
  - *Pale or blue colored skin, nails and/or mouth*

SUCTION DEPTH

The goal of suctioning is to clean out the trach tube, not your child's entire airway.

- Do not suction too shallow or too deep.
- During *routine* suctioning, the suction catheter must not be inserted any further than the end of the trach tube.

Suctioning well past the end of the tracheostomy tube can cause inflammation and damage to the tissue lining the trachea. Damage can lead to scarring within the airway; scars can then block airflow to the trach tube.

- If suctioning to the end of the trach tube is not successful, it is okay to advance the suction catheter no more than ½ cm beyond the end of the tracheostomy tube or just until the first side holes on the suction catheter peek out of the tracheostomy tube (whichever comes first) but no further than this.

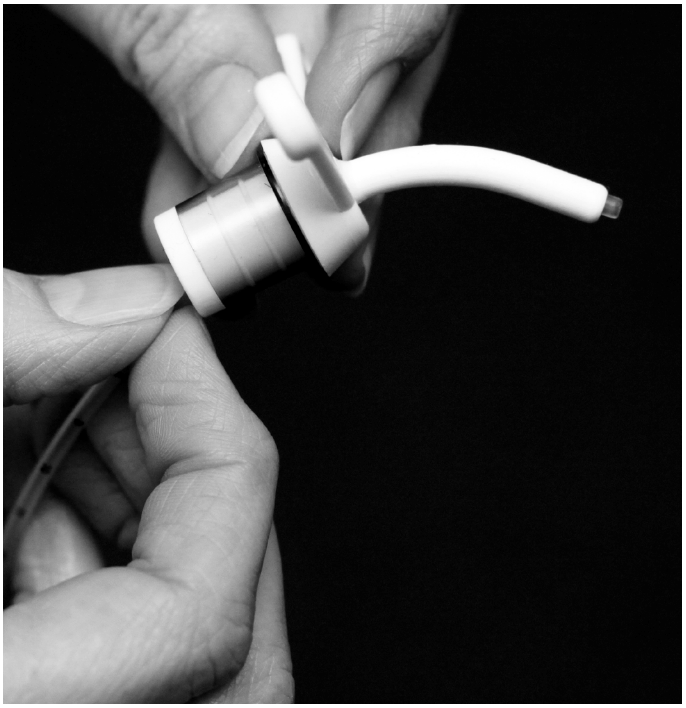


Photo 1: When suctioning using the Routine Suction Depth, the suction catheter is just peeking out of trach tube.

Photo 2

- You will be taught the proper suction depth for your child's tracheostomy tube. Get into the habit of re-checking the suction depth whenever you get a new set of tubes.

Re-check suction depth by inserting a suction catheter into the tracheostomy tube. Make note of the number your fingers are touching when the end of the suction catheter is just beginning to peek out of the end of the tracheostomy tube: this number is your Routine Suction Depth. (See Photo 1.)

- If your child uses a suction catheter that does not have markings on it, secure a tape measure to the suction machine so you can measure where to put your fingers on the suction catheter (see Photo 2). You may also place a piece of tape on the suction catheter to mark the proper suction depth.

ANYONE who suctions your child MUST know the proper suction depth and the reasons for not suctioning beyond that point.

ASSISTANCE NEEDED?

Suctioning can be performed by one person.

- Parents of children who require breaths with the resuscitation bag during suctioning may want to have assistance when available.

- If you prefer to have assistance, that is fine, but do not wait for assistance if your child is showing signs that suctioning is needed.

- Older children can suction themselves as long as they wash their hands first and follow the proper suction depth.

SUPPLIES NEEDED FOR SUCTIONING

- Suction machine
- Suction catheters
- Normal Saline vials
- Resuscitation bag if child needs breaths before and/or during suctioning
- Gloves (if in the hospital)
- Container of ¼-strength acetic acid or other disinfecting solution (to clean suction catheter after use at home)
- Container of boiled water (to rinse suction catheter after flushing in ¼-strength acetic acid at home)

HOW TO SUCTION

1. Gather supplies
2. Wash hands
3. Connect suction catheter to main tubing on suction machine.
4. Turn on suction machine.

Suction machine is set at no more than 90 mmHg negative pressure for infants and no more than 115 mmHg for older children and adults.

5. If your child requires breaths before suctioning, ask your child to take 3-5 deep breaths or give breaths with the resuscitation bag.

Ideally, if your child needs breaths, it is best to quickly suction one time before giving breaths with the bag.

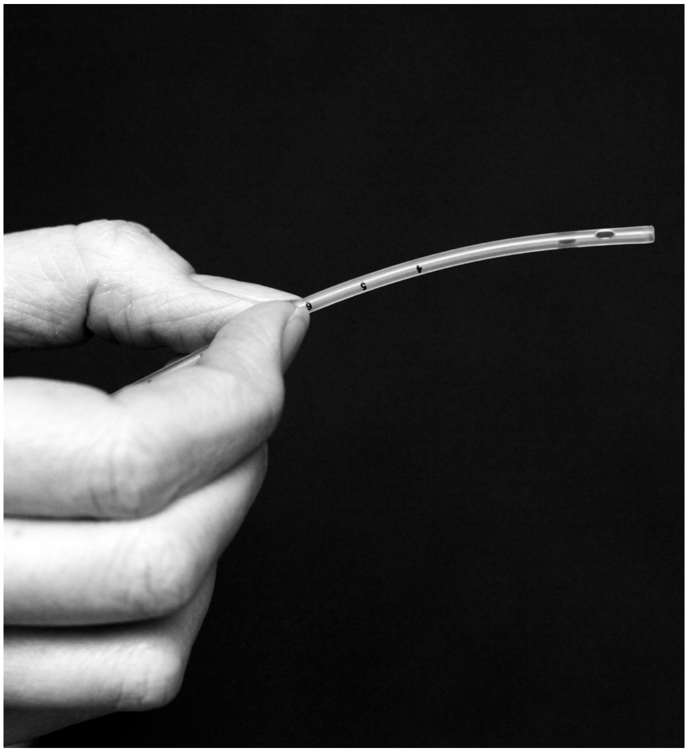
Suctioning the trach tube of excess mucus before bagging will help prevent the bag from blowing mucus into the lower airways.

6. Hold the suction catheter by placing thumb and forefinger of dominant hand at the number that matches the suction depth for your child's trach tube. (See photo above.)

7. Insert suction catheter into trach tube until your thumb and forefinger make contact with the tracheostomy tube. (See illustration on previous page.)

8. Apply suction by covering the thumb hole on the catheter with non-dominant thumb.

9. Spin the catheter between your thumb and forefinger as you gently and slowly withdraw the catheter out. This step takes about 5-10 seconds.



When suctioning, place forefinger and thumb on the numbers indicating your child's suction depth. Your fingers will stop the suction catheter from going further into the tube.

10. After suctioning, listen and watch your child's breathing effort.

If you still hear mucus rattling in the tube, or if your child is still struggling to breathe, then repeat suctioning until your child's breathing is easy, sounds clear, and there is little or no mucus return in the suction catheter.

There are various ways to manage the ventilator during suctioning. If your child is on a ventilator, you will learn the best way to manage the ventilator during suctioning.

WHAT TO DO IF SUCTIONING IS NOT ADEQUATELY CLEARING THE TRACHEOSTOMY TUBE

1. Try advancing the suction catheter ½ cm beyond the end of the tracheostomy tube. Do not advance more than ½ cm beyond the end of the tracheostomy tube.
   - For example, if your child's routine suction depth is 6 cm, try suctioning at 6.5 cm.
2. Try suctioning with normal saline lavage.
   - If your child has very thick mucus, which can occur when your child has a cold or mucus is dry, and you have tried suctioning as outlined above with poor results, add 3-5 drops of sterile normal saline to the trach tube just before suctioning.

Using normal saline lavage every time you suction is not good idea. Normal saline is used only if mucus is thick and suctioning without lavage is ineffective. Use the single-dose, sterile saline packets ONLY and throw out after one use.

3. If your child is still having trouble breathing after suctioning ½ cm deeper and after using saline lavage, change your child's tracheostomy tube. It is possible that there is a mucus plug.

Changing the tube will assure you that the tube is clean and free of obstruction.

If your child continues to have trouble breathing after changing the trach tube, immediately call your doctor. If your child is having great difficulty, is blue or pale, call 9-1-1.

FLUSHING THE SUCTIONING CATHETER FOR REUSE WHEN AT HOME

If your child is in the hospital, throw away the suction catheter after use and use a fresh, clean suction catheter for each suctioning session.

- When at home, you may reuse your suction catheter for 24 hours as long as you thoroughly flush the catheter clean with some kind of disinfecting solution immediately after suctioning.

- There are a number of methods for cleaning the suction catheter between uses. One method is as follows:

After suctioning, flush suction catheter until clean in a ¼-strength solution of acetic acid (1 part white vinegar to 3 parts water. This recipe is in the "Pull-Out" section).

After flushing in ¼-strength acetic acid, flush with water that has been boiled. The boiled water serves to rinse the acetic acid off the catheter.

Store catheter in the boiled water container, or allow to air dry in a covered, breathable container.

Make fresh flush solutions and clean out flush containers every 24 hours.

- Throw the catheter away if you are unable to flush the suction catheter clean within a few minutes of suctioning.

Flush bottles

A NOTE ABOUT RESPIRATORY SECRETIONS

The look and consistency of respiratory secretions or mucus tells you a lot about your child's hydration and health. It is important to take a look at respiratory secretions whenever you suction your child.

Mucus can be thin, watery, thick, or gluey.

Mucus may be a variety of colors such as white, pale yellow, dark yellow, green, brown, or blood-tinged.

- You will get to know how much mucus your child typically has and what color and consistency it normally is.

When children are healthy and adequately hydrated, mucus is usually thin and white for most of the day.

- There will be times during the day when your child has more mucus and the mucus is thicker or colored. If appearance of the mucus does not return to what is normal for your child after a couple of hours, then you have to wonder if your child needs more humidification or if your child is coming down with a respiratory infection.

For example, in the morning or after a long nap, it is not unusual for mucus to be thicker and colored.

You may need to suction more often after your child first wakes up.

You may need to suction more often when your child is fussy or teething.

If you have to be away from the house and humidification for extended periods of time, your child's mucus may get thicker and colored and/or blood-tinged.

All of this is normal.

Blood-tinged mucus

Mucus that is pink or flecked with blood can be a normal, passing, change. It may also be a sign of infection, inflammation of the airway, suctioning too deep, or the growth of scar tissue just below the end of the tracheostomy tube.

- You may see blood-tinged secretions for the first 24 hours after a trach tube change.

If blood-tinged mucus clears up after a couple of hours, there is no need to worry. If it persists, call your surgeon or your child's pediatrician.

If you suction bright red blood, enough to fill a suction catheter, take your child to the emergency room for evaluation.

If you see bright red blood flowing from the tracheostomy tube, call 9-1-1.

THE PURPOSE OF SKIN CARE

Mucus will leak and collect around the stoma and tracheostomy tube. This is normal. Mucus attracts germs and is also very irritating to the skin. To prevent inflammation, infection and skin breakdown, the skin around the tracheostomy tube is kept as clean and dry as possible.

WHEN TO PERFORM SKIN CARE

Clean and inspect the skin at least once a day and as often as needed to keep the skin clean and dry.

- Infants will likely need to have their skin inspected and cleaned 3 or more times a day because their necks are short and the skin around the trach tube tends to trap and collect moisture.
- If your child is teething, has a cold or other respiratory infection, you may need to clean and inspect the skin more often.
- If the skin around the tracheostomy tube is irritated or red, clean the skin at least 3 times a day.
- Between cleanings, you will blot the skin to remove excess moisture or drainage, just as you would wipe a child's runny nose.

ASSISTANCE NEEDED?

As long as you do not remove the trach ties, skin care can be performed by one person.

- For infants and smaller children who have trouble holding still, it may be helpful to have another person help hold and talk to the child. Infants can also be swaddled.
- If you would like assistance, it is okay to hold off on skin care for a short time until a helper is available.
- Older children and teenagers may be taught to do their own skin care.

SUPPLIES NEEDED TO PERFORM SKIN CARE

- Soft, clean, lint-free cloth or clean gauze
- Cotton-tipped applicators
- Mild soap and water or ¼-strength acetic acid
- Rolled up towel or blanket or "boppy" for babies

HOW TO PERFORM SKIN CARE

1. Wash hands.

2. Lay down infants and small children. Place a rolled blanket or towel placed under the shoulders to flex neck back and expose stoma.

   Older children may sit up or lay down and be asked to hold their head back.

3. Moisten cotton-tipped applicator, cloth, or gauze with mild soap and water or ¼-strength acetic acid.

4. Starting at the stoma, stroke away from tracheostomy opening using one stroke per clean swab or clean section of cloth or gauze.

The idea is to pull germs away from tracheostomy opening and not drag them back with a back-and-forth scrubbing motion. (See illustration at right.)

By using a clean swab or clean portion of cloth or gauze for each stroke, you are assuring that you are not re-soiling the area with the germs you just cleaned away.

- It is important to gently lift the trach tube away from the stoma to be able to adequately clean under the tube and get around the entire stoma.
- Your child may cough a bit when you do this, but if you lift the tube straight out without pushing from side-to-side, you will not hurt your child.

5. Clean top of neck plate and underneath neck plate. Remove all dried-on secretions which serve as a source for germs.

6. If you use mild soap for cleaning, rinse with water, taking care to not get water into stoma or trach tube.

If you use ¼-strength acetic acid, there is no need to rinse.

7. Thoroughly dry skin.

Arrows show the direction of cleaning. Clean AWAY from stoma.

INSPECTING THE SKIN

Inspect the stoma and surrounding skin at least once a day to check for granulation tissue (see description below), infection, inflammation, skin breakdown, redness, or rash.

- Take a careful look around the trach tube, under the trach tube, and all around the neck under trach ties.

USE OF TRACHEOSTOMY DRESSINGS

It is best to not use a trach dressing every day. Dressings, such as gauze, trap moisture and hold it against the skin.

It is okay to use dressings under the trach tube as long as you are able to change the dressing often, such as every two hours or whenever the dressing becomes damp.

- Occasionally, your child's doctor may order a special dressing for a limited period of time to treat a specific problem, such as excessive secretions leaking around the trach tube or skin breakdown.

IDENTIFYING & TREATING MINOR SKIN PROBLEMS

Granulation Tissue

Granulation tissue, sometimes referred to as a "granuloma," is immature scar tissue. It looks like a moist "bud" of pink or inflamed skin and usually appears around the inside edge of the stoma.

- Granulomas are quite common and typically do not cause serious problems.

A granuloma can become large.

A granuloma requires attention if it is getting in the way of tracheostomy tube insertion or if it looks sore or infected.

Granulation tissue often forms when there has been irritation, inflammation, or increased leaking of mucus around the trach tube.

Treatment

- Apply Bacitracin or Polysporin ointment directly to the granuloma 3 times per day for no more than 10 days.
- If the skin around the stoma also looks irritated or inflamed, increase skin cleaning to at least 3 times per day. Keep skin dry.
- If there is no improvement with increased cleaning or the antibiotic ointment, call your child's pediatrician or tracheostomy surgeon.

Your child's doctor may order a steroid/antibiotic drop or may want to cauterize the granuloma.

A very large granuloma

Redness

If the area around the trach tube appears slightly reddened, like a blush, the skin may be inflamed. This can happen after your child has had a cold or any time there is an increase in secretions or dampness around the trach tube.

- Redness can be prevented by keeping skin as dry as possible and getting airflow under the chin and around the neck a few times a day.

Treatment

Clean skin at least 3 times per day. Keep skin dry. Apply Bacitracin or Polysporin ointment 3 times per day for no more than 10 days.

Tip: When applying ointments, ALWAYS be sure to apply the ointment to skin that is freshly washed and completely dry to keep from sealing in moisture and mucus against the skin.

Deep Redness with Defined Border

Deep redness that has a sharp, defined border can be a sign of a very serious infection called cellulitis. If you are worried about cellulitis, take your child to the pediatrician for evaluation.

Rash

Children can develop a diaper rash or Candida infection around the trach tube, under the chin, under the ties and/or on the chest. A Candida infection is a blotchy red rash. The rash often appears shiny.

- A classic sign of a Candida infection is the presence of red dots surrounding larger red blotches; these are called "satellite lesions."
- The rash can sometimes become crusty and ooze.
- Candida infections can be prevented by keeping skin as dry as possible and getting airflow under the chin and around the neck a few times a day.

Sophie

Treatment

Candida infections can be cleared up simply by taking measures to keep skin as dry as possible and allowing airflow under the chin and around the neck.

- Change clothing and trach ties when they become damp or wet.
- Place a towel under your child's shoulders at least three times a day for 30 minutes at a time to allow skin under chin to dry out.
- If drying measures do not work to clear up the rash, use one of the following topical anti-fungal creams:

Nystatin cream or ointment 100,000 units per gram; this is a thin, yellow cream. Gently massage into skin, covering all affected areas, 2-4 times per day for 14 days. Nystatin requires a prescription.

Clotrimazole 1% Cream: Gently massage into skin covering all affected areas 2 times per day for 14 days. Clotrimazole can be ordered as a prescription or is available over-the-counter.

Abrasion or Wound Where Tracheostomy Tube or Other Devices Attached to the Trach Tube are Pressing into the Skin

When your child is in the hospital, we will make sure that the trach tube is a good fit and does not cause any pressure against the chin or chest. However, pressure points against the skin can develop over time if anything changes in the way the trach tube fits. For example, your child may grow, gain weight, or devices that attach to the trach tube may start causing problems. Constant pressure against the skin can affect blood supply to the skin and lead to small wounds or ulcers.

Treatment

Contact the medical person who follows your child's tracheostomy. This may be the surgeon who placed the tracheostomy tube or a nurse practitioner or physician's assistant who works with the surgeon.

- Arrange to have your child's skin looked at and the fit of the tracheostomy tube reassessed.

- In the meantime, place gauze, foam dressing or hydrocolloid dressing (Duoderm) between the trach tube and skin to help protect the skin from pressure.

Lucy wearing a speaking valve

WHEN TO HAVE A HEALTH CARE PROVIDER LOOK AT YOUR CHILD'S SKIN

- If redness becomes deeper in color or 'angry' appearing

- If redness seems to be spreading quickly

- If your child develops a fever

- If redness does not improve after 7 days of treatment

- If a rash does not improve after 14 days of treatment with an antifungal cream

- If rash gets worse despite measures to keep skin dry and use of antifungal cream

- If skin develops an open wound

- If there is any tenderness, swelling, foul odor or pus

Your child will wear Velcro tracheostomy ties around the neck (sometimes call "tracheostomy holders") to keep the tracheostomy tube in place and secure.

In general, there are two types of Velcro tracheostomy ties: one-piece and two-piece.

- The type of tie your child has will depend on what the hospital stocks while your child is in the hospital and what your equipment company provides once you go home.

In most cases, your equipment company can help you get the style of tracheostomy tie you prefer.

- Velcro trach ties can be handwashed. Most parents report being able to handwash the ties 3 times before the Velcro stops gripping properly.

After handwashing ties, always check Velcro to make sure it still holds strong.

PURPOSE OF TRACH TIE CHANGES

To keep the skin clean and dry to prevent skin breakdown and rashes.

FREQUENCY OF TRACH TIE CHANGES

Trach ties are changed at least once a day.

- It is also important to change the ties whenever they are wet or damp from respiratory secretions, sweat, or liquids.
- Change the tracheostomy ties promptly if your child vomits or spits up and soils the ties.
- Most parents like to change ties after skin care.

ASSISTANCE NEEDED?

Two people must always perform trach tie changes.

- The assistant holds the tracheostomy tube in place while the other person changes the ties.
- Teenagers can hold their own trach tubes during trach tie changes.
- If trach ties are soaked and no one is available to help you right away, you can slide pieces of gauze underneath ties to protect the skin and keep your child comfortable.

If the ties must be changed and you cannot wait for assistance, you may be able to place the new ties over the old ties. Once the new ties are secured, you can cut off or remove the old ties.

SUPPLIES NEEDED

- Clean set of trach ties trimmed to size as needed
- ¼-strength acetic acid or mild soap and water
- Towel for drying skin
- Scissors
- Hemostats (if needed to pull ties through the holes on the trach tube if holes are very small)

Mary, ready to get up and get going

HOW TO CHANGE TRACHEOSTOMY TIES

1. Assistant holds tube in place.
2. Person in charge of performing the tie change removes the old ties.
3. Inspect, clean, and thoroughly dry skin.
4. Thread the Velcro ends of fresh trach tie through the holes in the neck plate.
5. Adjust trach ties until they fit snuggly, but not tightly, and secure Velcro.
6. Check fit after securing. You should be able to slide one small finger between the neck and the tie.

If your child was crying and upset during the trach tie change, ties may be too loose once your child settles down. Therefore, it is important to check the fit of the ties again after the child has calmed down.

For infants, after checking fit the first time, let the child move around a bit and then check fit again.

7. Check ties throughout the day to make sure Velcro is secure.

PURPOSE OF TRACHEOSTOMY TUBE CHANGES

It is not possible to completely remove all traces of mucus with suctioning. Over time, residual mucus will begin to build up on the walls of the trach tube. Plugs of mucus can also develop and block the trach tube.

- Changing the trach tube on a routine schedule decreases the risk of mucus build-up.
- Changing the tube whenever you suspect that the tube might be clogged assures that your child is breathing through an open, unobstructed tracheostomy tube.

WHEN TO CHANGE THE TRACHEOSTOMY TUBE

Routine or Planned Changes

Tubes that do not have an inner cannula (all neonatal, pediatric and Smiths-Bivona brand tubes) are changed weekly.

- Tubes that have an inner cannula (adult size Shiley brand tubes) are changed monthly.

Emergent or Unplanned Changes

If trach tube comes out of your child's stoma, re-insert promptly.

- Change the tracheostomy tube immediately if you suspect that the tube is plugged.

If your child has an inner cannula, changing the inner cannula may be all you need to do. If no improvement after changing inner cannula, then change the trach tube.

Signs that the tube may be plugged:

- » *Infant is irritable or agitated and will not calm down after suctioning, changing diaper, feeding or holding and cuddling.*
- » *Your child becomes pale or bluish, especially around the nose and mouth.*
- » *You see pulling in of skin between the ribs, around the collarbone, or under the stoma (retractions).*
- » *You meet resistance when suctioning*
- » *You are having a hard time getting air in with the resuscitation bag.*

WHAT A TRACHEOSTOMY TUBE CHANGE IS LIKE

The first time parents perform a trach change, most are surprised at how quickly the trach tube slides into place.

- Performing the first trach change is a welcomed hurdle. Most parents feel much more relaxed about trach changes after experiencing it for themselves the first time.
- Some children cough during the insertion. You may feel the tube bounce back against your hand a bit. Just go ahead and ease the tube through the cough.
- With a tracheostomy tube, typically you will not hear your child's cough. A cough without sound tends to look like gagging. Some parents find this upsetting. Keep in mind that coughing is probably more distressing to you than it is to your child.

PREPARING FOR A ROUTINE TRACHEOSTOMY TUBE CHANGE

It is important that the tracheostomy change is as relaxed and stress-free as possible.

Behaving in a relaxed and confident manner, even if you have to fake it at first, will help your child remain relaxed and will prevent your child from perceiving trach changes as an unpleasant, scary event.

- Do not perform a routine trach change if your child is tired or irritable.

- Do not feed your child for at least 30 minutes before changing the tracheostomy tube. This will help prevent vomiting if your child happens to gag with the trach tube change.

- Suction your child at least 15 minutes before the trach tube change. Some parents like to suction just before inserting the fresh tube.

- The person inserting the tube gets everything together and has the fresh tube ready for insertion before getting the child into position. This way, for the child, the procedure is quick and easy.

- It is ideal to perform stoma care before the trach tube change so you will be inserting a clean tube and using clean ties on a freshly cleaned site.

If your child is a wiggler and has a limit for holding still, it is okay to separate stoma care from the trach tube change to reduce the length of time your child needs to hold still at one stretch of time.

ASSISTANCE NEEDED?

Routine tracheostomy changes are ALWAYS performed by two adults: an "inserter" and a "holder/remover." Both must be trained in tracheostomy tube changes.

- For emergent or unplanned tracheostomy changes, you must be prepared to change the tube by yourself.

SUPPLIES NEEDED

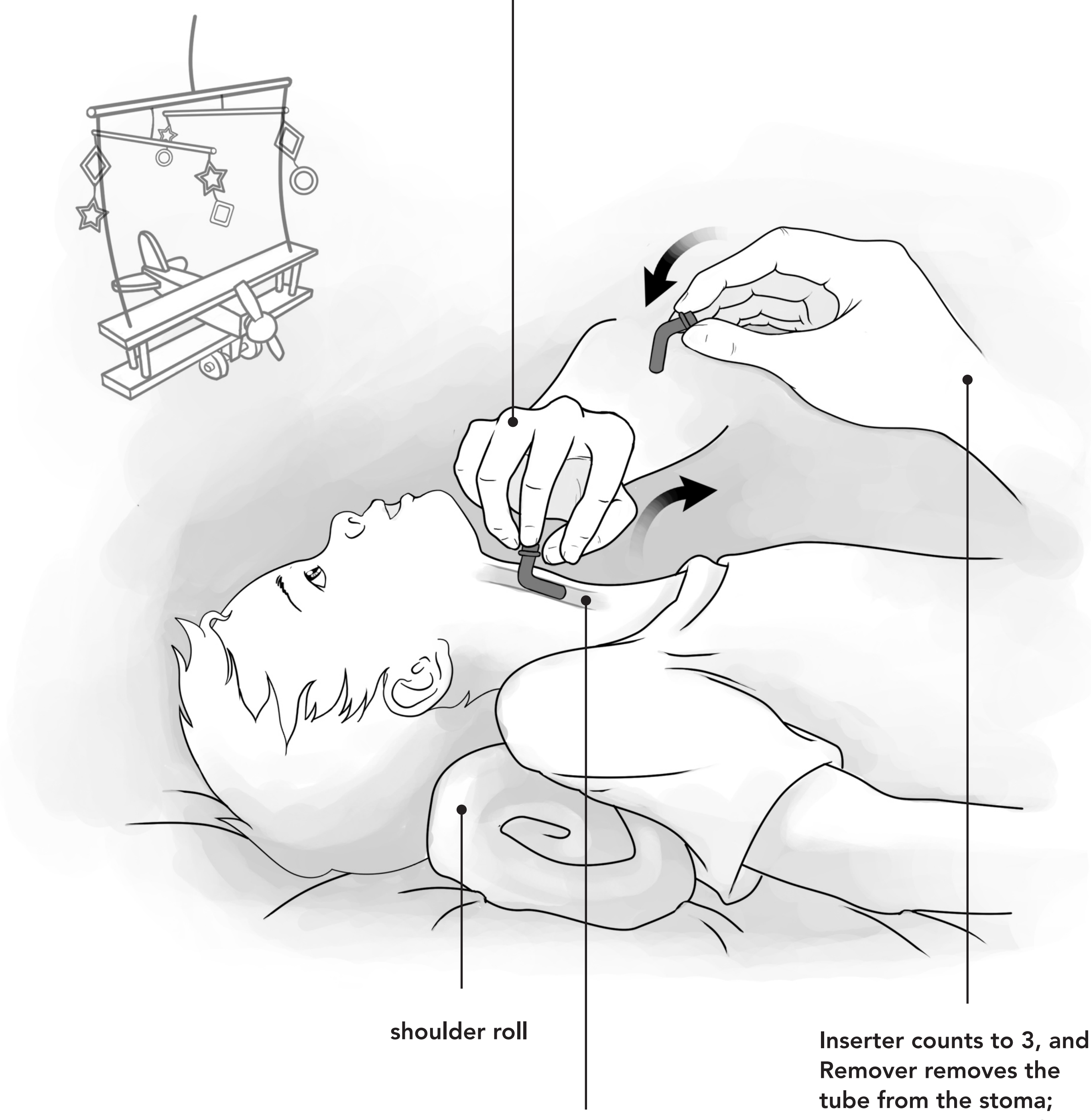
- A rolled blanket or towel to put under the shoulders of infants and small children to bring neck back and provide good view of stoma
- Tracheostomy tube with ties attached
- Obturator
- Water soluble lubricant with gauze for applying/spreading lubricant
- Clean surface to set prepared trach tube on
- Breathing bag (if your child needs breaths before changing the tracheostomy tube)
- Supplies for suctioning
- Go-Bag within reach
- Gloves (if in hospital)

HOW TO PERFORM A ROUTINE TRACHEOSTOMY TUBE CHANGE

1. Inserter arranges a clean surface and prepares supplies.
    - Get tracheostomy tube out. (Pat yourself on the back for having properly stored the trach tube with the ties already attached.)
    - Inspect trach tube. Make sure the tube is clean, is not damaged and that it does not look different to you in any way.
    - Insert obturator.
    - Lubricate trach tube with a light coating of water soluble lubricant. Wipe off any excess lubricant.
    - Set prepared trach tube aside on the clean surface.
2. Position child.
    - Have child lay on his or her back with a roll under the shoulders. Any position is fine as long as:
      a) your child's head is tilted back,
      b) the inserter has a VERY good view of the stoma, and
      c) insertion is done face-on (as opposed to approaching the child from the side, etc.).
3. Inserter removes old tracheostomy tie.
    - Holder/remover holds the child's trach tube with the dominant hand (with forearm lying on the child's body to limit movement) and calmly speaks or sings to child while the inserter removes the ties.
    - The holder/remover can sit the child up and move child's head with the free hand as needed to help the inserter get at the trach tie attachments.
    - Once ties are off, make sure Velcro ends are not stuck to anything so tube can be removed easily.
    - If your child has a cuffed trach tube, deflate the cuff at this point. (Even if you have not inflated the cuff, always deflate the cuff just in case it was somehow accidentally inflated).
    - If your child needs breaths before a trach change, the inserter gives breaths with the resuscitation bag at this point.
4. Inserter gets the freshly prepared trach tube and holds it securely in dominant hand.
5. Inserter counts to three. On count of three, holder/remover gently removes the existing tube and:
    - The inserter visualizes the stoma and gently eases the trach tube into the stoma in one smooth motion.
    - Inserter promptly removes the obturator with non-dominant hand.
    - Inserter keeps holding trach tube until holder/remover is ready to hold again.
    - Holder/remover attaches ventilator circuit at this point if child is on a ventilator.
    - The holder/remover resumes holding while inserter secures the ties.
6. Secure ties.
    - Allow room for one small finger to fit between neck and tie.

If your child has been crying or upset during change, re-check fit of ties after your child has had a chance to calm down.

7. If your child has a cuffed tube, inflate cuff at this point.
8. Suction if needed.



Remover removes old tube

shoulder roll

trachea

Inserter counts to 3, and Remover removes the tube from the stoma; Inserter then eases fresh tube into stoma

IF TUBE DOES NOT PASS EASILY

Do NOT force the trach tube.

Staying calm and relaxed, with a "matter-of-fact" attitude, as you try the following measures will help both you and your child.

Even if you do not feel calm, pretend and act as though you do. Do not scream. Speak in slow, measured, reassuring tones.

1. If tube is part way in, hold the tube in place and remove the obturator so your child can breathe.
   - Use the thumb and forefinger of your non-dominant hand to spread and open the skin over the stoma while advancing the tube when your child takes a breath in.
2. If no success with above, **STAY CALM**, remove the tube, re-lubricate, and try again.
   - Make sure your child's head is back and you have a good view of the stoma.
3. If no success with above two steps, try inserting the smaller (emergency) tube.
4. If unable to insert smaller tube, try inserting a suction catheter into the smaller tube.
   - Guide the suction catheter into the stoma first, and then slide the trach tube over the suction catheter and into the stoma. Remove suction catheter. (See illustration above.)
   - If you are successful in getting the smaller tube in, take your child to their doctor or emergency room as soon as you can safely do so to have your child's regular size trach tube inserted.
5. If you are unable to insert the regular tube or the smaller tube, have someone call 9-1-1. Be prepared to start CPR if your child stops breathing.

Suction catheter is threaded through the trach tube. Insert end of suction catheter into stoma, and then guide the trach tube into stoma over the suction catheter. When trach tube is in, remove the suction catheter.

Some children tense up their neck muscles during a trach change, making it hard to insert the tube.

If your child has a tendency to do this, consider using a special toy to distract the child at the time of insertion.

Make sure this toy is a novelty and one that your child does not routinely play with.

Some parents use a toy that has flashing lights or makes an interesting sound.

HOW TO PERFORM A NON-ROUTINE OR EMERGENCY TRACHEOSTOMY TUBE CHANGE

You may need to perform an Emergency or non-routine trach tube change if your child's trach tube has fallen out (accidental decannulation) or if you suspect the trach tube is plugged.

The possibility that you may need to perform an emergency trach tube at some time, is one of the reasons why it is essential that your supplies are within easy reach of your child AT ALL TIMES.

- The possibility that you may need to change your child's trach tube in a hurry and without assistance is one of the reasons you check your supplies the day you receive them from the equipment company and attach the trach ties to all available trach tubes.

When you perform an emergency trach tube change, remain CALM. Work deliberately but DO NOT RUSH.

Performing an Emergency Tracheostomy Tube Change with Assistant Trained in Tracheostomy Tube Changes

1. Follow steps for Routine Tracheostomy Tube Change.
2. If your child is pale, blue, or having any trouble breathing, do not take the time to wash your hands or lubricate the tube.

Performing Tracheostomy Tube Change by Yourself

1. Get tracheostomy tube with ties already attached.
    - Try to insert regular size tube first.
2. Lubricate tube if you feel you have time.
3. Lay child down with head extended back. If you have a towel or blanket within reach, place roll under child's shoulders.
4. Remove ties and take out tube.
5. Pick up prepared tube with dominant hand.
6. Insert tube.
7. Remove obturator with non-dominant hand while holding tube with dominant hand.
8. Secure ties.
9. Check your child's color and respirations. If your child is pale or blue or having any trouble breathing, suction your child and then give a few breaths with resuscitation bag.

Call 9-1-1 if your child's breathing does not return to normal or you are unable to insert either the regular tube or smaller size tube.

Some tracheostomy tubes have an inner cannula. These are generally adult sized Shiley brand tracheostomy tubes.

THE PURPOSE OF INNER CANNULA CHANGES

The purpose of changing the inner cannula is to remove excess mucus that is not expelled with coughing or suctioning and to keep the inside of the tracheostomy tube clean.

WHEN TO CHANGE THE INNER CANNULA

Change the inner cannula at least once a day.

- Change the inner cannula more frequently if your child has copious, thick mucus.

ASSISTANCE NEEDED?

You can change the inner cannula without assistance.

- Older children often change their own inner cannulas.

SUPPLIES NEEDED

- A clean reusable inner cannula, or a new disposable inner cannula
- Suction supplies

HOW TO CHANGE THE SHILEY *REUSABLE* INNER CANNULA

1. Twist connector on inner cannula your child is wearing to release lock and remove from trach tube.

2. Promptly insert clean inner cannula and twist to lock in place.

3. If your child has coughed after removing used inner cannula and before inserting the fresh one, you may want to suction the tracheostomy tube before inserting the fresh inner cannula.

4. Immediately clean the inner cannula you removed.

If not able to clean inner cannula immediately, place in a bowl of soapy water to prevent secretions from drying on the inner cannula.

HOW TO CHANGE THE SHILEY *DISPOSABLE* INNER CANNULA

1. Pinch connector of inner cannula to release from trach tube and remove inner cannula from tube.

2. Promptly insert fresh, disposable inner cannula.

3. If your child has coughed after removing used inner cannula and before inserting the fresh one, you may want to suction the trach tube before inserting the fresh inner cannula.

4. Throw away the inner cannula you just removed.

Cleaning & Reusing TracheostomyTube

In general, follow manufacturer instructions for reusing and cleaning tracheostomy tubes. Manufacturer instructions can be found in the insert booklet that comes with your tracheostomy tube. Below are reuse and cleaning instructions for Smith's-Bivona brand tubes and Shiley brand tubes.

REUSING TRACHEOSTOMY TUBES

Typically, you will have two tubes (a set) which you are actively using:
- the trach tube the child is wearing
- the spare trach tube of the same size

Smiths-Bivona recommends discarding tracheostomy tubes after 5 cleanings.

Shiley recommends discarding tubes after 29 days of use.

For the sake of simplicity, throw away Smiths-Bivona and Shiley trach tubes after 4 weeks of use.

Changing & Reusing Trach Tubes That Do *Not* Have an *Inner Cannula*

Remove trach tube and replace it with the spare trach tube once a week.

You will clean the trach tube you just removed, allow it to dry and store it in a clean manner until you perform your next trach change.

At the time of the next trach change, the tube you just cleaned will be the tube you insert and the tube you remove will be cleaned and then serve as the spare tube.

Since each trach tube is being used for one week and not being used the next week, it will take 8 weeks before both tubes have been used for a total of 4 weeks each.

- Therefore, every 2 months, throw away the set of tubes you have been using and start a fresh set.

Do not throw away your set of two tubes unless you have a new set on hand to put into use.

Call your equipment company if you have not received a total of 2 new tubes at the time your current tubes are due to be thrown away.

Changing & Reusing Trach Tubes That *Have* an *Inner Cannula*

Remove the tube once a month and replace it with the clean spare trach tube you have on hand.

At this point, you should have a brand new trach tube that has been delivered from your equipment company.

This new tube will now serve as the spare trach tube and you can throw away the trach tube you just removed.

- If you have to change your child's trach tube before it has been in place for a month, change the child into the clean spare tube.

Now, clean the tube you just removed, and use this as the spare tube until the end of the month, when your new tube arrives.

MANUFACTURER CLEANING METHODS FOR SMITHS-BIVONA & SHILEY BRAND TRACH TUBES

If you are unable to clean the tube immediately after removing, place the tube in a bowl of soapy water to prevent secretions from drying onto the tube. (See recipes for cleaning solutions in PART V.)

Smiths-Bivona Cuffless & Tight-to-Shaft Cuffed Tracheostomy Tubes

1. Rinse trach tube under running tap water, removing all visible soiling. Use trach tube brush or pipe cleaner to clean the inside of the cannula. Clean obturator in the same manner.

2. Once all visible debris is removed:
   - Soak tube and obturator separately in a bowl of soapy water for 60 minutes. Swish trach tube around in bowl to make sure soapy water gets inside the trach tube. (If you have access to an enzymatic instrument cleaner, after initial rinse, skip the soapy soak and simply clean the tube with the enzymatic cleaner, rinse and move to step 3.)

3. Boil a pan of water.
   - If you have city water, you can boil water straight from the tap.
   - If you have well water, boil bottled or distilled water.

4. When water comes to a boil, remove trach tube and obturator from soapy water and carefully drop into boiling water.
   - Remove pan from heat.

5. Once water and trach tube are cool enough to handle, remove tube from pan, taking care to not touch the cannula part of the trach tube (the part of the trach tube that goes into the stoma).

6. Shake off tube to remove excess water.

7. Lay tube on clean towel and allow to air dry.

8. When completely dry, attach trach ties and store in breathable container. Store obturator alongside tube, not in tube.

Shiley Brand Cuffless Tracheostomy Tubes

1. Rinse trach tube under running tap water, removing all visible soiling. Use trach tube brush or pipe cleaner to clean the inside of the cannula. Clean obturator in the same manner.

If you have well water, rinse tube in a bowl of bottled water, distilled water, or sterile normal saline rather than rinsing under the tap.

2. Once all visible soiling is removed, submerge tube in one of the following solutions and clean (do not soak for any period of time):

½-strength hydrogen peroxide (1 part boiled water to 1 part hydrogen peroxide)

Acetic Acid (white vinegar)

Mild soap and boiled water

3. After cleaning, rinse tube in boiled water to remove all cleaning residue.

4. Lay tube on clean towel and allow to air dry.

5. When tube is completely dry, attach trach ties and store in breathable container. Store obturator alongside tube, not in tube.

Shiley Brand Cuffed Tracheostomy Tubes

1. Rinse trach tube under running tap water, removing all visible soiling. Use trach tube brush or pipe cleaner to clean the inside of the cannula. Take special care to remove all crust from folds of cuff. Clean obturator in the same manner.

If you have well water, rinse tube in a bowl of bottled water, distilled water, or sterile normal saline rather than rinsing under the tap.

2. Once all visible soiling is removed, wipe tube down with one of the following solutions, taking care to avoid cuff—cuff must not be exposed to solutions other than sterile saline or boiled water.

½-strength hydrogen peroxide

Acetic Acid (white vinegar)

Mild soap

3. After cleaning, rinse tube in boiled water to remove all cleaning residue.
4. Lay tube on clean towel and allow to air dry.
5. When tube is completely dry, attach trach ties and store in breathable container. Store obturator alongside tube, not in tube.

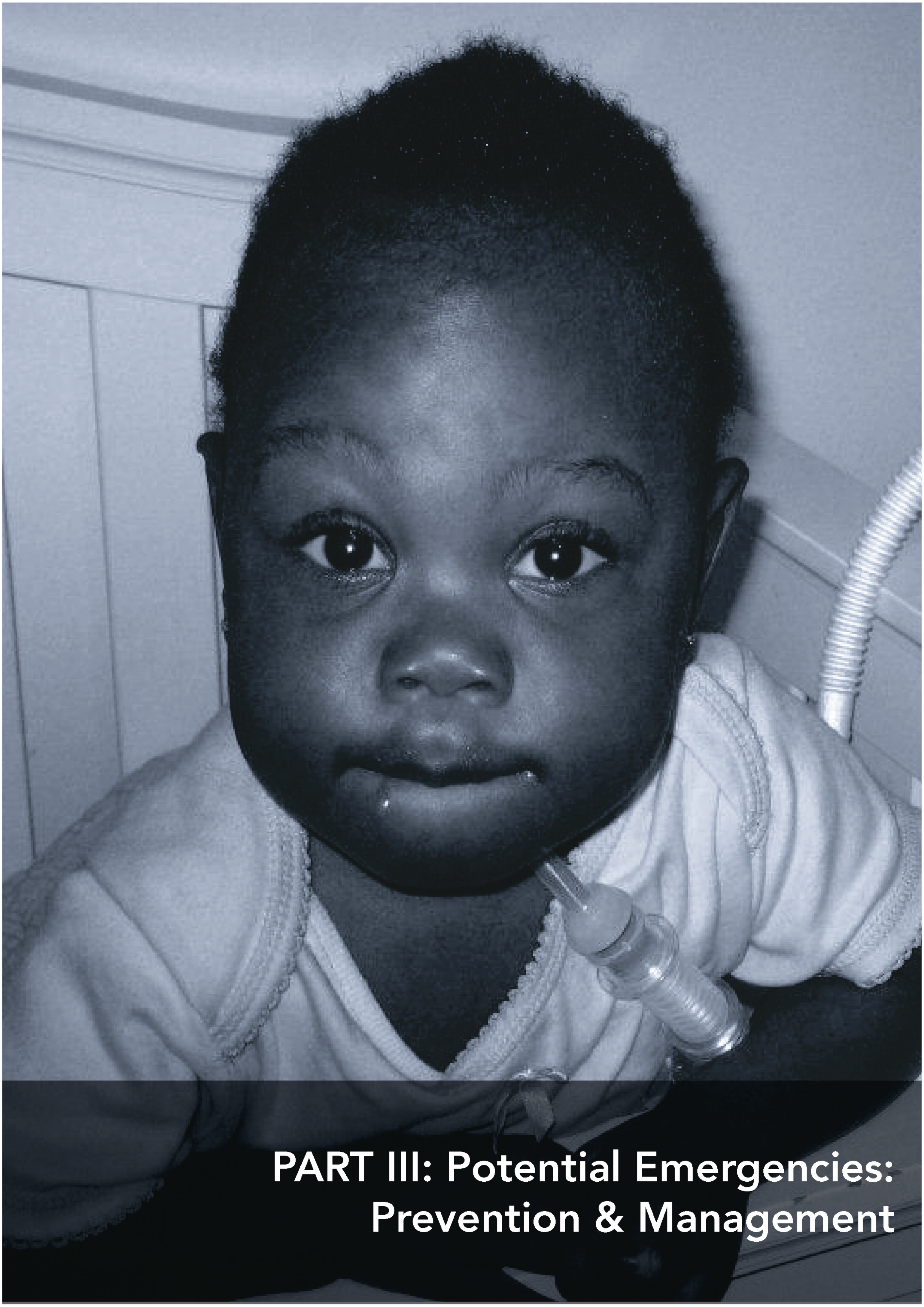
CLEANING THE REUSABLE INNER CANNULA
(Do not reuse or clean disposable inner cannulas)

1. Rinse inner cannula under running tap water, removing all visible soiling. Use trach tube brush or pipe cleaner to clean the inside of the cannula.

If you have well water, rinse tube in a bowl of bottled water, distilled water or sterile normal saline rather than rinsing under the tap.

2. When all visible soiling is removed, submerge inner cannula in ½-strength hydrogen peroxide solution. Clean.
3. After cleaning, rinse inner cannula in boiled water to remove all cleaning residue.
4. Lay inner cannula on clean towel and allow to air dry.
5. When inner cannula is completely dry, store in breathable container.

Potential Emergencies:
Emergency Preventions
& Management



PART III: Potential Emergencies: Prevention & Management

RESPIRATORY DISTRESS

You will learn to become familiar with signs that may mean your child is having trouble breathing. It is important that you promptly address any signs of respiratory distress. If your child is having trouble breathing and does not get help, your child could stop breathing.

SIGNS OF RESPIRATORY DISTRESS

- Your child seems agitated, upset or anxious
- Noisy breathing
- Fast breathing
- Shallow breathing
- Breathing pattern seems unusual or uneven
- Increased work of breathing: pulling in (retractions) of chest, neck or ribs
- Blue or pale coloring, especially around the lips, nose or nails
- Oxygen saturations are very low (if you have an oxygen saturation monitor)
- Your child is not responsive or less responsive

ACTIONS

1. Immediately suction your child as outlined in the previous section.
2. If no improvement with suctioning, change the tracheostomy the tube.
3. If your child continues to have trouble breathing despite your actions, immediately call your doctor. If your child is having great difficulty, is blue or pale, call 9-1-1.

If your child stops breathing, immediately call 9-1-1 and start CPR.

MUCUS PLUGS

A mucus plug is a collection or "glob" of mucus that is stuck in, or at the end of, the tracheostomy tube and is blocking airflow.

- Mucus plugs can occur at any time and with any size tracheostomy tube.

There is a greater risk of mucus plugging with:

» very small tracheostomy tubes

» when mucus is thick (such as when your child has a respiratory infection or has not received adequate humidification)

SIGNS THAT TRACHEOSTOMY TUBE MAY BE PLUGGED WITH MUCUS

- Signs of respiratory distress or increased work of breathing
- Child is anxious, agitated or acting differently
- Whistling sound from tracheostomy tube
- Child is making sounds when he or she usually does not, or voice is louder
- Older children may complain that they are having trouble breathing
- Suction catheter does not pass easily through tracheostomy tube
- Child is not breathing

HOW TO REMOVE A MUCUS PLUG

If Your Child is Breathing

1. Suction the tracheostomy tube.

2. If no improvement with simple suctioning, try suctioning ½ cm deeper and use normal saline lavage.

3. If your child has an inner cannula, change the inner cannula.

4. If still no improvement with suctioning, change the tracheostomy tube.

If no improvement after changing the tracheostomy tube, immediately call your doctor. If your child is having great difficulty, is blue or pale, call 9-1-1.

If Your Child is NOT Breathing

1. Give breaths with resuscitation bag attached to the tracheostomy tube.

2. If your child starts breathing, suction the tracheostomy tube.
   - As soon as your child settles down and it is safe to do so, change the tracheostomy tube.

If your child does not start breathing, call 9-1-1 and start CPR (remove the tube and give breaths mouth-to-stoma).

PREVENTING MUCUS PLUGS

Humidification is the number one way to prevent mucus plugging.

- Signs that your child may not be getting enough humidification:
  - thick, sticky mucus that may be hard to clear with suctioning
  - dried crusts of mucus on the outside and/or inside of tracheostomy tube when you change the tracheostomy tube
  - blood-tinged mucus
- For infants, use mist mask most of the day, always during naps, and at night when sleeping. Do not use artificial nose for more than 2 hours at a time, if possible.
- For older children, use mist mask during naps and at night when sleeping.
- Whenever you notice that mucus is thicker or stickier, increase the use of the mist mask.

If your child is on a ventilator, check that humidification is properly set, and decrease the use of the portable ventilator which does not supply humidification.

Talk to ventilator team about other measures to improve humidification.

- Use artificial nose whenever not using the mist mask.

If you are away from home and have to use artificial nose for longer periods of time than what your child can usually tolerate without getting dry, instill a few drops of normal saline without suctioning every hour or so.

- Talk to your doctor about nebulized saline treatments if your child tends to have frequent problems with thick, sticky mucus and/or needs to be away from mist mask or ventilator humidification for extended periods of time.
- Suction your child as soon as he or she requires suctioning. In general, infants are suctioned at least every 2 hours.
- Perform trach tube changes when they are due.

If your child has frequent problems with mucus plugging, notify the surgeon who follows your child's tracheostomy.

ACTIVE, BRIGHT RED BLEEDING FROM TRACHEOSTOMY TUBE

Active bleeding from the tracheostomy tube is an uncommon occurrence. When it does occur, it is often the sign of a serious problem, such as laceration, ulceration, or perforation of the trachea.

MANAGING ACTIVE, BRIGHT RED BLEEDING FROM THE TRACHEOSTOMY TUBE

If you note less than 1 teaspoon of bright, red blood from the trach tube, take your child to the emergency room for prompt evaluation.

- If you note more than 1 teaspoon of bright, red blood or more than one catheter full of bright, red blood:

1. Call 9-1-1.

2. Stay calm and use humidification until help arrives.

REDUCING THE RISK OF ACTIVE, BRIGHT RED BLEEDING

Always follow guidelines for proper suctioning and always use the appropriate suction depth for your child's tracheostomy tube.

- Teach other caregivers, such as private duty nurses and family members, the proper way to suction and the importance of never suctioning beyond the suction depth for your child's tracheostomy tube.

- Do not change the size or brand of your child's tracheostomy tube on your own or on the advice of anyone other than your child's surgeon, who is familiar with your child's airway.

A NOTE ABOUT BLOOD STREAKED OR BLOOD TINGED MUCUS

Mucus that is streaked or tinged with blood is not unusual and though concerning, it is not considered an emergent situation.

- However, do not ignore blood-tinged secretions; they may be a sign that:
  - » there has been some damage to the trachea
  - » there is granulation tissue at the end of the trach tube
  - » your child needs more humidification
  - » your child is coming down with an infection

Blood-tinged secretions can be normal in the first 24 hours after tracheostomy tube change or if your child has undergone direct laryngoscopy and/or bronchoscopy in the operating room.

MANAGING BLOOD-STREAKED OR BLOOD-TINGED MUCUS

- Make sure you and all other caregivers are adhering to proper suction depth.

- Make sure you are providing enough humidification. Increase humidification for a couple of days.

- Watch your child for signs of a respiratory infection such as fever, change in volume, thickness and/or appearance of mucus.

Call your pediatrician if you suspect your child is coming down with a respiratory infection.

Call your child's tracheostomy surgeon to report blood-tinged mucus that persists and does not clear up after a day.

ACCIDENTAL DECANNULATION

The tracheostomy tube may fall out for a number of reasons. Perhaps the ties were too loose, the child was tugging on the tube or in the case of children who are on breathing machines, the breathing tubing may have caught on something and then pulled on the tube.

SIGNS THAT YOUR CHILD'S TRACHEOSTOMY TUBE IS OUT

- Respiratory distress
- Child complains that they cannot breathe well
- You can hear your child's voice when normally you cannot, or your child's voice sounds louder
- Your child is not breathing
- You can see that the tube is out or is not sitting in the stoma properly or tube "looks funny"
- Your child is acting differently

MANAGING ACCIDENTAL DECANNULATION

1. Stay calm so as not to excite or upset your child. Act quickly and deliberately but do NOT rush.
2. If your child is having trouble breathing or is not breathing, and if the tube that fell out is the only tube that is immediately available to you, simply re-insert that tube.
    - You may change to a clean tube once your child is stable and you have help.
3. If your child is **not** having trouble breathing, immediately get spare tracheostomy tube from Go-Bag or other nearby supply source, and perform a tracheostomy tube change.
4. If you are unable to insert the spare/same-size tracheostomy tube, insert the smaller-size tube.

If your child is breathing fine without his or her tracheostomy tube in, NEVER assume that you can take your time to re-insert the tube. Things can change VERY quickly, and the longer the tube is out, the harder it will be to re-insert.

5. If unable to insert smaller tube, try inserting a suction catheter into the smaller tube.
    - Guide the suction catheter into the stoma, and then slide the trach tube over the suction catheter and into the stoma.
    - Remove suction catheter.
6. If you are successful in getting the smaller tube in, take your child to their doctor or emergency room as soon as you can safely do so to have your child's regular size trach tube inserted.

If you are unable to insert the regular tube or the smaller tube, have someone call 9-1-1. Be prepared to start CPR if your child stops breathing.

PREVENTING ACCIDENTAL DECANNULATION

- Make sure tracheostomy ties are snug and secure.

> *You should not be able to fit more than one small finger between the neck and tie.*
>
> *Check trach ties throughout the day to assure that they are properly secured.*

- Before using trach ties, check Velcro to make sure it is not worn out or faulty and it strongly adheres.
- Do not use damaged trach ties or trach ties that have been washed too many times.
- Do not over-trim Velcro.
- Children often go through stages where they like to pull on their trach tubes.

> *Correct your child when he or she pulls on the trach tube.*
>
> *Make sure your child is constantly supervised.*
>
> *In some cases, it helps to tie a small cotton-backed bib over the trach tube to make it hard for your child to get at the trach tube.*
>
> *In some cases, you may need to talk to your child's doctor about using arm restraints to prevent your child from pulling on the trach tube when not supervised such as during naps or at nighttime.*

- If your child is on a breathing machine, make sure that breathing tubing is not allowed to dangle or swing from trach tube. Not only can the weight of the tubing pull the trach tube out, the weight of the tubing can also put pressure on the skin around the stoma, causing skin problems.

> *Secure breathing tubing to your child's abdomen to prevent direct pulling on the trach tube.*
>
> *Some parents thread the tubing under their child's clothing to reduce pulling on the tracheostomy tube.*
>
> *Check with the ventilator team for additional suggestions.*

- Talk to your doctor if measures to prevent accidental decannulation do not help.

PART IV: Letters & Tips From Other Parents

A Blessing in Disguise: A Letter to Other Parents, From Carson's Mom & Dad

We will never forget the day that changed our lives forever. The day our son almost died. The day he fought back with a vengeance and showed everyone how strong he really could be. This was the day our son, Carson, was emergently trached at the age of 8 months because of pneumonia. This small piece of plastic in his airway not only saved his life, but greatly affected how we lived our lives as a family. This is our story. Our story about a little boy who never gave up and the family who loves him to pieces.

November 16, 2005. As Carson lay in his hospital crib, no one…not even the doctors, knew how sick he really was until he couldn't breathe anymore. The doctors, nurses, and respiratory therapists rushed him to the OR to intubate him and put him on a ventilator. As we sat in the waiting room, thinking that Carson was just going to be intubated and his airway cleared, a doctor ran up to us with a consent form for a tracheotomy.

Placement of the tracheotomy tube was necessary to save his life, which he said in so many words. We didn't want to sign the form, but we had to. In hindsight, we think about those five minutes we sat in the waiting room, making the doctor explain to us why Carson needed this procedure…convincing us that it was the only option. That was five minutes that Carson barely had. As the doctor took our form to the OR, we wondered what this all meant. Our heads were spinning and our hearts were aching. We had absolutely no idea what was involved with a tracheotomy and what this meant for our son's future.

It's important to point out that when all of this happened, Carson was not without complications in his life. He was born with a rare genetic condition called Smith-Lemi-Opitz syndrome, which left him with many physical issues and mental delays. A recessed jaw, floppy airway, and decreased ability to fight infection were among these issues, which further complicated the pneumonia and breathing problems. We were not strangers to the hospital, but this, by far, was our scariest hospital visit yet.

Soon after Carson received his tracheotomy, we were told more than once, "He's not out of the woods yet." He was very, very sick and fighting for his life. Carson remained in the PICU for nearly three weeks following the trach placement. For several days, he was on the maximum ventilator settings and barely getting by. He was on countless medications, many of which were to ease his pain and keep him asleep. Carson was completely sedated for nine days before he woke up. It was agonizing for us to see our baby like this. Then, on the ninth day, he opened his eyes and gave us the biggest smile!

We were stunned…he was smiling. He was happy to be alive! I took a picture…it is one of our favorite pictures of him still to this day. At that moment in time, we didn't care about the trach or what care might be involved with it. We were just overjoyed that our precious little boy was on the road to recovery.

One day that stands out is the day we realized that we would be going home with the trach. We just assumed that once Carson was recovered, the trach would come out and we'd go home! Well, one evening a nurse came in to suction Carson. She told us, "You're going to be pros at suctioning." WHAT? We didn't understand… what does that mean? We actually have to learn how to suction and…oh my goodness we're going home with this thing? Don't we have enough on our plates right now? But, as the days went on and we slowly got used to the trach (and how different his coughs, hiccups, and sneezes sounded), we realized that we could do this… we had to do this.

Another thing that was difficult to get used to was not being able to hear Carson's voice. Carson was starting to make noises at home, and that he'd laugh out loud sometimes. As we absorbed the news Carson may not be able to make noise with his trach tube, we remembered that the most important thing is that Carson is still here with us. In time, his voice will come back, too.

Once Carson was moved to Moderate Care, we began the training process of suctioning and cleaning and changing the trach. Suctioning was easy. Cleaning around the stoma was easy. Changing the trach…that terrified us. But, again, we had to get over our fears and be the parents that Carson needed us to be. We did several trach changes in the hospital before we were discharged and left feeling comfortable and confident and happy. The most important thing was that Carson was alive and even with the trach tube; we would do our best to give him a happy, comfortable life.

We were (finally!) discharged after spending four weeks in the hospital. The nurses did a wonderful job educating us and made sure we were comfortable before we were sent home. We came home two days before Christmas, 2005. How wonderful it was to spend our first Christmas together as a family...at home.

Soon after we arrived home from the hospital, our medical supply company came by with some Christmas presents…new equipment for Carson! We were slightly taken aback at how our cozy home had turned into a hospital room. The air compressor was louder than loud, and the suction machine sounded like a small lawnmower. Initially, we set everything up in the living room. The suction machine, go-bag, and air compressor/humidifier were set up on the coffee table. Carson's feeding pump was also close by.

We were afraid to take Carson off of his humidifier for longer than a minute. After all, he was on it 24/7 at the hospital so we figured he should be on it constantly at home, too (we later realized that this is not true...that's what the artificial noses are for). We had corrugated tubing running all through our house so that we could carry him around. Heading out for the holidays was completely out of the question, so we had friends and relatives come over in shifts to help celebrate the season.

We knew our lives would change once we got home, but we had no idea how much. Our evenings now consisted of "chores" that we'd do every night before bed (or some we only needed to do once per week). We would make solutions, clean suction catheters, clean the suction canister, fill the humidity canister with distilled (and only distilled) water, clean Carson's trach site, change the trach tie, and…of course, change his trach weekly. A nurse was sent to our house for the first three trach changes. Needless to say, we were more nervous than nervous could be. But, it went smoothly each time. She was there to observe us and help if we needed help. By the third week, she told us, "You guys don't need me anymore." What? Are you sure? We knew she couldn't come forever so we said our goodbyes and from then on, it was all on us to care for our big man.

One of the first things we did was to buy a new stroller. This was necessary because we needed a carrying basket wide enough to hold his suction machine and Go-Bag. Although everything fit fine in the stroller, we couldn't help but feel bogged down with everything we had to transport. Getting ready to go anywhere took longer than we had imagined. Even simple walks around the neighborhood weren't void of Carson's "stuff." We considered getting rid of our cat because of the pet hair. What if a cat hair got in his trach? We worried constantly. We also considered buying an air purifier for our house but realized after a while that we (and Carson) would be fine without one. We kept our house as clean as can be and put a gate up to keep the cat out of Carson's room. Trach changes were done on our immaculately clean coffee table in the living room, which was the perfect height for us. No powders, aerosols, or sprays were ever used anywhere in the vicinity of Carson.

As much as we wanted and needed Carson to be disconnected from his humidifier and trach mask/tubing, we simply could not get him to tolerate the artificial nose. It always seemed to make him very "junky" and have a lot of trach secretions. So, our solution was to have him wear a trach mask when we went out. It was not as protective as the artificial nose but better than him wearing nothing at all over his trach. The thought of anything other than AIR getting in his airway made us paranoid to no end. We have lots of pictures with Carson wearing his trach mask around his neck. In fact, he's wearing it in his first picture with Santa Claus when he was almost two years old. Only when it was really, really cold outside did we have Carson wear a nose no matter what. The cold air was very irritating for his exposed airway. Eventually, Carson was able to tolerate the artificial nose…he didn't have to wear the mask forever!

Time went on and believe it or not, as parents of a trached child…we eased up. We relaxed and realized that it's not all that bad and that Carson would be okay doing typical things that most kids and parents do. We wanted so desperately to live our lives like any other couple with a young child. Carson was born with challenges but this was his biggest challenge yet (and ours). We wanted to take him places and include him in as much as possible so that he could get the exposure, interaction, and education that he very much needed.

We started doing this as soon as we were comfortable, and it was rewarding for all of us as a family. We included him in as much as we could…birthday parties, horseback riding, swimming, traveling (by plane), and even school. Initially, the hardest part was getting over the stares from complete strangers… the questions (will he have that thing forever?). The suctioning in public was the worst. It was so loud we would always get looks and stares. Plus, it's big and heavy and a nuisance to tote around everywhere.

Luckily, Carson had a great cough. This was pointed out to us even while he was still recovering in the hospital. Most times, he would "cough it up" but of course there were times when he just had to be suctioned. We often used the "wipe" method, where he'd cough and we'd immediately wipe the goober from the outside of his trach. This worked wonderfully for us and was our technique of choice for keeping the area around Carson's trach clean throughout the day. Although, it was not unusual to be caught off guard and get hit with a flying goober. But, we got used to it.

Although it may seem like there are not many good things about having a child with a trach, surprisingly… there are. For example, Carson's sleep apnea…which dominated his sleeping life before he was trached… was completely gone. He slept, literally, like a baby. He slept soundly, peacefully, and quietly for the first time in a very long time. His apnea was completely gone and he was finally getting some rest! And, so were we. After Carson came home, and several months after having the trach, we noticed that he was more alert, aware, and active. He seemed happier and he was growing more. This, no doubt, was from the fact that he was experiencing restful sleep and his body was allowed to recharge and develop like it should.

Another positive thing about the trach is that you can always tell when your child is ill by the color of their secretions. Secretions in the morning are usually discolored and junky, but it goes away soon after waking up. When Carson was sick with a cold or pneumonia, we knew right away because his secretions would be very thick and discolored. We got analytical about the colors…Green? Yellow? White? Viral or bacterial? With Carson it was usually pneumonia, as he got them frequently.

We had a very scary experience one day when Carson started coughing up pink-tinged mucus from his trach. He felt feverish and was lethargic. I called the pediatrician's office and they told me to call 9-1-1. We literally live a minute from the fire station so soon after hanging up the phone, we heard the sirens coming down our street. The ambulance soon followed and we were soon whisked away to the U of M Emergency. The pink turned redder and after we finally got some X-rays taken, we were told that Carson had pneumonia.

After this episode, which was one of our scariest, we realized that Carson coughing up blood-tinged mucus and not feeling too well meant that he most likely had pneumonia. He had five or six pneumonias during his time of having the trach, some of which required hospitalization (and ambulance rides). The trach allowed us to help him keep his airway clear and made it much easier for him to cough up the constant secretions, which always accompany pneumonia. Besides pneumonia, we could tell when he had a simple cold (no pink but very junky secretions).

Another positive thing about having a child with a trach is that he/she cannot choke while eating…there is always an accessible airway. Carson is 100% g-tube fed but we have been working with a feeding specialist since he was born. Chewing and swallowing have always been a challenge, as is working with different textures, flavors, and temperatures. Carson made great strides in the area of feeding during his time with the trach. Having the trach in his airway made swallowing a little more difficult but he learned the best he could in spite of this and continued to make small, progressive steps.

The one thing we missed so much when Carson got his trach was…his voice. He is non-verbal, but before he was trached, he was laughing out loud and sometimes mimicking noises we would make. It was a very, very long time before we heard that sweet voice again. It was a very subtle adjustment…he slowly learned how to make noises around his trach and force the air through his vocal chords. After months of practice, Carson got really, really good at making noise! Lots of noise! Eventually, he learned how to plug his trach with his chin and make noise through his mouth (this made us nervous at first but eventually we realized that he was OK). He knew when he needed a breath and would lift his head up, then put his little chin back down over his trach. After months of doing this, Carson figured out that he could cover his trach with his fist and really be vocal! This was so exciting for us to see...not only how he could realize how to do this but that he could easily breathe with his trach completely covered with his fist. We started wondering if Carson was on the road to hopefully being decannulated someday.

Our journey to get Carson to the point where he could finally tolerate a speaking valve, and then a full cap, was often eventful and not without some bumps in the road. We genuinely felt that letting him grow into himself and get bigger and stronger would play a key role in his ability to be decannulated. During Carson's time with his trach, he had two surgeries to help move him along so to speak…removal of his tonsils and adenoids to open up his airway, and mandibular jaw distraction to bring his recessed jaw and his tongue forward.

Both procedures were very beneficial for him. The jaw distraction in particular was very difficult to go through, but had amazing results. Other than these two procedures, we just let him grow. And we were patient. He showed us when he was ready to start the capping process and we followed his lead.

We first started working with the speaking valve, it was very difficult not only for Carson, but for us as well. It was on and off…on and off. Carson would cough a lot as he got used to using the valve. He soon learned how to cough the valve off and got a kick out of watching it fly across the room. Then, he learned how to pull it off and throw it. All the while, he'd have his fist over his open trach and smile at us like he was playing a game or something. He was being mischievous and he knew it! He would breathe in and out of his mouth with his fist covering his trach. We decided that maybe we could just try the full cap and see how he did with it. Luckily, our doctor agreed and after examining Carson, gave us a cap to try at home, along with capping instructions. We were nervous and excited all at the same time!

Our capping experience was a slow one. It took months before Carson was able to wear the cap full-time with no problems. Don't be discouraged if it takes a while for your child to get used to the cap…it is a whole new way of breathing! At first, we'd put it on for a few minutes, then take it off, eventually working up Carson's tolerance. Not only was it difficult for him to get used to, but also for us. Every time he'd start to cough or appear to have trouble breathing, we'd immediately take the cap off. This was our initial reaction every time he appeared to need help. Take the cap off. We did this for a long time! Eventually, we realized that we could not always be there to "save" Carson when he started to cough. He needed to learn how to cough through it and keep breathing on his own. This was incredibly difficult for us as parents to get used to, but we forced ourselves to leave the cap on. As long as Carson wasn't in respiratory distress (which he never was), then he'd be okay and learn how to do this himself. After all, when the trach is gone, there will be no way to "save" him during a coughing fit, right?

Capping to us was not only a physical act, but very much a mental challenge. We were in the process of changing the way our child breathed! We had to mentally grasp the concept of this, and also to the prospect of life without the worries of a trach. It's all very exciting but at the same time, nerve-wracking. From beginning to end, the entire capping process took us about six months. That is from the time we received our first cap to the day he was decannulated.

Decannulated? Yes!! After having his trach for 3 years and 6 ½ months, Carson was successfully decannulated on June 2, 2009. This is another day that we will never forget. Taking that trach tube out and not having to put it back in was a momentous occasion for us. We felt as if a weight was lifted off our shoulders and our lives were beginning again!

The trach, as much of a hassle as it seemed to be, was probably the best thing that could have happened to Carson. We learned a lot, we grew a lot, and we are better parents for all that we have been through. Carson is our little Superman and we are forever grateful to the doctors and nurses who saved his life.

Tip from Carson's Parents
Add a splash of minty-fresh mouthwash to the bottom of the suction canister after cleaning. It smells much better when suctioning.

Carson without his trach tube!

Tips from Jackson's Parents

1. We preferred the T-shaped ("Thermovent") nose. It seems better for rolling over, sleeping on the stomach, under bibs, and in a baby front carrier. The T-shaped nose makes these "typical" baby things possible for your child because he/she breathes out of the sides of the nose. If you would like to use this type of nose, check with your supply company. They may be able to get it for you.

2. Our son wore a cotton bib constantly for the first eight months of life—we had a TON so I could color coordinate. No one can tell your child has a trach and this avoids questions while you are a new trach parent. The bib also helps keep typical baby drool from irritating the stoma and skin around the trach tube. By the time a baby bib started to look funny on our toddler, we were more comfortable with the trach and our lifestyle; I felt proud to show off his trach as a part of him, but this acceptance took time.

3. You can use the traditional plastic-backed bib while feeding solids as long as your child is wearing a T-nose. Place a folded piece of paper towel between the bib and your child's neck. The paper towel keeps liquids from running into the stoma during feeding.

4. Take advantage of any help available to you. If possible, train a relative or close friend to care for your child. We were told we could train friends/relatives ourselves because no one would know better than us how to do everything. I taught a good friend how to suction and feed our son, then our friend played with him while I napped and/or decompressed upstairs. She could call me downstairs if any problems arose. This was invaluable rest time in the beginning.

5. Consider learning sign language and teaching your child. This is a great way to communicate; it helps with later verbal language development, calms tantrums, and empowers your child. We learned to sign by watching "Signing Time" DVDs. Start with "Baby Signing Time," this is a series of four. You can find these DVDs at the library.

6. Put a big piece of foam under the compressor (the machine that provides nighttime humidity through the trach mask). (*See the picture of Jackson's room setup in CHAPTER 6, "Where Your Child Will Sleep." You can see the foam underneath the compressor.)* This little tip significantly dampened the annoying loud noise of the running compressor.

7. If you are able, purchase or borrow a video monitor. The video monitor allows you to move around the house and be able to see the baby. In the picture of Jackson's room, you can see the video monitor mounted on a wire above the bed.

What to Expect: The Tracheostomy Version by Olivia's Mom & Dad

I'm sure you may be familiar with the popular series of books "What to Expect While Your Expecting," "What to Expect the First Year," etc. They are full of information about pregnancy, infants, and toddlers. To the first time soon to be parent it is information that is useful, new, and maybe a little bit overwhelming. You read what you can and hope for the best. How much can you learn from a book anyway? How hard can it be?

And then you find yourself surrounded by doctors, nurses, and respiratory therapists in a hospital. There was no chapter that prepared you for this. In many ways, this trach manual is your new "What to Expect" book. What to expect after the unexpected happened. And though no one's story is exactly the same, the information in this book will help you know what to expect.

Our story started immediately after Olivia's birth. She was blue and not breathing. Soon she was on a Survival Flight and we were on a very unexpected journey. It took months in the NICU and endless tests before we were presented with a rare diagnosis. This diagnosis included the words tracheostomy and ventilator. In the months in the NICU we were also presented with our daughter. A bright eyed, strong-willed, and spunky little individual who has taught us more than we ever expected. And though we never planned on changing a trach, suctioning an airway, or troubleshooting ventilator alarms, these things have become part of our life because they are part of hers.

Being the parent of a medically fragile child brings with it many challenges and unexpected joys. Here are a few more things we never expected but you might:

1. We never expected to chase a crawling infant or a running toddler around with a ventilator attached to her trach. Every time we wondered how she was going to do something, she found a way.
2. We never expected to have so much stuff: Medical supplies in our pantry, back-up ventilators and suction machines charging in the closets, and oxygen tanks in the garage.
3. We never expected to have so many medical professionals involved in our life. At times, it can be frustrating dealing with home-care nurses, supply companies, and insurances, but they are all necessary to help provide care for your child.
4. We never expected that it would all get easier and we would become experts in her care.

Olivia will soon be five years old and we couldn't be more proud of the little girl she has become. She will tell you that her trach and ventilator help her breathe. And they do. And they will continue to. And, though, it is nothing anyone expects for their child, it is something that you get used to.

A Letter from Kloe's Mother

Kloe Elizabeth Halstead

A whole other world was introduced to us in October 2009, when the doctors said "tracheotomy." I felt overwhelmed and lost.

Kloe was born a healthy little baby girl and 2 weeks later we soon found out that was not the case. We were being readmitted into the hospital having located masses on her cervical spine. She underwent major spinal surgery, and was diagnosed with stage 2 neuroblastoma. Now she couldn't breathe on her own and tracheotomy was the only thing to assist in breathing successfully.

It seemed like every time we climbed over a hill there were more waiting in the distance. I was devastated.

I felt ill that my little girl was going through all this treatment and now I was being introduced to a tracheostomy. I sort of knew its meaning, but wasn't expecting all that came with it.

We watched a video which made me sick, mad, and sad all at once. I hated this, every bit of it. I wanted to have a special baby, but not in this way. I could never imagine a life like this, but God picked us, and we wanted nothing more than to love and take care of our baby.

Trach and vent "101" was what we took to know what is best for Kloe and thanks to our close knit family, who also were trained, we can leave Kloe comfortably with them. The nursery is her spot where we spend most of our time so we made it as comfortable as possible.

If you thought a baby had a lot of stuff, just wait for all the supplies. Organizing and setting things up will take time. Here are a few tips:

1. Clear tubs with labels are what I use for storage.

2. Once you get a handle on back-up equipment, you should list what you don't need on the next order so you aren't overwhelmed with things you don't need.

3. Don't forget to set up the acetic acid and sterile water for the suction machine.

4. Always keep a full box of catheters in the car and extra tubing for emergencies.

5. Putting the travel vent on the front passenger seat with the battery will give you room in the back.

Just like in a relationship, communication is what makes it all come together.

From Caleb's Parents

Dear Parents,

This is our story.

At about 18 weeks, Katrina had an ultrasound that revealed some problems with the pregnancy. Katrina was ordered on strict bed rest. Up until this point, she had been working two jobs and I had been attending the University of Michigan and working as a Heating and Air conditioning technician. We were both very busy!

The first week of bed rest was very hard for Katrina; having to rely on others for nearly everything was tough for a strong-willed, independent woman. I moved into Katrina's parents' home and continued working and going to school. The schedule was very rigorous. I would try and get Katrina everything she might need for the day so that she would only have to get up to go to the bathroom. Weeks went by. I would receive countless phone calls during the day asking what I was doing and when was I coming home. I also remember all the Lifetime movie marathons and how "Johnny hurt Sally, but in the end, Sally got her justice."

A couple of weeks went by and we wound up back at the University of Michigan triage. Katrina was bleeding. This happened a few times a week; Katrina would wake me up, we would spend the night and early morning in triage and then get home just in time for me to head off to work. The lack of sleep with work and school was just a hint of what was coming our way!

At about 26 weeks the doctors decided that it would be best to admit Katrina. Ten days after admission, while eating reheated Thanksgiving dinner, the team of doctors came in and said there was an infection. They needed to perform an emergency C-section. In the moments before they came back to take Katrina to surgery, we fired off phone calls to our families and friends to let them know that our little boy was on his way. Excitement, anxiousness, eagerness, pride and love were some of the emotions we were feeling. We knew there would be many complications with a pregnancy this early in the term. 27 weeks! But we were still excited about planning the upcoming baby shower and the idea that we were going to be parents!

We welcomed our son into this world on November 25, 2007. Caleb Anthony DiMassa was 3 lbs., 5 ounces, and 16 inches long. Our son was here. All his fingers, toes, arms, legs, everything was there, I thought. Little did we know his lungs did not develop nearly as well as his fingers and toes.

At this point, Caleb was receiving CPR with an AMBU bag and an ET tube. The doctors came and asked us if we wanted them to continue what they were doing to try and save his life and support his breathing. We both stammered at the questions and said of course! We wanted them to do everything.

A day after the C-section, Katrina had healed enough to get out of her room to meet Caleb for the first time. Caleb was in his incubator with a ventilator helping him breathe through a tube that went in his mouth. Feeding was performed through a tube in his belly button. He also was receiving medication through another IV. Heart and respiratory rate monitors and a pulse oximeter rounded out the numerous wires and tubes that were keeping our son alive. We were so proud and excited that he was here!

We talked to him all day! The nurses and doctors educated us on what was going on and what they were doing to evaluate his condition. Caleb had to be sedated. They did not want him trying to fight the machine and breathe on his own. With any medication comes a side effect. Side effects that sometimes required other medications that came with their own set of complications.

At this point Katrina and I were a mess! We would talk to each other about the simplest little things that Caleb did, like moving a finger or twitching an eyelid. Any sign of life was the greatest for us. We clung hard to our beliefs that Caleb was strong and he was going to get better.

In the following weeks things went from bad to worse. Caleb's little body was starting to lose ground. His kidneys were having a hard time and were beginning to shut down. His body began to retain fluid. Our 3 lbs., 5 ounce baby swelled to over 12 lbs. We decided it was best for all of us if no visitors be allowed to see Caleb. We were at the hospital all day. I was attending class at a minimum and off of work. Katrina stayed with him all day. We would stay until the wee hours of the morning, until the nurses assured us he would be fine and that they would call us if anything happened. I would call when we got home, when Katrina got up to pump, and when I woke up to go to school. It was hard to leave the hospital but the phone calls helped ease some of the worries.

The NICU doctors placed Caleb on multiple different ventilators, high settings, high rates, and nothing seemed to help him. He was on the highest settings on the jet ventilator. The machine was damaging his lungs but keeping him alive. The frequency of sit down meetings with multiple doctors was increasing. We knew if the NICU was pulling their best doctors away from all the other sick children to meet with Katrina and me, that Caleb was on the ragged edge of life and death.

Through out all of this, Katrina and I stood strong in our belief in our son and his strength. I started writing a blog, in Caleb's voice, to keep family updated on his condition. In every post I would write, "I am Caleb. I am Strong!"

The doctors had tried everything they could do with medicine and machine settings. They thought that a tracheostomy might allow the machines to ventilate his lungs with lower pressures. This was another crushing moment for Katrina and me. Not only is our son paralyzed from sedatives, hooked to all kinds of machines and wires, but now they want to cut a hole in his neck and give us something else to deal with. We were doing our best to get through each day without breaking down and now this. "Why us?" we asked.

Days before Caleb's scheduled surgery, another baby in the NICU had been given a trach and we asked to see it. It was possible, and we knew if it meant giving Caleb a better chance of survival, then there was no question about it. Caleb got his trach the day before Valentine's Day 2008 at 81 days old.

After the tracheostomy, Caleb, who earlier was not responding to the highest ventilator pressures with 100% oxygen, was now showing signs of improvement. He was taken off the jet ventilator and put on a conventional ventilator. The combination of this ventilator and the trach meant that Caleb no longer needed to be paralyzed to protect himself. This meant he could be awake and alert. Without the ET tube we also got to see his face with no tape or tubes. Caleb's kidney function was improving, and the diuretics were starting to reduce the amount of fluid he was retaining. Caleb soon began to shrink back down closer to his birth weight. The decrease in fluid made it easier for his lungs to oxygenate.

The effects of getting the trach and being put on lower pressures were starting to compound themselves in a good way. Every system of Caleb's body started progressing in a common direction. Caleb was getting better. In one week Caleb was eating out of a bottle. Not a common thing for babies who have been tube fed and sedated for most of their lives.

We did not allow negative thoughts to be entertained. Sometimes that might have seemed as though we were not seriously considering the reality that Caleb could have passed away but that wasn't true. We knew he could die at any moment. We knew he was holding onto a thread for his life. We believed in him and knew he was getting the best care possible.

It is no doubt to Katrina and me that Caleb is here today because the opportunity that he was given with the trach. That single operation opened up so many doors that allowed him to fight harder, eat better, and grow bigger and stronger every day. Without a doubt, we are glad that our son got a trach.

The road after the trach procedure was not without its up and downs. Caleb was still a very critically ill child. He had other complications that nearly took his life on numerous occasions. We had to fight just like he did every day to keep him alive. It was not easy. We did not sleep very much at all. We worried all the time. We would take turns breaking down and the other one of us would pull things together to keep us strong.

Katrina and I grew together as a couple throughout the experience in the hospital with our son. On the day of our discharge, just as we were about to walk out of the sliding hospital doors into the parking garage with our son, I asked Katrina to marry me. She said yes, and we cried even more.

We went home with our son with a trach and a ventilator and oxygen and it didn't matter at all. We were taking our son home after 148 days in the hospital. He was the child that even the best doctors at University of Michigan thought would not make it home. Caleb made it. Caleb has done more than make it. Caleb is now breathing all day without a ventilator, and in just a few months, he will be getting examined to see if he is ready to have his trach removed altogether.

Never give up hope, and always remain positive!

I am Caleb. I am Strong!

-Domenic and Katrina DiMassa

Tips from Caleb's Parents

Change your ideas of the meaning of "normal." Think about what is normal for your child.

Carry high chair cover in diaper bag to place over high chairs when out.

Take a blanket to lay over changing tables when you are out and have to use a public bathroom. You can easily wash the blanket later.

Hang the Go-Bag in the car behind the seat so it is always available.

Store all of your trach tubes, ready to go, with ties attached, in a sliding Ziplock bag. Save old one for just-in-case and place them wherever you might go: upstairs, downstairs, purse, diaper bag and in the car. If you have to use one of the older tubes in an emergency, you can change back to a newer tube when things are calmed down.

When there are parties or gatherings, wait until everyone is there before you leave. That way you can call ahead and find out if anyone has been sick recently or is sick. Then make your decision as to whether or not you should attend with your child.

Take your child's own blanket and toys when visiting to keep exposure to germs at a minimum.

Always have hand sanitizer available. You never know when someone might come up and touch your child because he or she is so cute.

Pull-Outs Sheets

PART V: Pull-Out Sheets

AT - A - GLANCE: Tracheostomy Care

My Child's Name, Address, & Phone Number

Tracheostomy Tube Type & Size

Emergency Tracheostomy Tube Size

Suction Catheter Size

Suction Depth

Precautions

- Wash hands before all trach care
- Have Go-Bag supplies within reach at all times
- Constant supervision
- Check trach tie tightness throughout the day
- Routinely suction only to pre-defined suction depth
- No swimming or showering
- No aerosol sprays, dust, powders, sand, or lint

Humidification

- For infants: wear mist mask for most of day and always during naps and at night while sleeping.
- For older children: wear mist mask during naps and at night while sleeping and more often if showing signs of dryness, i.e. thick, sticky mucus, blood-tinged secretions.
- Wear artificial nose when not using mist mask.
- DO NOT wear artificial nose when sleeping or when not being directly supervised.
- Use saline drops without suctioning if away from humidification for extended periods.

Skin Care

- Perform at least once a day and as often as needed to keep skin around trach tube clean and dry.
- Use mild soap and water or ¼-strength acetic acid. Clean away from stoma.
- Inspect skin at least once a day.
- Call pediatrician if you are unsure about the appearance of the skin.

Trach Ties

- Change at least once a day , with assistance, and whenever wet or damp
- Inspect skin under trach ties at least once a day
- Secure snuggly so that no more than one small finger fits between neck and trach tie
- Check tightness throughout the day

Suctioning

- Suction whenever child shows any signs of difficulty breathing, you hear mucus in the tube or you see mucus bubbling out of tube.
- For older children who cough up their mucus, suction at least twice a day.
- For routine suctioning, suction only to the end of the trach tube.
- Spin suction catheter between finger and thumb as you withdraw it.
- Suction ½ cm beyond end of trach tube if routine suctioning is not effective.
- Use saline lavage only if secretions are thick and suctioning without saline is ineffective.
- Change trach tube if child is having difficulty breathing and suctioning is not helping and/or you suspect your child has a mucus plug.

Tracheostomy Tube Changes

- Routinely change tube without inner cannula weekly. Change tubes with inner cannula monthly.
- Two people needed for trach tube change: Inserter and Holder/Remover
- Inserter prepares fresh tube, ties attached: lubricates and inserts obturator. Sets tube aside.
- Holder/Remover holds tube while Inserter removes ties.
- On Inserter's count, Holder/Remover removes tube; Inserter visualizes stoma, inserts fresh tube, and removes obturator.
- Holder/Remover returns to holding, and Inserter secures the ties. Checks trach tie security and tightness.

RECIPES FOR SOLUTIONS

In directions below, 1 ***part*** *means* ***one of any measurement****. For example if directions say to mix 1 part vinegar to 3 parts water, this means you can mix 1 tablespoon of vinegar to 3 tablespoons of water, or 1 cup of vinegar to 3 cups of water, or whatever amount you need, as long as there is 3 times as much water as there is vinegar.*

Boiled Water

The purpose of boiling the water is to kill the germs that are normally present in tap water and bottled water.

Boiled water is used for:

- diluting the disinfecting solutions used for flushing the suction catheter after use
- rinsing the suction catheter after it has been flushed with disinfecting solution
- diluting solutions for cleaning tracheostomy tubes

Recipe for Boiled Water

Gather as much water as you need.

- If you have city water, you can use tap water to prepare your boiled water.
- If you have well water, you must use distilled or bottled water to prepare boiled water.

1. In a clean pan, bring water to rolling boil.
2. Boil for 10-15 minutes.
3. Remove from heat and allow to cool to room temperature.
4. Store in a clean container labeled "Boiled Water."

¼-Strength Acetic Acid

Acetic acid, commonly known as vinegar, is a gentle cleaner that is safe for the skin and is also kills many of the germs that normally grow in respiratory secretions.

¼-strength acetic acid is used for:

- cleaning the stoma and surrounding skin
- flushing the suction catheter between uses

Recipe for ¼-Strength Acetic Acid

1 part white vinegar
3 parts boiled water (see boiled water recipe above)

1. Mix boiled water and white vinegar together.
2. Store in a clean container labeled "¼-Strength Acetic Acid."

½-Strength Hydrogen Peroxide

½-strength hydrogen peroxide is a disinfectant and antiseptic.

½-strength hydrogen peroxide is used to:

- clean Shiley brand trach tubes and inner cannulas
- clean crusts off the neck plate of any tracheostomy tube

Recipe for ½-Strength Hydrogen Peroxide

1 part hydrogen peroxide
1 part boiled water

1. Mix together hydrogen perioxide and boiled water.
2. Store in a clean container labeled "½-Strength Hydrogen Peroxide."

All solutions must be discarded 24 hours after they are made. See CHAPTER 8, page 53 for additional information on preparing and storing solutions.

AT - A - GLANCE: CPR

1

Check for signs of life: Color, Breathing, Movement, Coughing
Gently move child.
If no signs of life, place on firm surface.

- If **not alone**: have another person call 9-1-1 while you move to **STEP 2**.
- If **alone**: move on to **STEP 2** and perform CPR for 5 cycles before calling 9-1-1.

2

- Give breaths in trach tube with resuscitation bag.
- If air will not go in, change the trach tube.
- If unable to get trach tube in, remove trach adapter from resuscitation bag and put mouth mask on resuscitation bag. Cover stoma hole and give mask-to-mouth or mask-to-nose breaths. (If help is present, one person can cover stoma while the other person gives breaths.)

3

Check for signs of life again.

- **If no signs of life:** give **2 breaths** with bag, then **30 chest pushes**
- **If signs of life but not breathing:** give breaths once every 3 seconds

If alone: call 9-1-1 after 5 cycles or about 2 minutes.

- **Check for signs of life after every 5 cycles or about 2 minutes.**
- **Continue until child is breathing or help arrives.**

QUICK REFERENCE: Problem Solving & Emergencies

SYMPTOM	Your child is breathing, but has one or more of the following symptoms: ▪ Difficulty breathing ▪ Fast breathing ▪ Noisy breathing ▪ Pulling around breast bone and ribs ▪ Skin is very pale or blue ▪ Child appears anxious, worried, or agitated	No airflow from trach tube, AND Child's skin is blue or pale, AND Child is not responding	Bright, red blood coming from trach tube	Change in mucus lasting more than a couple of hours: ▪ Colored mucus ▪ Blood-tinged mucus ▪ Thicker mucus ▪ Sticky mucus ▪ Increase in amount of mucus
POSSIBLE PROBLEMS	▪ Respiratory distress ▪ Mucus plug ▪ Trach tube is out	▪ Respiratory arrest ▪ Mucus plug ▪ Trach tube is out	Perforation, ulceration, or laceration of trachea	▪ Respiratory infection ▪ Dehydration ▪ Granulation tissue at the end of trach tube
WHAT TO DO	Check to make sure trach tube is in. If not, replace the trach tube. If trach tube is in, try the following steps: ▪ Suction depth of trach tube ▪ Suction ½ cm beyond trach tube ▪ Suction w/ lavage ▪ Change trach tube	If you are alone, call 9-1-1. If there are others around, ask someone to call 9-1-1. Check to make sure trach tube is in. If not, replace the trach tube. If trach tube is still in: ▪ Give a few breaths with rescuscitation bag ▪ If you cannot get air in, then change the trach tube. Try to give breaths again. ▪ If your child has an inner cannula, change the inner cannula. If you still can't get air in, change trach tube. Try giving breaths again.	If you see less than 1 teaspoon of bright, red blood from the trach tube, take your child to the emergency room for prompt evaluation. If you note more than 1 teaspoon of bright, red blood, call 9-1-1. Stay calm and use humidification until help arrives.	Make note of any other symptoms, such as loss of appetite, sleeping more, or fever. Call pediatrician and report all symptoms. Pediatrician may want to see your child or may order a chest X-ray. Increase humidity: longer hours on mist mask; saline drops without suctioning, nebulized saline treatments
IF NO IMPROVEMENT	If your child is still having difficulty but otherwise seems okay, call your doctor. If your child is really struggling or is pale or blue, call 9-1-1.	If your child does not start breathing after trach tube change, continue giving breaths, start CPR, and call 9-1-1.		If no improvement after reporting symptoms to your child's doctor or by increasing humidity, call doctor again to report no improvement. Report blood-tinged mucus to tracheostomy surgeon if child has no other symptoms and blood-tinged mucus does not clear up after one day.

Emergency Information & Contacts

Child's Name

Date of Birth

Home Address

Parents' Names

Parent Contact Numbers

Home *Work* *Mobile*

Tracheostomy Tube

Brand *ID* *OD* *Length* *Suction Depth* cm

EMERGENCY	***9-1-1***
Pediatrician	**Phone**
Tracheostomy Surgeon	**Phone**
Other doctors/surgeons	**Phone**
	Phone
Hospital Emergency Room	**Phone**
Home Nurse	**Phone**
Pharmacy	**Phone**
Equipment Company	**Phone**

Medications

Other Important Information

GENERAL PRECAUTIONS WHEN CARING FOR A CHILD WITH A TRACHEOSTOMY TUBE

- Wash hands before all trach care
- Have Go-Bag supplies within reach at all times
- Constant supervision; never leave child alone unless napping and sound monitor is set up
- Immediately replace trach tube if it falls out or is plugged
- Check trach tie tightness throughout the day
- Child never wears artificial nose or speaking valve when sleeping
- Routinely suction only to pre-defined suction depth
- No swimming or showering
- No aerosol sprays, dust, powders, sand and lint
- No exposure to cigarette smoke

SUCTIONING THE TRACHEOSTOMY TUBE

When to Suction

The child should be suctioned whenever it sounds or looks like there is mucus build-up in the tracheostomy tube or if child has signs of respiratory distress. If you are not suctioning too deep (see section on Suction Depth below), you do not have to worry about suctioning "too much."

Typical signs that child needs to be suctioned:
- rattling mucus that does not clear with coughing
- bubbling mucus at opening of tracheostomy tube

Signs of respiratory distress signaling the need to suction immediately:
- Flared nostrils
- Chest retractions
- Fast breathing or increased work of breathing
- Dry, whistling sound
- Clammy skin
- Agitated behavior or restlessness
- Frightened or anxious expression on face
- Pale or blue colored skin, nails, and/or mouth

Older children are suctioned twice a day to assure that the tracheostomy tube is open.

Supplies Needed for Suctioning

- Suction machine
- Suction catheters
- Saline vials
- Resuscitation bag
- Gloves (if in the hospital or if it is your preference at home)
- Container of ¼-strength acetic acid or other disinfecting solution
- Container of boiled water

Suction Depth

The goal of suctioning is to clean out the tracheostomy tube, not the child's entire airway.

During routine suctioning, the suction catheter is inserted no farther than the end of the trach tube.

- If suctioning to the end of the trach tube is not successful, it is okay to advance the suction catheter no more than ½ cm beyond the end of the tracheostomy tube or just until the first side holes on the suction catheter peek out of the tracheostomy tube—whichever comes first—but no further than this.

You will be taught the proper suction depth for the child's particular tracheostomy tube.

If child uses a larger suction catheter that does not have markings indicating the proper suction depth, secure a tape measure on the suction machine so you can measure where to put your fingers on the suction catheter.

How to Suction

1. Gather supplies.

2. Wash hands.

3. Connect suction catheter to suction machine.

4. Turn on suction machine.

5. Suction machine is set at no more than 90 mmHg negative pressure for infants and no more than 115 mmHg for older children and adults.

6. If child requires breaths before suctioning, ask your child to take 3-5 deep breaths or give breaths with the resuscitation bag.

Ideally, if the child needs breaths, it is best to quickly suction one time before giving breaths with the bag. Suctioning out the trach tube of excess mucus will help prevent the bag from blowing mucus into the lower airways.

7. There are various ways to manage a breathing machine or ventilator during suctioning; it depends on the ventilator type and the child's needs.

8. Hold suction catheter by placing thumb and forefinger of dominant hand at the marking (number) on the suction catheter that matches the suction depth for your child's trach tube.

9. Insert suction catheter into trach tube until your thumb and forefinger make contact with the tracheostomy tube. (See illustration on next page.)

10. Cover the thumb hole on the catheter with non-dominant thumb to apply suction.

11. As you gently and slowly withdraw the catheter, spin it between your thumb and forefinger. This step takes about 5-10 seconds.

After suctioning, listen and watch the child's breathing effort.

If you still hear mucus rattling in the tube, or if the child is still struggling to breathe, then repeat suctioning until child's breathing is easy, sounds clear, and there is little or no mucus return in the suction catheter.

What to Do if Suctioning is Not Adequately Clearing the Tracheostomy Tube

1. Try suctioning ½ cm beyond end of trach tube. If secretions do not clear when suctioning to the end of the trach tube, then try suctioning just beyond the end of the trach tube by advancing the suction catheter to no more than ½ cm.

2. Try suctioning with Normal Saline Lavage.

3. If child has very thick mucus, which can occur when child has a cold or mucus is dry, and you have tried suctioning as outlined above with poor results, add 3-5 drops of sterile normal saline to the trach tube just before suctioning.

Using normal saline lavage every time you suction is not a good idea. Normal saline is used only if mucus is thick and suctioning without lavage is ineffective.

If child still seems to be having trouble breathing after suctioning ½ cm deeper and after using saline lavage, change child's tracheostomy tube. It is possible that there is a mucus plug.

- Changing the tube will assure you that the tube is clean and free of obstruction.

- If child continues to have trouble breathing after changing the trach tube, immediately call the doctor. If child is having great difficulty, is blue or pale, call 9-1-1.

TRACH TIE CHANGES

When to Change

Change trach ties only if ties became wet or soiled and only if you have assistance. Otherwise, slide gauze underneath ties to keep wet or soiled ties away from child's skin.

How to Change Tracheostomy Ties

1. Assistant holds tube in place.

2. Person in charge of doing the tie change removes the old ties.

3. Thread the Velcro ends of fresh trach tie through the holes in the neck plate.

4. Adjust trach ties until they fit snuggly, but not tightly, and secure Velcro.

5. Check fit after securing. You should be able to slide one small finger between the neck and the tie.

If child was crying and upset during the trach tie change, you may find that ties are much too loose once child settles down. Therefore, it is important to check the fit of the ties again after the child has settled down.

For infants, after checking fit the first time, move the child around a bit and then check fit again.

6. Check ties throughout the day to make sure Velcro is secure.

TRACH TUBE CHANGES

When to Change the Tracheostomy Tube

Routine or Planned Changes
Babysitters do not need to perform routine tracheostomy tube changes.

Emergent or Unplanned Changes
Babysitters must be prepared to perform emergency trach tube changes.

If trach tube comes out of child's stoma, re-insert promptly.

Change the tracheostomy tube immediately if you suspect that the tube is plugged. (If child has an inner cannula, changing the inner cannula may be all you need to do. If no improvement after changing inner cannula, then change the trach tube.)

Signs that the tube may be plugged:
- Infant is irritable or agitated and will not calm down after suctioning, changing diaper, feeding or holding and cuddling.
- Child becomes pale or bluish, especially around the nose and mouth.
- You see pulling in of skin between the ribs and/or around the collarbone (retractions).
- You are having a hard time getting air in with the resuscitation bag.

Assistance Needed?

Routine tracheostomy changes are performed by two adults, an "inserter" and a "holder/remover," who have been trained in tracheostomy changes.

For emergent or unplanned tracheostomy changes, you must be prepared to change the tube by yourself.

Supplies Needed

- A rolled blanket or towel to put under the shoulders of infants and small children
- Tracheostomy tube with ties attached
- Obturator
- Water soluble lubricant with gauze for applying and spreading lubricant
- Clean surface to set prepared trach tube on
- Breathing bag (if child needs breaths before changing the tracheostomy tube)
- Supplies for suctioning
- Go-Bag within reach

How to Perform an Emergency Tracheostomy Tube Change

You may need to perform an Emergency or non-routine trach tube change if child's trach tube has fallen out or if you suspect the trach tube is plugged.

- The possibility that you may need to perform an emergency trach tube at some time, is one of the reasons why it is essential that supplies are within easy reach of the child AT ALL TIMES.

When you perform an emergency trach tube change, remain CALM. Work deliberately but do not rush.

Performing Tracheostomy Tube Change by Yourself

1. Get tracheostomy tube. Try to insert regular size trach tube first.

2. Place child on back with head extended back. If you have a towel or blanket within reach, place roll under child's shoulders.

3. Remove ties and take out tube.

4. Pick up prepared tube with dominant hand.

5. Insert tube.

6. Remove obturator.

7. Secure ties.

8. Check your child's color and respirations. If your child is pale, blue, or having any trouble breathing, suction child and then give a few breaths with resuscitation bag.

Call 9-1-1 if child's breathing does not return to normal or if you are unable to insert either the regular tube or smaller-size tube.

If Tube Does Not Pass Easily

Do NOT force the trach tube. Staying calm and relaxed, with a "matter-of-fact" attitude as you try the following measures will help both you and child. Even if you do not feel calm, pretend and act as though you do—do not scream, and speak in slow, measured, reassuring tones.

1. If tube is part way in, hold the tube in place and remove the obturator so child can breathe. Spread the skin over the stoma and try advancing the tube when child takes a breath in.

2. If no success with above, STAY CALM, remove the tube, re-lubricate, and try again.

3. Make sure child's head is back and you have a good view of the stoma.

4. If no success with above two steps, try inserting the smaller tube.

5. If unable to insert smaller tube, try inserting a suction catheter into the smaller tube. Guide the suction catheter into the stoma, and then slide the trach tube over the suction catheter and into the stoma. Remove suction catheter.
   - If you are successful in getting the smaller tube in, take child to their doctor or emergency room as soon as you can safely do so to have child's regular size trach tube inserted.

If you are unable to insert the regular tube or the smaller tube, call or have someone call 9-1-1. Be prepared to start CPR if child stops breathing.

INNER CANNULA CHANGES

Some tracheostomy tubes have an inner cannula. These are generally adult sized Shiley brand tracheostomy tubes.

The Purpose of Inner Cannula Changes

The purpose of changing the inner cannula is to remove excess mucus that is not expelled with coughing or suctioning, and to keep the inside of the tracheostomy tube clean.

When to Change the Inner Cannula

Change the inner cannula if child has copious, thick mucus or you suspect that the tube is plugged.

Supplies Needed

- A clean reusable inner cannula, or a new disposable inner cannula
- Suction supplies

How to Change the Reusable Inner Cannula

1. Twist connector on inner cannula child is wearing to release lock and remove from trach tube.

2. Promptly insert clean inner cannula and twist to lock in place.

3. If child has coughed after removing used inner cannula and before inserting the fresh one, you may want to suction the tracheostomy tube before inserting the fresh inner cannula.

4. Immediately clean the inner cannula you removed, or if not able to clean inner cannula immediately, place in a bowl of soapy water to prevent secretions from drying on the inner cannula.

How to Change the Disposable Inner Cannula

1. Pinch connector of inner cannula to release from tracheostomy tube and remove inner cannula from tracheostomy tube.

2. Promptly insert fresh, disposable inner cannula.

3. If child has coughed after removing used inner cannula and before inserting the fresh one, you may want to suction the tracheostomy tube before inserting the fresh inner cannula.

4. Throw away the inner cannula you just removed.

QUICK REFERENCE FOR BABYSITTERS: PROBLEM SOLVING & EMERGENCIES

SYMPTOM	Your child is breathing, but has one or more of the following symptoms: ■ Difficulty breathing ■ Fast breathing ■ Noisy breathing ■ Pulling around breast bone and ribs ■ Skin is very pale or blue ■ Child appears anxious, worried, or agitated	No airflow from trach tube, AND Child's skin is blue or pale, AND Child is not responding	Bright, red blood coming from trach tube	Change in mucus lasting more than a couple of hours: ■ Colored mucus ■ Blood-tinged mucus ■ Thicker mucus ■ Sticky mucus ■ Increase in amount of mucus
POSSIBLE PROBLEMS	■ Respiratory distress ■ Mucus plug ■ Trach tube is out	■ Respiratory arrest ■ Mucus plug ■ Trach tube is out	Perforation, ulceration, or laceration of trachea	■ Respiratory infection ■ Dehydration ■ Granulation tissue at the end of trach tube
WHAT TO DO	Check to make sure trach tube is in. If not, replace the trach tube. If trach tube is in, try the following steps: ■ Suction depth of trach tube ■ Suction ½ cm beyond trach tube ■ Suction w/ lavage ■ Change trach tube	If you are alone, call 9-1-1. If there are others around, ask someone to call 9-1-1. Check to make sure trach tube is in. If not, replace the trach tube. If trach tube is still in: ■ Give a few breaths with rescuscitation bag ■ If you cannot get air in, then change the trach tube. Try to give breaths again. ■ If your child has an inner cannula, change the inner cannula. If you still can't get air in, change trach tube. Try giving breaths again.	If you see less than 1 teaspoon of bright, red blood from the trach tube, take your child to the emergency room for prompt evaluation. If you note more than 1 teaspoon of bright, red blood, call 9-1-1. Stay calm and use humidification until help arrives.	Make note of any other symptoms, such as loss of appetite, sleeping more, or fever. Call pediatrician and report all symptoms. Pediatrician may want to see your child or may order a chest X-ray. Increase humidity: longer hours on mist mask; saline drops without suctioning, nebulized saline treatments
IF NO IMPROVEMENT	If your child is still having difficulty but otherwise seems okay, call your doctor. If your child is really struggling or is pale or blue, call 9-1-1.	If your child does not start breathing after trach tube change, continue giving breaths, start CPR, and call 9-1-1.		If no improvement after reporting symptoms to your child's doctor or by increasing humidity, call doctor again to report no improvement. Report blood-tinged mucus to tracheostomy surgeon if child has no other symptoms and blood-tinged mucus does not clear up after one day.

LEARNING CHECKLIST FOR BABYSITTERS & OTHER CAREGIVERS THAT YOU WILL BE TRAINING

Friends or family who will be caring for your child must be taught all of the skills and concepts listed below.

No person is allowed to care for your child until he or she has been taught all items on the checklist, has properly demonstrated all skills, and shows comfort and confidence with all aspects of your child's care.

LEARNING AREA OR SKILL	COMPLETED		
The Basics			
Basic Understanding of Normal Airway, Breathing, & Airflow			
Types & Parts of a Tracheostomy Tube, Trach Tube Ties			
Risks & Precautions Related to Tracheostomy			
Go-Bag Contents & Use			
Infection Control: Handwashing & Clean Handling of Supplies			
Tracheostomy Skills			
Type & Size of Your Child's Trach Tube			
Type & Size of Your Child's Emergency Trach Tube			
Purpose of Suctioning & Signs of Need to Suction			
Reason for Suction Depth			
Suction Depth for My Child's Trach Tube			
Demonstrate Suction Technique			
Proper Use of Saline Lavage			
Managing Possible Mucus Plugs when Child is Breathing			
Managing Possible Mucus Plugs when Child is Not Breathing			
Tracheostomy Tie Change: Checking Tightness			
What to do if Ties Become Soiled or Wet			
Inner Cannula: When to Change, Cleaning			
Demonstrate Inner Cannula Change			
Unplanned Trach Tube Change: When & Why			
Demonstrate Tracheostomy Tube Insertion Practice			
Received CPR Training from a Certified Instructor			
Recognizing & Managing Potential Emergencies			
How to get Emergency Help			
Location of Emergency Numbers & Information List			

Letter for School or Child Care

Date:

To: School Staff

Re:

As you may know, the above mentioned student will be attending your school and has special needs due to his or her tracheostomy. We are providing this letter to help identify plans that must be in place to ensure that our patient can safely participate in school.

The Pediatric Otolaryngology practice requires that at least one adult is immediately available to the child during the school day, including on the bus to and from school. This adult must be trained in tracheostomy care. Specifically:

1. Adult who will have responsibility for a child with a tracheostomy must undergo or have had training in the care of tracheostomy. Training shall include: basic airway anatomy, signs and symptoms of respiratory distress, parts and functions of the tracheostomy tube, indications for suctioning and suctioning techniques, management of mucus plugging and tracheostomy tube changes. He or she must competently return demonstration of all suctioning and tracheostomy tube changes on a child in the presence of the person responsible for his or her teaching.

2. Adult responsible for student must be comfortable with emergency tracheostomy tube replacement. He or she must also have previous experience with changing a tracheostomy tube, or must practice at least one tracheostomy tube change on the student in the presence of a trained caregiver or the person responsible for his or her teaching.

3. Adult who will have responsibility for a child with a tracheostomy must possess the technical skills required and must be trained in CPR and use of resuscitation bag.

The primary caregiver (parent or guardian) will be responsible for ensuring that, each morning, the child brings his or her suction machine (and recharging unit) and "Go-Bag" to school. Go-Bag must be stocked with an extra tracheostomy tube of the same size the child is wearing with ties attached, a tracheostomy tube that is one size smaller with ties attached for use in emergency, extra suction catheters, ties, saline, scissors, extra artificial noses, and the resuscitation bag.

The school staff must check the Go-Bag each school day. The Go-Bag must be with the child at all times. The child cannot stay at school if they do not have a suction machine or Go-Bag supplies.

Parents must notify the adult who will have responsibility for the child during the school day of any changes in the tracheostomy tube or other supplies. The adult responsible must be trained in any new tracheostomy care procedures and/or the use of trach cap, speaking valve, a new trach tube, or other new supplies. Parents will give daily updates for procedures such as trach capping which may change from day-to-day. The child must not attend school until this training is complete and the adult who will have responsibility for the child during the school day is knowledgeable with the changes.

Hands shall be washed prior to any tracheostomy care to protect child from risk of infection. Universal precautions recommend that caregivers use barriers to body fluids. Therefore, all caregivers should use good handwashing and gloves when doing direct tracheostomy care. Gloves are not required for care that does not involve contact with body fluids.

The child must be under constant, direct, adult supervision for the duration of the school day. The tracheostomy trained adult must be in close enough proximity to the child to be able to attend to the child immediately if needed. The child may participate in all activities including non-contact sports in gym class, unless otherwise instructed by child's physician. The child must not participate in any type of swim class due to the risk of aspiration of pool water into the tracheostomy.

If you require any additional information, please do not hesitate to contact our office.

Sincerely,

Glossary of Terms

A

ABG
Stands for "Arterial Blood Gas;" a blood test that measures how well the lungs are working to oxygenate the blood

Acetic Acid
White vinegar

Airway
The path the air follows to get into and out of the lungs

Aleveoli
Tiny air sacs within the lungs; they play an important role in exchanging oxygen from the air to the bloodstream

Ambu Bag
A brand of resuscitation bag (*see Resuscitation Bag*)

Apnea
A period of time in which breathing stops

Artificial Nose
This is what your child wears on the tracheostomy tube to warm, humidify, and filter the air that is breathed in; also called an "HME" which stands for "Heat Moister Exchanger;" (*for more about artificial noses, see CHAPTER 3 under "Humidification and Warmth"*)

Aspiration
When substances that do not belong in the airway leak into the airway or are breathed in; examples of substances include food, liquids, fluids from the mouth, or vomit

Aspiration Pneumonia
An infection of the lungs caused by food, liquids, fluids from the mouth, or vomit getting into the airway and lungs

Atelectasis
Collapse of lung tissue affecting part or all of one lung

B

Bacteria
A microscopic organism commonly known as a germ; bacteria normally live in and on the body and can sometimes cause serious infections; bacterial infections are treated with antibiotics.

Bivona
The name of a company that makes tracheostomy tubes

Breathing
The act or process of inhaling and exhaling in order to deliver oxygen to the lungs and remove carbon dioxide from the lungs; also known as respiration or ventilation

Bronchomalicia
Floppiness of the bronchial airways; airway passages are made of cartilage; cartilage is normally firm; immature cartilage is floppy, sometimes causing bronchial airways to collapse during breathing; children with severe bronchomalicia may need to be on a ventilator to provide pressure to keep airways open as air is blown in; eventually, most children grow stronger cartilage and are able to keep his airways open without help

Bronchi
The two main branches leading from the trachea to the right and left lungs; the trachea splits into the right and left bronchi; the word "bronchus" is used when talking about both bronchi; the bronchi divide into the smaller "bronchioles;" (*see CHAPTER 1 under "Normal Airway" for a picture of the bronchi*)

Bronchitis
Inflamation of the bronchi

Bronchiolitis
Inflammation of the bronchioles

Bronchopulmonary dysplasia
Often referred to as "BPD;" BPD is a lung disease due to premature birth; the lungs are inflamed and scarred in the lungs; no available medical treatment can cure BPD; with good care, new lung tissue will grow to make up for the damaged lungs; damaged lungs do not absorb oxygen or carbon dioxide well; until new lung tissue grows, children with BPD may need ventilator support to help them breathe and get oxygen

Bronchoscopy
Examination of the bronchi using an endoscope

C

Candida
A fungus that typically causes yeast infections such as diaper rash; usually occurs in damp areas of the body

Cannula
A hollow tube for insertion into the body; the portion of the tracheostomy tube that sits inside the trachea is called the cannula

Glossary of Terms

Caregiver
Any person who cares for a child; can be a parent, a friend, grandmother, foster parent, aide, etc.

Carina
The point where the trachea divides into the right and left bronchi

Carbon dioxide
Also called CO2, it is a waste product that is removed from the body by breathing it out; if breaths are weak, carbon dioxide may build up; high levels of carbon dioxide are dangerous

Cartilage
Tough, elastic tissue found in various parts of the body such as the ears and nose; the airway passages are made of cartilage

Cellulitis
Infection of the skin

Cilia
Fine, small hairs that line the trachea and help move mucus and dust out of the airway

Clean
When something is free of dirt and most germs

Connector
The part of the tracheostomy tube that is outside body and to which things attach; for example, the artificial nose attaches to the trach tube connector

Contamination
When something is infected by dirt and/or germs

CPAP
Stands for "Continuous Positive Airway Pressure;" a type of mechanical ventilation that supports a child's breathing efforts

CPR
Stands for Cardio-Pulmonary Resuscitation; a technique used to get a person to breathe again once he or she has stopped and to circulate blood to the body

Cricotracheal reconstruction
A surgery that is performed to repair the trachea, usually to widen the airway

Cuff
Inflatable balloon on some tracheostomy tube cannulas; used to reduce the amount of air leaking around the tracheostomy tube.

Cyanosis
Bluish or gray color of the skin; caused by not getting enough oxygen to the blood

D

Decannulation
Removal of a cannula; in the case of tracheostomy tubes, removal of the tracheostomy tube; can be on purpose or accidental; when a tube falls out accidentally, it is called "accidental decannulation;" (*see PART III for information about preventing accidental decannulation*); when a child no longer needs his or her trach tube, they are "ready for decannulation;" (*see CHAPTER 2 for information about final decannulation*)

Diaphragm
Large muscle below the lungs that controls breathing

Direct Laryngoscopy and Bronchoscopy (DLB)
A procedure using a medical instrument that has a camera in it; used to examine the larynx, trachea, and bronchus; usually requires anesthesia and is performed in the operating room

Discharge
A patient's release from the hospital and return home

Discharge Planner
An employee of the hospital who makes sure everything is ready for a patient to be discharged from the hospital; usually responsible for getting tracheostomy supply list to the equipment company and helping with home care nursing

Durable Medical Equipment (DME)
You may hear your child's trach supplies referred to as DME; sometimes the medical equipment company is called a DME

Dysphagia
Difficulty swallowing

Dyspnea
Difficulty breathing, labored breathing, shortness of breath; also referred to as increased work of breathing

E

Early-On
A federally mandated education program for children ages 1-3 who are at risk for developmental delays or learning problems

ENT
Stands for Eyes, Nose and Throat; an ENT doctor is also called an otolaryngologist; typically, it is an otolaryngology doctor who places and manages tracheostomy tubes

Endoscope
A medical instrument that is used to examine the inside of the body; types of endoscopes include a bronchoscope or laryngoscope; a "bronchoscope," for example, is specifically designed to look at the bronchi

Endotracheal Tube
Also called "ET tube;" used to intubate a patient and deliver air; tube goes in nose or mouth, down through the vocal cords, and into the trachea

Epiglottis
A flap of tissue which closes off the opening to the lower airway during swallowing to prevent food from entering the lower airway

Expiration or Exhale
To breathe air out

Extubation
Removing the endotracheal tube

G

Glottis
The middle part of the larynx, where the vocal cords are located; often called the voicebox (*see Subglottic and Supraglottis*)

Granulation Tissue
Specialized tissue created by the body as a response to injury; it is rich in tiny blood vessels; can be red, raised, and irritated and can bleed, drain mucus, and be uncomfortable

H

HME
Stands for "Heat Moisture Exchanger," another name for an artificial nose; this is what your child wears on the tracheostomy tube to warm, humidify, and filter the air that is breathed in

Humidifier
A machine that provides moist air; can be warm or cool air

Hypercapnia
The presence of high amount of carbon dioxide in the blood

Hypoventilation
Shallow, slow breathing that is not providing enough oxygen to the body

Hypoxia
Abnormally low amount of oxygen in the blood

I

IEP
Stands for "Individual Education Plan;" a written plan and legal document that describes a child's present level of functioning, specific areas that need special services, annual goals, short-term objectives, services to be provided, and the method of evaluation to be implemented for children who have been determined eligible for special education

Inhale, Inspiration, or Inspire
To breathe air in

Inner Cannula
A smaller tube that fits inside the tracheostomy tube which can be removed daily for cleaning; can also be removed quickly if it becomes obstructed; only certain brands of adult tracheostomy tubes have an inner cannula

Intubation
Insertion of a tube through the mouth or nose, through the larynx or voicebox, and into the trachea to deliver air to the lungs.

L

Laryngomalacia
Occurs in infancy; the larynx is soft and floppy and collapses during breathing; infants usually grow out of this

Laryngoscope
A medical instrument that has a camera on it and is used for examining the larynx (*see Direct Laryngoscopy and Bronchoscopy*)

Laryngotracheal reconstruction (LTR)
A type of surgery to correct airway problems such as narrowing of the airway

Larynx
A protected passage between the base of the tongue and the lower airway; also often called the voicebox

Lungs
Two sac-like breathing organs in the chest; the lungs remove carbon dioxide from the body and deliver oxygen to the blood

Glossary of Terms

M

Micrognathia
An abnormally small jaw, especially the lower jaw

Mist Mask
Small mask that fits over the tracheostomy tube to deliver humidification

Mucus
A thick, slippery fluid secreted by mucus membranes that acts as a protective barrier and lubricant

Mucus Membrane
A membrane rich in mucus-producing glands that lines body passages and cavities

N

Neckplate
The part of the tracheostomy tube that rests against the neck; also called the neckflange; tracheostomy ties attach to the neckplate

Nebulizer
A machine that puts moisture or medicine directly into the airway

Normal Saline
A salt solution that has the same balance of salt to water as the fluids in the body

Normal Saline Lavage
The practice of putting drops of sterile normal saline in the tracheostomy tube to help remove thick mucus

O

Obturator
A device that is used to help insert the tracheostomy tube into the trachea

Oral Secretions
Saliva

P

Passey-Muir Valve (PMV)
The brand name of a type of speaking valve (*see Speaking Valve*)

Pulmonary
Involves the lungs; a "pulmonologist" is a doctor who deals with the lungs

Pulse Oximeter
A machine that measures oxygen in the blood

R

Retractions
Sucking in or pulling in of the skin between the ribs and or at the neck muscles; a sign of respiratory distress or increased work of breathing

Respiration
The act or process of inhaling and exhaling in order to deliver oxygen to the lungs and remove carbon dioxide from the lungs; also known as ventilation or breathing

Respiratory
Having to do with breathing and the exchange of carbon dioxide and oxygen

Respiratory Distress
Severe difficulty breathing; can lead to respiratory failure

Respiratory Failure
Inability of the lungs to deliver adequate oxygen to the blood and remove carbon dioxide from the body

Respiratory Secretions
Substance secreted in the airway (i.e. mucus)

Respiratory Tract
Also called the airway; the path air follows to get into and out of the lungs

Retrognathia
The lower jaw is positioned farther back than would be expected

Resuscitation bag
A flexible bag that is used to give hand-squeezed breaths to someone who is not breathing; can be placed over the mouth or nose, attached to the tracheostomy tube, or attached to an endotracheal tube; must have a resuscitation bag within reach when caring for a child with a tracheostomy

Routine
A regular course of action

Routine Suction Depth
The premeasured depth used to suction a child's tracheostomy tube on a day-to-day basis; the depth is equal to the length of the tracheostomy tube

S

Saline
Salt water (*see Normal Saline*)

Secretions
Any substance that is produced or secreted by the body (*see Respiratory Secretions and Oral Secretions*)

Shiley
A brand of tracheostomy tube

Speaking Valve
A one-way valve that is placed on the connector of the tracheostomy tube to help children speak

Speech Pathologist
A speech pathologist, sometimes called a speech therapist, assesses, diagnoses, and treats disorders related to speech, language, cognitive communication, voice, swallowing, and fluency

Stenosis
Abnormal narrowing of a body canal or passageway

Stoma
An opening into the body created by a surgeon

Subglottic
The area just below the voicebox

Subglottic Stenosis
A narrowing in the area of the trachea just below the voicebox

Supraglottic
The part of the larynx above the vocal cords; includes the epiglottis

T

Trachea
An air passage between larynx and bronchi; commonly called the windpipe

Tracheomalacia
The tissues (cartilage) supporting the trachea is immature and floppy and may collapse during inspiration; air cannot flow well through the collapsed portions of this airway

Tracheostomy
The opening in the trachea in which a tracheostomy tube is inserted; the term tracheostomy is sometimes used interchangeably with tracheotomy; strictly speaking, a tracheostomy is the actual operation

Tracheotomy
A surgical procedure in which a cut or opening is made in the windpipe; the term tracheostomy is sometimes used interchangeably with tracheotomy; strictly speaking, however, tracheostomy usually refers to the opening itself

V

Ventilation
Also known as respiration or breathing; the act or process of inhaling and exhaling in order to deliver oxygen to the lungs and remove carbon dioxide from the lungs

Ventilator
A machine that helps a person breathe

Virus
A microorganism commonly known as a germ; does not normally live in the body like bacteria and fungus do; a cold is an example of an illness that is caused by a virus; viruses are not killed by antibiotics

Vocal cords
Bands of tissue stretched across the larynx; the vocal cords open and close; the main purpose is voice; the vocal cords close to protect food and liquid from entering the lower airway

Voice box
The larynx and/or the vocal cords

W

Water soluble lubricant
A water-based gel used to provide a "slippery" effect; water-soluble lubricants, as opposed to oil-based lubricants, are often used for medical purposes because they are less irritating to the skin