





LIVING WITH A TRACHEOSTOMY

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Introduction

If you or someone you love has a tracheostomy, you may feel a bit overwhelmed. You probably have lots of questions about what it means to live with a tracheostomy. Having a tracheostomy doesn't mean sitting on the sidelines. With the proper equipment and a little instruction, a person with a tracheostomy can live a full, happy, and active life.

This brochure features three stories about people who have learned how to live with a tracheostomy, whether their own or a loved one's. Each story is unique from the perspective of the reason for the tracheostomy and the strategies used to cope. But one thing all three share is the determination to not let a tracheostomy hinder their lives.

The second half of the brochure contains practical information and advice on suctioning. Proper suctioning is important in caring for a tracheostomy. This brochure is a helpful guide for anyone wanting to know more about the needs of a tracheostomy patient. The information presented should not be a substitute for the advice of a personal physician. The best source for instruction on how to take care of a tracheostomy is your health care team.



Toni's Story

The social butterfly - Toni never considered her tracheostomy as an obstacle and searched bravely for herself and others for the best solution to have a more mobile life.

Nothing was an obstacle for Toni. When faced with the challenges of becoming tracheostomy and ventilator dependent, it didn't upset her. Toni achieved the seemingly impossible; defying doctors' prognosis, she was a true inspiration. As the winner of many charitable awards for bravery and achievement, Toni taught others about courage, strength and bravery. She met with countless celebrities, members of royalty and parliamentary figures, as a spokesperson on equality and disability rights.

Like many people with disabilities, Toni hated to stand out from the crowd. Her tracheal suctioning equipment was awkward and noisy and made her feel embarrassed when suctioning in public places. To overcome this, Toni explored her options to search for a quieter, sleeker-looking suction pump. She found the Clario; a quiet, easy-to-use device



that came in a small bag which seemed to tick every box. Toni always wanted to make things better for everyone, especially infants and babies, so she shared her excitement and recommended the device to others.

According to various studies, the number of children under the age of two with a tracheostomy is rising 1, largely due to the fact that a greater number of critically ill infants requiring chronic ventilation survive. This group relies heavily on a home care pump capable of achieving low level vacuum suctioning. When nasotracheal suctioning guidelines for neonates, children and young people were revised, Toni's helpful insight and experiences led Medela, the Swiss manufacturer of Clario, to develop a brand new pump with lower vacuum pressures, specifically designed for paediatric use. For minors, gentle suctioning is recommended to avoid further potential complications during this common, yet risky procedure.

As a believer in escapism, Toni used guided imagery to help her through tough times. She imagined she was a butterfly, her favourite animal, free to travel across the world on fun trips, visiting exciting places in her mind. The Clario Toni was designed to be just like a butterfly; gentle, lightweight and mobile, giving children freedom. Most importantly, it is quiet which is ideal for children who, like Toni, were scared of loud equipment, especially during the night, plus the non-medical design of Clario Toni no longer makes suctioning in public so embarrassing.



¹ Pediatric Tracheostomy: A Changing Procedure? Ralph F. Wetmore, Ann Otol Rhinol Laryngol July 1999

Amy's Story

Despite the challenges, Amy lives a full life. "Stay active and busy. This does wonders to improve your self-confidence and keep your mind off of your problems."

She played marimba in her high school band, was valedictorian of her class, and is a vegetarian. Amy Phillips also has a tracheostomy, but she clearly hasn't let that slow her down. "My airway problems will always be a part of my life, but I don't want them to limit me. I would much rather be involved in things and deal with my trach problem when I need to."

Amy first got a tracheostomy due to a complication from her premature birth. She was trached for the first three years of her life. During those years she couldn't speak and communicated via sign language. At 3½ years of age, her trach was removed, but her airway was still 80–85% obstructed. Because of this, Amy was unable to play sports or be involved in physical activities. Looking back Amy states, "Despite all this I was a very happy child."



At 17, Amy had 2 laryngotracheal reconstruction surgeries. As part of the process, Amy had to return to the trach she hadn't had since she was 3 years old. Amy admits that being a teenager is hard enough without adding a trach to the picture. "For the first year I wore a scarf or a turtleneck everyday to keep people from staring at my neck. After a while, I got tired of it and left my trach in plain sight. Learning to deal with people's reactions and your own self-consciousness is a necessary step toward developing a healthy attitude about your trach. Now, I am more worried about what my hair is doing than about how my trach looks."

Amy discovered that getting a trach had a positive side: she had virtually no trouble breathing. "This was something very new to me, and I took advantage of it by becoming more active. I ran the first mile of my life."

Amy admits that living with a tracheostomy has its challenges. She always carries an extra trach tube, trach tie, hand sanitizer and lubricant. She learned the importance of humidity the hard way. "Your doctors aren't lying when they tell you to use a humidifier. In the first few days after I got my trach, I thought I was being 'independent' by refusing to wear the humidity collar. As a result my airway and lungs got so dry that I coughed for days."

Despite the challenges, Amy lives a full life. Now 18, she has transitioned indefinitely to a t-tube, a type of tracheostomy that supports the airway so it can heal correctly. She is studying biology and anthropology at Washington University in St. Louis and dreams of becoming a physician. She feels her experiences with having a tracheostomy will give her a unique perspective. "Compassion is a great thing, but there is no substitute for experience. When someone with whom you are sharing an experience or feeling can tell you, 'I have been through that too,' it makes it so much easier to express yourself and feel understood. I want to have that openness and connection with my patients."

Amy's busy lifestyle illustrates that having a trach doesn't mean you have to stay home. Even travel is possible if you are properly prepared. "People who have a trach because they have a nervous or muscular disorder might not have a strong cough and will probably need a portable suction machine. I find that during the day I am okay with just a few vials of saline, but when I travel I always take my suction machine."

Coping with one's feelings about having a trach can be as challenging as the physical hurdles. Amy has found that reaching out to others and staying involved in life were important coping tools. She suggests, "Join a support group. Talking to other people who are dealing with your problem really, really helps. Also, stay active and busy. This does wonders to improve your self-confidence and keep your mind off of your problems."

Her most important piece of advice? "Don't give up. I know it is very difficult, even impossible to understand, but it truly does get better."



The Peichel Family's Story

The focus of their daily lives changed from Colin's tracheostomy to Colin, the boy they loved.

Having a child with a tracheostomy is a life-changing experience – just ask Cory and Bobbie Peichel. Their son Colin breathed through a tracheostomy tube for almost four years. The almost constant care a trached child needs can be overwhelming, but Cory and Bobbie want you to know that there is a light at the end of the tunnel.

Colin Peichel was born with Down syndrome and resulting heart defects. When he was four months old, doctors performing open heart surgery discovered that his tracheal tube was only 2 mm in diameter. The initial surgery to fix Colin's narrow trachea was unsuccessful, and Colin received a tracheostomy at five months old.

It was a difficult time for Cory and Bobbie. They were just coming to terms with the special needs that Colin had due to having Down syndrome and trying to balance those with the needs of their 2-year-old son Ryan.

Caring for a child with a tracheostomy is a full time job, and the physical demands can be very trying. Sleep deprivation is a common complaint. Cory and Bobbie opted not to have home nursing care and, in retrospect, regret this decision. Bobbie is very emphatic about this. "We should NOT have left the hospital before some private duty nursing was established and scheduled. Big mistake, looking back."

At first Cory and Bobbie both slept in the same room with Colin. But because of Colin's need to be frequently suctioned, a full night's rest was impossible. They found the best arrangement was to take turns caring for Colin at night.

Spending so much time caring for the needs of a trached child can stress a marital relationship. "I think it takes effort to stay connected as a couple under 'normal' circumstances with small kids. With Colin it was even more of a challenge. I think being able to laugh helps... laughing together. It releases stress and can diffuse a tense moment," advises Bobbie.

Taking care of each other, as well as Colin, helped keep their marriage strong. "It got to the point where we often worried about each other not getting enough sleep or starting to feel sick. We'd occasionally offer to take the other's night with Colin, just because one was getting weary. The shared hardship did much more to bring us together than to drive a wedge between us," recalled Cory.



Ryan, their firstborn son, was also a priority. It can be easy for the siblings of special needs children to get lost in the shuffle of daily care. "We had to be mindful that he needed our time and attention. When I had errands to run or work to do in the garage, Ryan was always with me. Most important was time spent together."

Feeling like a spectacle when you go out in public for the first time after your child has been trached is common. Strangers often ask questions. Suctioning your child in public can cause feelings of, as Cory describes, "living in a fish bowl," but it's unavoidable. "Our suction machine would go with us to school, the grocery store, to play in the front yard, on a walk, room to room, EVERYWHERE," explains Bobbie. "I would use a car battery charger for our suction machine. I plugged it into the cigarette lighter and say it is absolutely necessary to have this. If you are on a road trip or going to a doctor's appointment etc., it can be charging in the car until you reach home or your destination."

With time, Cory and Bobbie became more relaxed about taking care of Colin's trache-ostomy. Whether it was suctioning Colin in the stands at Ryan's soccer game or "diving" into the back seat at a red light to do the same, Colin's care began to feel more routine. And with that the focus of their daily lives changed from Colin's tracheostomy to Colin, the boy they loved. Bobbie explains, "Over time I bonded with Colin. It was hard to get to know him as a new son, when in the beginning I was just trying to keep him alive. I learned to love so many, many things about him. I learned he has a sense of humor and is also stubborn as a mule. The tracheostomy did not define him as it had in the beginning and it was not my focus as it once had been."



Tracheostomy & Suctioning

Frequently Asked Questions (FAQ's)

Why is suctioning of a tracheostomy tube needed?

Having a tracheostomy tube predisposes a person to an increased production of mucus and a decreased ability to rid themselves of that mucus. Suctioning promotes proper air flow by removing excess mucus that can block air from getting through the tracheostomy tube.

How often is suctioning needed?

This depends on the individual and their physical condition. For example, children who have had their trach since they were very young may have difficulty learning to cough and may need to be suctioned more often. Another factor is how long the person has had a tracheostomy. Over time the body adapts to the presence of the tracheostomy tube and there is a decreased need to be suctioned.

On average a child needs to be suctioned every 4 to 6 hours. Adults may only need to suction twice a day, first thing in the morning and then before going to bed. Because there are so many variables, this should be determined with the help of your health care team.

One mistake parents of a newly trached child may make is suctioning their child too often. Too much suctioning can actually irritate and dry out the sensitive tissue in the trachea, causing an increased production of mucus. This can set up a cycle of oversuctioning and increased mucus production. You should discuss any concerns with your health care provider.

How do I know if someone I am caring for needs to be suctioned?

If the person with the tracheostomy is an adult or an older child, they can usually communicate a need for suctioning. With a young child or a person who has trouble communicating their needs, it can be a little trickier. There are a number of signs you can look for that may indicate that a person needs to be suctioned.

Among these are:

- Breathing becomes increasingly noisy (a rattling or the sound of mucus bubbling)
- Rate of breathing increases
- The person appears uncomfortable, fussy, agitated or restless
- Inadequate chest rise upon inhalation
- Nasal flaring
- Infant has difficulty sucking
- Mucus can be seen bubbling at the trach opening
- Nonproductive cough
- Blue colour around the lips, mouth or fingernails

How do you determine what size suction catheter to use?

Catheter sizes normally range from 6-14 French. The general rule of thumb is the external diameter of the catheter should not be more than $\frac{1}{2}$ the internal diameter of the trach tube. If the catheter is too large it fills up too much of the tracheostomy tube making it difficult for air to get through. Your health care provider will help you determine what size is appropriate.

How deep should I suction?

Your health care provider will help you determine the proper depth to suction. If a good cough reflex is present, it may only be necessary to suction the secretions at the opening of the tracheostomy tube. If more aggressive suctioning is needed, "pre-measured suctioning" is usually recommended. First the length of the tracheostomy tube is measured. Suctioning is performed to that depth using a catheter with pre-marked gradations. This form of suctioning helps avoid suctioning too deeply, which can cause tissue damage, or not suctioning deeply enough, which may leave mucus at the tip of the tracheostomy tube.

How long should I suction at one time?

Suctioning should be limited to 5–10 seconds at a time. Suctioning for too long can cause tissue damage and can leave the person oxygen starved.

When suctioning was done in the hospital, everything was sterile. Is this necessary at home?

It is generally accepted that a sterile technique is not necessary at home and that a clean technique (clean catheter, freshly washed hands) will suffice. Even though not sterile, it is important that the catheter and everything that comes into contact with it be clean. Cleaning instructions can be obtained from the catheter manufacturer or your health care provider.

If the patient has an increased susceptibility to infection, your health care team may advise using a sterile technique. Always follow your health care provider's advice.

Why is it advised to only suction as you withdraw the catheter from the tracheostomy tube and not as you enter?

The purpose of suctioning is to remove mucus from the tracheostomy tube. Unavoidably, oxygen will also be removed during the suctioning process. By only applying suction as you withdraw the catheter, you are maximizing mucus removal and minimizing oxygen removal.

Is there a way to make suctioning the mucus easier and more productive?

Moisture is the key. If the secretions are too dry and thick they will stick to the sides of the tracheostomy tube and be difficult to suction. The following suggestions may help: First increase the humidity in the air that is breathed in. This can be done in a number of ways.

- Employ a humidification system with a tracheal mask.
- Install a humidifier in your main living and sleeping areas.
- Wear a HME (Heat Moisture Exchanger), also referred to as a trach "nose". The HME fits directly onto the trach. As air is breathed through the HME, it is cleaned, warmed, and humidified.

A second way to increase moisture in the secretions is to stay properly hydrated. Drinking plenty of water can go a long way in avoiding suctioning problems. This is particularly important during illness, especially if fever, vomiting and/or diarrhea are present. Finally, many people find that instilling sterile normal saline into the trach tube prior to suctioning helps make the mucus easier to remove. However, this should only be done with the approval of your physician. Using an ampoule of normal saline or an eyedropper, place a few drops of sterile normal saline into the trach as you take in a deep breath. This should cause a cough reflex which will help loosen the mucus, making the suction procedure more productive. Sterile normal saline can be purchased at your local drugstore or through your home care dealer.

Are there any other reasons to suction besides the removal of mucus?

Though removal of mucus is the main reason for suctioning, there are a few other situations where suctioning may be necessary. If a child with a tracheostomy is sick and vomiting, they might not have the control to avoid contaminating their tracheostomy tube. If this happens, suction immediately and contact your physician. Some

precautions can be taken to help lessen the possibility of this occurring. If you are aware that your child is about to vomit, have them turn their head to either side and then down away from their trach tube.

Covering the trach with a HME (Heat Moisture Exchanger) or loosely with a bib or scarf can help keep vomit from getting into the trach tube. If your baby is susceptible to spitting up after eating, laying him/her on their side lessens the risk of the child choking.

Another time suctioning may be needed is if water gets accidentally splashed into the trach tube. To help avoid this make sure baths are taken in a shallow tub of water. Some people like to use a HME to lessen the likelihood of water going down the trach. There are also special "shower shields" on the market that are made especially for persons with tracheostomies. Be sure to discuss any incidents of water in a tracheostomy tube with your health care team.

The mucus I suctioned is tinged with blood. Should I be worried?

It is not uncommon for suctioned mucus to be tinged with blood and it doesn't necessarily indicate a problem. But if the blood is copious and either bright red (new blood) or dark brownish-red (old blood) this can indicate a potential problem.

In addition, mucus should normally be clear with no odour. A yellow or green colour and a foul odour could indicate a possible infection.

Why choose Clario?

The Clario suction pump has earned a respectable place in the market for airway suctioning pumps. The vacuum settings are: 135/270/600 mmHg, ideal for airway suctioning of adults.

Why choose Clario Toni?

Clario Toni was developed using the original Clario as a solid basis. In order to offer the customer a choice of lower vacuum levels, as required by pediatric airway suctioning guidelines, the SafetyChamber was adapted.

Why choose Vario 18?

The Vario suction pump has variable vacuum settings. Vacuum can be set from zero to the maximum of –563 mmHg. It is powered by the silent QuatroFlex drive unit that makes it ideal for use at home when silence is necessary.

Procedure for Suctioning a Tracheostomy Tube – Clean Technique

Supplies needed:

- Suction machine
- Connecting tubing
- Catheter of correct size for patient
- Sterile normal saline
- Bowl with small amount of sterile water
- Eye dropper
- Soap and water
- Resuscitation bag
- Gloves
- 1. Wash hands thoroughly with soap and water. Have resuscitation bag ready in case needed.
- 2. Put on gloves.
- 3. Connect tubing to suction machine.
- 4. Cover thumb control valve on tubing to allow for vacuum build-up. If there is no thumb control valve, cover tube ending with your thumb. If necessary adjust vacuum regulator to proper setting. Vacuum pressure should be kept in the recommended range.
 - A balance needs to be found between suctioning strong enough to remove mucus but not so strong as to cause tissue damage. Your health care provider will give instructions on the proper suction strength.
- 5. Connect catheter to tubing.
- 6. Place tip of catheter in bowl of sterile water to moisten, then test suction.
- 7. Only if your health care provider recommends: Instill sterile normal saline into trach if mucus is thick and/or dry. Using a prepackaged ampoule of saline or an eye drop-

- per, place a few drops of saline directly into the tracheostomy tube while taking a long deep breath. The saline will help cause a cough reflex which will encourage the loosening of mucus and make suctioning more productive.
- 8. Using thumb and index finger, insert catheter into trach. Once the catheter is properly in place, cover the hole on the fingertip tubing (if available) to apply suction. Using intermittent suctioning, twirl the catheter between thumb and index finger as you exit the trach. This will allow removal of mucus from all sides of the trach tube. It is important to remember that suctioning should not be done more than 5–10 seconds at a time. Prolonged suctioning can cause tissue damage and hypoxia (lack of oxygen).
- 9. The catheter may be re-used if immediate suction is required, as long as secretions have not occluded the suction ports
- 10. Wrap the catheter around the gloved hand, remove the glove by inserting it over the used catheter and discard in yellow waste bag according to waste policy.
- 11. Rinse out catheter with sterile water until clear and repeat if necessary. Be sure to wait 1 to 2 minutes before repeating to allow for reoxygenation to occur.
- 12. Clean and put away supplies according to manufacturer's instructions. Wash hands with soap and water to complete the procedure.

Note: Suctioning a paediatric tracheostomy is different from suctioning an adult tube, so please adapt your practice accordingly.

Constant observation of the child during suctioning is essential, please observe for an improvement or deterioration in respiratory rate and quality, child's colour and oxygen saturations (if monitored).



Suctioning Equipment

It is important to find a pump that is small, lightweight and easy to carry.

What should I look for in a suction machine?

There are a number of considerations when deciding what suction machine would be best for you.

Portable/Lightweight

Since many tracheostomy patients are active, the size and weight of a pump is of prime consideration. This is especially important if you need to suction often and will be carrying your pump with you wherever you go. The portability of your pump is also a factor if you do a lot of traveling.

Quiet

The quietness of a pump is a very important consideration for many people. If suctioning at night, a loud and noisy pump can disturb others sleeping in the area. In addition, if suctioning in public is necessary, the quieter your pump the more discreet you can be in meeting your suctioning needs.

Ease of Use

Look for a pump without a lot of complicated tubing connections. Note how easy the pump is to clean and maintain and if there are filters to change. Look for an overflow protection system so that fluids aren't inadvertently suctioned into the interior of your pump, possibly leading to contamination or pump failure.

Battery

If suctioning will only be needed first thing in the morning and last thing at night, you may be satisfied with a suction machine that does not have a battery backup. If so, it is highly recommended that you have a manual backup pump in case of a power outage. If suctioning will be needed multiple times during the day for an active person, a portable pump with a battery would be a better choice.

I have so much equipment for my child with special needs... how am I possibly going to be able to carry a suction pump, too?

It is important to find a pump that is small, lightweight and easy to carry. If you are transporting your pump on a regular basis, a carrying bag is a must. The bag should be durable and big enough to carry the pump and all the accessories needed to suction.

Is it recommended to have a backup suctioning device on hand?

Yes, a backup suctioning plan is highly recommended. Although no manual pump can match the strength, efficiency and convenience of a suction machine, the possibility of malfunction, insufficient battery charge or power failure does exist. No matter how unlikely these events are, it's important to have a backup suction device available just in case.



Support Groups & Additional Information

- Useful hints and support for families living with a tracheostomy www.tracheostomysupport.org
- 2. Aid for Children with Tracheostomies www.actfortrachykids.com
- 3. Aaron's Tracheostomy Page www.tracheostomy.com
- **4. Tracheotomy.info** www.tracheotomy.info
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