



Understanding the Tracheostomy Option

OTHER PARENTS' EXPERIENCES



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DEPARTMENT OF PSYCHOLOGY
University of Michigan

Understanding Tracheostomy: Other Parents' Experiences

Considering whether or not to place a **tracheostomy** in a child is a difficult and emotional process.

In this booklet, we will share the experiences (challenges in particular) of other parents who have had to consider a tracheostomy placement for their child. We hope this information will help you understand the tracheostomy option in order to make the best choice for you and your family.

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About Tracheostomy

A **tracheostomy** placement involves a surgical procedure that makes a small hole in the throat to provide a stable airway that enables long-term breathing support. Some patients may also need a ventilator to support breathing. A tracheostomy usually serves as **the last resort** to optimize the chances for long-term survival.

There are some upsides of placing a tracheostomy:

- Your child may breathe more easily.
- Your child may be less sedated and more mobile, depending on your child's condition.
- Your child may be able to go home.

There are some downsides of placing a tracheostomy:

- Your child may have complications, such as infection.
- Your child may experience pain and discomfort with the procedure and need high doses of sedation post-operatively for a few days.
- Your child may be dependent on a tracheostomy and ventilator long-term.

There are some life-threatening risks of having a tracheostomy airway:

- The tracheostomy tube might become blocked.
- The tracheostomy tube might become accidentally removed or dislodged.

You and your family will need to accept the responsibilities of caring for a child who will be dependent on technology (their tracheostomy with or without a ventilator):

- You and a second caregiver will need to be trained to suction and change the tracheostomy tube.
- You and a second caregiver will need to be trained to handle emergencies.
- You will need to ensure that your child is being watched **24** hours a day, by you, other family members, or a home care nurse. When children are home with a tracheostomy with or without ventilation, some private insurance companies may cover home care nurses (usually for 12 hours each day) or you may have to apply for Medicaid.

There may be other options that your doctor can consider appropriate:

- Weaning down current breathing support to see if your child can breathe on their own.
- Continuing current breathing support, which may involve an unstable airway that requires sedation to maintain and hospital stay.
- Reconsidering goals of care to stopping or decreasing current breathing support.

Considering the Tracheostomy Option

You may feel scared and overwhelmed at the thought of a tracheostomy. There are lots of uncertainties and unknowns about the future.

You may have lots of questions:

- Will a tracheostomy improve the quality of life for my child?
- Is it worth it to put my child through this procedure?
- How should I prepare myself to take care of a child with a tracheostomy?
- How would my family life and dynamics change with a child with a tracheostomy?

You are not alone. Although every child and family has individualized situations, many parents have similar feelings to yours.

Other Parents' Stories Can Help

In this booklet, we provide information and challenges that other parents said were important for parents to be aware of when understanding the tracheostomy option.

The stories of these other parents may help you envision possible future outcomes. They help to explain what might happen and how it might feel.

Every family is different. Every child's medical condition and needs are different. But, learning about other parents' experiences may help you to decide what is right for your family.

You may not have to consider a tracheostomy right now. In fact, your doctors may not know exactly when it will be time to actually consider this option, because the timing depends on your child's medical conditions. It is also possible that, in the future, a tracheostomy may not be a reasonable option anymore.

We hope that reading about other parents' experiences will help prepare you for when it is time to make choices about a tracheostomy placement.

Moreover, it is important to find your team—a doctor, a nurse, a social worker, a therapist, other professionals, and your family members whom you trust, to help you with the process.

What Is My Child's Best Interest?

Every parent wants their child to live with the best possible quality of life.

In many cases, a tracheostomy is offered as the last resort to optimize the chances for long-term survival. Many families consider the chances of survival in making the decisions, and some of them feel that survival at all costs is most important. Many families, however, also carefully consider the quality of their child's life in making their decisions:

“At the start, I only focused on survival. This was the only message that stuck in my mind—my child is going to survive longer with a tracheostomy. I had no other choice because it sounded like the only way to help my child survive. I felt that survival had to come before everything else. But later, I realized that there are other important considerations than just whether my child would survive. I should think about my child's quality of life down the road, in particular if my child will stay on the ventilator for a long time.”

Many parents ponder over what the best quality of life would mean for their child. This may be different for every child and every family.

There is no right or wrong answer. It's about what you and your family think would be the acceptable quality of life for your child.

Remember, it is important and it is OK that you discuss your child's quality of life and goals of care with professionals such as social workers and palliative care doctors.

On the next few pages are examples of how parents perceive the effects of a tracheostomy on the quality of life of the child in the short term and the long term.

Parents' Perceptions of Quality of Life

- Some parents focus most on the benefits of breathing better and going home:

“My child had been hospitalized for several months, intubated and sedated. A tracheostomy gives my child a stable airway and it may not be permanent. My child is not struggling with breathing anymore. He now leads a calmer, more comfortable and mobile life with less sedation. He sometimes smiles and makes cute little sounds. I can hold him. He has more energy to gain weight, develop normal baby stuff, and get other kinds of treatments. My child is now enjoying some home life and thriving. He is a whole new child. Although I realize that my child’s life is different from what healthy kids can do, this is a better quality of life than staying in the hospital, sedated and not making any progress. I hope my child will have some quality time, even just several years. A tracheostomy gives my child the best chance at life.”

- Some parents focus most on pain and suffering:

“We know that our child may not live long. He has already gone through a lot. Tracheotomy is an invasive procedure. One more invasive procedure for him. It must be painful. There would be a hole in my child’s neck! Having the tube could lead to infection and more complications. We will probably come back to the hospital often and my child may die from complications. I am concerned about the medical aspects and more suffering. This is not the quality of life I want for my child. We value shorter ‘quality’ time with my child than longer time with suffering. Our child is enrolled in the hospice program and the team is awesome at attending to my child’s symptoms and needs.”

- Some parents focus most on how a tracheostomy influences their child’s daily life now:

“When the doctors were discussing the tracheostomy, it sounded like a perfect fix. However, my child is very active, unlike some children who had lots of sedation before having a tracheostomy. My child often touches her neck. It will be really bad if she pulled the tracheostomy tube out. A tracheostomy may restrict things that my child can do. She may not be able play with other kids freely anymore. She may not be able to eat and speak as before. I do not want to take away things from her.”

- Some parents focus most on what their child might be capable of doing many years in the future:

“My child has been on a tracheostomy and the ventilator for 2 years. Originally, I thought it was just going to be a few months, but now I realize that it may be years or indefinitely. I now understand that even the doctors may not know. Their estimates are just that: estimates. They could be wrong.”

“I thought that with a tracheostomy, my child would have a more meaningful life and a miracle would happen. But, it’s still a very difficult and limited life. We are able to have more interactions with her, but as she grows bigger and bigger, we realize that she probably won’t be able to experience many things. Even the things she will be able to do will be more complicated and challenging than they are for most kids. We can’t do everything that we want her to experience. Furthermore, my child is not making as much developmental progress as we had hoped for due to her underlying disease, even though her breathing is much better. It’s important to be prepared that it may be a long journey. There could be developmental delays or regressions. There may be new challenges when your child grows bigger and bigger. You have to think about your child’s quality of life in terms of whether they will be able to have everyday experiences.”

In summary, parents have diverse perspectives about “the best possible quality of life.” What “the best possible quality of life” might be for your child depends on your child’s medical conditions and your family’s situation. It is a case-by-case judgment. What works for one child and their family may not work for the other, and vice versa. You and your family can decide what is the best life for your child. Remember, there is not a single right answer—it is about what is right for your child and your family.

What Should I Expect with a Tracheostomy?

It takes lots of training to take care of a child with a tracheostomy. To be able to bring your child home from the hospital with a tracheostomy, you will need to learn the details about how to care for the tracheostomy and how to handle emergencies that may arise. You need to be prepared to manage situations first before counting on other resources. Many services may be advertised well but they are not guaranteed, so it may take you a lot more time and effort than expected to find the services that can actually help you.

Taking care of a child with a tracheostomy is a 24/7 responsibility. It can be life-altering. You may not be able to work or it may require changes to your daily routines (e.g., eating, sleeping, showering), while watching after your child with a tracheostomy.

Moreover, it is important to maintain your own physical and mental health. You will need nurses or other caregivers in your home to take care of your child, so that you can go to work or maintain a normal sleep schedule. Below are what many parents experience when they take care of their child at home.

Taking Care of a Child with a Tracheostomy

- Training of caregivers may vary between hospitals, units, individual providers, and families. Some parents feel that they are not adequately prepared by the training they are given to take their child home:

“I didn’t realize how difficult and complex it would be to take care of my child with a tracheostomy at home. I went through a two-hour training with nurses at the hospital and they watched me change and suction the tracheostomy tube and ties three times. It’s very important for parents and family members to take the training at the hospital seriously and be prepared for the home care. The more you practice, the more confident you will be. If you don’t feel prepared, definitely be honest about your feelings, write down what you are not yet comfortable with, and ask the nurses to retrain you on those skills. You need to be confident in the training you have received and your ability to use it because you might not be able to count on other people (e.g., a second caregiver, home care nurses) to take care of your child. You may have to stay in the hospital longer than expected for the training and get everything ready for home care.”

- Even with substantial training and preparation, it can be overwhelming and scary to take care of the child and coordinate care by yourself for the first few months. For many parents, things become more manageable over time.

“Once I got home, I felt alone, and everything was on me. The first days, weeks, and months of caring for my child at home had been scary and emotional. I had to watch out for signs of breathing stress and had to make a judgment of when suctioning and changing the tube was needed. I was not confident in solving clinical problems at first. The first tracheostomy tie change was very scary. You know, I am not a medical professional, but I gradually learned to judge and handle my child’s needs. I became more confident with practice and found a new normal. I check my Go-Bag every day in case there is an emergency.”

“I have to coordinate with different parties of caregivers, so it’s important to know the point person. It can be tricky to find out whom to call, but sometimes there will be a support team who can help you. I have to contact home care nurses, find social workers who can support our emotional needs (which parents often overlook, their own needs), and schedule follow-up hospital visits. I also have to interact with medical supply companies for things like trach ties. Not all the companies provide the same amount and types of supplies, so make sure that you talk to a few to find the one that meets your child’s needs.”

“It is really important to have a second caregiver helping, especially for times like changing trach ties. With time, things get less scary and easier, but having a second person able to help makes a big difference.”

- Emergencies do not happen to every patient, but all caregivers need to be prepared for one to happen at any time. Handling emergencies can be scary and emotional. And it is normal to feel that way.

“I was aware of caring responsibilities, but I have to admit that caring for her has been more overwhelming and complicated than I expected. There are emergencies and I get alarm fatigue. Somebody (either parents or nurses) needs to be alert at all times. Like once a week, she would have a choking episode or something. It has become our new normal. The tracheostomy tube fell out once—that was so scary. The tracheostomy nurses told me that a tube falling out or being pulled out was common. This is my child and I can’t afford to make a single mistake—but we are all humans, there is room for human errors as long as my child is not harmed, and parents just need to be alert and diligent in caring for a child with a

tracheostomy. I kept telling myself that I am a strong mother and I will do everything for her. Later I realized that it is OK and normal for me to feel anxious, overwhelmed, and scared. Many other parents have been in the same place. Accepting that emergencies will happen and will be scary has helped me to develop some confidence that I can get through them.”

Home Nursing

A child with a tracheostomy needs 24/7 care. Home care nurses (usually paid for by insurance) can cover some shifts and become good partners in your child’s care so that you can get some breaks. However, challenges in home nursing may exist.

- Finding a nurse can be more challenging than some families expect:

“We used to think that it’s just like finding a child sitter. However, home nursing is in low supply but in high demand. We had to stay in the hospital for an extra month because we could not find a nurse. After we went home, every now and then we couldn’t find a nurse. The ones we found stayed for one or two months and left for easier jobs. Or, if they were really good, the company then assigned them to a different family. I know a lot of parents who have to sacrifice their jobs to be at home with their child because they can’t find a nurse whom they can get along with.”

- Training and comfort levels of caring for children with tracheostomies vary between home nursing care providers:

“We love our nurse on Mondays and Wednesdays. She willingly practiced tracheostomy tube and ties changes on my child with us and got very comfortable taking care of my child. She actively participates in my child’s care so that she would know what to do at home. She becomes part of our family. The other two are awful. There is just an uncertainty of what quality of nurses you will get. I thought nurses were trained professionally on all medical conditions, but we have to guide them. Some home care nurses had no training in taking care of a child with a tracheostomy and had no idea what they should do. We ended up training the nurses. They were scared to change the tube. They were just learning. Later we learned that we needed to ask the agencies whether the nurses had specific training in tracheostomy care. You have to ask the right questions to get the right people.”

- Some families struggle to find home care nurses whom they can trust:

“We have had some great nurses. For example, one nurse we had always arrived on time and never called in to tell us that she couldn’t come. She absolutely loved our child and played with her. She was very responsible so that we could have a good sleep at night. We made a great team for our child. Others may not show up when you really count on them. I don’t know how much we can trust the nurses. I try to stay at home whenever I can. I don’t know if they are competent. We didn’t know it would be this hard to find good nurses. While some are good, others lie about what they did or even steal extra supplies. In addition, we try to get nurses at night so that we can sleep, but some nurses would nap. You really have to check your nurses’ behaviors. It is really important to be comfortable with taking care of your child by yourself and to find somebody who is competent, trustworthy, and dedicated to this job.”

- Having a nurse at home may change your home dynamics:

“Having a home care nurse at home is like sharing a room with a roommate you don’t even know. It is weird to have a stranger at home. There is just little privacy, like when you have family meals or at night you run into a nurse when you go to the bathroom. We got along well with the first nurse, but the second one was giving us so much trouble. She didn’t cover her food when using the microwave and spilled a lot. We told her so many times but she still didn’t do so. Another nurse we had was untidy, too—always putting her feet on our sofa and leaving socks there and putting chewing gum on the counter. Another nurse acted like she owned the house and ordered us to do things. I have learned to tell the nurses that they are partners with us for our child, not the primary caregivers. I always interview the nurses before having them in my house, but still, they may have different personalities and habits. It’s going to be evident once they are here. I need to communicate our house rules and set strict boundaries. And it’s OK to not keep nurses who are not a right fit with your family.”

In summary, taking care of a child with a tracheostomy requires parents to be skillful and resourceful. Make sure that you as a parent can accept and prepare for the responsibilities of taking care of a child with a tracheostomy. It is also important to think about what preparation you need and what resources (e.g., help from medical professionals, social workers) you can get to help you stay balanced and strong for your child. Be prepared to spend time finding nurses and training them to make sure that they can adequately take care of your child alone.

What Else Should I Know?

There are other practical matters that you should be aware of and prepared for as you consider a tracheostomy. Below is some advice that other parents shared.

Home Environment

Having a child with a tracheostomy may require remodeling your home:

“After getting a tracheotomy done on my child, we realized that our housing situation would not satisfy his needs. Our residence does not have enough room for an additional caregiver, like a nurse, to stay overnight. We also need storage room for the equipment and supplies. The neighborhood sometimes has power outage when the weather gets bad. If the breathing machine and equipment shut down, my child won’t be able to breathe. So it is important to tell the utility company that you are required to have a dedicated circuit and get a home generator in case there is a power outage. The living place has to be adapted for the child, like rewiring, building a handicap ramp or getting more furniture. We spent two weeks looking for a good contractor and fundraising for the remodeling. I try to set up the room and store things like what they do in the ICU so that I can quickly grab equipment and supplies for my child in case there is an emergency. As my child grows bigger, there are more and more things and the space just gets tighter. Maybe we need to move someday.”

Household Income

Having a child on a tracheostomy may impact household income if one parent has to quit their job to take care of their child:

“My wife and I both worked. With our child on breathing support, we need somebody to be at home and look after him. Sometimes when we didn’t find good home care nurses, we would have to take many days off work or ask our parents to help. In the end, my wife left her job. I am the only one working, and hence our monthly income went down by a lot. With our child’s medical condition, we really need more money and support. For instance, the utility bills go up a lot because of all the equipment. We could apply for Supplemental Security Income but it doesn’t cover much. For some families, their child may need to go to the state care home, which is often horrible. We can’t imagine if a single parent had to quit working because that’s a total loss of income.”

Support from Schools and Public

- Finding a special needs school that can care for your child can be challenging:

“Sometimes there is not enough support from school and community. For example, school may not have nurses who know how to take care of a child with a tracheostomy and may not allow our nurses to go with our child, so we don’t want to leave our child with somebody who may not be competent at taking care of our child and we end up home bound. Or we have to train the school nurses until they are very comfortable handling our child. They don’t have home schooling, either. One piece of advice we got from others is to seek services so that we have an advocate for our child’s educational needs.”

- Parents sometimes struggle to take their child to public places. Other people may not be understanding of your child’s circumstance and needs.

“Sometimes our child is doing well and we want to take him out to see the real world. He has been staying in the house for too long and he needs to interact with people. Taking him out can be nerve-wracking, especially in the winter when germs are spreading around. It is also cumbersome because we have to pack so many things. We have to apply to get a new stroller and buy a four-door car to transport our child with all the equipment. It is not easy to provide medical care outside. There is seldom a clean place to suction in a restaurant. Can’t do much in parks either. Public restrooms may not be accommodating. Sometimes public facilities do not have the right handicap accessibility. People stop and stare at us. When I take my child out for a walk, our neighbors always express their sympathy towards my child, and also our family. I got more comfortable answering people’s questions if they were just curious. Some people said my child was not worth living this way, because he could not do much except for smiling and breathing. I felt horrible that my child was undervalued, and I defend and speak up for my child whenever I can.”

Influence on Family Life

- For some families, having a child with a tracheostomy brings their family members together. For example, family members, friends, and neighbors come to help on a regular basis, so that the main caregiver can take a little break (to shower, to clean, to eat). For some, that is not the case. Either way, there will be some changes in family dynamics:

“There are certainly changes in family dynamics. We have the other two healthy children. They come second. I feel indebted to them. After we had the child with a tracheostomy, my husband and I have to be at the hospital a lot, leaving them to grandparents, babysitters, and daycare. We try to be there for our healthy kids as much as we can and to show that we care for them (and video chatting technology helps), so that they don’t feel forgotten. We involve them in the care so that they know that their voice is heard. We spent a lot of money on this child, so we couldn’t buy them toys as we used to.”

“My husband and I are very stressed and we couldn’t have a normal life anymore. Lots of burn out in an effort to support the family and a child with a tracheostomy. Especially as the main caregiver, I bear a huge emotional toll, and sometimes my family doesn’t understand my stress so I don’t feel supported by them. We just need to push through for the family and hope to see that our children bring us together as family.”

- Your partner and family may not accept the responsibilities to care for a child with a tracheostomy:

“My partner backed out after taking the training. He realized that it would take a lot of time and effort to take care of a child with a tracheostomy. He thought that it would be too much for him. His family also abandoned us. It hurts the most when your closest family do not understand and support you. It is important that two parents are on the same page about the child’s care. A spouse consultation might have been helpful at the time. But we ended up separated. Now I am a single mom. I came to accept that not everyone is willing to make the sacrifice that I signed up for.”

- Many families feel that their social life is impacted:

“Our life is in isolation in the first couple of weeks after taking my child home. We need some time to adapt to everything, but we feel home bound and don’t have much freedom to connect with friends or go outdoors. Our friends have healthy kids, and it’s hard for them to play with my child. Some friends have left us. However, I am going to try asking other family members, friends, and nurses to come take care of my child, so I can get some breaks. I am also gradually learning to pack the bag and vent and bring my child with me, if I have to go out. But still, we will be very much home bound as long as our child has the tracheostomy.”

What If I Have More Questions?

We hope that other parents' experiences help you as you consider what is important for your child and family when considering a tracheostomy. Nevertheless, this booklet may not include everything you want to know.

Parents suggest these support groups and resources that you can contact.

Facebook support groups:

- Southeast Michigan Tracheostomy Families
(<https://www.facebook.com/groups/SEMITrachs/>)
- Michigan Medical Foster Care and Adoption
(<https://www.facebook.com/groups/1704032786547691/>)
- Moms of Trach Babies Group (including groups for specific topics)
(<https://www.facebook.com/groups/momsoftrachbabies/>)
- TinySuperheroes
(<https://www.facebook.com/groups/tinysuperheroes/>)

Websites for more information about tracheostomy and parent network:

- caringbridge.org
- courageousparentsnetwork.org

There may be support groups through your hospital/region for children with similar diagnosis or conditions. You can ask your providers and social workers about support groups or past parents who are willing to offer help.

Disclaimer: Any information you receive from these support groups and websites is not a substitute for professional medical advice. Always consult with a qualified and licensed physician or other medical care provider.

Booklet created by:

Haoyang Yan, MS

Department of Psychology, University of Michigan

With guidance from:

Brian Zikmund-Fisher, PhD

School of Public Health, University of Michigan

Patricia Deldin, PhD

Department of Psychology, Department of Psychiatry, University of Michigan

Kenneth Pituch, MD

*Division of Hospital Medicine, Department of Pediatrics, University of Michigan
Medical School*

Cynthia Arslanian-Engoren, PhD, MSN, RN, ACNS-BC, FAHA, FAAN

School of Nursing, University of Michigan

Sandra Graham-Bermann, PhD

Department of Psychology, Department of Psychiatry, University of Michigan

Stephanie Kukora, MD

*Division of Neonatal-Perinatal Medicine, Department of Pediatrics, University of
Michigan Medical School*

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