

CHILD TRACHEOSTOMY

Decision Guide



Winnipeg Regional
Health Authority
Caring for Health

Office régional de la
santé de Winnipeg
À l'écoute de notre santé

Developed in Collaboration with Patient Education Committee; Index # 150.34.00b



INTRODUCTION

You are facing the decision about having a tracheostomy (trach) tube for your child. This guide will take you through steps to make it easier for you. The answers will come from yourself, any tests that can be done for your child, and from talking to the team who is caring for your child and the team who gives “second opinions”.

It is helpful if there is more than one family decision maker that each answers these questions on their own.

Some questions to ask yourself as you work through this process:

1. How are you feeling right now?
2. Which reasons to choose each option matter most to you and your family?
3. What else do you need to prepare for decision-making?
4. What are the next steps?

STEP 1: UNDERSTAND YOUR CHILD

There are several reasons why a trach may be considered for a child. Some are put in when there is an emergency. If this is the case, the decision is made quickly and this guide does not apply as it is important to make sure the trach is not delayed in an emergency.

In most cases when a trach is being considered, it is important to take time to review the decision carefully. There are three general reasons why a trach is considered:

1. The structure of the airway or breathing passage is not stable. It may not have formed properly before birth, or there may have been changes that prevent air from going to the lungs.
2. The child needs breathing help from a machine for a long time due to a condition or illness.
3. The child has an illness or condition where their ability to breath is slowly getting worse.

What type of breathing support is your child getting now?

- Long tube through the mouth (endotracheal tube) with breathing machine.
- Long tube through the mouth with only cpap to support breathing.
- Short prongs in the nose or mask on the nose or mouth with cpap.
- Other: _____

Why does your child need breathing support?

- Illness or injury that has damaged the lungs.
- Illness or injury that has led to problems with the brain, nerves or muscles needed for breathing.
- A growth or mass blocking the airway.
- An inherited problem in the larynx (voice box) or trachea.
- Weakness of the muscles that affect swallowing.

What is your child's future need for breathing support likely to be?

- Temporary and likely to improve.
- Permanent and likely to remain the same.
- Permanent and likely to get worse.
- Not known whether it will get better or worse over time.

With a trach your child is likely to need:

- Ventilator assisting breathing.
- Machine to support breathing.
- No ventilator.
- Other: _____

Rate your child's quality of life right now.

- Excellent – No pain or discomfort and is able to interact with people and enjoy life.
- Good – Some pain or discomfort at times but is able to interact with people and enjoy life.
- Poor – Pain or discomfort much of the time and very little ability to interact with people and enjoy life.
- Very poor - Pain or discomfort most of the time and no indication of any ability to interact with people and enjoy life.

What are your hopes, wishes and concerns for your child and are they achievable?

Hopes	Wishes	Concerns
Achievable?	Achievable?	Achievable?

STEP 2: EXPLORE OTHER OPTIONS:

The options for your child **may** include:

- Surgery or different medicine to correct or change airway or lung problems.
 - Review the pros and cons of doing and not doing each option that is possible for your child.
- Keep giving the current breathing support and wait to see what will happen with their condition.
 - Is there still a chance for improvement?
 - Has there been enough time?
 - Have symptoms been treated?
- Try to wean child from the support.
 - Is there still a chance for getting better?
 - Have you already given enough time?
 - Have you already tried this enough times?
- Comfort care. Decide on what to do and what not to do for your child. Your child's length of life is limited, and their comfort is the most important thing.
 - What are your goals for your child?
 - Where will your child be most comfortable?

Who did you include in the discussions?

- You and your family
- Child's Pediatrician
- Intensive Care Doctor or Neonatologist
- Surgeon(s) – *possibly more than one, including an Ear Nose and Throat Specialist:*
- Pediatric Respiriologist
- Nurse (*include those who know your child best*)
- Respiratory Therapist
- Social Worker
- Spiritual Care Worker (*preferably from your own community*)
- Other people:

Options for your child are:

- Surgery or different medicine to correct or change airway or lung problems: _____
- Continue to support your child the way they are currently being supported and wait to see which way child's condition will go.
- Aggressively try to wean my child from the support to see how he/she responds. Reasonable time frame: _____
- Palliation and comfort care with the goal of alleviating suffering. Initiate Advanced Care Plan.
- Tracheostomy

How clear are the options to you?

- Very clear
- Mostly clear – I would like to discuss them further.
- Not clear – I need to discuss with more people or need more time and explanations to understand them.

List the options that you need to talk more about:

Do you understand the reasons to choose each option?

Yes No

Do you feel pressure to choose any of the options?

Yes No

If so, describe the pressure:

Do you have a preference for any one option?

Yes No

Which one and why?

STEP 3: UNDERSTAND THE TRACHEOSTOMY OPTION

A tracheostomy is a surgical procedure to create an opening through the neck into the trachea (windpipe). A tube is usually placed through this opening (stoma) to provide an airway and to remove secretions from the lungs. This tube is called a tracheostomy tube or trach tube.

Once a tracheostomy tube is placed there is no guarantee that the results will be what are anticipated. Placing a tracheostomy changes the child's airway in many ways. The trach may or may not change or affect the reason that your child needs breathing or airway support. Some of the potential pros and cons of a tracheostomy are listed on the next page. There may be other pros and cons for your child.

It is not always known how long a child may need a tracheostomy once it is placed, but it is important to get input from as many people as possible.

The procedure:

The risks any time a child is given sleep medication are:

- Problems breathing
- Reactions to medications

The risks for any surgery are:

- Bleeding
- Infection

Extra risks that can occur during or after surgery include:

- Erosion of the trachea (rare)
- Nerve damage
- Scar tissue in the trachea

Do you understand the risks and legalities of the procedure for your child?

Yes No

Your child's trach will most likely be:

- Needed only for a short time and likely removed before the child goes home.
- Needed for a short time but still in place when the child is otherwise ready to go home.
- Needed for many years.
- Needed for life.

PROS

- Moves tubes and/or masks away from the face.
- Creates a more “stable” airway that is less prone to accidental removal than an endotracheal tube.
- May allow for food by mouth.
- May allow for speech.
- May allow for less medication for sedation and allow the child to be more awake and alert.
- May allow for child to be cared for in an area other than an intensive care unit.

CONS

- Bypasses the normal infection prevention structures and opens the lungs to different germs which may need to be treated with hospital or home IV medicines.
 - Frequent infections may need to be treated with stronger antibiotics which may interact with other medicines.
- May weaken the trachea.
- May plug or block more easily.
- If ventilation needed the lungs become damaged over time.
- May not allow your child to speak.
- Your child may need more breathing support with the trach than they did before because of physical changes.

**List the pros of a trach
for your child:**

**List the cons of a trach
for your child:**

Caring for a child with a tracheostomy includes providing the basic care to the child plus knowing how to manage the care of the trach. This will include learning:

- Suctioning the trach.
- Skin care for the stoma and how to manage problems or issues with the stoma.
- How to replace the trach, what to do if it comes out accidentally and what to do if a new one won't go in easily.
- What to do if the trach becomes plugged or blocked.
- How to recognize lung infections and what to do in that case.
- Managing equipment such as ventilator, monitors and suction machines and oxygen equipment, if they are needed.

To get a better idea of what trach care is like, the Tracheostomy teaching guide goes into more detail.

Leaving the hospital with a tracheostomy may be possible, but the following conditions must be met:

- The level of care for the child that can be provided with equipment that is available in the community.
- At least 2 caregivers are trained in care of the child and tracheostomy equipment. It is ideal to also have at least one person outside the immediate family who is trained to provide care.
- Reasonable proximity to health care workers who can provide care to the child in case of emergency.
- Adequate respite support for the caregivers is available.

Every family will have different options that are available to them. Discuss with the team which are realistic for you.

The options for care outside the hospital include:

- In your own home and home community.
- In your own home where you have relocated to a community where emergency care is available.
- In a medical foster home in a community where emergency care is available.
- In an institution or facility that is not a tertiary care hospital where staff can provide the care the child needs.

Caring for a child with a trach at home requires:

- **CONSTANT** presence of a trained caregiver. The child cannot be left in the care of a “babysitter” who is not fully trained and able to give both routine and emergency care.
- Equipment for both routine and emergency treatment. This includes suctioning and giving breathing support.
- Having a plan for how to get emergency help at any time of day and in any type of weather conditions. This plan includes notifying the fire department and ambulance services about your situation.

- Consideration of home location – an example is if your home is near a gas station where an accident or incidence may make it necessary for you to evacuate your home. Proximity to the hospital is also a consideration.
- Consideration of the increased costs to the family for items not provided by the health care system including: cleaning supplies for equipment, increased hydro and natural gas usage to run the equipment, home supplies used by caregivers.

Having a child with a trach at home puts a lot of added stress on a family including:

- Stress on relationships.
- Lack of sleep.
- Organization of equipment.
- Caregivers in your home.
- Sense of entrapment.
- Child (and siblings) recognition of stress on the parent/caregivers.
- Changes to parent employment
- Possible relocation of family to the city

Having your child at home also provides benefits that may be difficult or impossible in the hospital including:

- Child has access to the love of family members.
- Possible extension of increased “quality of life” experience with stability of health.
- Smiles can be shared with family rather than hospital staff!

Which of the following is most true about your home:

- My child can safely be cared for there.
- With some changes my child can safely be cared for there. (i.e. Teaching, modifications, adjustments, safety issues, insurance)
- I am not sure if my child can safely be cared for there.
- My child cannot be safely cared for there.

Which of the following is most true about your community:

- My child can safely be cared for there.
- With some changes, my child can safely be cared for there (i.e. Teaching, modifications, adjustments).
- I am not sure if my child can safely be cared for there.
- My child cannot be safely cared for there.

Which of the following options is best for your child if they do have a trach?

- To be cared for in my current home.
- I will relocate to another community and care for my child in my home there.
- Voluntary placement in a medical foster home – I will provide whatever care I can.
- Continue to stay in an institution.

Which of the following equipment is likely to be needed in the home?

- Suction machines.
- Ventilator
- Oxygen equipment.
- Oximeter.
- Other: _____

Which of the following is most true about your family's ability to deal with the increased costs:

- We will be able to manage the increased costs.
- With some help we should be able to manage the increased costs.
Need discussion with social worker.
- I am not sure if we can handle the increased costs.
- Without some considerable change in circumstances we will not be able to manage the increased costs.

After discussion of the care needs of a child with a trach how prepared do you feel to be your child's caregiver?

- Very prepared – I am able to care for my child with a trach.
- Somewhat prepared – with more teaching and practice I would be ready to care for my child with a trach.
- Not prepared – I am unsure of whether I will be able to care for my child with a trach.
- Not prepared – I do not think that I will be able to care for my child with a trach.

List the people who may be able to learn to care for your child:

STEP 4: MAKING THE DECISION

Are there any values that you have that are impacting your decisions?

In the table below rate your child's quality of life for each of the options that apply to your child:

- Not An Option: there are no surgical or medical options.
- Excellent – No pain or discomfort and is able to interact with people and enjoy life.
- Good – Some pain or discomfort at times but is able to interact with people and enjoy life.
- Poor – Pain or discomfort much of the time and very little ability to interact with people and enjoy life.
- Very poor - Pain or discomfort most of the time and no indication of any ability to interact with people and enjoy life.
- Don't Know – not sure if this is an option

Surgical or Medical Treatment	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Continue Present Support	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Give More Time/Keep Trying to Wean	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Palliation and Comfort Care	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information
Tracheostomy	<input type="checkbox"/> Not An Option	<input type="checkbox"/> Excellent	<input type="checkbox"/> Good	<input type="checkbox"/> Poor	<input type="checkbox"/> Very Poor	<input type="checkbox"/> Don't Know. Need more information

For the following questions, indicate the one that best reflects your feelings.

How ready are you to make this decision?

Very ready – my mind is made up. The decision that I have made is:

Somewhat ready – I need more time or more information

Not ready – I do not fully understand everything

What do you need or who do you think you need to talk to in order to help you make this decision?

What questions do you have?