

## Going home with a Tracheostomy





## How to...

### Contact your child's team

**It is important to us that you are managing your child's treatment safely at home.**

If you experience any problems or have any questions regarding your child's treatment please contact:

**Monday to Friday 8:00am – 4:00pm contact:**

Homecare Team \_\_\_\_\_

ENT Nurse Specialist \_\_\_\_\_

Nurse Specialist \_\_\_\_\_

Equipment provider \_\_\_\_\_

After business hours, weekends or public holidays contact:

Starship Hospital: 307 4949

EXT to Childrens Emergency Department : 24200

### Essential Tracheostomy Details

The type of tracheostomy tube my child has is a \_\_\_\_\_

My child's tracheostomy tube is a size \_\_\_\_\_

My child's suction catheter size: \_\_\_\_\_

Depth to suction my child to: \_\_\_\_\_

Suction pressure for my child: \_\_\_\_\_

The tracheostomy ties my child uses are: \_\_\_\_\_

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## Introduction

This booklet explains all about tracheostomies. It gives information and advice on managing your child's tracheostomy once you return home.

Having a child with a tracheostomy has many implications for your family. You will be pleased and relieved that your child can now breathe. However, you may experience grief brought about as a result of change in lifestyle, restrictions or changes in your child's verbal responses.

At the moment you may feel a little overwhelmed by the things you must learn to do, however the healthcare team is here to help support you. We understand that this is a big responsibility. It is important that before leaving hospital you are happy with all aspects of your child's care

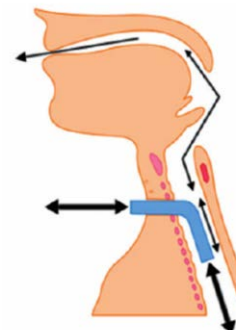


# Section One: Your Child's Tracheostomy

## 1.1 What is a tracheostomy?

A tracheostomy is an opening into the trachea through the neck with the insertion of a tracheostomy tube to aid breathing. The opening/hole is called a stoma. It can be temporary or permanent.

A tracheostomy tube is inserted through the opening to allow the passage of air and removal of secretions. Instead of breathing through the nose and mouth, the majority of air will pass through the tracheostomy tube.



The reasons for requiring a tracheostomy are varied. Your doctor will explain the reasons why your child requires a tracheostomy.

Some children who do **NOT** have a **critical airway** are able to breathe partially around their tracheostomy tube via their nose/mouth. If their tracheostomy tube were to come out or become partially blocked, the child may still be able to breathe sufficiently till help arrives.

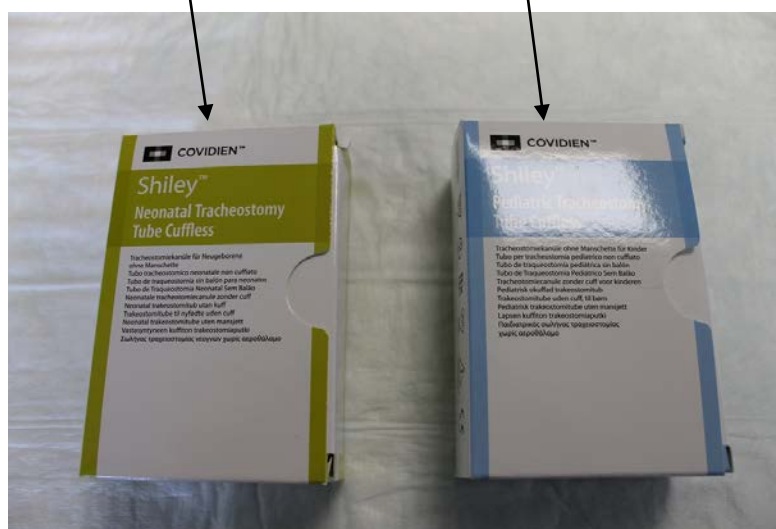


However, some children are completely reliant on their tracheostomy to breathe. This is described as an **obligate** tracheostomy or a **critical airway**. The healthcare team will inform you if your child's tracheostomy is obligate. The term obligate tracheostomy and critical airway are often used interchangeably by health professionals. For the purposes of this booklet we will use the term **critical airway**

Tracheostomy tubes come in different sizes (diameters). Shiley, the brand most frequently used at Starship, also comes in either paediatric or neonate specific length and curvature. The colours of the paediatric and neonatal boxes are different.

Neonatal

Paediatric



## 1.2 Beginning your journey

Following surgery your child's tracheostomy care will be undertaken by the medical and nursing staff. Once your child is stable with the tracheostomy, education and preparation for you and your child to go home will begin. We will start teaching you how to care for your child with their tracheostomy.

Your nurse will discuss and you will be provided with an education plan to ensure that you have been taught all tracheostomy cares and that you are safe and confident to perform the cares at home.





## Section Two: Managing your child's routine tracheostomy care

### How to...

#### Suction your child

##### 2.1

1. Make sure you have all the equipment you need ready.
  - a. Hand cleaning products
  - b. Suction machine with tubing
  - c. Suction catheter
2. It is a good idea to keep a suction catheter (in its packet) attached to the tubing from the suction pump in case you need to suction in a hurry and to ensure your suction pump is plugged in and ready to be used at all times.
3. Wash or gel your hands (skip in an emergency).
4. Verify the suction depth measurement on the catheter.
5. Turn on the suction and check the correct pressure (generally be 80-120 cmH<sub>2</sub>O).
6. Gently insert the catheter into the tracheostomy tube without applying pressure (with your thumb off the catheter side port) to the required distance.
7. Apply suction (up to 5 seconds) by covering the port with your thumb and slowly withdraw the catheter. Some find it helpful to gently rotate the catheter but this isn't necessary.
8. Give your child time to catch their breath and repeat as frequently as necessary whilst keeping the catheter tip clean between suction.
9. Turn off the suction, disconnect the catheter from the tubing and clean /



Suctioning a ventilated child is much the same. You can either briefly remove the ventilator circuit from the tracheostomy or suction through a suction port in the interface between the tracheostomy and the ventilator. If your child is on a ventilator you will be taught how to manage this.

## **2.2 Keeping your child's airway clear**

The most important thing when caring for your child and their tracheostomy is to keep the airway clear. This means ensuring that the tube remains safely in position and does not become blocked with mucous secretions.

This is done by:

- Making sure that the tube is tied securely and does not dislodge accidentally
- Preventing the tracheostomy tube from becoming blocked by providing suction to help your child clear their secretions when needed
- Maintaining humidity to the airway to prevent secretions drying out

This means that you will need to learn how to assess when to suction your child and how provide suction safely. You will also need to learn about:

- tracheostomy ties
- tracheostomy tube changes
- humidification

## **2.3 Suctioning**

The upper airway warms, cleans and moistens the air we breathe. The tracheostomy tube bypasses these mechanisms, so the air via the tube is cooler, dryer and not as clean. In response to these changes, the body produces more mucus.

The tracheostomy tube is suctioned to remove mucus from the tube and trachea to allow for easier breathing. There may be a large amount of secretions with a new tracheostomy. This is a normal reaction to an irritant (new tube) in the airway. The heavy secretions should decrease within a few weeks. You may find you observe differences in practice in Paediatric Intensive Care (PICU), such as pre oxygenation, that should not be required once your child is well enough to leave PICU.

Frequency of suctioning will vary from child to child and will increase with respiratory tract infections or colds. Try to avoid too frequent suctioning, as this will increase the production of secretions.

## 2.4 Signs your child needs to be suctioned

- Rattling/wet mucus sounds from the tracheostomy
- Fast breathing
- Bubbles of mucus in tracheostomy tube opening
- Dry raspy breathing or a whistling noise from tracheostomy
- Older children may vocalize or signal a need to be suctioned
- Signs of respiratory distress – skin colour change, desaturation, combative, in drawing around neck/chest
- Signs of tracheostomy occlusion – diminished chest wall movement, reduced breathing sounds, and desaturation/colour change.



Signs that a child on a ventilator needs suctioning or the tracheostomy is occluded are very similar. However, if your child is unable to make any or even very little effort to breathe on their own then signs include:

Decreased or absent chest movement

The ventilator may also start alarming.

If your child is on a ventilator you will be taught how to manage this.

## 2.5 Things you need to know in order to suction

- Size ( diameter) of the suction catheter
  - The suction catheter size (diameter) is determined by the size of the tube (for example 6fg or an 8fg)
- How far to insert the suction catheter
  - The suction catheter is inserted to a predetermined length to avoid damaging the lower airway
- How much suction to apply
  - The pressure of suction is set as low as possible to allow the secretions to be removed effectively whilst minimising damage from excessive pressure

Your nurse will show you what size catheter, the correct depth to suction to and level of pressure to use when suctioning.

**Note:** The size of your child's tracheostomy tube may change as your child grows or their condition improves. The size of the suction catheter and the depth of insertion will vary in accordance with this.



## 2.6 Humidification

The nose and mouth provide warmth, filtering and moisture for the air we breathe. A tracheostomy tube bypasses the usual airway mechanisms. Humidification must be provided to keep secretions thin to avoid mucous plugs because they may block the tube or lead to chest infections.

During the day your child will generally wear a Heat Moisture Exchanger or thermovent. This helps to keep their secretions thin as well as prevent them breathing in any dust.

Oxygen can be given via the humidifier if ordered by the doctor.

Children receive warm humidification therapy when sleeping to prevent the tracheostomy blocking with dry secretions.

### Heated humidifiers

These powered devices humidify similarly to the nose but are not portable



### Heat Moisture Exchangers ( HMEs

These use the body's own warmth and moisture to condition air (like breathing through a handkerchief) and are much more portable. They also protect from dust and are often called 'HMEs', 'Swedish noses' or 'thermovents'. We recommend them for portable / day time use

Please note that if your baby is small, for medical reasons, your Dr may advise using the smaller size HME. If this is the case you will need remember that the inlet filter is single (unlike the double inlet larger HME) and take extra care it does not become covered



The humidification needs of a child on a ventilator with a tracheostomy are the same. Both heated humidifiers and heat moist exchangers are used. The specific devices will look different. If your child is on a ventilator you will be taught how to provide humidification for your child.

## **2.7 Secretions and the Weather**

Different weather conditions may affect your child's tracheostomy and the consistency of secretions.

- Cold weather may cause secretions to become thick and dry
- Mild humid weather may keep secretions loose
- Windy dusty weather may cause thicker secretions
- Heaters and air conditioning may cause thick and dry secretion
- Ambient conditions can also effect heated humidifier performance sometimes leading to excessive condensation in tubing. If this is a problem speak with your health care team / physiologist

## Change your childs tracheostomy ties

## 2.8

## Safety Alert

Make sure that both caregivers are clear about their role to avoid accidental removal

1. Make sure you have all the equipment you need ready
2. Discuss what each person is to do prior to starting e.g. person to hold, person doing change
3. Position the child. Place a padded roll behind the child's shoulders / neck to better expose the neck area
4. Swaddle the younger child in a manner appropriate to their age in order to prevent struggling
5. Suction your child if required
6. One person secures the tracheostomy with two fingers
7. The ties are removed and the skin is cleaned. Barrier cream is applied if used
8. The new ties are attached and secured to provide a safe and snug fit,
9. The person holding the tube only lets go when the ties are attached and tension checked and they have been instructed that it is safe to let go
10. The child is praised to help the child accept treatment more easily



## 2.9 Skin Care

Because the tracheostomy must be tied in place you will also need to make sure your child's skin does not become sore and break down.

It is important to check the skin around your child's tracheostomy and neck area at least once daily (usually when you change the ties) for signs of any skin breakdown (redness, swelling, pain, blisters)

Clean the area around the tracheostomy with cotton tipped ear buds and gauze to remove any secretions. Pat dry and apply a barrier ointment as advised by the team if the skin is getting very moist or red.

## 2.10 Changing the tracheostomy tube ties

### Safety Alert

Make sure that someone is available to help you in case of difficulty

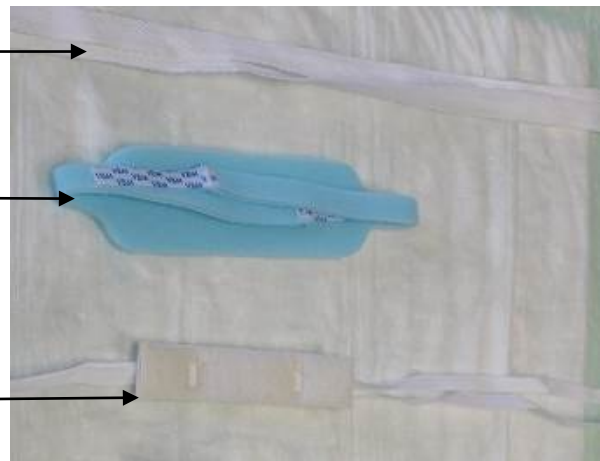
To prevent breakdown of the skin you will need to change your child's tracheostomy ties **daily** or more often if they become wet or dirty to prevent the breakdown of skin.

The tracheostomy ties secure the tube. The ties may be:

Cotton twill tape (non-fraying)

Velcro

Felt and cotton tape ties



Beaded silver chain (not pictured)

Your nurse will discuss the rationale for using a particular type of tie for your child. As your child grows and develops, the type of tie may need to be changed to avoid

accidental removal.

The ties must be snug but not too tight. You should be able to slip one finger under the ties.

Check the tension of the ties several times a day to ensure the ties have not loosened. This will prevent accidental removal.

A new tracheostomy may sometimes need to be dressed around the site while it heals. Ideally the site should not have a dressing as it presents a potential hazard if it dislodges leaving the tracheostomy too loose. It may also retain secretions and moisture at the site increasing risk of soreness or redness



Tracheostomy ties for children ventilated via tracheostomies are much the same. Sometimes additional ties or support arms are needed for the ventilator tubing ('circuit') so that it doesn't pull too hard or pop off the tracheostomy. If your child is on a ventilator you will be taught how to manage this.



## How to...

### 2.11

## Change your child's tracheostomy tube

1. Wash your hands and prepare the environment and equipment
2. Insert the obturator (introducer) into the new tracheostomy tube (to ensure it slides in and out easily). Avoid touching the end of the tube for insertion to reduce contamination
3. Clean Velcro trache tie or cotton twill tape. Secure Velcro tie to side of new tracheostomy tube
4. Prepare your child. Explain the procedure in a manner appropriate to your child's age and understanding. Put a neck roll in place and restrain appropriately. Wash your hands
5. Prepare the new tracheostomy tube. Attach the tie to one end of the flange and insert the obturator
6. One person must secure the tube with two fingers whilst the other person undoes and removes the ties. Always hold the tube when the ties are not secure as a cough can dislodge the tube
7. Clean the area around the tracheostomy site using gauze moistened with saline.
8. Remove the tracheostomy tube using an upward and outward arc (following the angle of the tube)
9. Clean the stoma quickly with saline and note the condition of the skin
10. Insert the clean tube in a smooth curving motion, directing the tip of the tube toward the back of the neck in a downward and inward arc, do not force the tube
11. Remove the obturator immediately whilst holding the tracheostomy tube securely with two fingers. Remember that the child cannot breathe with the obturator in place
12. Suction your child if required.
13. Secure the ties correctly (one finger under tape)
14. Praise your child to help them accept the treatment more easily.
15. Wash your hands.

2.

## 2.12 changing the tracheostomy tube

At home you will normally change your child's tracheostomy tube weekly. However, while your child's tracheostomy is still quite new and you are still in hospital learning tracheostomy care, your child's tube changes may be more frequent. This is to help you become well practised. Your child's stoma will be assessed by the ENT team and they will decide how frequently the tracheostomy tube can be changed.

### Safety Alert

Changing of the tracheostomy tube is to be completed by **two** trained caregivers unless it is an emergency and you don't have time to wait for extra help.

It is best to change the tube before you have fed your child to reduce the risk of vomiting and breathing in the vomit (aspiration).



Changing the tracheostomy tube of a ventilated patient is much the same with the additional consideration of the ventilator circuit and alarms. If your child is on a ventilator you will be taught how to manage this.



## Section Three: Dealing with problems

### How to...

#### Problem Solve

##### **3.1 Problem solving**

Serious problems can occur with your child when they have a tracheostomy.

##### **Accidental removal of the tracheostomy tube**

###### **Action**

- Attempt to replace the tracheostomy tube immediately
- If unsuccessful... dial 111
- Stay with your child and remain calm
- If your child is not breathing commence CPR

##### **Heavy bleeding from the tracheostomy tube (several teaspoons or more)**

###### **Action**

- Dial 111
- Keep suctioning to avoid tube blockage

##### **Foreign body in the tracheostomy**

###### **Action**

- Change the tracheostomy tube immediately
- Dial 111
- Stay with the child
- If your child is not breathing commence CPR

**We would advise maintaining membership of St Johns Ambulance Service while your child has a tracheostomy.**

## How to...

### Manage a blocked tracheostomy tube

3.2

#### Signs of a blocked tube

Poor / Absent flow through trache  
Increased work of breathing (indrawing, breathing around trache)  
Distressed child, skin colour change  
Lethargic, floppy, poorly responsive child  
Inability to pass a suction catheter to  $\frac{1}{2}$  cm longer than tube

#### Managing a blocked tube

Assess for Danger, Check responsiveness, Send for Help - Dial 111



Check the trache position and suction



If blocked: Change immediately with new tube of same size



Suction the trache



Assess for breathing and trache patency (is the tube blocked?)



CPR as appropriate

### Manage if the tube cannot be re-inserted

#### 3.3

#### **Managing if the tube fails to go in**

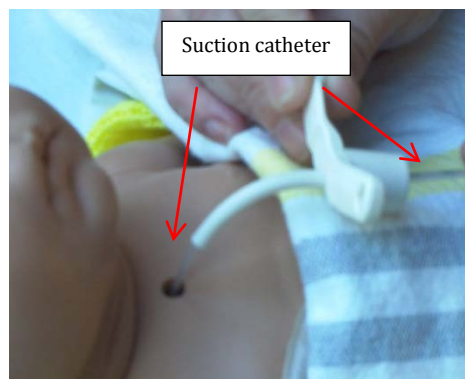
Attempt to insert the smaller size tube from the trache emergency box



2-3 drops of Otrivin junior into trache stoma site



Attempt to pass the smaller sized trache tube into the stoma using a suction catheter as a guide (seldinger technique – see photograph below)



### 3.4 Problems that need to be reported to your health care provider include:

- Your child is breathing faster than usual, more obvious sucking in of the chest wall, child has less energy to move( this could be a partial blockage or respiratory infection)
- You see a small amount of bleeding in or around your child's tracheostomy
- Change in secretions (colour, amount, odour, thickness)
- Fever
- Signs of infection around the tracheostomy
- Pain
- Difficulties in changing the tracheostomy tube
- Granulation

This is what excess granulation tissue around the tracheostomy tube might look like



If your child is ventilated these issues can also apply. Your team will provide you with a plan for what to do in these circumstances

### 3.5 Infection

If your child has a tracheostomy there is a higher risk of infection.

#### Preventive measures

- **Wash your hands** before and after cares
- Keep your child away from others who are sick
- It is recommended that your child receive all immunisations
- Avoid dust, dirt, smog, pet hair, powders, greasy creams or ointments and sprays that can irritate the lungs and make them susceptible to infection

## Section Four: Day to day living with your child and their tracheostomy

### 4.1 A new normal

A child with a tracheostomy is firstly a child and wherever possible we recommend that you treat your child as normally as their condition permits. The suggestions below will assist you to care for your child in a safe and effective way.

#### **Safety Alert:**

Eating and drinking with a tracheostomy must be discussed with the team to make sure that it is something that is safe for your child.

### 4.4 Sleeping

If your child is an infant, place them on their back for sleep. **Never place an infant on their stomach to go to sleep.** If your child is older than 1 year, they may sleep on their side or back.

Initially you may feel anxious that your child may have needs in the night when you are sleeping. This is a reality of caring for a child with a tracheostomy at home. Sometimes parents may find that having the child sleeping in their room helps with the adjustment. Other options may include purchasing a baby monitor.

### 4.5 Bathing

#### **Safety Alert:**

There is a risk that your child may drown if water enters the tracheostomy

Bathe your child in a few inches of water. Do not allow water to get into the tracheostomy. **Your child should never be left alone in the bath tub.** Older children may shower with a thermovent on. Avoid sprays and powders which may irritate the trachea.



#### **4.6 Hair washing**

Wash your child's hair carefully to avoid water flooding the tracheostomy. You may find that washing your child's hair whilst lying on their back may be useful, supporting your child's neck. Specially designed hair wash rims are available in most baby stores.

#### **4.7 Clothing**

Clothing should be open around your child's neck.

Clothing near the neck should be smooth, with no loose threads or fluff.

Roll neck tops and high cut tops may interfere with breathing.



#### **4.8 Toys**

Avoid letting your child have small toys with small detachable parts. Avoid very fluffy or hairy toys which may enter the tracheostomy. Soft toys may cover the tracheostomy tube opening and prevent breathing. Also avoid bits of paper or loose beads.

Supervise your child during play as it may not necessarily be your child that does something dangerous. Other children can be very curious about a child's tracheostomy and may interfere with it in an unsafe manner. Avoid plastic backed bibs as they may adhere to the stoma and block the tube.



## 4.9 Activities

**A child with a tracheostomy tube is encouraged to lead a full and normal life; however there are some things you need to consider to ensure your child's safety.**

- Avoid water sports
- Boating, swimming and fishing are all dangerous for children with a tracheostomy

**There is no way for your child to hold his breath under water. Your child may drown if water enters his lungs.**

When your child is young it may be best to avoid the beach. As your child gets older and more responsible you may be able to visit the beach under full supervision. A thermovent should be worn to prevent sand from being inhaled into the tracheostomy tube and lungs. Avoid windy days as the sand may enter your child's tracheostomy.

**Safety Alert:**

**Always be prepared to suction, do an emergency tracheostomy tube change and perform CPR if required. Always have your emergency equipment with you.**



#### 4.10 Travel

When travelling in a car seat ensure that the child can breathe easily by placing a **small rolled towel behind the shoulders**. This will keep his head from falling forward and blocking the tube.

If you are intending to fly some where it is advisable to let the airline carrier know that your child has special care requirements and equipment. Check with them about what the airlines requirements are. **A letter from the hospital may be required** stating the child's requirements and stressing the need for you to carry scissors and a suction machine. You may contact the Starship E.N.T nurse specialist for support with this.

Further arrangements are needed if you are administering oxygen.

##### **Safety Alert**

- Be prepared to stop suddenly and safely, if your child needs attention.
- An additional mirror attached to your windscreen mirror may allow you to see your child with-out interrupting your view of the road ahead.



A child on a ventilator may be able to participate in all the activities and travel of other children with tracheostomies. Additional planning and care may be required . Your health team with advise you on this



## Section Five : Your Equipment

You will need a variety of equipment to care for your child and their tracheostomy at home. The nursing staff will help you to become familiar with it all, what it is used for, how to look after it and how consumables are supplied to you.

### 5.1 Tracheostomy Supplies

- Tracheostomy tubes (same size and one size smaller)
- Tracheostomy ties
- Dressing supplies
- Saline ampoules
- Scissors
- Forceps
- Cotton buds
- Gauze
- Heat Moisture Exchanger / Thermovent O2 attachment if on oxygen therapy
- Vent easy valve

### 5.2 Suction Equipment

- Portable electric suction machine with battery backup
- Suction connecting tubing
- Suction catheters – the correct size for your child’s tracheostomy tube
- Saline ampoules
- 1ml syringe
- Mucus extractor/Suction trap

### 5.3 Humidification Equipment

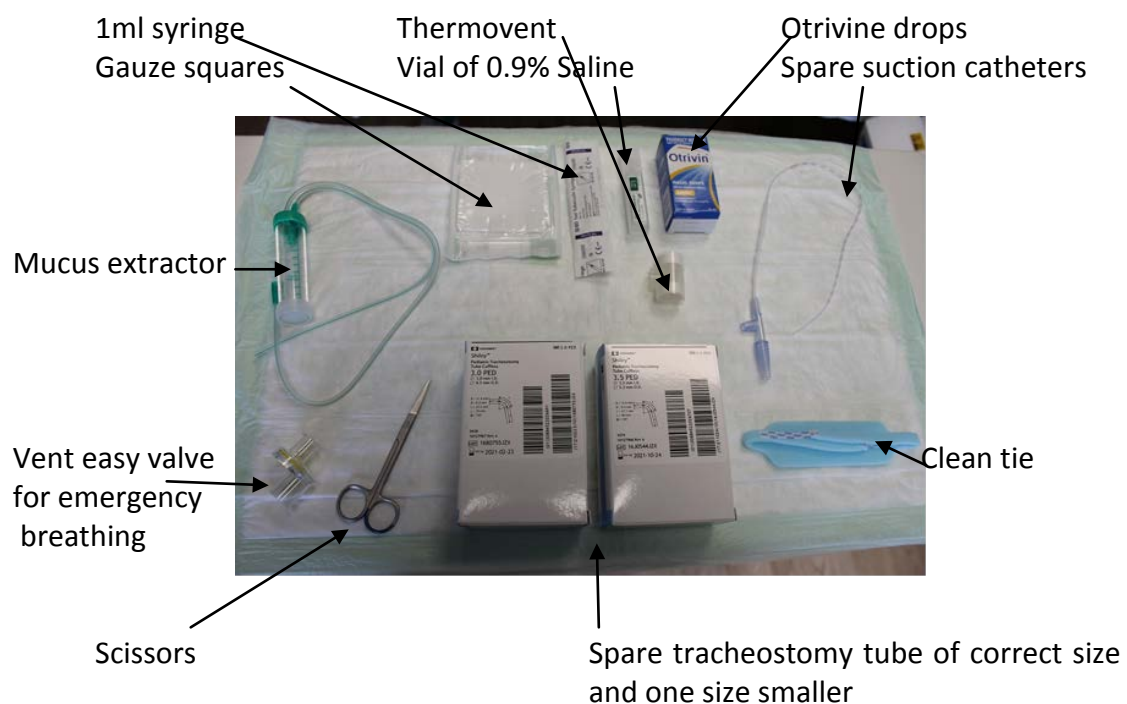
- Heat, Moisture Exchanger (HME) / Thermovent (sometimes referred to as a Swedish nose)
- Fisher & Paykel humidification system
- Sterile water (1litre bottles)

The tracheostomy humidification unit is supplied by:  
Respiratory Physiology Laboratory at Starship Children’s Hospital.  
They will provide you with the training you need to use this equipment  
They will also let you know what you need to do to have your unit maintained

## 5.4 Other Possible Equipment Needs

Speaking valves  
Oxygen equipment  
Non-invasive ventilation

## 5.5 Emergency Tracheostomy Box



### Safety Alert

- Label the emergency box with a list of contents
- Check contents daily and restock after use
- Check before travel that you have your fully-stocked emergency box with you
- Put your name and contact details on the kit so that it can be returned promptly

Additional/ different supplies may be appropriate in some children especially those with ventilators. Your health team will advise you on this.



## 5.6 Linking with your homecare team

You will be referred to the home care nursing service in your area that looks after children. Your homecare nurse will arrange to visit you and your child at home once you have been discharged. They are experienced nurses and will offer nursing support and advice on your child's care.

They will also provide you with consumable supplies and will liaise with you regarding the quantity and frequency that your supplies are delivered. Your local homecare team will also provide you with a portable suction unit. This may be rented from a third party supplier. Your homecare team will give you instructions for who to contact if you have a problem with your suction unit.

### **Safety Alert**

Be aware that you may need to take your child into hospital if your suction unit breaks down in the middle of the night or at the weekend when rapid replacement cannot occur

## 5.7 Equipment Cleaning and Maintenance

It is essential that your equipment is kept clean to reduce the risk of infection. Your nurse will instruct you about which items are disposable and which can be reused. You may notice a change in practice once you go home, as the hospital usually does not re-use items due to the higher risk of infections in hospital.

Care and cleaning of the humidifier system is important for your child's health. The Respiratory Physiology team will teach you how to do this and give you separate guidelines."

Suction equipment	
Each suctioning episode	<ul style="list-style-type: none"><li>• Flush the tubing with water</li><li>• Reuse of the suction catheter will be negotiated with the Homecare Nurse</li></ul>
Daily	<ul style="list-style-type: none"><li>• Empty the suction bottle</li><li>• Wash with soap and water, and rinse</li><li>• Wash connecting tube with soap and water</li></ul>
Fortnightly	<ul style="list-style-type: none"><li>• Replace the suction connecting tubing</li></ul>
Tracheostomy Ties	
Daily	<ul style="list-style-type: none"><li>• Velcro ties can be washed and reused Wash with soap and water and air dry</li><li>• Twill Cotton Ties are single use, dispose of daily</li><li>• Padded Twill ties are single use, dispose of daily</li></ul>



Equipment cleaning and maintenance for children on a ventilator may vary from those described above. Your health team will advise you on this.

## Section Six : School, respite and relief

### 6.1 School

Once your doctor feels that your child is well enough to attend school, you should discuss the return of your child with the school staff. Depending on your child's level of independence, additional support may be necessary to assist your child with suctioning and other specified cares.

The assigned caregiver at school must be able to suction and safely change the tracheostomy tube if required. Your child needs someone trained in tracheostomy care available to them at all times.

### 6.2 Respite and Relief

The high level of commitment to care for a child with a tracheostomy can lead to tiredness and exhaustion. It is important to accept help when offered and to share the load.

There are a number of supports that can be put in place to ensure caregivers have adequate breaks and rest. The health of caregivers is vital if the child is to obtain optimal care.

A social worker or your homecare nurse can assist you to access funding and additional support at home.

Caregivers must be trained. Remember that if you leave your child in the care of others that they must be competent to make good decisions and take prompt action if needed.

## Section Seven: Your Child's Team

You and your child will by now have had involvement with a variety of health professionals. All members of the health care team at Starship use their professional expertise to work together to provide the best care for your child. In this section we have asked them to provide you with some further information about what their role and involvement with you and your child might be.

### Team Talk

## Information from Our Speech Language Therapist

### 7.1 Feeding and Nutrition

A tracheostomy may have an impact on your child's ability to swallow safely. It may also influence how your child feels about eating and drinking. **Prior to starting oral intake** of food or drinks it is essential that the speech-language therapist assesses your child's ability to swallow. If feeding is safe, usual age appropriate infant and child eating and drinking should be started/continued with. If modifications are required your speech-language therapist will help to guide you.



### I Information from our Speech Language Therapist

Having a tracheotomy may have an impact on your child's ability to talk. Some of those reasons might be:

- If the laryngotracheal space is very small or scarred, your child will not be able to pass enough air up through the vocal cords to make sounds
- If the vocal cords are scarred, the sound from the cords may be hoarse or raspy. If one or both of the vocal cords cannot move, your child's sounds will vary based on the position of the vocal cords
- Often, children with tracheotomies have other problems. If your child was born early, has a history of head trauma or injury to the spine, this may impact their communication
- The size of the tracheotomy tube needed to keep your child's airway safe may decrease the amount of air that can pass up through the vocal cords to make speech
- It is important to remember that the removal of your child's tracheotomy tube may not necessarily resolve communication difficulties

#### **What if my child can't talk?**

Having mild to severe problems with talking does not mean being unable to communicate. Children communicate in many different ways, such as using gestures, facial expressions and body postures, as well as vocalising. Giving your child a solid language base is very important. There are many options that can help your child to communicate:

1. **Speaking Valve:** This valve is placed on the tracheotomy tube. It lets the child inhale through the valve and upon exhaling, the valve closes allowing air to pass through the vocal cords. IT IS NOT FOR ALL CHILDREN WITH TRACHEOSTOMIES, and does not work well for children who continue to have narrowing above the tracheotomy. It requires skilled assessment before usage and an individualised speaking valve care plan. It is only used with your ENT doctor's permission. Check with your ENT doctor to see if this valve is an option for your child.
2. **Signing:** Signing is not only for children who cannot hear. If your child does not have the voice to communicate his/her needs well, then he/she can sign his/her needs and thoughts.
3. **Augmentative Communication Device:** This device is more like a computer. The child selects the word on the board, and the computerised voice says the word selected by the child.
4. **Picture Communication Device:** This can be made for the child with different pictures or personal objects. By pointing to the object, the child relays his/her needs or thoughts. The child can help in the making of his/her personal picture board.

### Information from our Social worker

#### 7.3

On each ward in Starship there is a Ward Social Worker. It is important that families who have children with tracheostomies are seen by a Social Worker. Their role is to visit families that might need practical or emotional support while in hospital and to help plan for your child's discharge.

We recognise that coping with a child's illness or diagnosis, and being away from home, can be extremely stressful and scary. Therefore Social Workers are available to help alleviate some of the stress or anxiety you may experience. Social Workers will talk to you about your family, your situation at home, how you are managing hospital life, and post-hospital life.

Social Workers can help families feel assured and confident about going home with their child, and feel equipped with knowledge and resources to manage.

We have put together a list of things you might want to talk to your Ward Social Worker about. You **may or may not be eligible** for the following:

- **Work and Income NZ:** Work and Income NZ provide employment services and financial assistance to families. Sometimes families find themselves financially pushed while in hospital; therefore Social Workers are able to link families in with WINZ for eligibility of benefits and other financial assistance. There are some benefits that are offered to parents who are specifically caring for a child with a disability or a medical condition
- **Child Disability Allowance (WINZ):** The Child Disability Allowance is a fortnightly payment made to the main carer of a child or young person with a serious disability or a medical condition. It is paid in recognition of the extra care and attention needed for that child. This is not income tested
- **Disability Allowance (WINZ):** The Disability Allowance is a weekly payment for people who have regular, ongoing costs because of a disability, such as visits to the doctor or hospital, medicines, extra clothing or travel. This allowance is income tested
- **National Travel Assistance:** If you are eligible for travel assistance, you may be able to claim for kilometres travelled by private car, public transport, accommodation, and specialised transport (such as taxis, mobility taxis, or air travel). Speak to your nurse or Social Worker about this

- **Carer Support (MoH):** Carer Support provides reimbursement of some of the costs of using a support person to care and support a person with a disability. This means you can take some time out for yourself. The number of hours or days that carer support is funded for depends on your needs and those of the person you care for
- **Home care and Respite:** Depending on your child's circumstances, there are often other ways to receive respite or relief. Services such as Family Options Respite Programme offer relief to families who cannot cope with their current situation. Referrals would be discussed amongst the medical team, nurse specialists and the Social Worker
- **Community Support:** Social Workers are good at liaising with community organisations or support services. It depends on your circumstances but sometimes we refer to services such as Family Start, Parenting programmes, Disability Support services and a number of others. Let them know if you think this might help

Depending on where you are from in the country, sometimes the above points might be arranged by the Social Worker or medical team from your local hospital. It would be important to double check with someone before your child is discharged from Starship Hospital to ensure these were not forgotten.

If you feel as though you need more information about support services for families who have a child with a tracheostomy, please do not hesitate to ask the ward staff looking after you to refer to Social Work.

### **We strongly advise obtaining supporter membership of St John ambulance service.**

It is possible to join online at: <http://www.stjohn.org.nz/Support-us/Join-our-Supporter-Scheme/>

or

by completing and posting a form available from the hospital. Speak with the ward social worker as you may be eligible for support with the cost of this.



### Information from our Respiratory Physiologist

#### 7.4

Your humidification equipment will go with you on discharge. Education is done with you initially, when the tracheal humidification unit is delivered to your child as well as on a weekly basis while your child is in hospital.

During the hospital stay, one of our physiologists will make regular visits to ensure you understand how the equipment works and how to change the tracheal humidification circuit. We make ourselves available if you have any questions or concerns.

Prior to discharge, there is a checklist that is signed by the physiologist once all education is completed with you. On discharge we will make sure that you have all the equipment and supplies required for the humidification unit. We ensure that you also have regular home visits by a community nurse who will provide water for the humidifier chamber.

Always bring your child's equipment with you when admitted to hospital. This is a good time to plan to get it serviced

**It is essential that the equipment is not carried anywhere with water in it as the units are not sealed at the bottom and the equipment will be ruined.**

- The AIRVO humidifier is to have annual maintenance and safety checks; this is done through our biomedical department.
- The AIRVO will have a 'GREEN' sticker on the unit which shows the month and year the machine is due for service.
- A full performance test is performed along with a safety test which is tested to the current medical electrical standard.
- Please notify the Respiratory Lab if you need your equipment serviced, this **takes 2-3 hours and needs to be booked in advance.**

Contact : Starship Respiratory Physiology Laboratory  
Outpatients Department, Level 3, Room 3.15  
Phone: 09 307 4949 Ext 22295  
Mobile: 021 938 256  
Email: [ssresplab@adhb.govt.nz](mailto:ssresplab@adhb.govt.nz)



Whilst humidification needs of a child on a ventilator are the same, the devices and tubing may differ. Your health team will advise you on this.

## Section Eight : Looking to the Future

### 8.1 Your child's journey

Each child and family's journey is unique although some elements along the way may be similar. Some of the things that may feature in your child's future care may include the following.

### 8.2 Laryngoscopy and Bronchoscopy (L&B)

After discharge you can expect that your child will require regular L&B's to check the airway and remove any granulation tissue.

This will require a general anaesthetic and sometimes your child may need to stay in hospital overnight. This is an opportunity for the ENT specialist doctor to see how the airway is growing and assess your child's readiness for removal of the tracheostomy (decannulation) or to determine further surgery or treatments.

### 8.3 Increasing or decreasing the tracheostomy tube size

During an L&B the ENT specialist doctor may decide to change the size of the tracheostomy tube in relation to the findings.

If this occurs you will be supplied with the new size. The nursing staff should liaise with the paediatric homecare team to let the homecare nurses know so that they can order the new size for you.

### 8.4 Decannulation (removal of the tracheostomy tube)

When your ENT specialist doctor decides that a trial decannulation is indicated, this will generally occur in the Operating Rooms or Intensive Care. This will ensure that in the initial period following the removal that there are no complications or need to reinsert the tube urgently. For most children a tracheostomy is temporary. The child may outgrow the original problem. In some cases the problem may need surgical correction.

Sometimes the ENT specialist doctor will request capping of the tracheostomy tube to see how the child adjusts to using his upper airway. Other assessments may include oximetry or sleep studies.



These considerations are much the same for a child on a ventilator with additional consideration of their ventilation needs and issues with tracheostomy air'leak'. In some circumstances ventilator support may be possible by a mask instead ( at night) allowing the tracheostomy to be removed. Your health team will advise you

## 8.5 Scar Management

Once the tracheostomy has been permanently removed, healing begins. Sometimes the stoma does not heal completely or the skin is scarred. It may be necessary to have a small operation to remove the scar tissue and obtain a better aesthetic result.



## Section Nine: Parent Perspectives

### 9.1 Not feeling alone

For the vast majority of families having a child with a tracheostomy is a new and frightening experience. It can feel isolating and overwhelming dealing with the emotions involved along with all the new things you need to learn. Some of our Starship tracheostomy families have been kind enough to share parts of their journey and things they have picked up along the way.

### Parent Talk

### Some Top Tips from other parents

#### 9.2

- Have a really good monitor so you can hear them when they are sleeping if you are up watching TV
- Get a good bag to hold both the suction machine and emergency box – The LL Bean family size toilet bag is a perfect fit for both, you can order online with free shipping to NZ
- [www.trendytrachs.com](http://www.trendytrachs.com) is where you can get cute material trache ties made and shipped to you
- <https://www.etsy.com/shop/Milostones> is where you can get cute trache pads instead of using split gauze
- There are loads of really good facebook support groups – NZ/Aus Trachie Support Group, (NZ and Australia) Moms of Trach Babies (mainly American but still useful and very active). There are also a couple of Subglottic Stenosis groups that are semi active.

**NB.** All these groups are closed so you have to search for them on Facebook and then request to be a member.

### Advice from Lara (Joshuas mum)

#### 9.3

- Take One day at a time
- Empower yourself by reading research, textbooks, web sites, finding support groups
- Write a journal of progress, thoughts and feelings to look back on the milestones
- Change the way you think about this plastic tube. It's not a sentence, it's a life saving device and part of your family
- Sure your child can't swim or play in a sandpit, but there are so many things they can still do. You are only limited by your imagination. Be creative
- Normalise the tube as much as possible
- Talk about it with friends/family
- Teach/train as many people as possible so your child can be free to spend time with friends and family
- Get rest/time out. You can't look after your child if you're not looking after yourself.
- You're not alone. Support is a phone call away
- Accept the journey as unique and yours
- Understand that not everyone can know what your family is experiencing and that's ok It's your journey. Embrace it





## Parent Talk

### Halos story as told by her mum Ana

#### 9.4

Halo was born early and was in NICU with breathing problems. She has an abnormal airway and eventually ended up on a ventilator in PICU. It was a really nerve wracking time as she was very unwell. She was in PICU for a long time. She used to get red in the face and find it hard to breathe or sleep.

When the ENT doctors talked to me about a tracheostomy I had never heard of a tracheostomy before and was really scared and unsure about it. I was so worried I didn't sleep the whole weekend before Halo had her operation on the Monday. Afterwards I was so pleased I had trusted the doctors because Halo came back a different baby with the tracheostomy. She was so much happier.

We had been in PICU a long time by then so I was familiar with the equipment that Halo had when she came back with a tracheostomy. The scary part for me was when we went up to the ward and started learning to care for her with the tracheostomy. Changing the tube was especially frightening. It took me ages to get my confidence at doing everything. At first I was even nervous of doing the suctioning. I wanted to only practice changing the tube weekly because I was scared. The ENT team encouraged me to practice daily and now I'm pleased they did as I managed to overcome my fear quicker.

It's been pretty hard, I don't live in Auckland and I have a 2 year old as well. Luckily she has been able to stay with me in Ronald McDonald House and Halos grandma has been here learning to care for the tracheostomy too. I still feel like it will be surreal when we finally get to go home.



## Parent Talk

### Marcus's story as told by his mum Shona

#### 9.5

Hi, welcome to the Trach World ..... We are Shona and Damon and like you, we were once at the beginning of our journey. We too had the anxiousness, nerves and questioned ourselves with can we handle this huge responsibility? Will our son have the fun childhood he was meant to have?

We are writing this to let you know that after the hospital and going home, life does get better and much easier. You may even be so comfortable with it all that you head to the Supermarket and then realise the suction unit is at home and this is OK, we have all been there haha

This year we are in our seventeenth year into our Trach journey.

Our biggest piece of advice to you is try and not let the things you get told your child can't do rule your life. Everyone's Trach journey is different but when they are ready your child can play with sand and water and they can attend kindy & school too - it is all about living life but being sensible about it.

We wanted to share some pictures of our son Marcus with you - here he is enjoying life from riding his trike with a super long oxygen cord through to Zip Lining and Meeting a Dolphin.

Best of luck to you and your journey - enjoy going home.



## Section Ten: Supporting you learning your new skills

### 10.1 Support

We developed this booklet to assist you in learning about your child's tracheostomy and hope it has been helpful. We will also provide you with practical learning sessions and plenty of supported time to practice the skills we have taught you.

In order to feel assured that we have provided you with all of the education and skills required to be competent and confident caring for your child and their tracheostomy at home, we have created a checklist. This is both for your child's nurses to be able to quickly assess at what point of your learning you are at and ensure we cover everything necessary as well as for you to see your progress as you learn your new skills.

Your ward nurse will provide your education and facilitate your practice of the necessary skills and sign on the checklist when they have observed you perform the skill independently and competently.



Don't worry, with a little time and practice you'll soon have your tracheostomy L plates off

**Just ask – Anytime**

## Caregiver education plan

Name of Caregiver \_\_\_\_\_

Caregiver skilled to	Demonstrated to caregiver	Performed with support	Competence Achieved	Nurse Signature
<b>Assess need for suctioning and perform suctioning</b>				
Recognise the need for suctioning				
Select correct size suction catheter				
Determine correct depth for suctioning				
Maintain clean technique				
Assess need to change H.M.E / thermovent				
Be aware of maximum suction pressure				
Able to use mucus extractor				
Demonstrate use of portable suction machine and cleaning measures				
<b>Perform Tracheostomy Tie change</b>				
Demonstrate holding tracheostomy tube whilst someone else changes the ties				
Demonstrate changing the ties whilst someone else holds the tube				
Perform both skills independently if required				
<b>Perform Tracheostomy Tube Change</b>				
Select correct size tube				
Organise the procedure				
Demonstrate withdrawing tracheostomy tube while someone else inserts the tube				
Demonstrate inserting the tracheostomy tube while someone else withdraws the tube				
Demonstrate performing both skills independently				

Name of Caregiver \_\_\_\_\_

Caregiver skilled to	Demonstrated to caregiver	Performed with support	Competence Achieved	Nurse Signature
<b>Perform regular skin/tracheostomy cares and recognize abnormalities and take appropriate action</b>				
Irritation or skin breakdown around the tracheostomy				
Granulation tissue				
<b>Recognise signs of illness or deterioration and know the correct action to take</b>				
Respiratory deterioration				
Signs of bleeding from the tracheostomy				
Blocked tracheostomy				
State contents of emergency box and importance of having a fully stocked box with the child at all times				
<b>Demonstrate an ability to perform CPR as evidenced by</b>				
Watch CPR video				
Know how to use one way valve for rescue breathing				
Be able to perform cardiac compressions				
Be able to initiate help in an emergency knowing emergency contact numbers				
Have practiced on a manikin the basic life support of babies and children with a tracheostomy at home.				

Tracheostomy Scenarios	
Date Scenario Completed: __/__/__	Scenario Pack Completed: __/__/__
Scenarios are to be completed with a facilitator who has not been responsible for the caregivers prior tracheostomy education	
Caregiver signature :	Scenario Facilitator signature:

## Section Eleven: Acknowledgements and Contributions

We would like to acknowledge and thank everyone who has contributed to the development of the “Going home with a tracheostomy” information booklet for families

Families of Halo, Joshua and Marcus

Starship Child Health Senior Nursing Team:

Helen Waldron, Melanie Lanigan, Helen Noble, Debby Sandow, Fiona McIver, Katrina Hutching

Starship Allied Health Team

Cathy Douglas, Melissa Keesing and Ashleigh Dudley

Medical Team

Jacob Twiss and Nikki Mills

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## Section Twelve: Basic Life Support

**Child CPR**



**Infant CPR**



**Infant Link:** <https://www.youtube.com/watch?v=ZsJBnTxRmA0&feature=youtu.be>

**Child Link:** <https://www.youtube.com/watch?v=pFDxHIJooD0>



## Information for St John Ambulance Crews

### 12.1

My child's tracheostomy / airway is:

**Critical / Obligate** or **Non critical / Obligate** (circle one)

### If the Tracheostomy tube cannot be replaced

#### Critical Airway / Obligate tracheostomy:

My child has a critical airway and is **always** dependent on their tracheostomy.

Attempts to replace the tracheostomy even if a smaller size should continue because attempts to maintain my child's airway with a face mask over nose / mouth may be ineffective.

If necessary use of a face mask over the tracheostomy stoma may be needed

#### Non critical airway / Non obligate tracheostomy

It may be possible to maintain my child's airway via nose / mouth with bag / mask.

**Ventilated:** It is important to know whether breathing can be supported through the normal airway (mouth & nose) if a tracheostomy is difficult to replace

### Further Information about my child

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### Basic Life Support of babies and children with a tracheostomy

Assess for **Dangers**, Check **Responsiveness**, Send for Help – **Dial 111**

Check and open the **Airway**

**Suction** the tracheostomy

If you cannot pass a suction catheter perform emergency tube change immediately

Caution if stoma is less than 1 month old

If the tube fails to go in:

Attempt to insert the smaller sized tube

2-3 drops Otrivin Junior into stoma site

Attempt to pass the smaller size tube into the stoma using a suction catheter

Look, listen and feel for **Breathing**

If not breathing normally:

**Two breaths** via tracheostomy if patent

**Start CPR** if unresponsive and not breathing

30 compressions: 2 breaths

Continue CPR until responsiveness or normal breathing returns