The BreathEasy Training Manual

How to look after your child with a tracheostomy
Welcome to the Breatheasy Family
This special book will help you understand and learn how to look after your child with a tracheostomy so that you can live a happy life at home.
Dear Caregiver,

You and your child have joined the home care programme at the Red Cross War Memorial Children’s Hospital and are now part of our Breatheasy Family. It will be our pleasure to work closely with you to teach you all about tracheostomy care.

The Breatheasy home care programme is centered on the family. Parents and other family members are encouraged to observe from the very beginning and participate in treatment, along with nurses, doctors, social workers, speech therapists, dieticians, physiotherapists, occupational therapists and many other hospital personnel. We are here to help you look after your child.

It is important that you both receive as much tender loving care and support as possible. The next couple of weeks will be a time of adjustment, with difficult days in the hospital and maybe financial or family pressures at work or at home.

You may feel anxious or more nervous than usual, you might even have feelings of guilt, anger and helplessness. These emotions are normal as you adapt to the reality that your child needs a tracheostomy, but you should also be happy and relieved that he or she is in capable hands.

It is easy to forget about caring for yourself during stressful times - try to eat well and get enough sleep. And remember that our skilled and dedicated staff understand your needs.
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A tracheostomy
What is breathing?

When you breathe in or inhale, air (with oxygen) goes into the nose or mouth. When you breathe out or exhale, air (carbon dioxide) flows out of the nose or mouth. Without breathing, our most important body parts like the heart and the brain would not be able to work.

What is a tracheostomy?

A tracheostomy is a hole in the throat that helps your child to breathe. The hole, or stoma, is created by specialist doctors during an operation called a tracheotomy. Once this heals, it is held open by a small hollow pipe called a tracheostomy tube.
Why your child needs a tracheostomy

1. To relieve breathing problems due to a blockage in the nose, mouth or breathing tubes.

2. If your child is too weak to cough.

3. To help your child breathe on a ventilator (breathing machine) for a long time. Not all tracheostomy patients need to be on a ventilator.

How long will your child need the tracheostomy?

Some children grow out of the need for the tracheostomy or have another operation that makes it possible to remove the tube. Others will always have one. Remember that each child is different and that the amount of time your child needs to live with a tracheostomy can change over time and will be evaluated when you come for regular check-ups. An experienced social worker and a qualified nurse will sit down with you to discuss the best way to manage your situation.
### Words you need to know

<table>
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<th>Term</th>
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<tr>
<td><strong>Tracheostomy Tube</strong></td>
<td>...is the small white tube that goes into the hole in the neck.</td>
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<td><strong>Introducer</strong></td>
<td>...is the stick you place into the tracheostomy tube to help guide it into the neck.</td>
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<td><strong>Stoma</strong></td>
<td>...is the hole in the throat where you put in the tracheostomy tube.</td>
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<td><strong>Ventilator</strong></td>
<td>...is a machine that attaches to the tracheostomy to push air in and out of your child. If your child cannot breathe on their own, he/she will need to be on a ventilator to breathe.</td>
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<td><strong>Secretions</strong></td>
<td>...are the slimy fluid that is made in the lungs and the windpipe. Secretions come out of the tracheostomy and need to be suctioned away.</td>
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<td><strong>Suctioning</strong></td>
<td>...is vacuuming up the secretions in the tracheostomy tube with a catheter attached to a suction machine.</td>
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<td><strong>Sterile</strong></td>
<td>...means clean and free of germs.</td>
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Your hospital stay
THE OPERATION
Your child’s doctor will explain the operation to you. You must feel comfortable to ask any questions. Your child will be taken to the operating theatre and given a general anaesthetic, which is a medicine to make your child sleep and feel no pain while the doctor operates. The surgery is performed by an Ear, Nose and Throat specialist, also known as an ENT doctor.

IMMEDIATELY AFTER THE OPERATION
Recovering in the ICU
After the operation, your child will go to the Intensive Care Unit, also known as ICU, with a tracheostomy tube held in place with cotton tapes. There will be temporary stitches that keep the hole open if the tube has to be changed early. Your child will not be allowed any food or drink for a minimum of 3 hours until the sleeping medicine wears off. After that, your child will be able to eat. Swallowing may be difficult at first.

This usually does not last a long time, but if it continues, a speech and language therapist will be there to help.

Your child will be looked after very carefully for the first 2-3 days by nurses and doctors who will monitor breathing, heart rate and blood pressure. You may feel worried about the amount of care your child needs. This is because the tracheostomy is new and needs special attention.
Children who need a ventilator may have this special care for much longer. As you get to know the equipment, you will feel more comfortable with your child’s routine.

Once the opening in the neck from the tracheostomy tube into the windpipe is healing, your child can be transferred to the ward.

A diagnosis is your child’s medical condition that will be explained to you in a very important, private meeting with the doctor. You must feel free to ask any questions. The diagnosis will determine the length of the hospital stay and the kind of treatment and home care for which you must prepare.

You will spend time in ICU and also meet with the social worker and speech therapist. After about 7 days, your child’s tube will be changed for the first time. During these first two weeks after the operation, you will start to help with suctioning, tape changes and cleaning around the tracheostomy tube. The stitches will dissolve, the hole will need careful cleaning at least twice a day and the tracheostomy tube will be changed once a day.
We will teach you and you will practice cleaning around the tracheostomy tube and changing the tube. With our help, you will soon feel comfortable to do it on your own. Remember, practice makes perfect, so be patient with yourself.

Things may not always go according to plan, but if your child is well enough, he/she may be sent to the ward at this stage.

**LEARNING AND PRACTISING IN THE WARD**

The first week in the ward will be spent getting used to your child’s tracheostomy. We will start teaching you some basic skills and preparing you for home care by explaining the following:

- **Supplies and equipment** you will need
- **Cleaning** the supplies and equipment
- **Changing** the tracheostomy
- **Cleaning** the tracheostomy
- **Suctioning**
- **Feeding your child**
- **Bathing** your child with a tracheostomy
- **Speaking**
- **Travelling** with your child
- **Medication** your child might need
- **Emergency procedures**.
You will soon learn to look after your child with a tracheostomy on your own. Once you feel that you are confident about caring for your child, you may be ready to go home.

You will be given all the necessary supplies for home care. You should attend your appointments in the out-patients clinic. It is your responsibility to reschedule if you cannot make it.
We are here to help you
Sister Jane Booth
Sister Booth is the Paediatric Tracheostomy Clinical Nurse and will be the main person co-ordinating your child’s care.

Doctors
Red Cross Children’s Hospital is a specialist hospital so you and your child will meet many doctors and specialists during your stay. The paediatric doctors will manage your child’s condition.

Nurses
Ward sisters and nurses are experienced and caring and will be responsible for your child’s day-to-day care. They will guide and teach you to look after your child.

Social Worker
A social worker will be present at the first interview. They can offer advice about benefits and other services, planning for going home and liaising with your local social services about support that might be available to you when you go home.
Speech Therapist
A speech and language therapist will work with you to manage your child’s swallowing, feeding and speech or communication development.

Physiotherapist
A physiotherapist will assess, plan and implement a program of physical rehabilitation to help reduce your child’s pain, maximize mobility and restore strength and body movement following illness or injury.

Occupational Therapist
An occupational therapist will help with various needs to improve cognitive, physical, and motor skills and enhance self-esteem and a sense of achievement.

Dietician
A dietician is available to help with maintaining your child’s growth according to the normal standards for their age.
What you will learn
In the following chapter, you will:

- Get to know the **equipment**

- Learn how to **change and clean** a tracheostomy tube

- Be taken through the process of **suctioning** your child’s tracheostomy

- Be educated on the importance of **humidification**

- See how your child **eats** with a tracheostomy

- Learn how to **bath** your child with a tracheostomy

- Understand how your child **talks**

- Find out which **things could go wrong** and what to do

- Be guided through **emergency procedures**.
Getting to know the equipment

- Tracheostomy tube & introducer
- Protective guard
- Speaking valve
- Mask
- Manual suction machine
- Hand-held syringe suction
Humidifier for ventilator

Older child’s humidifier

Baby’s humidifier

Humidifier for ventilator

3 different catheter sizes

Flat cotton tape

Scissors
Changing & cleaning the tracheostomy tube
Plaque on your teeth is the buildup of bacteria that sticks to them and secretes a slimy substance. This same plaque, called biofilm, can grow inside the tracheostomy tube, causing it to block and making it difficult for your child to breathe. If the tube is not changed every day, your child could get an infection.

Tapes to hold the tracheostomy in place

- Use flat cotton tape
- The tape should not contain silk or nylon - no ribbons! (Knots will slip and tracheostomy could fall out)
- Tapes should be replaced at every tracheostomy change. Tapes can be washed and used again.

Caring for the skin around the tracheostomy tube

- Keep the skin around the tracheostomy stoma (hole) clean and dry at all times
- If your child develops redness or a skin rash around the tracheostomy tube, keep it clean and dry and apply a barrier cream.

Important to remember

- Check the position of your child
- If the tracheostomy tube does not slip in easily, pass the suction catheter into the airway and feed the tracheostomy tube in over the suction catheter
- Check the tube for cracks and other damage.
The supplies you will need

- Introducer must be inside tracheostomy tube
- Flat cotton tape and scissors
- Cream
- Soapy cloth, wet cloth & dry cloth
- Pipe cleaner to clean the inside of the tube and toothbrush for outside
- Have everything ready before you change the tracheostomy tube
What to do before changing the tracheostomy

1. Fold the cotton tape in half.

2. Thread loop through 1 side of the tracheostomy tube. Thread the loose ends of the cotton tape through the loop and pull tight.
Wash your hands and clean the area where the change will take place.

Put down a clean cloth or paper on which to place your supplies.
Apply a drop of K.Y. Jelly to the tip of the tube/introducer to help the tube to slide into the tracheostomy stoma (hole) smoothly.

Set up suction machine, suction tubing, suction catheter and water.
Baby’s position:
Lay your child down with the shoulders raised on a roll (towel, pillow or a cloth) so that the head falls back slightly and the tracheostomy is easy to reach.

Older child’s position:
An older child should sit in a chair in front of a mirror to understand what is going on and learn to change their own tracheostomy tube.
Clean the stoma (hole) and neck with a soapy cloth.

Wipe the soap away and dry the area.
Cut the tape and remove it gently from around the neck.

Remove the tube in one slow smooth movement forward and out.
Take the new tube and put it into the stoma (hole) and remove the introducer.

Take the 2 tapes around the neck.
Thread the one end through the tracheostomy tube hole and tie once.

Bend the neck forward so that only one finger can fit between the back of the neck and the tape. Do not make it too tight or it will cut the skin. Do not make it too loose, otherwise the tracheostomy may fall out.
Clean the dirty tracheostomy tube using soap and water and a pipe cleaner for the inside.

Use a clean toothbrush to clean the outside.
Suctioning
We all have mucus that comes up from our lungs. We can cough it up and spit it out or we can swallow it, but in a child with a tracheostomy, this mucus comes out through the tracheostomy tube and needs to be suctioned.

Suctioning sucks the mucus out of the tracheostomy tube, making it easier for your child to breathe. This is very important in babies and young children with a weak cough.

How do I know when my child needs suctioning?
- Before a tracheostomy change
- When you hear noisy, ‘wet’ breathing
- Difficulty with breathing
- When your child is coughing a lot
- Before travelling
- If your child asks to be suctioned.

What do I use to suction?
Catheters attached to a suction machine are used to suction the secretions through the tracheostomy tube in the child’s windpipe.

What kind of catheter should I use to suction?
The nurse will show you the size and type of catheter used for your child. At home the catheters are reusable and not disposable.

How to clean the catheter
Catheters are cleaned once a day with soap and are rinsed under running water. Direct sunlight is a good way of sterilizing tubes.

Sterilize catheters using a hypochlorite, Milton or ‘Jik’ solution:
Jik solution is the same solution that is used to clean babies’ bottles. The recipe is: 5ml Jik + 1 litre water to make a hypochlorite solution. Replace the solution daily!
The Gabler Manual Suction Machine is mobile, light, easy to use and does not require electricity. The pedal must be covered with a piece of plastic that can be thrown away when it is dirty. Make sure the cup into which the secretions flow does not turn over. Empty it often.

Cut a piece of catheter to fit your child’s tracheostomy tube and attach it to a syringe for this hand-held suction device.
How to suction

1. Wash your hands.

2. Prepare a clean catheter by removing it from the Jik water (used to sterilize the catheters) and wiping it with a tissue on the outside.
Using the portable suction machine, attach the clean catheter to the tubing.

Suction clean tap water through the catheter to prevent any drops of Jik water going into your child’s tracheostomy tube.
Put the clean tip of the catheter down the tube to the correct length. Measure the catheter against your child’s spare tracheostomy tube - only push the catheter through as deep as the tip of the tube to make sure that you do not hurt the windpipe.

Make sure that the end of the catheter does not touch an unclean area before suctioning. We don’t want germs to go into the tracheostomy tube.
Suction the tracheostomy tube by ‘pumping’ the portable suction machine with your foot gently.

Clear the tube with clean water.
Repeat the procedure until the mucus is cleared.

Wipe the outside of the suction catheter so that there is no mucus on the outside of the tube.
Suction clean water through the catheter again.

Put the humidifier, speaking valve or guard, as well as the mask, back over the tracheostomy.
Have a happy day
Humidification
A child who does not have a tracheostomy breathes air in through the nose or mouth. The nose, pharynx and trachea then warm up, humidify (keep wet) and filter the air.

In a child with a tracheostomy, the tube bypasses this upper airway and dry air is breathed straight into the airway and lungs. This can cause drying of the lower airways and mucus which can block the tracheostomy tube. Foreign substances like water, sprays like deodorant, dust and other particles in the air can easily be inhaled through the tracheostomy. This is why children with a tracheostomy should wear a humidifier to filter the air they breathe.
Humidifiers help to:

- Generate humidity from your child’s own body moisture
- Filter the air you breathe
- Protect the airway from inhaled foreign substances and particles
- Keep inhaled air moist at night, when travelling and in areas where the air is very hot and dry.

Humidifiers cannot be worn with a speaking valve. If your child wears a speaking valve, you need to make sure that the airway is kept moist by using 1ml of saline drawn up into a syringe then squirted into the tracheostomy tube.

Sometimes the humidifier increases the resistance of breathing and your child may struggle to breathe, talk to your nurse about it.

Small babies should always wear infant-sized humidifiers.

Other ways to keep the airway moist:

Normal Saline is used to loosen and clear thick, dried secretions from the tracheostomy tube. Small children have narrower tubes and they breathe faster than older children and adults, so the mucus in the tracheostomy tube and airways can dry out easily, especially in dry weather.
Using Saline

1. Wash your hands.

2. You will need saline.
You will need a clean syringe.

Use 1ml of saline in the syringe.
5. Insert the saline into the tracheostomy tube to loosen thick secretions.

6. Suction your child to clear secretions.
Eating
Sucking, swallowing and eating should not be any different with the tracheostomy tube. You just need to take special safety measures to make sure that food does not enter the tracheostomy tube.

Things to remember when your child wants to eat:

- Suction your child before feeding
- Maintain your child’s hydration by making sure that the fluid intake is enough to maintain loose and thin secretions
- **Do not** cover the tracheostomy with a plastic bib - it will block the tracheostomy tube
- Never leave your baby alone while drinking a bottle
- Burp your baby after their feed
- Always stay with your child during meals.

**Children or infants may have swallowing or feeding difficulty if they:**

- Refuse food
- Choke or cough when drinking or eating
- Get food in the tracheostomy
- Drool
- Vomit
- Have large amounts of watery substance coming from the tracheostomy tube
- Have lots of infections
- Have ‘lung sounds’ (sounds like fluid is in them).

A swallowing problem is most common in children with burns of the larynx, herpes simplex infection, neurological damage, and following laryngeal surgery. This can cause problems in closing the epiglottis and vocal chords. Talk to your doctor if you notice this.
The epiglottis is a lid or flap that covers the trachea and stops food from going down the airway. When the epiglottis and the vocal chords do not close properly, this may cause food and drink to enter the airway during swallowing, called aspiration. Aspiration can cause breathing problems like pneumonia.

**Important things to remember when feeding your child:**

- Good mouth hygiene and regular dental check-ups are important
- High-calorie feeding may be needed for some babies
- Constipation (trouble pushing out poo) can happen because the child can’t close the glottis when pushing out poo. This is worse in children with chronic lung disease, weak muscles and mechanical ventilation. Talk about any constipation issues with your nurse or doctor.
- Breastfeeding is best for your baby’s brain development.

A speech therapist will be able to help you with any feeding or swallowing problems your child might have.
Breast is best
Bathing
Important things to remember when bathing your child:

- Never leave your child alone in the bath
- Bath your child in very shallow water
- Your child should wear a humidifier for extra protection during the bath
- Suction your child well before bathing
- Plastic bathing chairs may help if you are bathing an infant, small child or a disabled child that cannot sit up by themselves

- A good way to wash your child’s hair is to lean the head backwards. This will run water and soap towards the back of their head and keep it away from the tracheostomy tube
- Always keep an extra towel nearby to dry off your child’s face and to stop water from running down their neck.
Vocal Cords
Speaking sounds happen through the vibration of the vocal cords when we breathe out, combined with moving our tongue and lips to speak.

Vocal cords are two bands of tissue in the voice box located in the neck above the tracheostomy.

Will my child be able to talk?
Children with a tracheostomy sometimes can’t speak for a while. This is because the larynx (voice box) is bypassed by the tracheostomy. The voice box has not been removed, so most children will learn to talk. The size and the condition of the airway can help determine if the child will be able to speak or not. Small babies have narrow airways and no air can move from the lungs over the voice box because the tracheostomy tube fits into the airway tightly, blocking the way.

A speaking valve is a one-way flap that lets air in but closes when breathing out. The air is forced up past the tracheostomy tube and over the vocal cords through the mouth, allowing the child to talk.
How does a child speak with a tracheostomy tube?

Many young children learn to manipulate the air they breathe out to pass over the larynx to create a voice without any help. Blocking the tracheostomy tube can be done by holding a finger over the tube.

It could take some practice for your child and family to understand what your child is saying. Speaking is not always an option for certain children but there are other ways of communicating. A doctor, nurse or speech therapist will be able to tell you what choice is best for your child.
Things that could go wrong
When a child has a tracheostomy, they are not able to filter the air which they breathe. This makes them more likely to get an infection.

What do I do if there is blood coming from the tracheostomy tube?

- Fill tracheostomy tube with normal saline solution
- Recheck for blood
- If a large amount of bright red blood comes out of the tracheostomy, change the tube, and go to the hospital.

Bleeding is not uncommon if there are just small amounts of pink or red in the secretions.

The cause of the bleeding may be:

- Irritation from pushing the catheter too deep into the airway
- Infection
- Air too dry, especially in winter with the heater on indoors
- Foreign substance in the airway
- Lots of coughing during a chest infection
- Some type of trauma.

What do I do if a lot of mucus forms around the tracheostomy?

This is called a mucus plug and it makes it hard for your child to breathe. When this occurs, change the tracheostomy tube immediately!

What is a granuloma formation?

A granuloma formation occurs when extra scar tissue is formed and irritates the area around the stoma (hole). Usually granuloma formations can be avoided by keeping the skin around the tracheostomy clean and dry. If your child develops a granuloma, keep the area clean and dry and show it to the nurse during your next visit to the hospital.

Scar tissue is thick tissue that forms over or around a healed wound or cut; it is the body’s way of fixing damaged tissues (and protecting surrounding tissues from foreign bodies).
How do I protect my child from getting an infection?

- Wash your hands often
- Do not allow people with colds or flu near your child
- Keep the house and child’s bedroom well aired
- Keep your child away from smoke
- Use throw-away tissues
- Get a flu vaccine before the winter
- Day care/crèche children will increase the risk of your child catching an infection
- Personal hygiene
- Change the tracheostomy tube daily
- Humidification
- Keep tracheostomy supplies and equipment clean and dry
- Use the sun to sterilize where possible.

How do I identify an infection?

- Mucus may change color (yellow, green or blood-stained)
- Secretions may become thicker or very loose
- Lots of secretions
- Secretions smell ‘funny’
- Rate and rhythm of breathing may change
- More coughing than usual and it may seem painful
- Sound of the mucus in chest and tracheostomy tube
- Difficulty breathing
- Inflamed stoma site
- Pain to touch or suction tracheostomy
- Fever
- Feeding problems
- Change in sleep patterns.
What are the signs that my child is becoming sick?

- Unhappy
- Crying
- Not feeding well
- Sleeps a lot
- Fever
- Secretions may change colour, consistency and smell of secretions
- Coughing and not breathing the usual way.

How do I take care of a suspected infection?

- Increase amount of normal saline
- Fill 1 ml normal saline until mucus clears. If there is no improvement and the fever does not stop, go to hospital
- Discuss the problem with the nurse to help her work out what is wrong. If there are any side effects of the treatment or the child does not improve, let the nurse know
- Wash all your equipment
- Give your child extra fluids.

A child with a tracheostomy should breathe normally and in a regular pattern or sometimes they might have jerky or irregular deep sighs. Both of these are normal. You must just get used to your own child’s breathing pattern and must be aware of what to do if they change.
What do I do if the child pulls the tracheostomy tube out?

Children sometimes start fiddling with the tube and may pull and remove it accidentally. If this happens:

- Stay calm
- If possible, put the tube back in immediately. When the situation is under control you can replace it with a new one.
- Follow the procedure to change the tracheostomy tube with the spare emergency replacement you must carry at all times.
- Always keep scissors with you to cut the tapes.
- If the tracheostomy tube does not slip in easily, pass the suction catheter into the airway, cut off the tip and feed the tracheostomy tube over the suction catheter.
- The introducer of the tracheostomy tube is also a good dilator for the stoma to guide you where to place the tube.
- Try not to make a big deal about the tracheostomy tube because as soon as your child realizes that it causes a reaction, he/she could use it to get attention.
- Once your child has developed a pattern of pulling out the tracheostomy it is more difficult to control, especially if your child has developmental disabilities.
- A tracheostomy guard and mask protect the tracheostomy tube and should be worn at all times. The guard/mask helps stop your child from removing the tracheostomy.
- Children learn to understand voices quickly. Often just the tone of your voice can stop them from getting too interested in the tracheostomy tube.
Guard is good
Emergency Procedures
Signs of respiratory distress are:

- Fast breathing
- Difficulty with breathing
- Fast pulse
- Grunting, noisy, whistling, wheezy breathing
- Restlessness (not able to sit still or relax)
- Cyanosis (lips and/or skin are blue)
- Recession (Pulling in of the skin between the ribs and below the breast bone. Above the collar bones or the hollow about the sternum in the neck)
- Look scared
- Unable to drink/suck
- Unable to wake the child
- Bobbing head because of use of accessory muscles
- Unable to breathe lying down
- No air moving through the tracheostomy tube.

Change the Tracheostomy tube immediately and get to the doctor!

How to be prepared in case of an emergency

- Put emergency numbers next to your telephone at home and into your cell phone
- If your child is on a ventilator, ask the nurse to notify the nearest ambulance station of your address and details and that you might need emergency assistance
- Notify the fire department if you have an oxygen cylinder in your house
- Have your child wear a Medic Alert Bracelet when outside the house
- Have an emergency pack you will take with you as a travel kit whenever you go out
- Have an emergency plan with the family and make sure that all members are trained to take care of your child with a tracheostomy tube.
What do I do if my child is not breathing?

Call his/her name and shake them firmly. Raise their chin to expose the tracheostomy tube.

If there is no sign of life and your child is not breathing, shout for HELP!

Change the tracheostomy tube!
Look, listen and feel for signs of life.

If your child is still not breathing, get the helper to dial 10177.

DO NOT LEAVE YOUR CHILD ALONE!

Give 2 breaths into the tracheostomy tube

Check for signs of life
Give 15 chest compressions

Continue with 15 chest compressions for every 2 breaths

Continue until help comes.
Phone for help if no one else has already done it.

DIAL 10177
STAY CALM

Do not leave your child alone, even if their breathing returns to normal.

Do not stop resuscitation until your child recovers or professional help takes over.
What do I do if I can’t put the tracheostomy tube in?

Use a catheter to guide the tracheostomy over it into the airway. The introducer of the tracheostomy tube may also be used to open the stoma.

Suction the tracheostomy tube.

Holding the new tube, listen over the opening for breathing and observe your child for breathing movements.
If the child is not breathing or is gasping for air, breathe into the child's mouth.

Give 2 breaths into the tracheostomy tube

Give 15 chest compressions for every 2 breaths: repeat 5 times before checking for a pulse

After 1 full minute, phone for help if no one else has already done it.

DIAL 10177
# Emergency Contact Numbers

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If your child is sick, go to MEDICAL EMERGENCIES at the hospital
Going home
You will be very fortunate to be able to take your child home where he/she can be loved and surrounded by family. You will feel empowered because you have learnt how to look after your child and perform all of the daily procedures and care that happens in hospital. You will only need to come to hospital for regular check-ups, although we are only ever just a call away if you need advice.

The nurses and doctors will tell you when your child is ready to be discharged home. They will talk to you about the tracheostomy, your child’s diagnosis, the care your child will need at home and any family problems you may wish to discuss.

What are the benefits of home care?

• Children recover better at home
• Children feel safe and secure with their families
• Families are more sensitive to their own child’s needs
• It is more comfortable for your child
• You and your child are able to attend family events
• Your child will be able to go to school or creche in your community
• It is better for your child’s confidence
• There will be fewer respiratory infections for your child at home
• Nobody knows your child better than you do as a parent. You will notice any small symptoms with your child before they become sick (preventing hospital visits).
Important things to remember when caring for your child:

• Never leave your child alone in the bath
• Take your child with you from room to room
• Never block the tracheostomy tube
• Only apply cream your doctor has given you around the tracheostomy stoma (hole)
• Do not use powder, bleach, aerosols like deodorant, and food sprays around your child
• Prevent foreign bodies from getting into the tracheostomy e.g. dog hair, sand etc.
• Always wear the mask
• Be careful not to cover the tracheostomy with clothing filled with lint e.g. wool
• Be careful of plastic near the tracheostomy
• No plastic bibs
• No smoking around your child
• No swimming

• Make sure your child wears the humidifier when travelling, sleeping and in very hot, dry weather
• A trained person should always be with your child
• Avoid areas and people with cold, flu and other sicknesses
• Make sure all immunizations are up to date.
It is important to treat your child like any other child. They will need lots of love and care.

- Try not to overprotect your child
- All children are different and you know your child best
- Husband and wife should both care for their child and still find time to spend together
- Make sure to share your feelings with other people. This will help you to deal with any problems
- Allow your other children to help care for their brother or sister so that they can talk and play together
- When your child requires a lot of attention, your other children may feel like they are left out. Make sure to set time aside for them too.
TO DO before you go home

<table>
<thead>
<tr>
<th>Name (sticker)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>T.T.O medication ordered</td>
<td></td>
</tr>
<tr>
<td>Has it arrived in the ward? Is it complete?</td>
<td></td>
</tr>
<tr>
<td>Do you know how to give your child their medication?</td>
<td></td>
</tr>
<tr>
<td>Do you know the type of feed, supplements and how to make up a feed for your child?</td>
<td></td>
</tr>
<tr>
<td>Do you have your appointment card with your next appointment on it?</td>
<td></td>
</tr>
<tr>
<td>Is the hospital number written on the card?</td>
<td></td>
</tr>
<tr>
<td>Do you have all your supplies? (see what you need to have when you go home)</td>
<td></td>
</tr>
<tr>
<td>Do you have all your equipment?</td>
<td></td>
</tr>
<tr>
<td>Do you have the form with permission to remove equipment from the hospital?</td>
<td></td>
</tr>
<tr>
<td>Have you signed the permission for publicity form?</td>
<td></td>
</tr>
<tr>
<td>Do you have your letters for the clinic, day hospital and your employer?</td>
<td></td>
</tr>
<tr>
<td>Suction Machine</td>
<td>Speaking valves x 5 (if child needs one)</td>
</tr>
<tr>
<td>-----------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Equipment forms signed by Medical Superintendent and caregiver</td>
<td>Portable disposable humidifiers or vents</td>
</tr>
<tr>
<td>Syringe 20ml for suctioning if machine breaks</td>
<td>Syringes 2ml x 3 and needles x 3 (to draw up and insert normal saline)</td>
</tr>
<tr>
<td>Suction tubing x 3</td>
<td>Normal saline 50ml x 6 and 10ml for travel</td>
</tr>
<tr>
<td>Suction catheters x 1 packet</td>
<td>K.Y. jelly</td>
</tr>
<tr>
<td>Bag to carry suction machine etc.</td>
<td>Antiseptic cream</td>
</tr>
<tr>
<td>Tracheostomy tubes x 3 (1 in child, 1 in bag + 1 spare)</td>
<td>Discharge letters</td>
</tr>
<tr>
<td>White flat cotton tape</td>
<td>Appointment card</td>
</tr>
<tr>
<td>Pipe cleaners</td>
<td>Feeds</td>
</tr>
<tr>
<td>Scissors</td>
<td>Grant forms signed</td>
</tr>
<tr>
<td>Toothbrush</td>
<td>Medication</td>
</tr>
<tr>
<td>Tracheostomy masks x 3 (1 in child, 1 by bedside + 1 spare)</td>
<td>Travel indemnity</td>
</tr>
<tr>
<td>Tracheostomy guards x 5</td>
<td>Signed permission for photography</td>
</tr>
</tbody>
</table>
Mzwakhe Dlakadla
This Home Care Book is dedicated to Mzwakhe, a special little boy who had a tracheostomy for six years and died in 2010 from an incurable lung condition at the age of eight. Mzwakhe was the most delightful character. He had incredible emotional intelligence and inspired everyone he met with his positive energy and courage. He showed us all that a child can live a full life with a tracheostomy. His courage and happiness serves as an inspiration to us all.