

When Your Child Is Unwell

How Can You Tell if Your Child is Unwell?

We all get unwell from time to time. Children on a ventilator are more vulnerable and need more help than others when they do get sick. It is important to recognise when your child is getting unwell and when to get help. Your health team will help you learn these skills and be available to advise you.

Children needing a ventilator to help with their breathing are a little different from other children and have some different needs when they get sick. You will get to know what is normal for your child – their 'baseline'. It is important that you notice change from the baseline early. Your health team might recommend you use an 'Observation Chart' to help keep track of what is normal for your child and when something is changing (see monitoring below).

It's good to have a general sense of your child's wellness, and it's helpful to monitor for certain signs:

Decreasing oxygen saturations:

Your child may be monitored with an oximeter. Your health team will have taught you what is normal for your child. If their oxygen levels fall below this it may be an indication your child isn't getting enough air or oxygen. They may also look blue or dusky – this could be their lips or their entire face. You should check the oximeter/sensor, their airway/mask, the circuit and the ventilator for a fault and act accordingly.

Change in secretions:

This is particularly apparent for a child with a tracheostomy, as secretions are commonly suctioned, but this applies to children with mask ventilation also. Secretions are usually the mucus from your child's lungs/airways and they are an important indicator of health.

Changes include:

- **Coughing:** This is another way for your body to clear secretions. Coughing more than usual is often a sign that secretions have increased.
- **Increased secretions:** If you need to suction your child more frequently than normal or you are getting more secretions from your child's tracheostomy tube when you suction, this may be an indication that your child is sick.
- **Change in secretion colour:** If your child is getting sick, his or her secretions may become yellow, green, bloody, or brown.
- **Increased secretion thickness:** If your child's secretions are thicker than normal, they may be getting unwell and this may also increase the risk of airway plugging. This can also be a sign that their humidification isn't working properly.

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Change in work of breathing or chest wall movement:

It's important to know how your child looks when breathing normally. This will vary from child to child, especially if they have little or no breathing effort of their own. Your health team will teach you what to look for.

Signs of change include:

- Chest muscles pulling (retractions): pulling inward between or under their ribs or above their collar bones are signs they are working harder to breathe. This might be because they are unwell or because there is a problem with their airway/mask, circuit or ventilator.
- Reduced chest wall movement may also be a sign that things aren't right. This is particularly true in a child with little or no breathing effort of their own, and indicates reduced air through their lungs. Check their airway/mask, circuit and ventilator, and act accordingly.
- Breathing fast: Breathing faster than normal is a sign your child is working harder to breathe and may be getting sick. Sometimes it may instead be a problem with the ventilator wrongly giving too many extra breaths.

Noisy breathing:

If your child is sick, you may be able to hear him or her wheezing.

Fever:

A temperature above 38 degrees often indicates an infection. The temperature does not tell you what type of infection they might have or how bad it could be.

Change in ventilator numbers:

You may be taught to watch some of the ventilator numbers, such as the pressures achieved, the respiratory rate and even the tidal volume (VT). Changes in these numbers may indicate that something is wrong.

Assess your child for signs of deterioration

- **Look at your child's colour**
 - Do they look pink, or are they pale, grey, flushed or mottled?
- **Count the number of breaths your child takes in a minute**
- **Feel your child's breathing and watch their breathing pattern**
 - Is it regular or irregular? Is it fast or slow?
 - Do they look like they're working harder than normal to breathe?
- **Feel your child's pulse in their arms and groin**
 - Does it feel strong or weak? Is it faster or slower than normal?
- **Take your child's temperature**
 - Do they feel warm? Are they sweating? Do their hands and feet feel warm or cool?
- **Monitor your child's oxygen saturations**
 - Are they within normal range for your child?

If you're worried about your child at any time, follow your pathway to have your child medically assessed

In an emergency, call 111

Monitoring Your Child

All children who require a ventilator need some type of monitoring. How closely they need to be monitored depends on what would happen if there was a problem with their ventilator or their breathing, and how quickly your child would get into trouble. Your health team will help advise you on this.

If your child could suffer severe harm by their ventilator not working for a short period (for example, one night) they may require continuous monitoring by an 'awake carer' who can competently monitor them and provide care. As parents, you cannot provide 24/7 awake care to their child. Your health team will tell you how you can get the extra support you need.

The specific needs for each child will vary, but a general approach to monitoring a ventilator-dependent child includes:

- **Setting up: Your child's room needs to be set up to help monitoring and cares:**
 - They need to have an appropriate bed that ensures they can be seen and accessed quickly and easily.
 - The child should be positioned in a way that lets the carer can see their breathing (chest movement), airway/mask and circuit.
 - Equipment (ventilator, oximeter, suction) needs to be readily visible and accessible to the carer. The ventilator/oximeter displays and alarms are an important aid to carers monitoring your child – it is essential that these can be seen easily.
 - There needs to be enough space for the carer – perhaps a chair and small desk.
 - The room should be lit well enough, night and day, for the carer to be able to see the child and equipment clearly. This includes at night (a night light is recommended).
 - The carer needs to be able to get help quickly. There should be a phone and potentially an ambulance-call system in the room. Sometimes a door bell may be arranged to call for help within the home (e.g. to alert the parents that the carer needs help).
- **When travelling**
 - For most children, monitoring needs to continue wherever they are – within the home, in a pushchair, in the car, on a plane. Careful planning is required but travel outside of your house is possible and enjoyable.

Monitoring Your Child

- **Transitions:**

- Transitions (e.g. moving between ventilators, beds and chairs) can be potential hazards. Pay close attention and check your child, their airway/mask and ventilator afterwards.

- **Monitoring – this refers to not just your child but also their equipment:**

- Equipment should be regularly cleaned and maintained as per recommendations.
- Equipment and setup should be checked regularly as recommended. This includes a leak valve if fitted. Your health team will tell you how often this is needed, but in a dependent child it will typically be *every hour*.
- Specific signs of your child's health should be noted at regular intervals. Your health team will advise which signs or observations are the most important for your child.
- Your health team may recommend using an observation chart to:
 - Help remind carers to do appropriate checks
 - Regularly document important health signs to help identify changes early
 - Allow everyone caring for your child to see how they have been recently and to easily see any changes.
- Monitoring also means acting when something isn't right. Your health team will teach you what to look for and what to do. This includes calling for help.
- Monitoring may also refer to the long-term follow-up of your child's health. Your health team will advise you about planned reviews. These may include clinical assessment and specific tests/procedures (sleep studies, X-rays, bronchoscopies).

Medical Emergency Plans

All children can become unwell and this is more complicated if the child is dependent on a ventilator. It can be an emergency. Your health team will create and teach you Emergency Medical Plans for your child. These will focus on their most serious health problems.

Charts help all of us manage an emergency. You may like to keep these handy or put them on the wall.

- Tracheostomy Emergency Plan
- Respiratory Illness Action Plan
- CPR Instructions

Sometimes plans need adjustment for your child or for your home environment. Your health team will help you with this.

When planning for emergencies, also consider non-medical emergencies (see guide). If you have other children, consider a Sibling Safety Plan (see guide).

Ambulance Services:

In an emergency, ambulance services provide emergency health care at your home and will help you transport your child to hospital if necessary.

In an emergency, call 111.

When you have a child with complex medical needs, we recommend telling your local ambulance service about your child and their needs before any emergency occurs. Your health team can help with this.

Calling emergency services

- In an emergency you will want to call for help while you provide care for your child.
- Ensure your child's carers and other family members know how to call emergency services – dial 111. You can make this someone else's job in an emergency. Calling 111 is free and you can do this from a mobile even if it is out of credit. The hearing impaired can register to use TXT-based '111' services.
- Notifying your ambulance service ahead of time of your child's needs may make things easier in an emergency.
- Have a phone in the child's room. Write down important numbers on or near the phone.
- Write down what to say to emergency services (e.g. wall chart on next page) – this can be a big help when you are stressed in an emergency. Your health team can help with this (example included) and can practise it with you.
- For some families, it makes sense to utilise a medical alarm. This makes calling for emergency help as simple as pushing a button so that you can concentrate on other things.

How To Call An Ambulance

- 1. Call 111**
- 2. Ask for 'Ambulance'**
- 3. They will ask you where you are and then to repeat your location.**
 - My home address (if that is where you are) is:**
- 4. They will ask for your phone number**
 - My phone number is (if this is the best phone):**
- 5. They will ask you to tell them what happened.**

Tell them “I have a tracheostomy-ventilated child in a medical emergency.”

- My child's name is:
- DOB: Hospital number:

6. You may be asked more details about the medical emergency. If emergency services are now on the way you may need to focus on helping your child.

7. When ambulance services arrive, they will assess the situation, help support your child and transport them to the nearest or most appropriate hospital, depending on the situation.

Cardio-Pulmonary Resuscitation

Home Use



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

How To Ventilate A Child By Hand

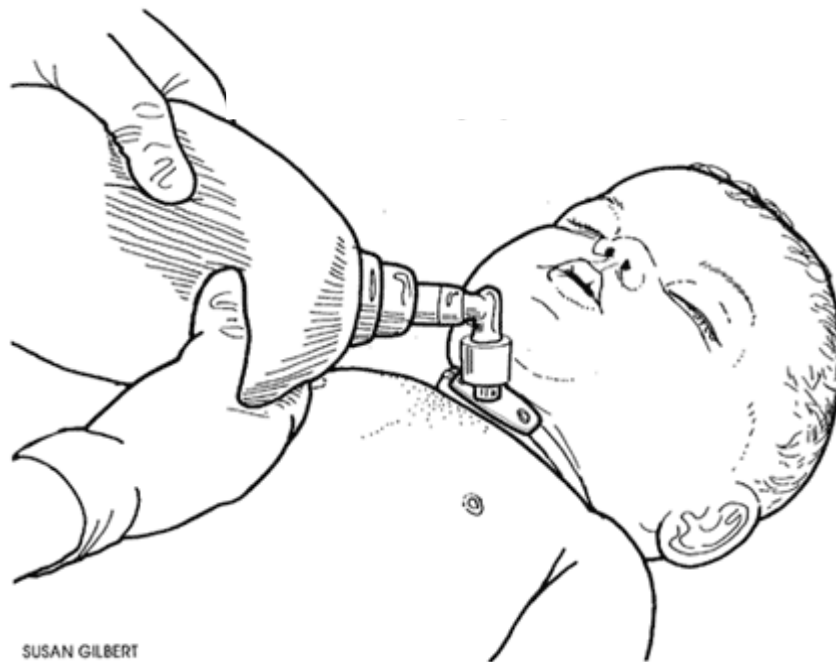
If there is a problem with the ventilator or during an emergency, you might sometimes need to help your child to breathe manually. In these situations a self-inflating bag is used. You may hear this referred to as an Ambu-bag.

When the self-inflating bag is squeezed, it lets air and volume enter your child's lungs. The bag re-expands by itself after being squeezed.

The adaptor at the top of the self-inflating bag attaches directly onto the tracheostomy, or onto a mask if needed. There is a valve between the adaptor and bag. This lets the air escape as your child exhales.

There is a small port at one end of the bag that allows oxygen to be connected. If using oxygen, a reservoir bag can be connected so that high concentrations of oxygen can be given.







It takes practice to be able to use a self-inflating bag correctly. While in hospital you will have the chance to practise using the bag under supervision. Use the opportunity to practise on a doll so you can build your confidence before practising on your child.



Some children with tracheostomies have normal breathing passages above the tracheostomy and can be helped to breathe by mouth to mouth or using a face mask if needed. Your health team will talk to you about this. It is always good to know your options.

Respiratory Illness Action Plan Chart

Name: Date:

Status	Symptoms	Action
Well 	Looks like usual. Normal thin white secretions. Breathing normal. Oxygen saturations above 93%.	Routine cares. Normal ventilation settings.
Mild 	Mildly unwell. No fever. Secretions slightly increased or yellow. Breathing effort normal. Oxygen saturations above 93%.	Continue as above. Suction as necessary. Contact your home care nurse or doctor. If it's a weekend or at night, call the hospital and ask for a medical assessment. Prepare yourselves for a hospital visit.
Moderate 	More unwell looking. May have a fever. Secretions increased / thicker. Breathing effort not normal. Oxygen saturations above 93%.	Call your urgent health team contact. Stop any oral tastes/oral feeding. Suction as necessary. Continue with normal feed. Team may ask you to change the ventilator programme. Prepare / consider transfer to hospital.
Severe 	Unwell, tired, lethargic +/- fever. Thick copious dark secretions. Breathing not normal (↑↓). Oxygen saturations below 93%.	Call your urgent health team contact. Suction as necessary; check tracheostomy. Check circuit / ventilator. Add oxygen on the ventilator via the white connector at the back. Transfer to hospital.
Extreme 	Unresponsive. No chest / poor chest movement Oxygen saturations below 90%.	'Major Emergency' – follow Emergency Plans Call ambulance – dial 111 Safety, Shout for help, Suction, Airway, Breathing, Circulation If in doubt, replace tracheostomy and bag, ventilate with oxygen. 

Note: This chart will need adjusting for your child's specific needs.