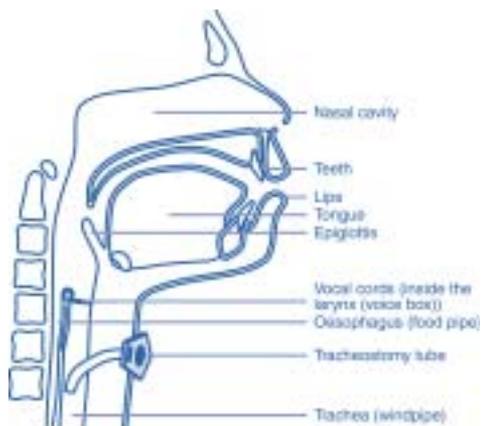


Tracheostomy ward decannulation

Information for families

Great Ormond Street Hospital
for Children NHS Trust

This leaflet explains about the methods of decannulation used at Great Ormond Street Hospital and what to expect during the process.



What is tracheostomy decannulation?

Tracheostomy decannulation is the process of removing your child's tracheostomy and making sure he or she is breathing well without it. There are two ways to decannulate: surgical decannulation and ward decannulation.

The most common one is ward decannulation, which is covered by this leaflet. If your child is likely to have a surgical decannulation, the clinical nurse specialist and doctors will explain this fully to you.

Your child may be able to 'trial' a ward decannulation if he or she has recovered naturally from the problem or if it has been surgically corrected. The decision about how and when to decannulate your child is

always made after discussion with you. Throughout the process, the clinical nurse specialist, nurses and doctors will keep you informed of your child's progress and any future plans. You will also meet the ward psychologist throughout the decannulation process so you can talk about any worries or concerns.

The process of ward decannulation has been developed and refined over many years by studying patient records and results, so you only have to stay in hospital during the most critical stages of decannulation. This balances the need for a safe process of decannulation with your need for a normal family life.

What does it involve?

The ward decannulation process takes about five days, but this can vary from child to child, depending on how he or she copes without the tracheostomy. The process is as follows:

- **Day one**
 - Admission to ward.
 - Reduce tracheostomy tube size to a 3.0 ID
 - Can leave the ward area
- **Day two**
 - Block tube for 24 hours
 - Can leave the ward area
 - Your child should be encouraged to cough
 - Do not suction them unless absolutely necessary
- **Day three**
 - Remove tube.
 - Your child must remain on ward
 - Review basic life support (BLS) training
- **Day four**
 - Your child can leave the ward but must remain within the hospital and local area
- **Day five**
 - Discharge home, usually after lunch.

This is a rough guide so do not worry if things do not always go to plan. For instance, if your child is older and therefore using a large size tracheostomy tube, he or she may need to downsize to a smaller size in stages

rather than in one go. This can take an extra couple of days at the most.

If your child has had an MLB (Microlaryngoscopy and Bronchoscopy) there will be a rest day after the procedure to allow the airway to settle before we start the decannulation protocol.

If your child is very small and usually under one year old, we may vary the protocol and downsize to a 2.5 tracheostomy tube - this is quite normal.

Are there any risks?

The main risk is your child will not be able to breathe well enough without the tracheostomy. However, as your child will be closely monitored during the first few days, there will always be someone on hand to put your child's tracheostomy tube back in if he or she has breathing problems.

It is more likely any breathing problems will happen during the night when the muscles around the airway relax. For this reason, your child will be closely monitored overnight.

Experience has shown us that when your child has passed the first few days without any problems, there is only a very small chance of him or her developing breathing problems at home.

Day one

When you and your child are admitted to the ward, the clinical nurse specialist or ward nurses will explain the decannulation process again, answer any questions you have and discuss any worries. You will also meet the psychologist at this point too.

During the day, your child will have a smaller tracheostomy tube inserted. You will need to continue your usual tracheostomy care, such as suction and tape changes.

Day two

The nurse will block off your child's tracheostomy tube using a special 'stopper' or 'bung'. This can be removed easily if your child shows any signs of breathing difficulties. This stage of the process prepares your child for the next stage when the tracheostomy tube is completely removed, and he or she has to breathe normally.

Overnight, a nurse will monitor your child closely to check he or she is breathing well. The nurse will take 'observations' every half an hour of breathing rate and effort, pulse rate and any noisy sounds when your child breathes. If your child shows any sign of breathing difficulties, the nurse will remove the 'stopper' in your child's tracheostomy tube. Your child's situation will be discussed at the morning ward round, and the decannulation process may be stopped.

Day three

The nurse will remove your child's tracheostomy tube and cover the stoma site with a dressing. It is very bulky but it is vital to make the covering airtight so that it encourages your child to breathe through his or her mouth and nose. It will absorb any secretions and also prevent bacteria and dust entering the stoma. Your child will only need this dressing for the first 24 hours, when it is replaced with one that is less bulky. He or she will need to stay on the ward, but the play specialist will have plenty of ideas and activities to keep your child occupied.

Overnight, a nurse will monitor your child closely, taking the same observations as the previous night.

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Day four

Your child will be allowed to leave the ward but should still stay in or around the hospital, in case he or she develops any breathing problems. The stoma site will still need to be covered by a dressing. You will revise Basic Life Support Skills (mouth to mouth).

Day five

You and your child will be able to go home, but the stoma site will probably still be open and will need a dressing. This dressing is much thinner but will still absorb any secretions. We will give you a small supply of these dressings, but you should order them from your community team. When you remove the dressing, you may find secretions seem to leak out of the stoma. This is completely normal, and will continue until the stoma site has healed completely. The dressing will save your child's clothes becoming dirty from the secretions.

Your child will be reviewed in the outpatient department in 8-10 weeks (unless you call us earlier).

The stomal opening may never close and may require closing under anaesthetic in a few months.

How will you feel?

You have probably found the last five days very emotional. We realise you may have felt both scared and excited during the process. You may be thankful for the freedom from carrying heavy suction equipment and restrictions on your family life. You may also be scared your child might have breathing difficulties like he or she did before the tracheostomy. However you feel about the decannulation process, you will not be the only one feeling like this.

The worries may continue when you go home. You will probably feel the need to keep checking your child's breathing, especially at night, and keep him or her close to you all the time. This is perfectly natural and can also be a good idea, particularly in the first few weeks. As your child gets used to life without a tracheostomy, and starts to enjoy normal childhood activities without any problems, you will probably start to relax.

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Frequently asked questions

Should we return all our suction equipment?

We advise you to keep all your suction machines at home for at least six months. This means if the tracheostomy does need to be replaced, you will not have to wait for supplies to be provided for you at home. However, you should return any unopened disposable equipment to your community team so it can be used for another child.

Can my child go back to school?

Your child can return to school as soon as he or she wants. There should be no restrictions on what your child can do, as long as he or she avoids sand and water activities. Other children may be curious about your child's stoma site, so it is best to keep it covered with a dressing for a while until it closes completely.

If your child has a trained carer at school or nursery, this should not stop for at least six weeks or until your child's next outpatient appointment. Your child's airway is still at more risk than other children's and so he or she will still need support.

Can my child go swimming?

This is usually the first thing children look forward to once the tracheostomy has been removed. However, your child should not go swimming or take part in other water activities until his or her stoma site has closed completely.

What do I do if my child catches a cough or cold?

If your child catches a cough or cold, this can make his or her secretions thicker, which can be harder to cope with now that he or she does not have a tracheostomy. If the secretions are very thick and your child is not coping well, you should visit the GP.

Do we have to give up our benefits?

When your child no longer has a tracheostomy, you should inform your local benefits office of this change. All your benefits should continue for six weeks until your next outpatient appointment. Depending on your individual circumstance, the benefits may be reduced or stopped, or may be continued. If you have any concerns about benefits, please speak to a social worker.

Is there a support group?

ACT (Aid for Children with Tracheostomies) continues to offer support and advice to children who have been decannulated and their families. Their details are:

ACT

Lammas Cottage

Stathe

Bridgwater

TA7 0JL

Tel: 01823 698398

Email:

support@actfortrachykids.com

Website:

www.actfortrachykids.com

Notes

in an emergency

You should contact the ward or your GP if your child shows any of the following signs:

- lethargy, tiredness or sleepiness
- loss of appetite
- irritable or more 'clingy'
- increased tiredness after exercising
- noisy breathing or 'stridor'

If your child is showing any or a combination of these signs, this could mean he or she is not coping as well as expected without a tracheostomy.

You should call an ambulance immediately and tell them your child has recently been decannulated if he or she shows any of the following signs:

- severe sucking in of the chest or neck area
- blueness or 'cyanosis' around the lips and nail beds
- unconsciousness.

If you have any questions about decannulation, please contact the Tracheostomy Nurse Specialist on 020 7405 9200 bleep 0712 or ring 020 7405 9200 and ask for the ward from which your child was discharged.