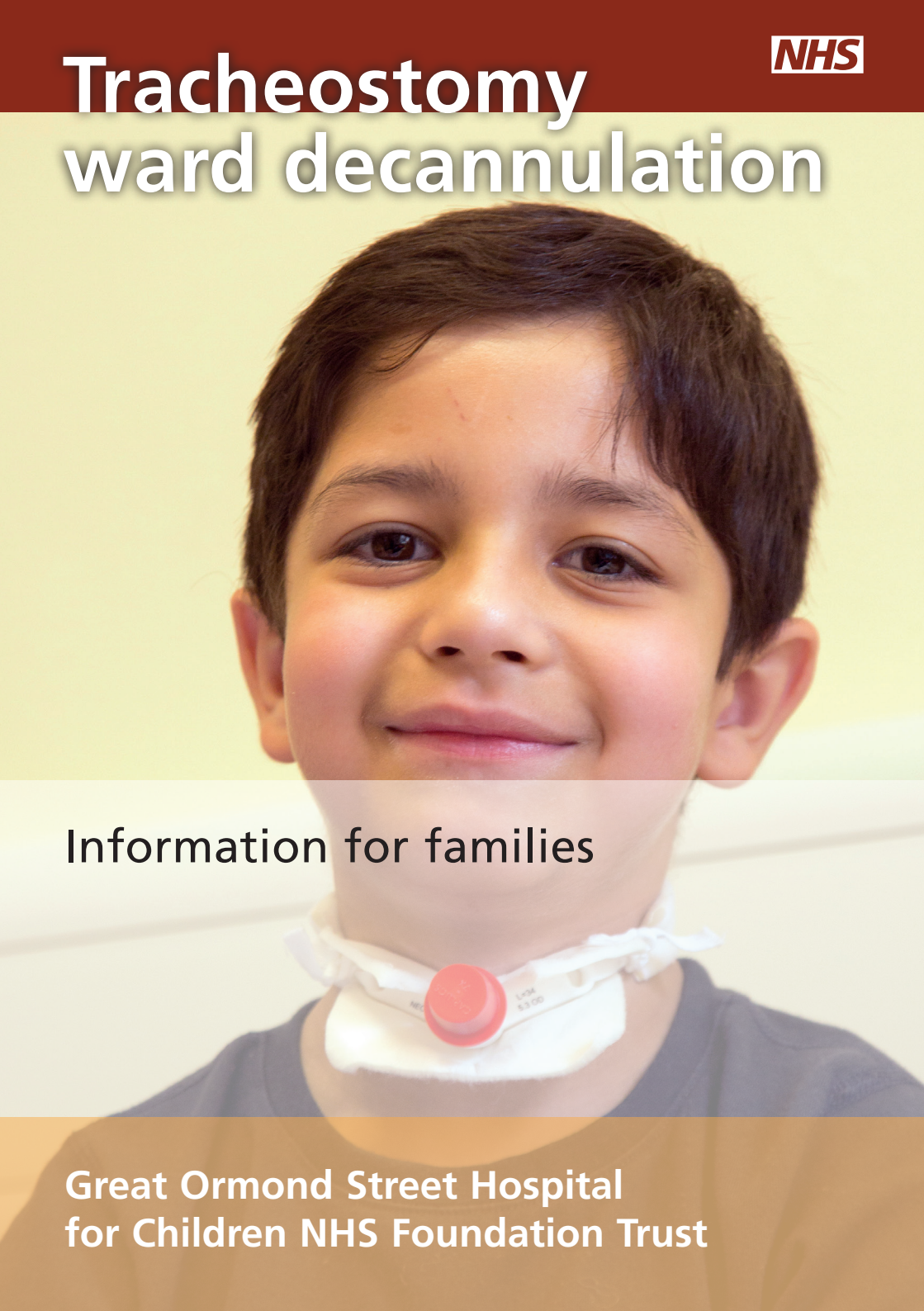


Tracheostomy ward decannulation

A close-up portrait of a young boy with dark hair and a gentle smile. He is wearing a grey t-shirt and a white tracheostomy collar with a red cap. The background is a plain, light-colored wall.

Information for families

Great Ormond Street Hospital
for Children NHS Foundation Trust

This leaflet explains about the methods of decannulation – planned removal of a tracheostomy tube – used at Great Ormond Street Hospital (GOSH) and what to expect during the process.

What is tracheostomy decannulation?

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

The most common method is ward decannulation which is covered by this leaflet.

The other method is a surgical decannulation. This is where surgery is needed at the same time as removing the tube and your child will recover on the Intensive Care Unit following this type of decannulation. Each method and choice will be discussed with you individually.

Your child may be able to 'trial' a ward decannulation if they have outgrown the medical condition that led to the tracheostomy in the first place or if the condition 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.

The process of ward decannulation has been developed and refined over many years by viewing 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. Your child will be closely monitored and breathing assessed during these five days.

We understand that the decannulation process is a stressful time for you and in most cases; parents report that it is 'worse than when the tube went in'. We will support you as much as we can during this period – if you have any questions at any point, please ask us. If you feel it would help, we can refer you to a psychologist to talk through any worries or concerns.

What does decannulation involve?

The ward decannulation process takes five days, but this can vary from child to child. Older children with a larger size tracheostomy tube may need to downsize in stages rather than in one go. This can add an extra couple of days.

Day one

When your child is 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. The tracheostomy tube will be reduced to a size 3.0 tube. This can either be done as a one-off tube change or in small steps depending on your child's current tube size.

For smaller babies and those weighing less than 12kg, we will downsize them to a size 2.5 tube. This is so we create a larger space around the tube for your child to breathe once the tube is capped.

Day two

If there have been no concerns over the previous 24 hours, we will place a decannulation cap on the end of the tracheostomy tube. This can easily be removed if your child has any breathing difficulties. This cap remains in place for the next 24 hours. Repetitive removal of the cap is classed as a fail should encourage your child to cough around the tube rather than suction them. You can walk around the hospital. We will closely monitor your child's breathing rate and effort especially while they are sleeping but if you are concerned, please tell a member of staff.



Day three

If there have been no concerns during the past 24 hours, we will remove your child's tracheostomy tube. If the stoma remains quite large, we may leave a dressing off for a few hours to allow the stoma to close a little. However, in the majority of cases, we can apply an airtight dressing over the stomal opening straightaway. This occludes the stoma and forces air up through the nose and mouth it also absorbs any ooze from the stoma. It also gives you and your child the encouragement that they can breathe by themselves without the tube.

The airtight dressing will remain in place for 24 hours. You should encourage your child to cough and clear their own secretions. They may find it more comfortable to place their hand over the dressing when coughing. If the dressing comes off, we will replace it tightly over the stoma. As it is a new thing for them, their technique for clearing secretions will not be as good as a child who has never had a tracheostomy. The team will discuss ways to improve your child's cough and secretion clearance technique. If your child is struggling to cough productively, we can encourage them using bubbles or party blowers.

You must stay on the ward on day three so please bring in lots of things from home that your child likes to do. We will of course involve the play specialist to keep them occupied during the day. We will continue to monitor your child's breathing rate and effort during this time, especially while sleeping. If you are concerned, please tell a member of staff.

Day four

If there have been no concerns during the past 24 hours, we will remove the dressing, check the stoma and clean around the area. The airtight dressing will be replaced and stay in place for a further 24 hours. You should carry on encouraging your child to cough and clear their own secretions. We will revise your basic life support skills training, using mouth to mouth resuscitation. We will continue to monitor your child's breathing rate and effort during this time, especially while sleeping. If you are concerned, please tell a member of staff. You may leave the ward.

Day five

If there have been no concerns during the past 24 hours, we will remove the dressing, check the stoma and clean around the area. If the stoma is small and not oozing, we can leave it open to the air. If it is oozing and quite large, we will cover it with a gauze dressing.

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 to assess and if necessary put your child's tracheostomy tube back in if they have 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. We encourage one parent to stay with their child during the entire decannulation process so that you can be involved in any decisions we need to make.

After decannulation

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 that you no longer have to carry heavy suction equipment and the restrictions on your family life may improve. You may also be nervous your child might have breathing difficulties like they did before the tracheostomy. However you feel about the decannulation process, you will not be the only one feeling like this.

You will probably feel the need to keep checking your child's breathing, especially at night, and keep them close to you all the time. We will talk to you about monitoring if it concerns you.

Getting back to daily life

Should we return all our suction equipment?

We advise you to keep all your suction machines at home until the first outpatient appointment (usually within six to eight weeks). 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. Community teams have different policies on this so we will discuss the process with them.

Can my child go back to school?

Your child can return to school as soon as they want. There should be no restrictions on what your child can do, as long as they avoid 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.

We will discuss the need for continued supervision and support at home with you. This varies from child to child but if they will benefit from continued support for a few weeks, we will talk to your community team.

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 their stoma site has closed completely. We will determine this at your first clinic appointment. Please do not be tempted to take your child swimming before then as it could be very dangerous.

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

Try to avoid close contact with people with coughs and colds, although this is no guarantee of avoiding infection. Catching a cold too soon could make their secretions thicker and harder to shift. However, coping well with a cough or cold can be a good marker for whether the decannulation has been a success.

Who do we have to tell if the decannulation is successful?

The decannulation process is not deemed a success until we have reviewed your child in clinic. Therefore, you should inform the local benefits office of the decannulation but allowances should continue until we have seen you in clinic. If there have been no complications, your allowances may be stopped or reduced depending on your circumstances.

Stomal opening

The stoma may or may not close completely. If it is small with no oozing, you can leave it open. If it is larger and oozing, you can cover it with a simple gauze dressing. Some people use a neck scarf or bandanna to keep the area covered. We will not close the opening surgically until at least six months after decannulation.

If it does need to be closed, this will involve a short procedure of stitching over the tract under a general anaesthetic and a one to two night admission.

Replacing the tracheostomy tube and carrying equipment

You should never attempt to re-insert the tracheostomy tube into the stoma, even if your child is having difficulty breathing. You should call 999 for an ambulance if you have any concerns about their breathing.

There is no need to continue to carry around your equipment, unless, for instance the suction was used to suction the mouth as well as the tracheostomy.

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. Call them on 01823 698 398 or visit their website at www.actfortrachykids.com

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 they are 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 they show 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 7813 8257 or 020 7405 9200 and ask for bleep 0712. You could also ring 020 7405 9200 and ask for the ward from which your child was discharged.

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Compiled by the Tracheostomy Nurse Specialist in collaboration with the Child and Family Information Group with the assistance of parents on Peter Pan ward

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