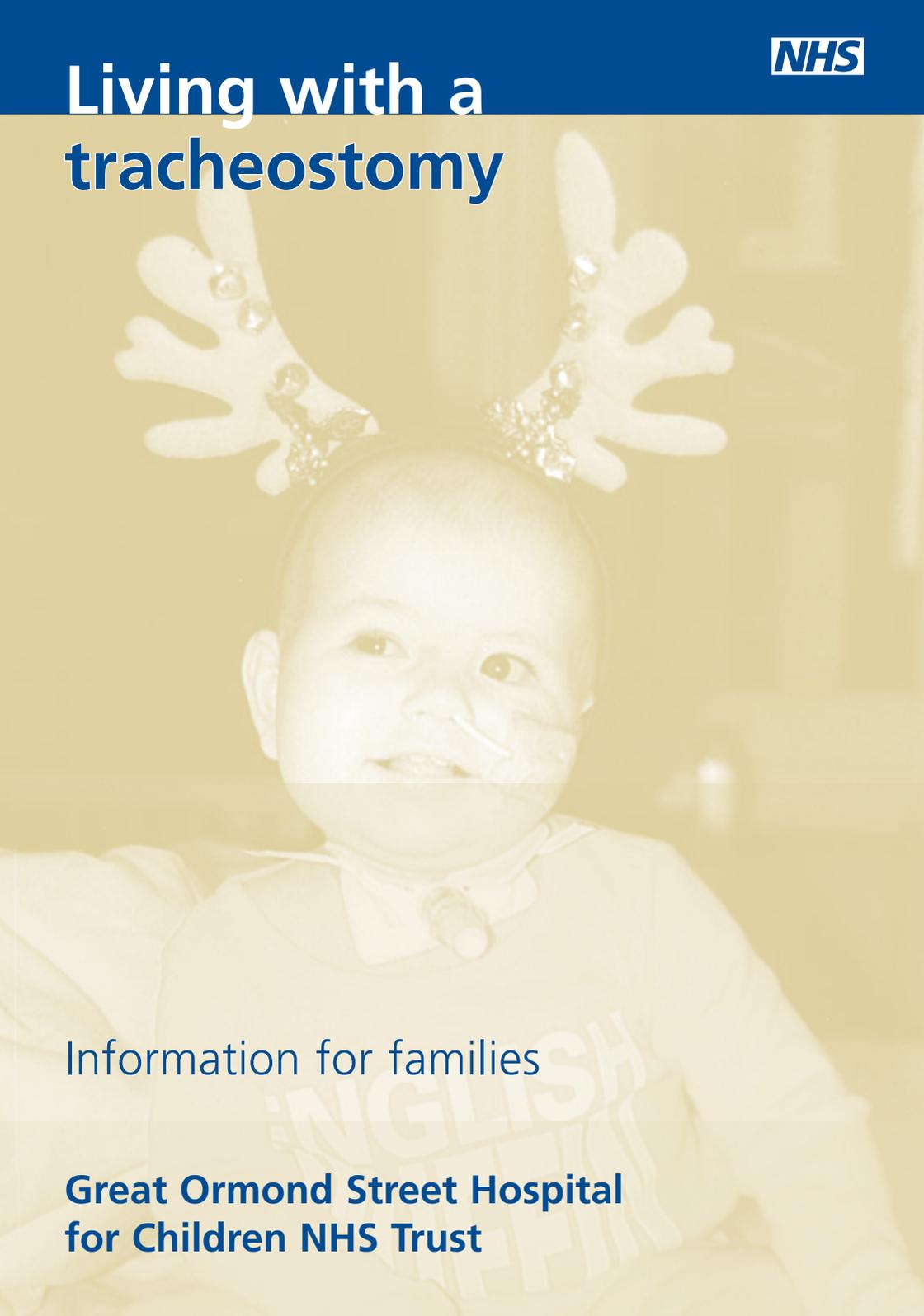


Living with a tracheostomy

A photograph of a baby wearing a reindeer antler headband and a tracheostomy tube. The baby is smiling and looking towards the camera. The image is overlaid with a semi-transparent yellow filter. The text 'Information for families' is positioned in the lower-left area of the image.

Information for families

**Great Ormond Street Hospital
for Children NHS Trust**

This booklet explains all about tracheostomies and what to expect when your child comes to Great Ormond Street Hospital (GOSH) for the operation. It also gives you information and advice about how to cope once you return home.

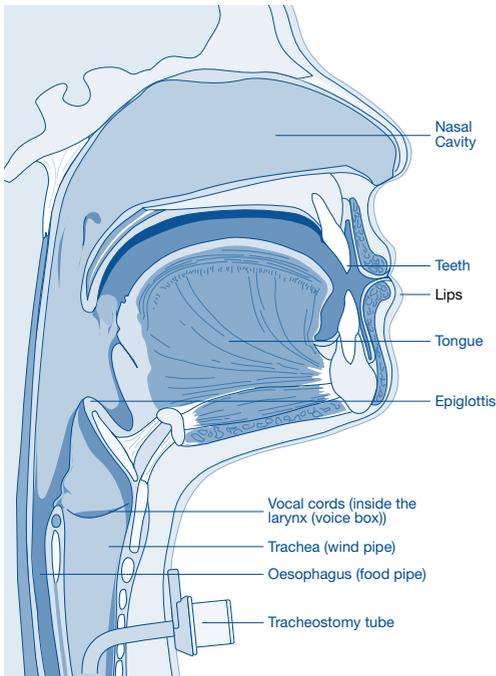
There is a lot to learn about your child's care, so we strongly advise that you have the support of another adult who will be able to share this care with you.

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What is a tracheostomy?

A tracheostomy is an artificial opening into the windpipe (trachea) that is held open by a tracheostomy tube. This helps your child to breathe more easily. Air now goes in and out through the tracheostomy tube and bypasses the nose and mouth. The decision to perform a tracheostomy will have been reached as a result of investigations and tests. There are a variety of reasons why a child may need a tracheostomy, ranging from a narrow airway to the need for long-term mechanical respiratory support from a ventilator.



Meet the team

There may seem to be a great many people looking after your child while you are in hospital and after you return home. Some people you will meet include:

- **Medical team:** They will decide with you when a tracheostomy is required as a result of previous investigations. They will create the trachy under anaesthetic.
- **Tracheostomy nurse specialist:** she will probably be your first port of call for any questions you have and will be the **main person training you to care for your child's tracheostomy. She will contact your community team, arrange discharge home and offer advice once you are at home.**
- **Ward nurses:** they will be responsible for your child's day-to-day care and for teaching you to look after your child's tracheostomy.
- **Play specialist:** they will help you to prepare your child for the operation and will support you afterwards.
- **Speech and language therapists:** they will work with you in managing your child's communication development and help if there are any difficulties in swallowing.

■ **Social worker:** they are available to see any family who needs practical or emotional support as we recognise that coping with your child's illness and being away from home can be very stressful. They can also offer help and advice about benefits and other services, financial help during your stay here, and planning for going home. They can liaise with your local social services department, housing department and education services to try to ensure you are getting the help you need, and that your child's needs are being met in the community.

Remember that all the team are here to help you and will always be on the end of a telephone if you need help and advice. Once you get home, you will have the support of your community team, which will include your health visitor or community paediatric nurse and your family doctor (GP).

Your hospital stay

Your child's surgeon and nurse specialist will explain the operation in detail, discuss any worries you may have, and ask you to give your permission by signing a consent form. The operation will be carried out under a general anaesthetic.

Your child will stay in hospital for a minimum of two weeks after the operation. This is so that you can learn the necessary skills to care for your child's tracheostomy at home. If your child needs ventilator support after the operation, this will be much longer. This may seem a daunting prospect at this stage but you will be supported throughout your stay. You may be discharged straight home or more likely via your local hospital, depending on your child's recovery and any other medical or social requirements needed.



Back from theatre

After the operation, your child will return to the ward with a suitably sized tracheostomy tube, held in place with cotton tapes and temporary 'stay sutures'. Stay sutures are long stitches, brought out through the wound and taped down onto your child's chest. These sutures keep the stoma (hole) open if the tube has to be changed early.

After the operation, your child will not be allowed any food or drink (whether by mouth or feeding tube) for a minimum of three hours until the anaesthetic wears off.

Occasionally some children experience difficulties with their swallowing. This is normally a temporary problem that resolves itself. If it does persist, a speech and language therapist may help in assessing and managing your child's swallowing. Infants or children who have never fed before or have an underlying medical condition where feeding may be problematic will always be reviewed by the speech and language therapist before feeding is started.

During the two weeks after the operation, you can expect the following events. This is only an approximate guide.

Day 1	Tracheostomy is formed; Chest X-ray usually carried out in Recovery.
Days 2 to 7	Parents/carers observe suctioning, tape change and stoma care; Practice suctioning and tape change.
Day 7	Observe first tube change; Removal of stay sutures.
Day 8 to 14	Practise tube changes – during the training period, we will carry out more tube changes than usual.
Day 12 to 14	Emergency care training; Allowed off ward unaccompanied after emergency care training; Overnight stay – each parent/carer to have one overnight stay
Day 14 to 18	Discharge home or to local hospital – this will be discussed further with you

The first week

During the first week you may feel overwhelmed at the amount of care your child requires. This is because the tracheostomy is new and needs special attention at this stage. For this reason your child will be under constant supervision for the first two to three days after the operation. Children requiring respiratory support from a ventilator may have this level of supervision for much longer. As you become more familiar with the equipment and routines, you will feel more comfortable with the special care needed for the tracheostomy and supervision from the clinical teams will be reduced.

For the first seven days the opening in your child's neck (stoma) will look red and inflamed. This is aggravated by the humidification (moistened air) that your child needs at this stage and also by the tube, which can irritate and rub on the skin around the stoma. During this period the stoma site will need careful cleaning at least once a day and a protective dressing placed behind the tracheostomy tube.

After about seven days the tube will be changed for the first time. The stay sutures will be removed and then the area cleaned and redressed.

Types of tracheostomy tube

There are many different types of tracheostomy tube and your child will be given one that most suits his or her needs. The tubes are usually made of plastic or silicone. The tracheostomy specialist and ENT team will discuss with you the most appropriate tube for your child. Different tubes may be tried on your child until the most comfortable and appropriate one is found.

Learning to look after the tracheostomy

A tracheostomy needs extra care because it is a direct route into the lungs and therefore the air moving into the lungs will not have the benefit of the warming, moistening and filtering effect of the nasal passages. It is more difficult for a child with a tracheostomy to clear secretions adequately by coughing so the tube needs special care to prevent it blocking with secretions. The tapes holding the tube in place will need changing daily or when they become soiled or wet. The tube will need to be changed weekly or monthly, depending on the type of tube.

Before you take your child home, you will be competent in the following areas:

- suctioning the tube
- tape changing
- caring for the stoma
- changing the tube
- care of equipment and supplies
- general care
- emergency care

You may feel that this is an awful lot to learn, but we will make sure you are confident before you go home. Most parents feel like this but with practice they become experts in the care of their child. Every child is different and in time you will find a routine that suits you.



Suction

Suctioning is the removal of secretions from the airway, keeping it patent (open) and improving ventilation and oxygenation. Suctioning is commonplace in the treatment of children with a tracheostomy. However, it is not a procedure that should be taken lightly as it has both long and short term potential complications.

A clean technique must be used and the catheter should be discarded if the tip is contaminated by touching hands or cot sides for instance. As carers, you are not required to wear gloves but it is essential to wash your hands before (if time) but certainly after carrying out suctioning. Your child should never wait for suctioning.

Suctioning is not a painful or distressing procedure. In fact, most infants will remain asleep throughout. If the child becomes distressed during suctioning then you should review your technique. It is important that you only suction the length of the tube, to avoid damaging the lower vulnerable structures.

Size of suction catheters, suctioning technique and pre-oxygenation requirements will be discussed with you as it depends on the size, style and length of tracheostomy tube.

During suctioning, observe the secretions. You will be familiar with what they look like normally.

If you notice that:

- they have changed colour
- they are thicker than usual
- you are suctioning more often than usual
- they have an unpleasant smell
- they are tinged with small specks of blood.

It is important to contact your family doctor (GP) or community nurse for review.

Instructions for suctioning

1. Make sure you have all the equipment you need ready:
 - suction unit;
 - suction catheters;
 - suction unit connecting tubes;
 - bowl or bottle of tap water to flush the suctioning tube.
2. It is a good idea to have a new 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 that the pump is ready to be used at all times.
3. Wash or gel your hands. (If suction is required in a hurry this may be impractical).
4. Turn on the pump and check the pressure as instructed.
5. Gently insert the catheter into the tracheostomy tube (with your thumb off the side port of the suction catheter). The distance it is passed depends on the length of the tracheostomy tube – this will be explained to you while you are in hospital.
6. Apply suction, by covering the port with your thumb, and slowly withdraw the catheter.
7. Do not rotate or twirl the catheter as you remove it.
8. Repeat if your child still needs suction. Give your child time to catch a breath between suction.
9. Disconnect the catheter from the tubing and dispose of it safely. Clear the tubing by suctioning a small amount of water through it. Discuss waste disposal with the ward staff as different arrangements may need to be made when you are at home. Attach a new catheter ready for next time.

Note: The lining of the trachea is very sensitive and can be damaged easily by the suction catheter. In order to minimise the trauma to the trachea, pass the catheter just to the end of the tracheostomy tube. This removes the secretions and reassures you that the tube is not blocked.

Tape changes

A tracheostomy tube is held in place by cotton tapes. It is essential that the knots are secure and the tension of the tapes is correct. If they are too tight your child will experience discomfort and the skin may break down. If they are too loose the tube can fall out or be pulled out.

At GOSH, we only use cotton tapes following two incidents with Velcro® tapes. We recommend that you continue to use cotton tapes when you get home. Please discuss this further with the nurse specialist or ward nurses.

You will be shown how to change the tapes and will usually be fully involved in this care by the end of the first week. During the second week of your stay, you and your partner will be able to change the tapes together with minimal supervision.

At home, this will usually be done once a day. It is essential to change tapes with two people, as one person is needed to hold the tracheostomy tube in place while the other ties the tapes.



Instructions for tape changing

1. Make sure you have all the equipment you need ready:
 - round-ended scissors;
 - two lengths of ¼ inch cotton tape with plastic backing (you will be shown how to make up the ties);
 - saline and gauze to clean the skin;
 - trachy dressing.
2. Wash your hands
3. Have all the equipment within easy reach
4. Suction equipment and your emergency box must be kept close at hand

5. Position your child on his or her back with their neck extended over a rolled-up towel to give better access to the area around the tracheostomy tube. If your child is very young it may be easier to wrap him or her up in a blanket to prevent you being jugged by thrashing arms. Older children may prefer to sit, but this should be assessed individually.
6. Place the new tapes behind the neck.
7. Carefully hold the tube in position to stop it falling out (one person), cut and remove the old tapes and dressing (the other person).
8. Clean and dry around the tracheostomy tube (see next section) and put the dressing under the tube.
9. Thread the end of one of the tapes through the tracheostomy tube flange on the far side and tie it with three knots, ensuring that the tape is flat to the skin.
10. Repeat this procedure on the other side, but instead of securing the tapes with a knot, just tie a bow. Try to achieve the correct tension before tying the bow.
11. Continue to hold the tube in place and sit your child forward. With your child's head bent forward it should be possible to slip one finger comfortably between the tapes and the neck. This is our recommendation as the safest tension for tapes. The plastic backing should make this checking process easier, as the plastic backing allows you to slide your fingers under the tape more easily.
12. If the tension is correct, lie your child down again and change the bow into three knots by pulling the loops of the bow through to create a second knot. Then tie the third knot. If the tension is not correct, undo the bow and loosen or tighten the tapes until the correct tension is achieved and then secure the knots. Be careful to check that the knots are tight and the tension is correct for a second time at the end of the procedure.

Although it may feel daunting at first, and there is a lot to learn, it will quickly become easier. Remember, there is always someone on the end of the telephone both at GOSH and in your local area, to advise and reassure you.

Care of the stoma



When you are changing the tapes, check the skin around, above, and below the stoma for red or irritated areas. A dressing is usually applied behind the flanges to protect the skin. The dressing should be changed regularly as wet dressings can cause infection and irritate the skin. Some creams cannot be safely applied to the neck area near the stoma, so please check with your nurse specialist before applying. Tracheostomy tubes can cause the skin to develop granulation tissue (excess new tissue) in and around the opening to the stoma. This can cause bleeding and can sometimes make it difficult to change the tube. Discuss this with the tracheostomy nurse specialist or community nurse if this problem arises. Granulations need to be treated or may need to be removed or cauterised if they become problematic.

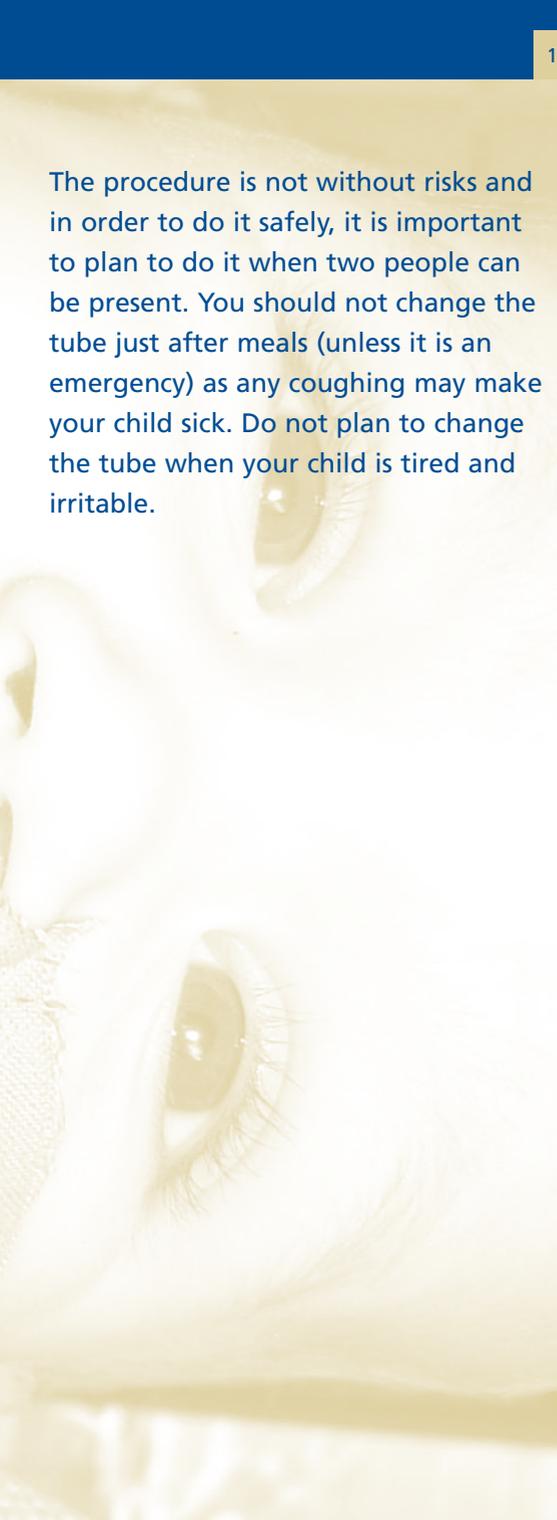
Tube changes

Secretions from the lungs coat the inside of the tracheostomy tube.

At GOSH, we mostly use silicone tubes. It is therefore recommended that, under normal circumstances, the tube is changed once a month. You may have to change the tube more often if secretions begin to coat the tube.

After the first week, the tube will be changed and you can observe this. The following day (this will be discussed with you) you can carry out the tube change. Each day after this, you will be helped by the nurses to change the tube, until you are able to do it safely. By the time you are ready to go home, you will have changed the tube as a team at least three times.

Remember that the tube is being changed frequently in hospital so that you can learn the skills yourselves. When you are at home, the tube should only need to be changed once a month, depending on the type of tube used. This will be discussed with you at the time of teaching. It is important that you feel confident and competent in tube changing before you go home with your child.



The procedure is not without risks and in order to do it safely, it is important to plan to do it when two people can be present. You should not change the tube just after meals (unless it is an emergency) as any coughing may make your child sick. Do not plan to change the tube when your child is tired and irritable.

Instructions for tube changing

1. Prepare equipment:
 - working suction equipment;
 - round-ended scissors;
 - two lengths of 1/4 inch cotton tapes with plastic backing;
 - new tube – check correct size and that the tube is intact, in good order and not passed its expiry date;
 - a smaller sized tube in case the usual one will not go in;
 - suction catheter;
 - water-based lubricant to help the tube glide easily into the stoma;
 - equipment needed for cleaning stoma and tying tapes (as in previous section).
2. Wash your hands.
3. Prepare tube – take out of wrapping and hold by the flanges. Put in the introducer. Apply a small amount of lubricant to the outer edge of the curved section of the tube, taking care not to let it drip down the tube. Place the tube on the sterile wrapper.
4. Have all equipment within easy reach.

5. Suction if necessary.
6. Position your child as you do for tape changing (an older child can sit up).
7. Hold the tube (one person). Cut and remove the old tapes and place new tapes behind your child's neck (the other person).
8. Continue to hold the tube . Hold the new tube by the flanges and position the tip near your child's neck.
9. Gently remove the old tube following the curve of the tube and stoma.
10. Firmly but gently slide in the new tube, again following the curve of the tube and stoma so as not to damage the trachea. Remove introducer (obturator) immediately.
11. Hold the new tube in securely – changing the tube may cause your child to cough which could dislodge it.
12. Allow the coughing to settle – this should take two or three seconds. Check air flow through the tracheostomy tube and your child's breathing pattern and colour. Suction if necessary.
13. Clean and observe the skin around the tube.
14. Tie the tapes.
15. Do not let go of the tube until the tapes are secure.

Emergency care training

When you are both comfortable with changing the tube, you will have emergency care training.

Communication

Having a tracheostomy may temporarily affect your child's speech and language development. However, with early speech and language therapy intervention, your child's understanding of spoken language and production of speech will catch up. Referral to a speech and language therapist is recommended for all children with a tracheostomy. Your speech and language therapist will also advise you if your child has additional problems that may affect his or her communication development. You can ask your family doctor (GP), health visitor or the speech and language therapist at GOSH to arrange for you to see a specialist in your area.

Soon after your child's tracheostomy is put in, the speech and language therapist will meet you to discuss communication options for your child and ways to develop his or her speech and language skills. A tracheostomy alters your child's communication by affecting the passage of air through the voice box and mouth for speech. Air from the lungs passes out of the tracheostomy tube instead of passing up through the 'voice box' (larynx) and out of the mouth (see diagram on page 3).

Babies

A baby (under six months) with a tracheostomy tube will communicate with you using facial expressions such as smiles and frowns. You will learn to 'read' your child's expressions. Even though your baby is unlikely to be able to make a voice at this stage, it is important to continue to talk to him or her in a natural and enjoyable way and to respond to his or her communications as you would any other child.

Infants and children

As your child develops he or she will begin to make mouth shapes and early sounds like kisses and blowing raspberries. These sounds should be encouraged and will lead to the development of more speech-like sounds over time. Your child's communication options will depend on their airway and the reason for the tracheostomy. The speech and language therapist will discuss these options with you and together you can decide on the most appropriate way forward for your child.

Communication options include:

- **speech and speaking valves:** A speaking valve is a one-way valve which sits on the end of the tracheostomy tube. There are several different types of valve. The valve opens as your child breathes in through the tracheostomy and closes as he or she breathes out directing the air up through the larynx and out of the mouth. This allows your child to create words and sounds. Not all children can have a speaking valve as a good air leak around and above the tube is needed. Your speech and language therapist will assess your child's suitability for a speaking valve. If your child cannot tolerate a speaking valve, he or she may still be able to achieve a voice thanks to air leaking around the tube. Voice quality without a speaking valve is often quieter and may be more difficult to understand. Some children with tracheostomies may have a voice that sounds different in quality, pitch or volume from that of other children of the same age. This is most likely if they have known changes to their vocal folds or larynx. The speech and language therapist will explain this to you and discuss how to help your child's voice production.
- **'pseudovoice':** this includes 'buccal speech' and 'pharyngeal speech'. This speech is created by using air trapped in the mouth or throat and some children learn it spontaneously. While it can be an effective way for your child to speak to close family and friends, this type of speech can be more difficult to understand for people who are unfamiliar with your child.
- **sign language:** there are many different types of sign language developed for different needs and abilities. Makaton and British Sign Language are two examples. Makaton is frequently recommended for young children to help encourage their language development and to reduce their frustration. The signs are produced alongside speech so do not interfere with development of spoken language.
- **electrolarynx:** this is an electronic aid which produces an artificial 'voice' when held against the neck. This requires that children mouth words as they would in normal speech and so an electrolarynx tends to be suitable for older children.

Planning for going home

Communication with your community team will start at the time the tracheostomy is inserted. The tracheostomy nurse specialist/ward staff will contact your health visitor and a community paediatric nurse so that support is available for you when you get home. During your stay at GOSH, you will also meet the ward social worker to discuss what support you might need while you are here and what help you and your child might benefit from when you go home. This covers financial, emotional and practical support and help, as well as information and advice. He or she can also refer you to your community social services' disabled children's team. This team will then contact you to discuss your child's needs further and what support may be available in your local area.

Sometimes plans for going home are made once your child has been transferred back to your local hospital, but arrangements are usually made from GOSH.

The following things should have been discussed before you go home:

- Equipment and supplies
- Housing
- Telephone
- Power cuts
- Financial help
- Help at home and respite care
- Getting out and about
- School/nursery

Going home will feel like a huge step; you may feel eager to get back to family life at home, you may also be concerned at the thought of coping by yourself. These are all very normal thoughts and feelings for families taking a child with a tracheostomy home for the first time. Your community nursing team will be available to advise and assist you when you are at home.

Try to remember that all the staff are here to help you. They have a great deal of experience and are happy to answer your queries and help you with your child's care. Working in partnership with the family, we aim to provide the best and safest care for your child, both here and at home.

Equipment and Supplies

A list of recommended equipment and supplies will be sent to your health visitor or community paediatric nurse who will be responsible for supplying them for use at home. A copy will be given to you so that you can check that you have all the equipment. Supplies will come from your local health authority. Always ensure that you have at least two weeks' worth of supplies at home.

When you go home you will need three suction pumps:

- Sam 12® mains electric pump (for use in the house);
- Laerdal®/Vacu-aide® or other rechargeable, portable pump for use when out and about;
- Ambu Hand/Foot® pump (for emergency use only – especially in small babies);
- or equivalent makes.



A Sam 12® is the suction pump that is used on a day-to-day basis in the home. It requires mains electricity. The collection jar must be cleaned every day. The filter should be changed monthly or earlier if it becomes discoloured. The suction pressures will have been set before you go home and this should not be altered.

The Laerdal®/Vacu-aide® is a portable suction unit which comes with a transformer that enables you to recharge the unit. It can also be run off the mains. The portable suction unit should always be left on charge when not in use. The collection jar and suction tubing are easy to remove and should be cleaned daily.

An Ambu Hand/Foot® pump does not require electricity and should only be used in an emergency when all other suction units have failed. It is easy to operate by placing your hand/foot on the pad and moving it up and down and can be very effective if used correctly. Suction pressures cannot be regulated on these pumps so should only be used in an emergency.

You will be shown by your community teams how to use all your equipment before your child goes home. If you have any problems with any of the machines please contact your health visitor or community paediatric nurse.

Equipment should be cleaned with a mild detergent in warm water and rinsed and dried thoroughly. All suction pumps should be checked and serviced at least once a year as per your local policy. Your community team will advise you about this.

Housing

It would be better if you were housed in ground or first floor accommodation, as getting up and down stairs with suction equipment, as well as your child, can be difficult. The ward social worker will be able to advise you about this.

Telephone

It is essential that you have a telephone in the home before discharge from hospital. It is a good idea to inform the telephone company that you would need urgent attention in the event of a fault on the line.

Power cuts

Before your child comes home, you should contact your electricity supplier and tell them that you need a continuous supply for medical equipment. They can then put you on their special system for power cuts.

It is always wise to keep a torch handy.

Financial Help

■ **Disability Living Allowance (DLA):** A parent looking after a baby or child who needs more care than another of the same age is entitled to claim DLA. This benefit is tax-free and non means tested and is paid at three different levels, according to the amount of care given. A child with a tracheostomy should receive the highest level of payment.

■ **Carer's Allowance (CA):** You should apply regardless of your partner's earnings if:

- your child receives DLA at the middle or higher rate
- you spend at least 35 hours every week caring for him or her
- you do not earn more than £95 per week

This benefit counts as earnings and is liable for tax.

You can ask for claim forms for both of these allowances or Freephone 0800 882200. Forms are also available in the social work department at GOSH.

■ **Families receiving Income Support:** If you are not already getting Income Support and have to stop working due to care needs or were claiming Job Seekers Allowance but are no

longer available for work, you may be able to claim this benefit. Income support is made up of personal allowances and premiums for you and your partner. Allowance and premiums for your children are now nearly always paid through Child Tax Credit (CTC). When your child is awarded DLA, you should be given the disabled child element of CTC. If you receive the high rate of the care component of DLA, you will additionally be entitled to the severe disability element of CTC.

If you are still paid these extra amounts for your children through Income Support, then this will be increased in a similar way. It is important that you claim CA and inform the Tax Credit Office on 0845 302 1444 as soon as possible after the award of DLA as backdating is usually for a maximum of three months.

When you receive Carers Allowance, you will be paid separately and the amount of CA will be deducted from your Income Support. However, a Carers Premium should be added to your Income Support, which means you will be better off each week.

If you think you are not being paid all your entitlements, ask the Benefits Agency to send you details

of how they have made their calculations and/or seek independent advice from an advice agency.

- **Families with income from employment:** If your family has a partner in work for 16 hours or more a week, you are likely to be entitled to a Child Tax Credit (CTC). This will increase (or you could become entitled if your income was previously too high) in the same as for those on Income Support. If you are work, you may find that an award of DLA or CA entitles you to, or increases, help with council tax and/or rent. Contact your local authority to claim housing and council tax benefit or inform them if you are already getting housing and/or council tax benefit when you get an award of DLA or CA.
- **The Family Fund Trust:** The Family Fund helps families with severely disabled children to have choices and the opportunity to enjoy ordinary life. They give grants for things that make life easier and more enjoyable for disabled children and their families, such as washing machines, driving lessons, hospital visiting costs, computers and holidays. Their address is in the 'useful addresses' section. Your ward social worker (or

family support worker) can apply for you while your child is in hospital if your need is immediate and this will be dealt with straight away. If you apply from home yourself, one of the fund's visiting social workers will come to see you to discuss how the fund can help. This will take a lot longer. Family Fund forms can be obtained from the GOSH social work department.

- **Short breaks:** This used to be called respite care. It will of course have to be provided by a fully trained tracheostomy carer. Families' needs for help vary, as does provision in different parts of the country. Some get help from the local health authority and some through community social services. If your child needs very frequent suctioning at night, you may become too tired to cope by day. The health authority can sometimes provide help at night, using carers with nursing skills or training in the care of a tracheostomy. Short breaks can be provided by disabled children's teams, for instance, so you can have some time in the day to go shopping or spend more time with your other children. The usual way of offering this is increasingly through the Direct Payments scheme.

- **Direct payments:** These are cash payments which can be made to you by the community social services disabled children's team once they have met you and assessed your child's needs. They can be made to disabled people aged 16 or over, to people with parental responsibility for disabled children and to carers aged 16 or over in respect of carer services. A person must be able to consent to have a direct payment and have the capacity to manage one, although they can have assistance to manage their payment on a day-to-day basis. The aim is to give families more choice and control over their child's care, and to give more flexibility in how it is provided.

The law has been changed so that it is a duty for your community social services to make direct payments. This means that councils must make a direct payment to eligible individuals who are able to provide consent. Direct payments should be discussed as a first option when your child is assessed by the disabled children's team. You can obtain more information from the Department of Health website under Direct payments.

General care hints



Keep things normal

Try to treat your child as normally as you can. Children who are overprotected or treated as sick can become demanding. Your child is only 'different' in the way he or she breathes and will be happier if rules stay the same and daily life can carry on almost as before.

Feeding/eating

Most babies and children with tracheostomies will have no problems feeding. However, some may experience difficulties. Your child may find it hard to swallow saliva or cough during feeding. Food or fluid may come out from the tracheostomy. If your child is having swallowing difficulties, the speech and language therapist will assess your child and recommend ways of improving his or her feeding in conjunction with the medical and nursing team.

Meal times

Babies: Most babies with tracheostomies can be fed like any other baby, but they should never be left alone with a bottle in case they start to choke. Older brothers or sisters can help with feeding but an adult should always be there. It is a good idea to use suction before a feed as secretions tend to increase with feeding. This may also avoid the need to suction for a while afterwards (coughing brought on by suctioning may make the baby sick). Be careful that milk or food does not get into the tracheostomy tube. A bib without a plastic liner could be used to prevent this.

Children: Your child can eat and drink normally, but watch that fingers or food are not placed in the tracheostomy tube. Give plenty of fluid each day to help maintain hydration. Avoid using suction right after a meal if possible in case it makes your child sick.

Bathing and hair washing

Always stay with your child when he or she is near water. Make sure that the water line is well below your child's waist and avoid too much splashing. A non-slip bath mat is a good idea and you should keep a manual suction pump handy just in case. For hair

washing your child should be laid on his or her back in shallow water or held tipped back in the bath and the hair washed by spraying or pouring water from a cup. Another method is to use a 'shampoo shield' available from baby equipment stores and lean your child forwards over the bath or sink. An older child can take a shower with care to avoid the spray going into the tracheostomy. A bib could be used to prevent splashing into the tube.

Clothing

Avoid covering the tracheostomy with tight clothing and avoid clothes that shed a lot of fibres that could get into the tube.

Smoke and fumes

Remember that the tracheostomy provides a direct route to the lungs. Cigarette smoke or fumes from an aerosol could irritate your child's lungs. Smokers should go to another room or go outside. Try to avoid spraying aerosols like deodorant or furniture polish in the same room as your child.

Pets

Long-haired pets and caged birds can cause problems because of the amount of fur or feathers they shed. If possible, keep your pet restricted to a different area of the home.

Night time

Many parents worry that they will not hear when their child needs suction at night. It is safer for a baby or small child to sleep in the parents' room. A baby intercom, which can be bought from any large store, will amplify noises from your child's room, allowing you to hear what is happening. Some community teams offer 'respite at night' or monitoring devices, but this varies from area to area. The community team will discuss this with you.

Play

Your child will be able to take part in most activities. If he or she is a baby or toddler, check that all small toy parts or objects are cleared away in case they are put into the tracheostomy. We do not recommend that your child play with dry sand as it may get into the tracheostomy. However, your child can play with wet sand under close supervision. Covering the tracheostomy

loosely with a Swedish nose will help. This hospital does not recommend swimming as the risk of water getting in the tube is too high. Keep a careful watch if your child is paddling or playing near the water. Hydrotherapy could be considered after careful risk assessment by practitioners.

School or nursery

Any child with a tracheostomy must of course have a carer with them at all times who is competent to carry out suction, tape changes and able to perform an emergency tube change if necessary. This carer does not have to be a nurse, but must be trained fully in tracheostomy care and must not have other duties that would take him or her away from your child.

Children with tracheostomies should be considered to have special educational needs. This does not mean they necessarily have difficulty with learning but that without special provision (a trained carer) they cannot make use of educational provision.

You should get in touch with your child's intended nursery or school early, even if your child is still under two. If you are not certain who to contact, ask your social worker to help. If your child

already attends school, ask to speak to the special educational needs co-ordinator at the school.

The education authority should assess your child's situation and, if your child is over two, should draw up a statement of special educational needs. This outlines what help your child will need in order to attend. Sometimes however, a school will provide funding for a special carer without the need for an educational statement.

The Department for Children, Schools and Families provide a helpful booklet called *Special educational needs: a guide for parents and carers* free of charge. You can download it from their website at <http://publications.teachernet.gov.uk> [note no www] or order it by telephoning 0845 60 222 60. Advice and leaflets can also be obtained from the Advisory Centre for Education (ACE) (see 'useful addresses' section). If you experience any difficulties or resistance, you should contact the tracheostomy nurse specialist or social worker for advice.

Getting about and travel

There should be no restrictions on travelling, but it is useful to be prepared when going out, however short the distance.

- **Disabled Person's Badge (Blue Badge):** You can get this for your car when you are using it to transport your child with a tracheostomy. From September 2007, this is the case for a child of any age so long as they are 'technology dependent', which includes a child needing to have tracheostomy equipment with them at all times. This scheme is operated by individual local councils. You should telephone or visit your town hall to ask for an application form. You will probably need a letter from your family doctor (GP), tracheostomy nurse specialist or consultant, confirming that your child is technology dependent.
- A small box containing the following equipment should accompany your child at all times. This can be a plastic box or small bag or rucksack. Ideally two bags should be made up – one of which goes out on journeys and the other which stays with your child around the home and garden.

Emergency box (for home)

- A spare tracheostomy tube of the same size, style and make as your child's usual one
- a smaller sized tube in case there are difficulties inserting the usual one
- round ended scissors
- lubricating gel
- cotton tracheostomy tapes
- suction catheter – in case it is difficult to change tube
- Velcro® tapes – only for emergency use if you need to change the tube on your own
- disconnection wedge
- Portex® extension
- suction unit
- Enough suction catheters to cover your journey – always carry more than you think you might need.
- Syringe of normal saline.
- Small bottle of tap water to flush the suction tubing.
- Empty syringe if your child has a cuffed tube

It is a good idea to keep your travel kit handy in the house in case of emergencies.

Going abroad

Care should be taken when choosing a destination, ensuring that adequate health care provision is always at hand. Always discuss your plans with the consultant and nurse specialist to ensure that your child's current and future treatment supports travel abroad. Assuming that this is all right, there is no reason why you cannot travel abroad with your child with a tracheostomy.

- You will need to make adequate insurance provisions to ensure that you can be flown home quickly if necessary. You will have to shop around for this. Alternatively ACT (see 'Useful addresses' section) or the tracheostomy nurse specialist will be able to suggest a company used by other families. As with all insurance documents, make sure you read the small print so that you are covered properly. Take the policy with you on holiday.
- Take enough supplies of equipment to last for the whole of your holiday plus a few extra, whether at home or abroad. Some insurance companies will not cover this and it may work out quite expensive to buy equipment abroad.
- If you are flying, you will need to advise both the airline and the airport authority of the equipment that you wish to take on board, either as hand luggage or in the hold, and follow any special requests they have. Carry equipment in your hand luggage as well just in case your luggage in the hold goes astray.
- Some airlines require a letter from the tracheostomy nurse specialist. You can get further information about travelling abroad from ACT or the tracheostomy nurse specialist or consultant explaining why the equipment has to be taken on board, especially now that security surrounding certain items has heightened. We would certainly recommend carrying a letter to avoid delays at security.
- If your child requires oxygen, a 'fit to fly' oxygen test is required before flying. This may take some time to arrange so start planning early.

Car journeys

If you drive a car, it is helpful to buy an extra internal mirror so that you can always see your child in the back.

Decannulation



The eventual goal is to remove the tracheostomy tube from your child. This process is called decannulation. Most parents, while longing for the day when the tube can come out, are still worried. Will their child be able to breathe without the tube? Will the hole (stoma) close? Parents and older children can talk to the ward child psychologist or tracheostomy nurse specialist about these concerns.

Removal of the tube can be done in a number of different ways and is closely supervised in hospital. Ward decannulation takes five days and the process usually follows these steps:

- A smaller tube is inserted as a routine tube change. This allows the stoma to begin the gradual process of closing.
- Once the smallest possible tube is used, it is blocked with a small cap for 24 hours.
- If your child has tolerated this, the tube is removed completely and the stoma covered with an airtight dressing.
- Your child will be kept in for a further 48 hours for observation of his or her breathing.

Sometimes the stoma does not close on its own and the child has to be admitted at a later stage to have the hole closed under anaesthetic.

Important: If you have been receiving Disability Living Allowance for your child, you should notify the DLA office that your child's tracheostomy has been removed. You will probably be able to keep the allowance for a while until it is certain that your child is coping well, but once you do no longer have to supervise your child closely, the allowance will stop. If you have been receiving Carer's Allowance, that will also have to stop once DLA is removed.

Occasionally surgical decannulation under general anaesthetic, rather than ward decannulation, is recommended. In this case, once the tube has been removed and the stoma closed in the operating theatre, your child is taken to the intensive care unit and spends a short time with his or her breathing supported by a tube and/or ventilator.

After your child's tracheostomy is removed, the speech and language therapist will meet you to discuss the need for future therapy. Some children may have voice changes that need ongoing advice and others may need continued help with their speech and language development and/or their feeding.



Glossary of commonly used medical terms

Bronchoscopy

An examination of the inside of the trachea and of the large air passages leading to the lungs. Usually done as a way of assessing the degree of narrowing of the trachea and the overall general condition of the trachea and the air passageways.

Cyst

A fluid-filled swelling, which may occur in the larynx and obstruct breathing.

Decannulation

This is when the tracheostomy tube is removed – hopefully for good!

Epiglottis

A flap of cartilage situated immediately behind the root of the tongue. It covers the entrance to the larynx (voicebox) during swallowing to stop food or fluid going down the wrong way and getting into the lungs.

Granulation

A term used to describe the presence of excess new tissue or scar tissue. It sometimes appears in and around the opening in the neck. Suctioning or rubbing by the tube flanges may make it bleed.

Haemangioma

A swelling containing abnormal blood vessels. This usually stop growing and then shrinks as the child grows older.

Incision

A cut made during a surgical operation.

Larynx

Situated at the top of the trachea and better known as the voice box or Adam's apple. It is made up of muscle and cartilage and has two important functions:

- **Airway protection** – During swallowing the vocal cords close, the larynx rises and its opening is closed off by the epiglottis. This prevents food or fluid entering the trachea.
- **Production of voice** – This occurs when air passes through the larynx which causes the vocal cords to vibrate and generate sound.

Laryngomalacia

This is the name given to a condition in which the structures of the larynx are particularly soft and collapse inwards as the child breathes. This can cause varying degrees of obstruction to breathing and is often first noticed when the child breathes noisily or has an unusual breathing pattern. As the child grows older the larynx becomes more rigid and the condition usually disappears.

Laryngotracheobronchitis (“croup”)

A common viral infection of the upper respiratory tract that causes the larynx and tracheobronchial tree to become inflamed and reduces the airway size.

Laryngotracheoplasty or Laryngotracheal reconstruction (LTR)

This is an operation sometimes performed to enlarge (widen) an area of narrowing in the upper trachea, often using a piece of rib cartilage.

Microlaryngoscopy

The examination of the inside of the larynx (voice box) using a microscope.

MLB

Microlaryngoscopy and bronchoscopy. A procedure carried out in the operating theatre, where the ENT team pass a camera via the mouth to examine the larynx and trachea.

Papilloma

A type of wart. If it grows very big or there are a lot of them they may interfere with the voice or with breathing.

Respiratory tract

Consists of the air passageways involved in breathing; for example the nose, larynx, trachea, and lungs.

Stenosis

Narrowing.

Stoma

Abbreviation for tracheostoma. This is the opening made at the front of the neck through which the tracheostomy tube is placed.

Stridor

Noisy breathing, usually indicating some obstruction.

Subglottic stenosis

When narrowing occurs in the area where the larynx meets the trachea. (The larynx or the vocal cords are sometimes referred to as the glottis and “sub” means under.)

Trachea

Also known as the windpipe, it is a semi-rigid structure which leads from the larynx to the lungs.

Tracheomalacia

An area of softening of the trachea which may collapse inwards as the child breathes and may obstruct breathing. This condition usually disappears eventually as the trachea enlarges and becomes more rigid.

Tracheotomy

The surgical opening of the trachea through the neck.

Tracheostomy

The completed opening leaving an artificial airway.

Useful addresses

ACT (Aid for Children with Tracheostomies)

Email: support@ACTfortrachykids.com

Website: www.ACTfortrachykids.com

Makaton Vocabulary Development Project

Tel: 01276 61390

Email: mvd@makaton.org

Website: www.makaton.org

Information on the Makaton system of sign language communication

The Royal College of Speech and Language Therapists

Tel: 020 7838 1200

Website: www.rcslt.org

Advice about delay in speech, language or communication.

Contact a Family

Tel: 0808 808 3555

Email: info@cafamily.org.uk

Website: www.cafamily.org.uk

Contact a Family is a UK charity which helps families who care for children with any disability or special need. It is a main source of information about rare disorders and is able to assist affected adults as well as children.

Family Fund Trust

Tel: 0845 130 45 42

Email: info@familyfund.org.uk

Website: www.familyfundtrust.org.uk

A national charity offering financial assistance and information to families caring for a child/children with special needs and disabilities under the age of 16 years.

Action for Sick Children

Tel: 0800 07 445 19

Website: www.actionforsickchildren.org

Supports families of sick children and works to ensure effective planning of health services for children

ACE – Advisory Centre for Education

Tel: 0870 770 3306

Website: www.ace-ed.org.uk

Guidance on Special Education and all other aspects of education

Network 81

Tel: 0870 770 3306

Email: info@network81.org

Website: www.network81.org

Advice on special needs education including assessment, statementing and negotiation with schools and local authorities

Personal stories

Maia has had her tracheostomy tube for 18 months.

Maia has Treacher Collins Syndrome and the tube was put in when she was 4 months old to overcome her breathing difficulties. Her symptoms include boneblocked nasal passages and a small jaw (her tongue lies partially over her airway).

The surgeons at Great Ormond Street operate regularly on Maia to keep her nasal passages stretched open and to assess the space at the top of her trachea.

Hopefully when Maia's jaw has grown sufficiently and her nasal passages are in a good state she will be able to cope without her trachy.

Maia's feeding, general health and development took off when the tube was put in. She uses baby signing and Makaton to communicate and wears a speech valve for several hours a day. It is wonderful to finally hear her chuckle.

The early months were exhausting as we adjusted to our new lifestyle and thankfully caring for Maia's tracheostomy has got easier as Maia has got older and more robust. As parents we have to be constantly vigilant but with organisation (and a large buggy!) Maia is able to lead a very normal and full life.

There are always stares and questions from others but we would rather



Personal stories

Ryan had a tracheostomy done when he was 3 weeks old. After the operation, we could immediately see the big difference it made for Ryan, which helped us to come to terms with it all.

After getting all the necessary training in tracheostomy care, we finally brought Ryan home when he was 6 weeks old. The level of care Ryan needed was very high – aside from daily routine tape change, monthly tube change, we had to be always ready to suction (day and night). There was a time when we were going through 300 catheters a day!

Getting out and about was difficult – with all the equipment we had to carry around and with the constant suctioning, the most simple things, as going to the supermarket, were a big challenge. Also people would very often stare and wonder when they saw us giving Ryan suction (it was very normal for us but not normal at all for other people) – sometimes we just got sick and tired of explaining things over and over again.

Unfortunately for us, we never got any respite care. With no family around, sometimes it was very hard to cope. My husband was a big help though so it made things easier (also his boss was very understanding and Paul got lots of time off work).

Ryan coped with tracheostomy really well. It didn't seem to bother him at all and certainly didn't stop him to develop as any "normal" child would.



Sources of support at GOSH

- Tracheostomy Nurse Specialist – 020 7405 9200 and ask for bleep 0719
- Social Work department – 020 7829 8896
- Speech and Language Therapy department – 020 7813 8110

If you have any questions, please contact the tracheostomy nurse specialist on 020 7405 9200 and ask for bleep 0712.

Notes

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Ref: 09F0502

Compiled by the Tracheostomy Nurse Specialist
in collaboration with the Child and Family Information Group.

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www.goshfamilies.nhs.uk www.childrenfirst.nhs.uk

BASIC LIFE SUPPORT OF BABIES AND CHILDREN WITH A TRACHEOSTOMY

**Action to take
on a blocked tube**

SAFETY

STIMULATE

SHOUT

Check and open airway
Suction the tube

If blocked change immediately
Caution if stoma is less than 1 month old

Suction the tube

Assess for breathing

Rescue breathing

Signs of life
(Pulse check)

Chest compressions
if appropriate

Reassessment

**Action to take
if the tube fails to go in**

**Attempt to insert
the smaller sized tube**

**Attempt to pass the smaller
tube into the stoma using
a suction catheter**
(Seldinger Technique)

**If unsuccessful, ventilate
via the nose and mouth if the
underlying condition allows**