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What is a tracheostomy?

A tracheostomy is an artificial opening into the windpipe (trachea) which 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, for example, 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:

• **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.

• **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:** who will help you to prepare your child for the operation. He or she will show your child a photo book of children who already have a tracheostomy and maybe a special doll who also has a tracheostomy.

• **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 support or a listening ear. They can also offer help and advice about benefits and other services, financial help, planning for going home and liaising with your local social services department, and what help might be available to you when your child is discharged.

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 GP.

Your hospital stay

Your child’s surgeon will explain the operation in detail, discuss any worries you may have, and ask you to sign 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. This may seem a daunting prospect at this stage but you will be supported throughout your stay. You may be discharged straight home or via your local hospital.
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 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. After this, your child will be allowed to have his or her normal diet. 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 his or her swallowing abilities.

During the two weeks after the operation, you can expect the following events. This is a rough guide, so do not worry if things do not always go to plan.

Day 1  Operation to form the tracheostomy; Chest X-ray (on the ward).

Days 2-7 Observe suctioning and tape change; Practice suctioning and tape change; Meet speech and language therapist and social worker.

Day 7  First tube change; Removal of stay sutures; Allowed off ward (if with an adult trained in basic life support and tracheostomy care).

Day 8  Observe tube change; Practise tape change.

Day 9  Practise tube and tape change.

Day 10  Partner practises tube and tape change.

Day 11-14  Practise tube and tape change with partner.

Day 12-14  Basic life support training; Allowed off ward unaccompanied after basic life support training; Overnight stay (2 consecutive nights).

Day 14  Discharge home or to local hospital.
After about seven days the tube will be changed for the first time. You are advised not to observe. This is because the stoma (opening) is still new and may require attention. The stitches will be removed and then the area cleaned. Humidification may be stopped and the stoma site will continue to heal. Tape changing can then be done once a day and the stoma site cleaned when necessary.

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 a plastic material and are soft to touch. The tracheostomy nurse specialist and ENT team will discuss with you the most appropriate tube for your child. There are four main types of tube used for children and each is slightly different.

Different tubes may be tried on your child until the most comfortable and appropriate one is found.

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 nursing 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.

You may feel quite awkward during the initial period after the tracheostomy. You may feel that the nursing staff are becoming more familiar with your child’s everyday needs than you are. You will be encouraged to continue with their usual care like feeding and bathing as far as you feel able.

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) which 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. If it is very inflamed this will be done more often and the nurses may put a protective dressing around the stoma, behind the tracheostomy tube.
These include:
• suction
• tape changing
• care of the stoma
• tube changing
• care of equipment and supplies
• how to deal with difficulties
• resuscitation

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. Remember there is always someone here on the end of a telephone to advise and reassure you.

Suction
This is probably the first skill you will learn after the first day or so. You will gradually learn to recognise when you need to suction and how much to do at each episode. The nurses will supervise you and help you when necessary.

Why is it so important? We need our larynx (voice box) to be able to cough properly and get rid of lung secretions (mucus or phlegm) that can block the airway. The tracheostomy tube is sited below the larynx so this means that the child will not be able to cough out secretions so well. The tube is an irritant and may cause excess mucus to be produced in the lungs.

Learning to look after the tracheostomy
When you are used to watching the nursing staff looking after your child’s tracheostomy, you and your partner will be taught to look after the tracheostomy yourselves. A tracheostomy needs extra care because it is a much more direct route to 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 the 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 dirty or wet. The tube will need to be changed regularly depending on the type.

Before you take your child home, at least one person in your household must be confident in the main activities involved in caring for the tracheostomy.
Suction is required regularly to remove these excess secretions. At first the child will need suction often, but the frequency may reduce as the lungs become accustomed to the tracheostomy tube.

The tracheostomy tube and the trachea must be kept clear of secretions for two main reasons:

• If the secretions are allowed to accumulate, they will block the tube and the child will be unable to breathe.
• Secretions left in the tube could become contaminated and the child could develop a chest infection.

When to use suction

It is recommended that you use suction when your child is coughing in order to remove the secretions and to prevent them sticking to the inside of the tube. You will soon learn to recognise when secretions are building up and when the tube is becoming coated on the inside from the sounds the air makes as it goes in and out of the tube.

Suction is required if your child asks for it or shows any of the following signs:

• noisy breathing (the sound of air bubbling through secretions)
• visible secretions at the tracheostomy tube opening
• a cough with the sound of secretions in the tube
• restlessness, crying (crying also increases the amount of secretions)
• increased respiratory rate, working hard to breathe.

Infections

A child with a tracheostomy tube is at risk of infection being introduced into the lungs. It is very important that you try to prevent this happening. You can do this by making sure that you do not let secretions remain bubbling in the child’s tube or lungs. Other ways to avoid infection include washing your hands thoroughly before carrying out any procedure relating to the tracheostomy and keeping the equipment very clean and well maintained. When you have completed each episode of suction, you should dispose of the catheter and use a new one on the next occasion. It is not essential that you wear plastic gloves to do suction, but if you prefer to do so, make sure you have some supplied. It is also important to try to give your child a healthy lifestyle with good exercise and a well-balanced diet. Try to avoid being near someone with a heavy cold.

When you do suction, observe the secretions. You will be familiar with what they normally look like and if you notice that:

• they have changed colour
• they are thicker than usual
• you are using suction more often than usual
• they have an unpleasant smell
• they are tinged with small specks of blood, then it is likely that your child has a chest infection. When this occurs it is important to contact your GP as they may need a course of antibiotics. You should suction more regularly to remove the secretions.
Instructions for suctioning

1. Make sure you have all the equipment you need ready:
   - suction unit;
   - catheter;
   - connecting tubes;
   - syringe of saline;
   - bowl or bottle of tap water to flush the tube.

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.

2. Wash your hands. (If suction is required in a hurry this may be impractical).

3. Turn on the pump and check the pressure as instructed.

4. 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, you will be told of this at the hospital.

5. Apply suction, by covering the port with your thumb, and slowly withdraw the catheter. This should take only 5 or 6 seconds.

6. Repeat if your child still needs suction. Give the child time to catch a breath between suctionings.

7. 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 at home. Attach a new catheter ready for next time.

The lining of the trachea is very sensitive and can be damaged easily by the suction catheters. 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.

(This is something you can practise with a spare tube and catheter.)

Tape changes

A tracheostomy tube is held in place by cotton ties or occasionally Velcro tapes which need to be changed when soiled or wet. It is essential that the knots or Velcro are secure and the tension of the tapes is correct. If they are too tight the child will experience discomfort and the skin may blister. If they are too loose the tube can fall out or be pulled out. Skin that is constantly in contact with wet tapes will develop sores or rashes.

You will be shown how to change the tapes and will usually be 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 need to be done only once a day, usually after a bath. It is essential to change tapes with two people, as one person is needed to hold the tracheostomy tube while the other ties the tapes.

5. Position your child on his or her back with the 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 jogged by thrashing arms.

6. Place the clean tapes behind the neck.

7. Carefully hold the tube in position to prevent it becoming dislodged (one person), cut and remove the dirty tapes (the other person).

8. Clean and dry around the tracheostomy tube (see next section).

9. Thread the end of one of the tapes through the tracheostomy tube flange on the far side and tie it to the other with three knots.

10. Repeat this procedure on the other side, but instead of securing the tapes with a knot, just tie a bow. Keep the tapes as unwrinkled as possible and try to achieve the correct tension before tying the bow.

11. Continue to hold the tube in place (one person) and sit your child forward (the other person). With your child's head bent forward it should be possible to slip one finger comfortably between the tapes and the neck. This is recommended as the safest tension for tapes.

12. If the tension is correct, lie the 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 last knot. If it is not correct, 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.

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 or Velcro tapes (the nurse will show you how to make up the ties);
   - saline and gauze to clean the skin.
2. Wash your hands
3. Have all the equipment in easy reach
4. Suction if necessary
The day after the first tube change, your child's nurse will show you how to change it. You will have the opportunity to observe the whole procedure and ask questions as you go along. Each day after this, you and your partner will be helped by the nurses to change the tube, until you are able to do it between the two of you. By the time you are ready to go home, you will have changed the tube as a team at least twice. It is important to remember that the tube is being changed daily 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 week, 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 in case you need to change the tube in an emergency.

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 as any coughing may make your child vomit. Do not change the tube when your child is tired and irritable.

**Care of the stoma**

When you are changing the tapes, check the skin around, above, below and behind the stoma for red or irritated areas. If the skin is sore, a sterile keyhole dressing can be applied between the skin and flanges, taking care not to cover the tracheostomy tube. The dressing should be changed regularly as wet dressings can cause infection and irritate the skin. Barrier cream should not usually be necessary, but we will discuss this with you.

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/community nurse if this problem arises. Granulations need to be cauterised or removed.

**Tube changes**

Secretions from the lungs coat the inside of the tracheostomy tube. It is therefore recommended that, under normal circumstances, the tube is changed once a week, although some children may be fitted with a different tube which can be left in longer. You may have to change the tube more often if secretions become very dry (for example in hot or cold weather or if the atmosphere in your home is too dry) or if your child has a chest infection and is producing more and thicker secretions.
Instructions for tube changing

1. Prepare equipment:
   - round-ended scissors;
   - two lengths of 1/4 inch cotton tapes or Velcro tapes;
   - new tube - check correct size and that the tube is intact and in good order;
   - a smaller sized tube in case the usual one will not go in;
   - water-based lubricant to prevent the tube sticking to the skin as it is inserted.
2. Wash your hands.
3. Prepare tube - take out of wrapping and hold by the flanges. Put in introducer (if applicable). Apply a small amount of lubricant to the outer side of the tube, taking care not to let it get into the ends of the tube. Place the tube on the 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 dirty tapes and place clean tapes behind your child’s neck (the other person).
8. Continue to hold the tube (one person). Hold the new tube by the flanges and position the tip near your child’s neck (the other person).
9. Gently remove the old tube following the curve of the tube.
10. Firmly and gently slide in the new tube, again following the curve of the tube so as not to damage the trachea. Remove introducer if this has been used.
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. 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 training
When you are both comfortable with changing the tube, you will have formal training in basic life support (BLS) often called the “kiss of life”. This will usually take place the day before you are discharged home.
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 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. The placement of the tracheostomy tube below the level of the vocal folds and larynx can be seen in the diagram on page 4.

• Babies

A baby (under 6 months) with a tracheostomy tube will communicate with you using facial expressions e.g. 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. Whilst 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. Children mouth words as they would in normal speech and so an electrolarynx tends to be suitable for older children.
Planning for going home

When your child is ready to leave hospital, a letter will be sent to your GP. The tracheostomy nurse specialist/ward staff will contact your health visitor and a community paediatric nurse (if there is one in your area) so that support is available for you when you get home. You will also see the ward social worker to discuss any help you might need, including help with housing, benefits or respite care.

Sometimes plans for going home are made once your child has been transferred back to your local hospital, but arrangements are usually made from Great Ormond Street Hospital. In all cases, the ward social worker will meet you to discuss what help is needed.

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

Going home will feel like a huge step; you may feel eager to get back to a more normal environment but be frightened and nervous at the thought of coping by yourself. This is quite a common feeling amongst families going home with their child and his or her tracheostomy. Your community nursing team i.e. the health visitor, home care team or community paediatric nurses will be available to support 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 will 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. The first two weeks’ supply will be provided by Great Ormond Street but after that supplies will come from your local health authority. Always ensure that you have at least two weeks worth of supplies at home.

You will need:
• suction catheters;
• suction tubing;
• round-ended scissors;
• tracheostomy tubes;
• tracheostomy tapes;
• saline;
• gauze;
• 2ml syringes;
• water-based lubricant (if required);
• heat and moisture exchanger (H M E).
This hospital does not advocate the re-use of tracheostomy tubes (unless advised) or suction catheters.

When you go home you will need three suction pumps:

- Sam 12 mains electric pump (for use in the house);
- Laerdal or Vacu-aide (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 and the suction tubing changed every day. The filter should be changed monthly or earlier if it becomes discoloured. The suction rate will have been set before you go home and this should not be altered.

The Laerdal 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. It takes 36 hours to recharge fully and it should always be left on charge when not in use. Suction should never be attempted when the unit is being recharged. The collection jar and suction tubing are easy to remove and should be cleaned daily.

A Vacu-aide is a lightweight portable suction unit which comes in its own carrying case with a power cord and battery charger with warning light to indicate when it needs recharging. It takes 24 hours to recharge the pump fully and it may be used when on charge. The collection jar and suction tubing can easily be removed for daily cleaning.

An Ambu Hand/Foot pump does not require electricity and should only be used when all other suction units are out of action. 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. The collection jar and suction tubing should be cleaned after every use. Always keep your hand/foot pump in a readily accessible place.

You will be shown how to use all your equipment before your child goes home but 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.

- **Housing**

  It would be better if you were housed in ground floor accommodation or a flat with a reliable lift, as getting up and down stairs with suction equipment, as well as your child, can be difficult. If you experience any difficulty or resistance, please
• 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 paid at three different levels, according to the amount of care given. A child with a tracheostomy should receive the highest level of payment.

Invalid Care Allowance (ICA): 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 £50 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.

• Families receiving Income Support

Income Support is made up of personal allowances and premiums. When your child is awarded Disability Living Allowance, you should be given the Disabled Child Premium. When you receive Invalid Care Allowance, you will be paid by a separate book and the amount of ICA will be deducted from your

• Telephone

It is essential that you have a telephone in the home before discharge from hospital. Sometimes the local social services department will pay for installation and rental. If not, a grant may be obtainable from the Family Fund Trust (see the ‘useful addresses’ section). 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. The hospital social worker will discuss this with you and can make necessary contacts on your behalf.

• 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 and you need not worry.

It is always wise to keep a torch handy and to know where your manual suction unit is just in case of a power cut and to practise suction under these conditions to familiarise yourself.

contact the tracheostomy nurse specialist or social worker for advice.

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provide someone to care for your child with a tracheostomy, although some areas can arrange this. Help at night can sometimes be provided by the health authority, using carers with nursing skills or training in the care of a tracheostomy. Respite care for a child can sometimes be arranged to allow you to have a break and perhaps go away with your other children.

**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.

- **The Family Fund Trust**
  This is a government fund which is able to help many families whose children have tracheostomies. It can give small grants for such things as a holiday or outings for the whole family, driving lessons, telephone installation or hospital costs. Their address is in the “useful addresses” section. Once you apply, one of the fund’s visiting social workers will come to see you to discuss how the fund can help.

- **Help in the home/respite care**
  Families’ needs for help vary, as does provision in different parts of the country. Some parents of children with tracheostomies have no extra help. However, if your child needs very frequent suctioning at night, you may become too tired to cope by day. If you have other small children to cope with, extra help might be needed in the home or with taking children to school. Sometimes the social services department can provide help in the home or with other children. They are usually not able to provide someone to care for your child with a tracheostomy.
• 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. Your baby should be burped well and placed on his or her side after a feed.

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 keep secretions thin. Avoid using suction right after a meal if possible in case it makes your child vomit.

• 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 the tracheostomy and avoid too much splashing. A non-slip bath mat is a good idea and you could keep a manual pump handy just in case.

For hair washing the child should be laid on his or her back or held tipped back in the bath and the hair washed by spraying or pouring water from a cup.

An older child can take a shower with care to avoid the spray going into the tracheostomy.

• Clothing
Avoid covering the tracheostomy with tight clothing and avoid clothes which shed a lot of fibres that could get into the tube. Soft toys which shed should be kept away from your child.

• 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 before lighting up or, better still, 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 which can get into the tracheostomy. If possible, keep your pet restricted to one room, or send it to stay with a relative for as long as your child has his or her tracheostomy.

• **Night time**

   Many any parents worry that they will not hear when their child needs suction at night. It is safer for a baby to sleep in the parents’ room. An older child can come and get you or could have a bell by the bed to call you if help is needed. An intercom, which can be bought from any large store, will allow you to hear what is happening.

• **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 scarf or fine mesh gauze or 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.

• **School or nursery**

   Many children with tracheostomies are successfully placed in ordinary (mainstream) schools and nurseries. They must, however, have a carer with them at all times who is ready to carry out suction and to perform an emergency tube change, if necessary. This carer does not have to be a nurse, but must be trained in tracheostomy care and must not have other duties which would take him or her away from your child.

   Children with tracheostomies are 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 local education authority early, even if your child is still under two. If you are not certain who to contact, ask your health visitor or social worker to help. If your child already attends school, ask to speak to the special educational needs co-ordinator at the school.

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The education authority will assess your child’s situation and, if your child is over two, should draw up a statement of special educational needs. You can ask your child’s consultant for a letter to support the need for a carer.

The Department for Education has produced a helpful booklet ‘Special educational needs - a guide for parents’ - available from DfES Publications Centre, PO Box 5050, Sherwood Park, Annesley, Nottinghamshire NG15 0DJ. Tel 0845 6022260. 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: You may be able to obtain a Disabled Person’s Badge for your car when you are using it to transport your child with a tracheostomy. This scheme is operated by individual local councils, usually by the social services department. You should telephone your town hall to ask for an application form. You will probably need a letter from your GP or consultant. You will need to stress how much equipment has to be carried around with you.

Note: The regulations do not permit badges to be issued for children under two years old and very few departments will waive this rule.

Travel kit

• A spare tracheostomy tube of the same size as the one your child is using. You should also pack a smaller-sized tube in case there are difficulties inserting the usual one.

• Tracheostomy ties.

• A pair of scissors. Try to get a very small round ended folding pair.

• Some form of suction. This should be a battery-operated portable unit with a foot or hand-operated pump as back-up.

• 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.

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

• Going abroad: There is no reason why you cannot travel abroad with your child with a tracheostomy. You will need to make adequate insurance arrangements.
provisions to ensure that you can be flown home quickly if necessary. You will have to shop around for this and your travel agent is probably the best person to advise you. Alternatively ACT (see ‘Useful addresses’ section) or the tracheostomy nurse specialist may 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. If you are flying, you will need to advise the airline of the equipment that you wish to take on board, either as hand luggage or in the hold. You may need to request that oxygen is available on board. You can get further information about travelling abroad from ACT or the tracheostomy nurse specialist.

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. Many children with a tracheostomy learn that the best way to get instant attention is to pretend that they need suction!

**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 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 several days. 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 bung for 24 hours. If the child has tolerated this, the tube is removed completely and the stoma covered with an airtight dressing.
This process usually goes well, but sometimes the original tube needs to be replaced for a period until the consultant decides that decannulation can be tried again.

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.

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, the child is taken to the intensive care unit and spends a short time with his or her breathing supported by a ventilator.

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 are no longer having to supervise your child closely, the allowance will stop. If you have been receiving Invalid Care Allowance, that will also have to stop once DLA is removed.

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**

**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 disappears.

**Laryngotracheobronchitis** (*“croup”*)
A condition that causes the larynx and tracheobronchial tree to become inflamed and reduces the airway size.

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**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 shrinks as the child grows.

**Incision**
A cut made during a surgical operation.

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A swelling containing abnormal blood vessels. This usually shrinks as the child grows.

**Incision**
A cut made during a surgical operation.
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 using a microscope.

MLB
Microlaryngoscopy and bronchoscopy

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
Narowing.

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)
72 Oakridge
Thornhill
Cardiff CF14 9BQ
Tel/Fax 029 2075 5932
e-mail: actuk@hotmail.com

Makaton Vocabulary Development Project
31 Firwood Drive
Camberley GU15 3QD
Tel 01276 61390
Information on the Makaton system of sign language communication

The Speech Language and Hearing Centre
1-5 St Christopher Place
Chalton Street
London NW1 1JF
Tel 020 7383 3834
Fax 020 7383 3099
Minicom 020 7380 0350
e-mail: info@speech-lang.org.uk
http://www.speech-lang.org.uk
Assessment, nursery education and therapy for under 5s with hearing impairment or delay in speech, language or communication.

Contact a Family
209-211 City Road
London EC1V 1JN
Tel 020 7608 8700
e-mail: info@cafamily.org.uk
http://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
PO Box 50
York YO1 2ZX
Tel: 01904 621115
Text phone: 01904 658085
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
1st Floor
300 Kingston Road
London SW20 8LX
Tel 020 8542 4848
Fax 020 8542 2424
e-mail: enquiries@actionforsickchildren.org
http://www.actionforsickchildren.org
Supports families of sick children and works to ensure effective planning of health services for children.

ACE - Advisory Centre for Education
1C Aberdeen Studios
22-24 Highbury Grove
Highbury
London N5 2DQ
Tel 020 7354 8321
(Helpline Mon-Fri, 2pm-5pm)
http://www.ace-ed.org.uk
Guidance on Special Education and all other aspects of education

Network 81
1-7 Woodfield Terrace
Stansted CM24 8AJ
Tel 01279 647415
Advice on special needs education including assessment, statementing and negotiation with schools and local authorities
Great Ormond Street Hospital Contact Numbers

Ear, Nose and Throat Department
Great Ormond Street Hospital for Children NHS Trust
Great Ormond Street, London WC1N 3JH
Tel: 020 7405 9200

GOS Hospital telephone no.: ____________________________
Ward or unit: ____________________________
Ward or unit telephone: ____________________________
Lead consultant: ____________________________
ENT consultant: ____________________________
SHO (bleep): ____________________________
Social worker: ____________________________

Telephone: ____________________________
Fax: ____________________________
Bleep: ____________________________
E-mail: ____________________________

Speech & language therapist: ____________________________

Telephone: ____________________________
Fax: ____________________________
Bleep: ____________________________
E-mail: ____________________________

Tracheostomy nurse specialist: ____________________________

Telephone: ____________________________
Fax: ____________________________
Bleep: ____________________________
E-mail: ____________________________

Waiting list co-ordinator: ____________________________

Telephone: ____________________________
Fax: ____________________________
Bleep: ____________________________
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Other: ____________________________

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## Local Hospital Contact Numbers

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**Personal Stories**

Ella was born with a laryngeal cleft - a rare condition that means she has a hole between her airway and her oesophagus. Every time she tried to swallow, some of her food went into her lungs rather than her stomach. Ella was to have nothing by mouth until the repair and had a gastrostomy formed so that she could be fed. At the age of nine months, two months before her repair surgery, Ella had a tracheostomy. This was to enable her to breathe easily during the operation and afterwards while the site healed. Her mum, Suzanne, describes what happened:

“Once we'd got over the shock of knowing that Ella needed a tracheostomy, we just had to get on with it. After the operation, we soon found the hardest thing was the level of care she needs. Aside from the routine daily tape change and weekly tube change, Ella requires frequent suctioning both day and night. We go through about 100 catheters a day. We have to be constantly alert and ready to react. It can’t be put off - you have to do it there and then.

“Because we have so much equipment it’s very hard to get out and about. Even going to the park becomes a major expedition because of Ella’s regular suctioning. People often seem to stare when we’re out and they see her being suctioned. It seems a very normal thing to do while you’re in hospital but you realise when you’re out in your local community that it isn’t a normal thing at all.

“For us, the biggest help is the nurse who comes two nights a week to look after Ella. It means we can get a proper night’s sleep (or go out together!) which makes all the difference.
“As a family we have had to readjust our lives enormously. I had been planning to go back to work but that’s not possible at the moment. Martin (Ella’s Dad), who is by no means a natural nurse, has even learned to do the tube changes and all the suctioning!

“As for Ella, she did seem very subdued after the tracheostomy but she is coping really well. She looks rosy and well now, she’s putting on weight and she seems happy. She has just learned to roll over which was very exciting!

“Hopefully she will not have the tracheostomy long-term. She’s had her repair operation and once it has healed well we hope she will be able to be decannulated.”
Personal Stories

After 12 years, Kayleigh is used to her tracheostomy tube.

The first one was put in when she was just five months old after doctors diagnosed an extremely rare condition, recurrent respiratory papillomatosis (RRP).

The disease blocks her airways with non-cancerous growths or papillomas that develop constantly.

Although surgeons at Great Ormond Street operate regularly on Kayleigh to keep her lungs and bronchial tubes working, the papillomas are so widespread and grow so quickly that they cannot also remove them from her nasal passages and her throat.

Kayleigh is philosophical about the tracheostomy tube – and has some simple advice for others in her situation.

"Don't worry. It's got to be done."

She personalises the tube by changing the ribbon that keeps it in place to match her outfits. "It makes it look a bit prettier!" says her mum, Karen.

For Karen, it's vital to treat Kayleigh as normally as possible, despite her health problems. "I have absolutely no compunction about telling her off!" she laughs.

One problem the family has to deal with is the reactions of others to Kayleigh's tracheostomy. "Some people can be rude," Karen says. "Most of the time people just tend to ask what it is. You do get a bit tired of explaining sometimes."
in an emergency

Tube will not go in

Child seems OK?
Ring Community Paediatric Nurse or GP for advice or a visit or ring ward

Smaller size will not go in?
Cut off a piece of section catheter and insert. Ring 999 for ambulance. Try to slip trachy tube in over the catheter.

Child stops breathing

1. Call for help if someone in earshot.
2. Check if child is responsive.
3. Turn child onto back on firm flat surface.
4. Tilt head back slightly to expose trachy.
7. Look, listen, feel for breathing.
8. If not breathing, shout for help – get someone to dial 999. Do not leave the child alone. Commence basic life support immediately.
9. Give 5 breaths (either through trachy tube or direct to stoma if tube change unsuccessful).
10. Check for signs of recovery.
11. If no pulse, give 5 chest compressions.
12. Give 20 cycles of 5 chest compressions to 1 breath.
13. After one full minute of basic life support, phone for help if no one else has done so (dial 999).

Do not leave child alone, even if breathing returns to normal.
Do not stop resuscitation until the child recovers or professional help takes over.