Starship
Child Health

Tips for Daily Life

Tips For Daily Life

Siblings and friends

Showing your acceptance and comfort with the tracheostomy and/or ventilator helps others become comfortable with them. Talk about your child's tracheostomy with your other children and family. Speak about it in a matter-of-fact manner. Allow and encourage your other children to express their feelings.

Bring siblings to the hospital to visit as much as possible. Show them how you care for their brother or sister. They will feel part of things if you let them help. Younger brothers and sisters can do simple tasks such as handing you pieces of equipment.

Teach your other children how best to communicate with your child – how to read their facial cues, sign language (such as Makaton) or a picture-exchange-based system.

Friends coming over – supervise and support play, ensuring others understand not to touch or pull the trache. This is particularly important for other children who are under the age of five.

Hygiene – if hands are visibly soiled with dirt or body fluids you must use soap and water to clean your hands, washing them for at least 30 seconds. If hands are not visibly soiled, you can use an alcohol hand sanitiser to clean them.

Play

Play remains an essential activity in your child's life. They will be able to take part in most activities. If your child is a baby or toddler, check that all small toy parts or objects are cleared away so they are not accidentally put into the tracheostomy. Close supervision is required if your child is playing with materials such as sand (wet sand is recommended rather than dry). Having the tracheostomy covered loosely e.g. Swedish nose will also help during play.

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.

Car journeys and outings

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.

Cars should be fitted with straps to secure equipment.

Always take more supplies than you need in case your return home is unexpectedly delayed.

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Storage bag for outings

Suitably sized bag to contain only emergency equipment – have a separate handbag/bag for your own things.

Medications

Storage – think about access safety if there are other children in the house e.g. keep medication out of reach. Have directions for use on the wall/cupboard door where you store the medications as an easy reference and reminder.

Ordering – think about ways to track what you use and when you need to request more to ensure you always have enough medication for your needs. This is especially important around public holidays or planned trips away.

Routine for administration – have a routine for giving medication so that you don't forget to administer it.

Storage – Remember to store medications safely away from other children. Always keep cool medications in the fridge as per the pharmacy instructions. Always keep medications in the containers they come in so you know what they are and when they expire. Putting medications into other containers can lead to accidents with other children or yourself.

Ordering – Community pharmacies will need to order some medications in and this can take time. Keep a record of when you need to re-order medications and watch out for public holidays. A week's notice is advisable for most medications.

Bathing

Be prepared for the activity – supplies (suction machine), transitioning (assistance carrying items), room temperature and water temperature, distractions such as music or toys for waiting times, as bathing may initially take longer than previously.

Consider – are there things in the bathroom that could be removed to create more space?

Avoid use of aerosols and powders. Use a non-slip mat inside and outside the bath area.

By using a step or stool for the caregiver to kneel on, you can reduce any potential strain on their back when reaching over the side into the bath.

Use a bath chair inside or over the bath and consider if you need a specialist option for additional support.

Allow your child time to play in the water but continue to monitor to ensure water does not get into the tracheostomy tube.

Bathing (continued)

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.

Skin care

Mucus may collect around the stoma and tracheostomy tube. This is normal. Mucus attracts germs and is also very irritating to the skin. To prevent inflammation, infection and skin breakdown, the skin around the tracheostomy tube needs to be kept as clean and dry as possible. Follow the guidelines for care of the skin in the tracheostomy book that your health care team has given you.

Meal time

Having your child at the table with you is great for their development and is also part of normal family life. You will need an appropriate highchair or seating system, and you need to know how to get them out of the chair quickly. Have scissors available to cut straps in the case of an emergency.

If your child is cleared by the health care team to eat, they should never be left alone with food or a bottle in case they start to choke. Older brothers or sisters can help with feeding, but an adult must 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 a child 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.

Dressing and clothing

It is essential that your child’s tracheostomy is clear of their clothes or bibs at all times, even if ventilated. This is to ensure that their airway is clear and, if ventilated, that their connection can be observed.

Sometimes finding clothes that can be put on from the bottom up is easier than putting them over a child’s head, especially when tracheostomies are new. Suits for babies that open all the way down the front can be easier than tops that go over the head. Similarly for older children, tops that zip or button down the front can be easier to start with.

Avoid clothes that shed a lot of fibres as these could get into the tube.

If your baby or child has a mickey button/gastrostomy, please don’t cover it with gauze or padding to save clothes. If it is leaking, contact your homecare nurse who will resize it.

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Bedroom and sleep

Think about where you will want your child to sleep. Your child will need to sleep in his or her own room with a night time carer. The carer will need a chair and light; they will also need access to a bathroom and the ability to get a drink.

Bed placement – if possible, it's helpful to have both sides of the bed away from the wall to allow easy access from either side of the bed. If your child is in a crib, it's best if the crib has rails that lower on both sides. Try to put the bed near an electrical outlet so equipment can be plugged in.

Keep in mind that equipment will create additional noise and possibly warmth in the room where your child is sleeping.

Think about power outlets in the bedroom for the additional equipment.

Storage

Think about where you will spend most of your daytime hours when you and your child are at home. You will want to store supplies wherever you spend most of your day, as well as in your child's bedroom.

You may want to set up some type of portable supply container you can easily move around with your child.

Some parents store a few days' worth of supplies in an easy-to-reach area. The bulk of supplies can then be stored in an out-of-the-way area, such as on a wardrobe shelf or in a large plastic container that can be stored under a bed or in a wardrobe.

Storage Box, Kmart or The Warehouse and other similar shops have many options for drawers, shelving, hanging shoe storage racks that are cheap and effective ways of organising equipment so it's readily available at all times. These items can be personalised with stickers, posters and tags to suit your child's room or interests. Try not to make any drastic or expensive changes or purchases for supplies until you are actually home and caring for your child for a while – what you thought would be perfect might not work as well as you imagined.

We recommend arranging equipment so your most frequently needed items are easily accessible (e.g. top drawer) and together. Items that may be needed urgently should also be stored together in a place everyone knows where to find them.

Consider a stroller that has capacity to carry your child and all of the supplies, or one that has space for additional bags to be carried on it.

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Cleaning equipment

Most children only need normal household products to clean their toys and equipment. In the community there is no need to use hospital-grade cleaning solutions. Always follow the equipment cleaning guidelines and do not use anything that is not recommended.

A dishwasher can be used for equipment like syringes, bottles and toys for hygiene purposes.

Rubbish disposal

All used equipment, such as suction catheters, nappies, and old syringes, should be disposed of in the normal household rubbish. If there is any difference to this, your medical team will advise you.

Day care or school

You should get in touch with your child's intended day care 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 appropriate member of staff who works with children with additional needs. They may not necessarily have difficulty with learning, but without special provision (a trained carer) they cannot make use of educational provision. The trained carer does not have to be a nurse but must be trained fully in tracheostomy care.

Organisations such as CCS disability and the Ministry of Education will be able to provide additional support and advice related to this.

Community support networks

Talk to your homecare nurse/therapist, ask about other families caring for children at home with tracheostomies, and consider online networks to chat with families going through similar situations.