

The background features a large, light-orange triangle pointing downwards from the top left, and a large, light-blue triangle pointing upwards from the bottom left. These triangles overlap a white background. Scattered across the white background are small, light-grey dots. On the left side, there are overlapping geometric shapes in red, dark red, and blue. On the right side, there are overlapping geometric shapes in blue, red, and teal. The main title is centered in a large, dark blue, serif font.

Health Facts for You



**Support for you and your
child with a
tracheostomy**

This guidebook will help you learn more about support for you and your child.

Your Child's Development

Most children with special needs need more help reaching developmental milestones. Your child will have regular visits with physical therapy (PT) and occupational therapy (OT) to help reach these goals. Therapy focuses on helping your child to be as independent as possible for life outside the hospital.

Your child's PT and OT will create a program specific to your child's needs. The program focuses on:

- Taking part in developmental play.
- Tolerating or taking part in daily activities; like brushing teeth, bathing, getting dressed.
- Muscle and joint alignment.
- Promoting sensory and motor skills.
- Education for positioning your child.
- Helping you find resources for equipment; like seating for toilets, bathing, feeding and mobility.
- Helping you find resources in your community for follow-up.

As we create your child's developmental program, we teach you about the different activities and exercises we do. You need to take part in your child's therapy sessions. This is the best way for you to learn how to help your child achieve goals.

By the time you and your child are ready for discharge, you will know how to continue your child's program at home. We will suggest plans for follow-up which may include working with a Birth to Three program, school district therapy, or rehab clinic. We will work with you to decide which will be best for your child.

Speech and Sound with a One-way Speaking Valve

A trach tube often changes a child's ability to use their voice. Speech and sound are made when air passes the vocal cords. A trach tube enters the trachea below the vocal cords causing air flow through your child's vocal cords to be decreased. This is why your child may have a soft voice or no voice at all.

If your child has a trach tube, some sounds are possible. This is more likely to happen when the trach is uncuffed or when the cuff is deflated. It is often called an air leak. It is common for children to have a softer voice because less air is flowing through the vocal cords.

A speaking valve, also called a "Passy Muir Valve" or "PMV," can give your child a stronger voice. The valve works like a one-way swinging door. There is a thin membrane at the end of the valve that allows air to come in, but not go out. It then forces your child's breath to go up through the vocal cords and out the mouth during an exhale, allowing a voice.

Speech therapy, respiratory therapy (RT), and your child's doctor will decide when your child is ready to use a speaking valve. Your child will then need to have three 30-minute trials with RT and Speech present. Caregivers are taught after that.

If your child has trouble moving air through the vocal cords, help your child find other ways to communicate. Your child's speech therapist will work with you to improve your child's speech and language development.

Ways to Help

Whether your child can vocalize or not, it is important for your child to be interested in what is going on around them. You can do this by talking to your child, reading stories, and letting your child communicate in whatever way is possible.

Other ways to help:

- Use picture and symbol boards.
- If your child is able, use a paper and pencil to write things down or draw pictures.
- Use a computer or tablet apps with pictures and symbols that may also have an electronic voice to allow your child to “talk” using pictures.
- Teach sign language or gestures to help your child express needs.

Your child’s speech therapist will work with you to create a plan that works for your child’s abilities.

Once your child is able to go home, keep helping to improve speech and language skills. You may wish to contact the UW Health Communication Aids and Systems Clinic (CASC). This clinic helps children who are having trouble communicating. Your child’s medical team will help you create a plan that works for your family.

Planning for Care at Home

There can be many changes that you need to make at home to prepare for bringing your child home. This can include arranging your home, making space for equipment and supplies and your schedule.

Arranging Your Home

When you hear an alarm, you need to reach your child within 10 seconds. Check all rooms to make sure you can hear the alarms. In a large home you may not be able to leave your child in a room far from where you are. Using an intercom system to hear alarms may be helpful, if you are still within 10 seconds of your child. Other tips:

- Keep the pulse ox unit on a table or flat, stable surface. Keep it out of the reach of siblings or pets.
- Try wrapping the cable around a railing. This will prevent it from falling if it is pulled during sleep.
- Place the monitor near an outlet to avoid tripping over the cord.
- Keep a lamp or flashlight near your child’s bed. Used it to check your child at night if an alarm sounds.
- Keep a clipboard, flowsheet and pen nearby to write down when the alarm sounds.
- Have easy access to a phone and important phone numbers in rooms where your child spends most of their time.

Arranging Your Schedule

Every day things may make it difficult to hear your child’s pulse ox alarm. For example, taking a shower, drying your hair, or running the vacuum may prevent you from hearing the alarm. You may find it helpful to arrange your day so that you can do these things when someone else can watch your child or notify you of an alarm.

Skilled Nursing in Your Home

Children with trach tubes need special medical care throughout the day. Your child needs someone who is trained to take care of your child at all times. This can be hard for families to do without help from private duty nurses or home care nurses.

There are two options for private duty skilled nursing:

- Agency nursing
- Independent nursing

To start the home care process, the agency or independent nurse learns about your child and completes an assessment. They create a plan of care based on this and the doctor's orders. They submit requests for prior authorization to your child's insurance company. There may be a long wait for approval. For example, Medicaid can take up to 20 days.

Finding and Hiring Nurses

There are benefits and obstacles when finding a home care nurse through an agency or by doing so on your own.

- If using agency nurses, the agency screens, hires, and trains these nurses. Some families like this; others would rather be more involved in the process.
- Some families prefer to find home care nurses themselves. These nurses then apply to be hired and work for the nursing agency.
- Some families prefer to hire nurses who are not part of an agency. These are called "independent nurses or private duty nurses." You have control of who is hired to care for your child. If you choose this option, you need to do all the screening, hiring and training of nurses. One of these independent nurses will need to

act as your Prior Authorization Liaison (PAL).

Families often report feeling overwhelmed when trying to find good quality home care nurses no matter which option they decide to use. Although you may be approved or qualify for home nursing, it may be hard to find home care nurses in your area. Causes might include:

- Lack of transportation in rural areas.
- Lack of nurses trained to take care of children with a tracheostomy and a ventilator.
- Limits on insurance coverage.

Some families find nurses through word-of-mouth. Others use the Wisconsin Professional Homecare Providers website at <http://www.wisconsinphp.org>.

Home nursing agencies all work a little differently. Each has their own set of policies and rules. Know what to expect from them by calling the agency. This may help you decide if you prefer using an agency or independent nurses.

While it can be hard, there are some things you can do to help. You are more likely to have a good outcome by taking an active role in choosing a home care nurse and/or nursing agency. Take some time to think about what qualities you would like in your child's home care nurse. Some tips for interviewing nurses and nursing agencies are on the next pages.

Tips for Interviewing Nurses

If you decide to use independent nurses, interview those who apply. Be sure the nurse has proper training. They need to be tracheostomy and ventilator certified. Make sure to tell the nurse about the full range of your child's medical condition. This prepares the nurses you hire to be able to do a better job.

Other things to consider during the interview:

- Does the nurse come to the interview on time?
- Watch the interaction with your child. Is the nurse greeting or talking to your child? Is the nurse making eye contact?
- Do you have a gut feeling about whether the nurse will be a good fit? Or, is there something about this person that really bothers you?
- Are this person's values a good match with yours?

Questions for Interviewing Nurses

- Make sure they are qualified: Do you have a tracheostomy and ventilator certification? Do you have any other certifications that will help you in your job?
- Ask about their experience: Have you ever cared for a child with a tracheostomy or ventilator?
- General work history: What home health nursing experience do you have? What nursing experience do you have?
- References: Do you have any references from previous jobs? What is their contact information?
- Find out the length of commitment: How long do you think you will work here?
- Personality: Can you tell me about a time when you have had a conflict in your workplace? Can you tell me about a time when you had to be creative to make a situation successful?
- Hobbies or special interests: What do you like to do in your spare time?

Questions for Interviewing Nursing Agencies

- Are nurses hired specific for my child's case?
- How do you recruit nurses?
- How do you do background checks?
- Will there be specific nurses assigned to my child's case?
- Will the nurses assigned to my child have pediatric nursing experience?
- What skill level can I expect of the nurses caring for my child? Will they be RNs? LPNs? Will they be tracheostomy and ventilator certified?
- Will my child be assigned a primary nurse or do the nurses rotate? If they rotate, how often?
- Will I be able to meet the nurses before they start working with my child?
- What happens if a nurse isn't a good fit for our family?
- Expectations of nurses: Do they get breaks? Do they need to be awake when they are in our home? Are they allowed to smoke?
- What do I need to provide for the nurses (chair, desk, TV, refrigerator)?
- Are the nursing hours scheduled based on the needs of my child and family?
- How much input do I have to decide what hours are scheduled? Are the shift times flexible?
- How will I know which nurse is scheduled for the day?
- Does your agency guarantee shift coverage?
- What if there is a sick call? How soon will we be notified?
- How will schedule changes be related to us?
- Will the nurse be able to come with my child to appointments?
- Will the nurse go to events outside of our home?
- How do your nurses communicate with each other about my child?
- Will your company assist me in getting medical supplies and equipment?
- How do you create a plan of care for my child?
- How will your agency keep my family's privacy?
- How can I reach someone during and after business hours if I have concerns?

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 3/2024 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing HF#8274.