

### *You and Your Child*

- Trust your parental instincts. Take cues from your child. You do know your child best and what is best for your child.
- Allow your child to be a child first. It is easy to let the medical care and treatments take over your daily lives. Make a point to schedule fun time with your child.
- Appreciate the small things your child does. It does wonders for you, as a parent, to enjoy the smaller, less obvious accomplishments in life.
- As hard as it can be, carve out one-on-one time for your other children.
- Schedule relaxation time for yourself and also relaxation time with your spouse, partner, and/or friends.
- When other children approach your child with questions about his trach, embrace them and encourage the children to ask the questions. Adults are typically nervous and may react by drawing them away. Let the adults learn from their children. Help them learn about trachs and children with trachs and how it is just a different way of breathing. We are all more similar than different.
- Embrace your baby, not only emotionally but physically. When a child is in the NICU and all hooked up to tubes and wires, it can be frightening to hold your baby. It is important to hold them close to you and skin to skin as much as possible. Studies have shown that the body's stress level decreases, heart rate regulates, and respiratory status improves, all of which can help improve the health and recovery time of a baby/child.
- If your child needs to stay in the hospital for a long time, it could be helpful for the nurses to have some visible notes next to your child's bed that has a list of likes and dislikes, specific daily wishes you would like nurses to do for your child, cues of expression and what they mean if your child is nonverbal or hard to understand.
- If your child needs pureed foods, work with a nutritionist to have a good blend of nutrients and calories.
- Do not microwave any liquids or food if at all possible. It destroys some nutritional content and if plastic is used, some of the plastic chemicals stick to your food or liquid.
- Bring a small music player if hospital allows and play classical music or your child's favorite tunes. Music is great for brain development and can be very soothing or up-lifting.
- Consider alternative medicines and treatments. For example, homeopathic medicine, all natural products, essential oils, massage, acupuncture, reiki, shiatsu, cranial sacral therapy, etc.
- Remember to read, sing, play, give hugs and kisses and massages to your child. It's amazing what the human body knows and feels.
- Studies have shown if you massage the area of the body that will get a shot or needle, the stress level and pain will decrease.
- Use less antibacterial gel and more hand washing.

### *Working with Your Team*

- Everyone has the best of intentions for your child. Work with the team and never think of anyone as your adversary.
- When in doubt, ask and clarify with your child's care-taking, educational and medical team. Do not assume. No question is too silly or unimportant.
- Do your homework by searching online or asking someone who has been there. Knowing what you are talking about really helps when working with supply companies, insurance companies, caregivers, therapists, nurses and doctors.
- Spend time to work with your child's caretakers. Discuss your child-rearing philosophies and expectations and come to an agreement with your team. It is important to keep an open mind during discussions, but an agreement needs to be reached to maintain consistency for your child.



- Record a movie on any infrequent medical occurrences or occurrences that are hard to describe. "A picture is worth a thousand words."
- Start early to develop an organization process that works for you. At first, it may be easy to remember all the information. As time passes, relevant dates and salient details multiply at a rapid rate. Having an information input system in place is extremely helpful.

## ***B**uilding Relationships*

- Build good relationships with your child's caretakers, healthcare providers, therapists, teachers, staff and administrators at school. As Leslie Seid Margolis, Esq. from Maryland Disability Learning Center ([www.Wrightslaw.com](http://www.Wrightslaw.com)) writes: "Good relationships will generally ensure that issues you bring up will be taken seriously. Do not complain about every issue that comes up ...

## ***E**mergency Contacts*

- Put a list of emergency phone numbers in a visible place, preferably near the phone. Make sure frequent visitors know where it is. It will give you peace of mind.
- Make sure the local rescue squad knows you have a child at home with a trach. They usually keep a list of children with special medical requirements. Be sure to touch base with them annually.
- Discuss with your doctor to get a referral to obtain a handicap placard for your car when traveling with your child.

## ***M**edical Procedures*

- Follow universal precautions, particularly when the caretaker is sick. A mask should be worn and hands washed frequently.
- Use non-split 4x4 sponges to clean delicate areas like the eyes, nose, mouth, and around the trach area. They are soft and absorbent. You can get these from your medical supplies company.
- Always tell your child before suctioning to reduce anxiety.
- If your child has a g-tube, tape the med-port at night to avoid accidental opening and leaking all over bed.

- Before you go to a meeting, jot down questions you want to ask and points you want to clarify. If it is helpful, hand out notes. Include your child's picture in the notes if your child will not be present.
- Make time to say thanks to those who have gone out of their way for your family.

This is the equivalent of crying wolf, and ensures that when a serious issue does arise, you will not be taken seriously."

- Make friends with a therapist or a nurse at your medical supplies company. They are great resources to help you find the right equipment.

- Make sure the electric company has your home listed on their medical emergency list. They keep a list of homes with life-sustaining medical equipment. Call them as soon as there is a power outage. Don't assume that they already know. Let them know you are on the list and that you have medical equipment upon which your child depends. If possible, you will get priority service. They will also keep you posted of their progress.

- Discuss with your child's pediatrician to see if flu shots and synergis are recommended. Synergis is a vaccine against the respiratory syncytial virus (RSV), a virus that can cause bronchiolitis.
- If you can, provide breast milk for your child in the best way you can. According to the editors of Prevention Magazine in *Food and Nutrition*, one of a series of health books: "Early breast milk contains substances that bolster a baby's immune system to help fight off allergies and infections."

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### *Equipment and Supplies*

- Be relentless and persistent in pursuit of your child's healthcare or technology needs and supports. The "squeaky wheel does get the grease."
- Keep a non-cordless phone in your home that does not require AC power to work. In the event of a power failure, cordless phones won't work.
- Carry a cell phone with you at all times when away from home.
- Invest in a stroller that has a sturdy and roomy storage space for your equipment. A double stroller can provide the space and the convenience you need. You can use the front seat for the suction machine and the back seat for your child.
- Put a roll of paper towels in EACH bathroom and near the kitchen sink. Use paper towels instead of dishcloths, facecloths, guest towels, or hand towels. This practice will help prevent the spread of germs.
- Put a bottle of hand sanitizer and a box of tissue paper in EVERY room of your house, in the car and in your diaper bag, etc. Have everyone use them when hand washing is not available.
- Make sure you have a "To go bag" with all the essential trach supplies that you need in case of an emergency: spare trach, one trach a size smaller, scissors, extra trach ties, ambu bag, etc.
- Invest in a video-enabled baby monitor as the cry of a child with trach is often soft or not audible. These monitors work well even in a dark room.
- You can now easily put your child's vital medical information on a flashdrive and carry it with you at all times. Be sure to update frequently.
- Put your monthly order schedule on your calendar. The calendar will remind you when to place your order.