**Equipment:** What type of equipment would I have at home? For example: Ventilator on stand, stationary and portable suction, IV pole for feed, saturation/pulse oximeter, and nebulizer.

**Organizing the room and equipment:** Depending on the equipment and power outlets you can plan how you could organize the room. Plastic drawers with a hard top (so you can put heavy equipment on it) are always a good storage idea for all the durable medical equipment that you will receive in boxes. This way you can store your daily usage close by and put the rest in a storage cupboard. Don’t forget a table/desk and chair for nursing staff in the room or available nearby so they can do their charting/documentation. A table/desk lamp would also be a good idea, which can be dimmed or turned away from your child for nursing at night.

**Cleaning process and schedule for respiratory and GI equipment** (e.g. trach’s, nebulizers, syringes)
- Syringes can be washed with a dishwashing detergent and water.
- Tracheotomies can also be reused and instructions on how to clean these can be found inside the box, whether it is boiling water and/or a mild clear detergent.
- Nebulizer kits have to be rinsed with water after each use and then left to air dry. You can soak the kit in diluted vinegar (1:4) to clean the nebulizer kit. If you use the nebulizer daily it normally can last for 2 weeks; after that it is not as effective.
- Plan on developing a schedule with your nurse for cleaning of equipment, for example suction jar and catheter and changing of tubing.

**Calendar:** Display a visual calendar with appointment dates for nursing and you in the room. This is a good reminder.

**List of important phone numbers:** (fridge door/room on magnetic calendar board): First of all your telephone numbers and address, emergency numbers and then all the doctors, specialists, DME, nursing, therapies, insurance etc. You also might want to program all these numbers into your cell phone for easy access.

**Home hygiene e.g. hand washing routine and set up at sinks:** Always remember to let everyone wash their hands, so have soap and paper towels available to clean hands at every sink. Hand sanitizer in the room is also a good idea.

**Planning ahead for back orders from DME:** From time to time certain equipment will be out of stock or unavailable so therefore plan ahead and reuse.

**Traveling with equipment:** Initially going just for an appointment needs planning ahead. Make a list for example:
- Diaper bag -Remember to keep a copy of the Medical Discharge Summary and a list of current medications in your diaper bag for reference at your appointments.
Feeding bag
✓ Suction bag
✓ Medicines
✓ Emergency bags (Tracheotomy and GI supplies) - having 2 is a good idea, one for the house and one that you can leave in the car.

Ventilator and oxygen bottles should be secured or fastened in the car. You can use a crate on the floor in front of your child’s seat with bungee cords to help keep it secured and prevent it from falling.

When you plan on going away on holiday or vacation be sure to arrange in advance for medications and with your equipment company for feeding and equipment (e.g. liquid oxygen).

A few more tips that were very helpful as a parent:

- Make lists to prepare for discharge for example: paper towels, vinegar, hand sanitizer.
- About two weeks before discharge instead of discarding your child’s hospital syringes, start collecting them in a bag, wash them for reuse at home as they are good quality syringes which could be reused for several years. Also collect the little stoppers for the syringes which ease giving medication when you are out for appointments.
- Also collect the used medicine cups for your child; wash them so you can reuse to draw medicine up.
- Velcro straps (from home depot) are very handy to attach any kind of tubing (vent/feeding) to a stroller or wheelchair so it is not at risk of dragging on the floor or getting caught in the wheels.
- Remember to contact your electric company to inform them that your home would be a priority in case of electrical power failure.
- Ask your physician in advance if your child would be eligible for disabled parking.
- Contact your local police, fire department and first aid squad to let them know about your child’s special needs situation.
- If you are unable to complete above mentioned prior to discharge you can contact your primary care pediatrician for assistance.

This list of reminders might seem overwhelming, but just take one step at a time and all the preparation will be worth it!

Developed by Family Faculty and Staff