

## Bringing Your Medically Fragile Child Home

### Before You Come Home:

- Ask the hospital for one single piece of paper that has the contact information for your primary care doctor and all the different specialists who will be following your child after discharge, and when to call them. For example, who should be called if your child spikes a fever? Who should be called when your child is struggling for breath, etc. The hospital may give you individual cards, but a single sheet with all relevant contact information is much handier. Better still, suggest compiling a book/binder about your child and his/her special needs.
- Interview nursing agencies before making a selection. Find a company you feel comfortable working with that has a track record of specializing in working with medically fragile children. If you know your child has a medically complex condition and will need long-term nursing care, be sure to ask the agency if it will stay with you over the long term. Some agencies don't deal with long-term medical conditions and may drop your care depending on insurance coverage after a specified period of time.
- Encourage family members and friends to go through hospital training to provide suitable backup when needed. Better yet, identify key people who will be in the home consistently staying up-to-date on the care your child needs and how to administer the necessary care. Ensure that backup care providers are fully trained and ready to take on that responsibility. If someone is trained in the hospital then asked to help six months later, they may not remember what to do. This can be more of a danger than a help to the child and family.
- Make sure vaccinations are up-to-date before going home and ask for a copy of the schedule to keep in your personal records.
- Learn to work within insurance limits or find other payment options. At-home insurance coverage will be different than in the hospital and there will likely be extra expenses not covered by insurance. Contact your insurance provider before discharge for specifics about in-home care.
- Build your confidence before you go home by spending as much time as possible, including overnights, with your child under hospital staff guidance at the hospital.
- If the doctor has not suggested it already, ask if medication/feeding schedules can be safely rearranged to simplify the workload at home (for example, could an infant on electrolyte supplementation go from 4x/day to 3x/day or 2x/day?). While still in the hospital ask to adjust the schedules to the way it will be done at home at least one week before discharge. This will give you and your child time to acclimate.
- Have your home set up prior to discharge. Continuum helps families of high-tech patients sort through equipment and supplies so that you don't come home to a room that isn't ready or to boxes full of unfamiliar products.



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### Getting Adjusted At Home:

- For the first month, take as much skilled nursing hours as are available, 24-hour coverage if you can. This is when you will learn the most so request 24-hour coverage if there is even a slight chance you will get it. It is hard to get approval from third party payers to increase staffing, but easy to decrease staffing once you have achieved a comfort level.
- Consider rearranging your home to accommodate the nursing staff, the child, and the family. If the family has night nursing, it's nice to set up the child's room away from the parent's room, so that they are not awakened by noises from the equipment during the night.
- If possible, set up nursing staff with a separate access to the house so they can come and go and switch shifts late at night without disturbing the family. Some families use walk-out basements as the primary room to care for the child, creating a quiet and private setting and fewer interruptions for the rest of the family.
- Organize so that your child's room feels like a kid's room and not a hospital room. Arrange supplies and equipment in bins and drawers (plastic rolling bins with drawers are great). Put things under a bed or in a closet. Pre-organization helps you keep the area clean and helps you keep track of supplies so you do not over or under-order.
- Determine who will be case manager. Mom, dad, both, or a nurse? Continuum encourages you to have one primary point person responsible for all calls to the various physicians and home care companies and to order supplies. This ensures efficiency of insurance dollars, relationship building and continuity of care.
- Stable room temperatures help keep the child healthy. If central air conditioning is not an option, consider a window unit for the room where your child receives primary care.
- Don't expect the nurses to know everything about your child. You are the expert, orient them as much as you can and let them be helpful to you.
- Missed shifts will happen. Families have to learn to go with the flow and be prepared with contingency plans.
- Having a couple of main/primary nurses is best, but it's also important to have a few backup nurses who are familiar with your child and his or her care requirements. These nurses can serve as potential back-ups if shifts are missed.
- Give the nursing staff a list of "need to know" issues. For example, tell them if you wish to be awakened for fever or other signs or symptoms of an impending illness during the night.



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### Managing Your “New Normal”:

- Find time for yourself, whether it is alone, with your spouse, your other children, or outside the home with other friends and families. Make date nights and give each of your children one-on-one time with mom and/or dad.
- Having a technology-dependent child in the home is very stressful. Try to keep marital discord private. Make an effort to not involve the nursing staff, allow them to overhear arguments, or ask them to take sides.
- Take advantage of having nursing staff in the home to find time to do other activities as a family while they care for your child.
- Communicate expectations with the nursing staff. Each family needs to decide on boundaries early on and keep communicating (where nurses should park their vehicles, can they use the refrigerator or should they bring lunch in a cooler, can they use kitchen appliances, or a separate bathroom). If something isn't working, make changes so the family can maintain some level of privacy.
- Try using a “Communications Book.” Nurses and family caregivers make notes throughout the day and as shifts change, nurses can read through the book to see how the child is doing or if anything has changed since they were last in the home. This ensures everyone is on the same page, plus parents can use the book to communicate something they might feel more comfortable putting in writing (e.g. reminding all the nurses to please be careful about cleaning up after themselves or to be more careful as they are in someone's home).
- Address any concerns with nursing. Don't let issues fester and jeopardize your relationship. If you are uncomfortable directly confronting a nurse over a certain issue, ask her/his supervisor.
- Understand that personalities may clash. You may be able to overlook that, but if there is a nurse in your home you know will not work with your family, ask the nursing agency for a replacement.
- Seek support. Communicate with other parents in similar situations. Make use of other community resources. Request contact with other families working with Continuum. At the same time, take your medically fragile children out in the real world. As long as they are stable and not in danger, allow you kid to be a kid. Learn how to adapt and function under your “new normal.” Don't let their unique challenges allow you to forget they are children and that the flexibility to do things together with the family is one of the best things about being at home.

