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*Statewide Parent
Advocacy Network*

Empowered Families: Educated, Engaged, Effective!

Surviving a Hospital Stay with your Child with Special Needs...and After!

Night Shift... & general child stress

- Once your child is recovering, the nurses may only check on the child once an hour. Each time your child is moved to a new room, find out who will be with the child at all times if you're not there. There are different staff people that can help the child depending on their needs. Remember, if your child has special needs, they may require extra care, especially overnight.
- You may need to set up night nursing at home depending on the needs of your child. Even if it's in the discharge plan, set up the actual schedule with the agency *before* going home. Also, you should appeal if insurance says it's not covered, so you need to get the denial in writing, not just over the phone.
- Another thing to keep in mind is the fear any child would feel if they are in an unfamiliar setting and don't understand what is happening to them. Hospitals also usually have "Child Life" departments which will help your child if they're scared about a procedure, especially if they have special needs. They'll come in with puppets or dolls and show the child what to expect.

Discharge-Going Home

- Make sure you have as much in place as possible and a written "discharge plan" (what your child needs at home) with instructions on how to best care for your child. Review the plan with the nurse and/or doctor and be sure to clarify anything you don't understand. Don't be afraid to ask as many questions as you need to ask to feel confident about going home!
- There are practical things you can do. If your child will be on many medications or it's difficult to get to the drugstore, set up pharmacy home delivery. Make sure before you leave the hospital that you know how to give the medications and if there are any side effects. If your child was already on medication before, ask if you should still give it to him/her. Ask if there is anything like food that would affect medications. You can also use an online tool to create a medicine chart (and also bring a copy for doctor visits), a pill organizer, and a checklist to fill it.
- Other practical ideas are things like whether or not your child can have a bath or shower, and if not, what to do (no rinse soap or shampoo), and if so how to do it (how to wash around stitches or staples).
- Make sure your child has no problems with the usual bodily functions such as going to the bathroom, eating, etc., before leaving the hospital.
- Ask if your child's diet needs to change.
- Find out if there's anything they'd like you to keep track of at home such as blood pressure, weight, temperature, measuring intake/output, etc. and that you know how to do this and have the equipment at home. For example, you can get a digital scale and ask the pharmacy for help with a blood pressure cuff, quick thermometer like the one the nurses use, etc., and actually get everything before leaving the hospital.

Insurance

You may need to figure out which insurance (private, Medicaid, Medicare) covers what.

- Your private insurance is usually first.
- Medicare is usually second. Part A covers hospital stays; Part B covers clinic visits and immunosuppressive drugs. Part D is the prescription plan. If your child is a “dual eligible” (Medicaid/Medicare), Medicare automatically enrolls the child in the prescription plan. Be careful to check with the Human Resources Department at work because Part D could cancel private prescription and health insurance. Also, if you have Part D, Medicaid will put your child into a “limited benefit pharmacy wraparound program” which only covers certain medications. Parents must call both Medicare to opt out of Part D and also disenroll by calling the actual prescription plan.
- Be prepared to prove you legally can make decisions for your child if s/e is 18 or over, which is important because otherwise they won’t give you information or let you speak on your child’s behalf. You may have to send them documentation such as guardianship or power of attorney. NOTE: Medicare, SSI, Medicare Part D plan, Medicare Coordination of Benefits all need this separately because the systems don’t link. The Medicare national number (open 24 hrs.) and SHIP (State Health Insurance Program) Medicare counselors are very helpful.
- Medicaid is always the “payor of last resort” which means they are billed after either private and/or Medicare. *Helpful Hints on Medicaid:* If your state is switching from traditional “fee for service” Medicaid to managed care, make sure you get to choose and don’t get “autoassigned” to an HMO. You need to check if each doctor, not just office or hospital, is listed as a participating provider in the HMO. If your child gets care outside of your state, you may also need to get a Medicaid “out of state authorization”. Also, pharmacies aren’t included in the out of state authorization so stay local for medications. Be aware that even pharmacies that do take Medicaid fee-for-service, may not accept Medicaid HMOs.
- Don’t pay bills until you’ve checked that all insurance was billed first.

Home Instruction

Besides a doctor’s note, you may need your doctor to fill out additional paperwork. Parents may also be asked to sign a HIPAA (health information privacy) release form so you need to decide if you want the school to have access to all of your child’s medical records or just some, if any, and for what time period. Also it may take some time for the school to set up home instruction so give them as much notice as possible beforehand in writing, especially if the surgery is planned and you know the dates you’ll need. If you have concerns setting up home instruction, contact your Parent Training and Information Center.

Resources:

Medication tools

www.mymedschedule.com

National Medicare Office

www.medicare.gov or 24 hr. hotline (800)633-4227

SHIP (State Health Insurance Assistance Program) Counselors for Medicare

www.medicare.gov/contacts/search-results.aspx?customresult=AllSHIP

Centers for Medicaid/Medicare “Who Pays First” guide on insurance (private/Medicaid/Medicare)

www.medicare.gov/Publications/Pubs/pdf/02179.pdf

Parent Training and Information Centers (special education)

www.parentcenternetwork.org/parentcenterlisting.html

Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.