



Complex Child E-Magazine

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Creating a Care Notebook for Your Child

by Susan Agrawal

As parents of children with complex medical needs, we are experts in the day-to-day care of our kids. But there are times when our children must be left with relatives, friends, respite workers, or nurses who know little or nothing about their care. A sudden illness, a car accident, or a death in the family are just a few unfortunate occasions that may require our children to stay with a friend or relative. While we hope that events like these will never occur, we need to be prepared if they do. One of the best ways to prepare is to create a Care Notebook with all of your child's information in it.

I began my daughter's Care Notebook a few weeks before I was due to give birth to her little brother. During my hospitalization, my daughter was to be cared for by her out-of-state grandparents, who had not had much experience handling her medical needs. Her Care Notebook contained detailed instructions on her medications, her feedings, her doctors, how to operate her feeding pump, and how to handle emergencies. It made what might have been an extremely difficult situation much simpler.

Over the years, my daughter's Care Notebook has expanded to more than 50 pages as her needs have increased. It contains everything from how to troubleshoot her IV pump to a list of where her medical supplies are stored in the house. It has been an invaluable resource for us, her nurses, and even her doctors.

The American Academy of Pediatrics (AAP) is currently sponsoring a Medical Home Initiative [<http://www.medicalhomeinfo.org/>], describing a medical home as "a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care." As part of this Initiative, the AAP recommends that all children with special needs have a plan of care for both their medical and non-medical needs. Certain doctor's offices that focus on children with special needs, often called Medical Home Practices, will help you to develop a care plan or Care Notebook. Unfortunately, most of us do not have access to these sorts of medical practices and must create our own Care Notebooks.

In creating your own Care Notebook, the most important form to include is the standard AAP emergency form for children with special health care needs. It can be downloaded as either a PDF or Word file, and the Word version can be filled in on the computer and updated as needed. It is available here:

http://www.medicalhomeinfo.org/tools/emer_med.html Copies of this document should be stored in the Care Notebook, in each car, in the diaper or nurse bag, at school, at the

pediatrician's office, at the local emergency department, and on file with Medic Alert if your child wears a Medic Alert decal.

To create the remainder of your child's Care Notebook, you can use a pre-designed template or develop your own forms based on your child's needs. My favorite template was developed by CoACH Care Center, a respite and transitional care facility for children with complex medical issues in Naperville, Illinois. Their Medical Home Care Organizer contains detailed sections on family, medical history, home care needs, financial and insurance information, emergency information, and education. All forms may be downloaded off of their website as PDFs at:

<http://www.coachcarecenter.org/coachcarecenter/coachcareplan/careorganizer/index.htm>

Additional Care Notebook templates may be found at:

<http://www.medicalhomeinfo.org/tools/assess.html> and

<http://www.medicalhomeinfo.org/tools/coordinating%20care.html>

If you do not wish to use a template, you can create your own Care Notebook from scratch. My daughter's Care Notebook, for example, contains or has contained the following sections:

- Emergency Information
- Emergency Medical Form
- Emergency Plans for Seizures, Sepsis, and Anaphylaxis
- Daily Schedule
- Current Medications
- Current Feeding/Infusion Schedule
- Daily Nursing Needs
- Central Line Care
- Daily Routine
- Therapy Routine
- Equipment Descriptions and Instructions (Positioning Chair, Wheelchair, Stander, etc.)
- Computer and Communicator Instructions
- Cognitive and Fine Motor Activities
- Bathing
- TPN Preparation and Pump Use
- GJ-button Care and Use
- Feeding Pump Use
- Medication Preparation
- Formula Preparation
- Suctioning Instructions
- Cathing and Foley Placement
- Vomiting, Seizures, and Illnesses
- Braces
- Location of Supplies
- Supply Order List

- Important Phone Numbers
- Insurance Information and Copy of Insurance Cards
- Medical History
- Medical Consent Forms

Your Care Notebook will of course be different, customized to your own child's needs, but should include the same sort of information.

Keeping a physical notebook that you can take with you to appointments is very important, and it can also be a good idea to store this information on a portable device such as a USB Flash drive. This allows you or Emergency Medical Services to have immediate access to all of your child's information. You can even add test results, X-rays, and other medical reports to the drive. Some groups, including Medic Alert and the home health agency Nutrithrive provide their clients with these devices either for free or for an additional charge.

While I have used my daughter's Care Notebook almost daily since its creation, its true importance was demonstrated when my child went to the Emergency Room with rapid-onset sepsis. She was very sick and I was very scared, too frantic to remember some of her most basic medical history and care information. I was able to hand her doctors a list of her medication doses, her medical history, and even instructions on how to access her central line. Not only did this cut down dramatically on the time needed to go through all of her medical history, but it enabled me to provide accurate and detailed information despite my worried state.

In my opinion, an accurate and updated Care Notebook is one of the most important things your child can have. I hope that this information helps you to create one.