

## What is a Care Notebook, and What Belongs in One?

A Care Notebook is a good place to keep all of your child's health care information. Bring it with you to every appointment and update the information as needed after visits with medical specialists and x-rays or laboratory tests. Examples are available on the web site of the [National Center for Medical Home Initiatives](#) (care notebook).

If you are maintaining some of your child's health information on your home computer, make sure to update it after each visit and print a current copy to place in the Care Notebook for the next visit with your child's primary care provider or medical specialist.

Keep the following information in your Care Notebook:

- A copy of your child's care plan
- Information about current services
- Allergies and Immunizations
- Emergency Information Form
- Reports from service providers
- Information on hospitalizations and emergency room visits . Results of tests and procedures
- Forms, for example a medication log or seizure log.
- Family information

### Your Child's Care Plan

The Family and Physician Management Plan is one example of a Care Plan. It is constructed to invite information from families and also provides a "checklist" to remind physicians about the clinical issues to address for a given diagnosis. It includes some of the health information you should keep in the care notebook. Most importantly the care plan is an action plan. It will identify what needs to be done, by whom and when. We have included the management plans for children with developmental delay, cerebral palsy, cleft lip and palate, autism and ADHD. Links to other examples of care plans are available from the [National Center for Medical Home Initiatives](#) and the [Center for Medical Home Improvement](#).

### Information about Current Services

- Health Care Providers (Primary Care, Specialists and Dentists)
- Mental Health Services/Providers
- Educational Services
- Other community services/providers (for example, the speech pathologist and community health nurse)
- Medications (If your child is taking several medications regularly, you may want to use the medication log)
- Special Diet/Procedures (for example, gastrostomy feedings)
- Equipment (for example, braces or wheelchair)

- Complementary/Alternative Treatments (for example, herbal or homeopathic treatments)

**Allergies:** Record medication, food and environmental allergies, such as latex.

## **Immunizations**

### **Emergency Care Management Form**

The [American Academy of Pediatrics](#) (AAP) and the [American College of Emergency Physicians](#) have developed the [Emergency Information Form](#). Instructions for parents on how to complete and use the form are available at <http://www.aap.org/advocacy/epcparent.htm>. This form should be updated with each change in service and each time your child's care plan is updated.

### **Reports from Service Providers**

Request copies of reports from office visits with health care professionals; copies of your child's IFSP, IEP or 504 plan; school progress reports and any testing done by educational staff. Make sure you keep your copies of reports in the Care Notebook so that this information is readily available to share when needed. Include reports from:

- Medical Specialists
- Mental Health Providers
- Educational Staff, e.g., Early Intervention/Early Childhood Special Education (EI/ECSE) Providers
- Other Community Providers

### **Results of Tests and Procedures**

- X-rays procedures
- Laboratory tests

### **Surgeries, Hospitalizations, Emergency Room Visits**

Request copies of the reports describing surgical procedures, hospital discharge summaries and emergency room chart notes for your Care Notebook. Please list the name of the surgical procedure, the primary reason for the hospitalization or the issue addressed at the emergency room visits.

#### **Surgical procedure**

- Over-night hospitalization
  - Number of days and issue addressed
- Emergency room visit
  - Issue addressed

## **Family Information**

This information will enable your child's health care provider to address the issues that you may think are important for your child and for the family. It may include health issues as well as other issues such as your child's participation in activities at school and in the community.

*Your assessment of your child's progress/accomplishments:* In general, how is your child doing this year compared to last; a lot better, a little better, the same, a little worse or a lot worse? If you rated your child a little or a lot worse, what are your specific concerns? Did he or she achieve the goals that you identified at his last well child visit? Specific data forms may be helpful to you in monitoring your child's progress, for example, a daily behavioral, seizure or toileting log.

*Your goal for the next 6-12 months:* Identify 1 or 2 specific, realistic goals that you would like your child or family to achieve; for example, walking without a walker, participating in field trips at school, and involving an older sister in a sibling program.

*Your Questions:* Identify 1 or 2 questions that are your highest priority to have answered at this visit. Review the Guidelines of Care and the Management Plan for your child's specific condition. The Guidelines of Care provide a brief review of clinical issues at each age, diagnostic tests as well as potential treatments and referrals. First review the Guidelines of Care and then complete your portion of the Management Plan including the 1 or 2 questions you would like to address at that appointment.