

## **Care Coordination Toolkit (Care Notebook) Introduction**

<http://www.health.ri.gov/family/disability/SpecialNeedsBinder.pdf>  
<http://www.medicalhomeinfo.org/tools/Downloads/UTCareNotebook.pdf>  
<http://cshcn.org/planning-record-keeping/care-notebook>

### HOW TO USE YOUR CARE NOTEBOOK

#### *What is a Care Notebook?*

Being the parent of a child with special health care needs can feel overwhelming at times. Your child may need care and services, on a regular basis, from many different types of providers. This Care Notebook was designed to help you keep track of and organize important information about your child's health and healthcare.

#### *How can a Care Notebook help me?*

In caring for your child with special health care needs, you may get information and paperwork from many sources. A Care Notebook will help you organize the most important information about caring for your child in a central place. A Care Notebook makes it easier for you to find and share key information with others who are part of your child's care team.

#### *Use your Care Notebook to:*

- Store emergency information about your child and family.
- File information about your child's health care history.
- List telephone numbers for health care providers and community organizations.
- Track changes in your child's medicines, treatments, and health condition(s).
- Keep track of medical appointments and conversations with healthcare providers.
- Share new information about your child's care with doctors, school or daycare staff, and others caring for your child.
- Track expenses related to your child's care.
- Create and monitor goals for your child. (if we add in these components)

#### *What are some helpful hints for using my child's Care Notebook?*

- Store the Care Notebook where it is easy to find.
- Add new information to the Care Notebook whenever there is a change in your child's diagnosis, treatment, or development.
- Consider taking the Care Notebook with you to appointments and hospital visits so that information you need will be close at hand.

- Rather than carrying the entire Care Notebook to your child's appointments, you may consider using a folder to carry individual pages of the Care Notebook.

*How do I set up my child's Care Notebook?*

1. Gather information you already have about your child's health
  - This may include reports from recent doctor's visits, a recent summary of a hospital stay, names and phone numbers of physicians and hospitals, this year's school plan, test results, or informational pamphlets
2. Decide which information about your child is most important to keep in the Care Notebook and file it in the appropriate section.
  - Which of these pages could help you keep track of information about your child's health?
  - What information do you look up often?
  - What information do others need for your child?
  - How can you organize the Care Notebook so it will be most helpful to you?
  - Choose the pages that you like. You can either print copies of any that you think you will use and fill them out by hand, or download a copy and save it to your computer so that you can easily update the pages in the future. *(can update this bullet once a final format is decided for our Care Notebook)*
3. Put your Care Notebook together.
  - Everyone has a different way of organizing information. The key is to make it easy for you to find the information you need. Some supplies that may be used to create a Care Notebook include
    - 3-ring binder - hold papers securely
    - Tabbed dividers - create your own information sections
    - Pocket dividers - store reports
    - Plastic pages - store business cards and photographs
4. Update your Care Notebook regularly.
  - Identify which forms require updating.
  - Add information to the Care Notebook as it becomes available. For example, if you receive new information from health care providers, update the appropriate pages. Keep track of your child's condition(s) on a regular basis. Log phone conversations with providers, and track expenses related to your child's care.