

How To Use Your 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 maintain an ongoing record of your child's care, services, providers, and notes. It is also a way to maintain the lines of communication between the many service providers that help care for your child and family.

Health professionals recommend that parents/caregivers bring this notebook to all medical appointments, therapies, care conferences, on vacations, etc. Health professionals can encourage the use of these notebooks by either having them available at the first office visit, upon discharge from the hospital, or in the waiting room on a resource table. This notebook should be a team responsibility. Medical offices can support families by copying visit notes, immunization records, and doctors' reports and then giving them to families to insert into this notebook.

How Do I Set Up My Child's Complete Care Notebook?

- ♥ Care Notebooks are very personal to your child and should be customized to reflect your child's medical history and current information. Remove pages that are not useful to you and your child.
- ♥ 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, hospitals, and relatives, or test results. Store business cards in a plastic holder after Tab #3.
- ♥ Decide which information about your child is most important to keep in the Care Notebook and file it in the appropriate section.
- ♥ **UPDATE** the Care Notebook regularly. Extra copies of Care Notebook pages will be available for download from the Family Voices of Alabama website www.familyvoicesal.org.
- ♥ **ADD** information to the Notebook as it becomes available. For example, if you receive new information from health care providers, update the appropriate Care Notebook pages. If tests results are available electronically, request a DVD to store in the provided holder just after Tab #4. Keep track of your child's condition(s) on a regular basis including updating medication changes. Log phone conversations with providers using either the "Doctor's Visit Notes" (found within Tab #4 section) or the "Appointment & Questions Log" (found within Tab #5 section).
- ♥ Track expenses related to your child's care. Store receipts, bills, etc. in a clear pocket added to the back of the Care Notebook. This is especially useful to track out-of-pocket expenses for tax purposes.