



Children with disabilities stemming from brain injuries such as hypoxic-ischemic encephalopathy (HIE) can often require documentation from many parties. These parties can include:

- Doctors and Therapists, who keep track of medical records
- Government programs, which can provide services and funding for disability-related and Early Intervention programs
- Schools, which keep track of Individualized Education Plans
- Other parties

Documentation of the care of a medically complex child can be daunting, so organizational strategies are needed to keep track of appointments, consultations, medications, therapy and other needs. Maintaining a care notebook helps parents evaluate a child's progress, easily retrieve documentation when requested, and help reconcile insurance requests and tax credit reimbursements.

Developing a 'Medical Care Notebook'

There are many ways to document a child's health and development history, but some medical professionals recommend the development of a 'Medical Care Notebook,' a comprehensive running document of all of a child's care. To print out and look at an example of a complete care notebook, please see this [sample care notebook](#) (PDF download). Each family will organize information slightly differently, especially given the varied nuances of a child's given medical conditions. Generally, however, important information includes a child's diagnoses, medications, prescriptions, allergies, emergency contact information, and receipts and documentation of health care expenses.



A quick note regarding medical records, one of the crucial components of a complete care notebook: depending on the state, hospitals and medical care facilities are only required to keep records for a set number of years before they are destroyed or placed in off-site record storage. This can range from 3 to 10 years, but guidelines vary vastly from state-to-state. To ensure the child's records are complete, parents can ask for copies of their child's records when a doctor is explaining test results or prescribing treatment. If the doctor points out information in charts, graphs, or test results, you can request a copy to 'put in your child's medical file' so you have it handy when needed. Otherwise, getting records can take weeks and even cost an additional administrative fee, in some cases. The parents of a minor legally have the right to view, copy and amend their child's medical records. Any individual can do the same with their own records. These records can be obtained through a hospital's or medical facility's records department. In very limited circumstances, physicians may withhold access to medical records, but this situation is fairly unusual. If a patient gets a denial for their medical records, a reason should be provided to them.

Sample Medical Care Notebooks

If parents prefer a digital record of their child's medical notebook, there are [apps](#) designed specifically for this purpose, including [Andaman7](#) (Free), [CareSync](#) (Price varies), [iBlueButton](#) (\$9.99), [Medical e-Folder](#) (\$1), and [Microsoft HealthVault](#) (Free).



Learn More About Record-Keeping

- [Tips for Handling Medical Records for Medically Complex Children](#)
- [Center for Children with Special Needs: Planning and Record Keeping](#)
- [Care Notebook Web App](#)
- [Printable Care Notebook 1 \[PDF\]](#)
- [Printable Care Notebook 2 \[PDF\]](#)

Sample Care Notebooks and Forms

- [Printable Care Notebook 1 \[PDF\]](#)
- [Printable Care Notebook 2 \[PDF\]](#)
- [Printable Care Notebook 3](#)
- [Printable Care Notebook 4](#)
- [Printable Care Notebook 5](#)
- [Printable Care Notebook 6](#)
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