

A **Care Notebook** is an organization tool for families who have children with disabilities or special health care needs. The notebook is used to keep track of important information about a child's healthcare. Some programs provide families with notebooks, some families purchase Care Notebook software, and some create their own. For these reasons ASK decided to focus on the parts of a Care Notebook rather than one specific product.

The content details of a Care Notebook depend on the individual child's needs, yet there are some topics all notebooks should contain.

### Care Notebook Sections

- Contacts
- Emergency Information
- Medical
- Related Medical
- Medication
- Insurance and Waiver
- Medical Equipment
- School

### Contacts

This section is a list of the "go-to" people that you need. Provide information like "this number is a direct line to the nurse at the doctor's office". Think if your mobile phone wasn't available, does someone have the names and phone numbers to cancel an appointment? The key is to put information in one accessible place so grabbing one notebook will be all you have to do to be organized.

*One goal of a Care Notebook is to provide another person the necessary information to care for your child.*

### Emergency Information

This section should be more than phone numbers. Provide an emergency plan. Details are the difference! List everything that needs to happen in steps—first do this; then this. Think about possible interventions to prevent a trip to the hospital. Share information such as, "If you see this -- it could mean -- next, do this --".

Place copies of the list of current medications, including over the counter medications and supplements in this section. It is a quick way to give emergency responders the information they need.

Another successful strategy is a non-emergency planning meeting. For example, if your child has a medical condition that might require immediate transport to the hospital, meet with local first responders to provide your child's medical information before that happens. Include doctor orders and/or medications needed to have if ever called to your home.

### Medication Information

Keep in mind, this is your child's medical history in progress. Make sure past lists of medications are still in your notebook along with the current list. Label them clearly. This way, providers know the medications already tried, dosages and any side effects.

Include over the counter medications taken by your child including vitamins, enzymes, etc.

Each medication entry should include:

- Name of the medication and dosage
- Name of prescribing doctor
- Why the medication prescribed
- Reactions or side effects
- Date the medication was started and end date
- Instructions how to take (with food, at bedtime, etc.)
- Number of doses per day and times
- Medication fact sheets
- Number of refills available
- Any need for extra bottles such as for school, and
- Dosage directions other caregivers will need.

## Medical Information

It is useful to have space to keep notes after each doctor visit. Record questions and updates. Ask your questions, and write down the answers. Have the following questions handy in your notebook, and be sure you can answer each before you leave:

- What is my child's primary issue or problem?
- What do my child and I need to do?
- Why is it important to do this?

Allergies and immunization records can be included in this section.

**Dental Care** The dentist's name and contact information. Note any special circumstances, such as "needs to be asleep for teeth cleaning".

**Vision Care** List the provider's information. Include diagnosis, vision condition and/or any lens prescriptions.

**Tests & Procedures** Record the dates of tests or procedures along with the outcome. Record the outcome and any follow up that is required including who is responsible for the follow-up. Make notes on any improvements or changes you see. Make copies of recent medical bills to clarify procedure information.

## Related Medical Information

This is a good place to record specialist appointments, services, or therapies your child receives and any notes. Record basic information about your child and the appointments. Are there things that can be done to make the visit go smoothly? What pre-visit information or picture symbols will help your child?

Other types of information to include in this section:

**Specialists** Record any tests needed before a visit and answers to your questions at each visit.

**Private therapy** Record all types of therapy such as speech or physical therapy used, the contact and basic information for each.

**Counselors** List names and contact information about mental, behavioral or emotional health counselors on your child's team.

**Medical Home** Record any Medical Home information. A medical home is not a place it is a team approach to your child's care. Record the names of the team members, their role, contact information, and any "go to person".

**Care Coordination** Is there a Care Coordinator involved in your child's care? Ask questions so you understand the role of the care coordinator. A Care Coordinator is a broad term that can mean different things. A coordinator may be part of the medical team or their role might be related to the payment resources such as insurance, Medicaid, or managed care. Write down names, contact information, and the agency or company of each Care Coordinator. Ask questions to understand the role of each one - It makes you a smart health care consumer!

## Medical Equipment

This is the section to list all the equipment your child uses. Take a photo of the serial numbers on the equipment and add it to your notebook. Include a copy of the billing statement from when the equipment was purchased—this helps if you ever need to order a replacement part.

**Insurance Information** Copy both the front and back of all insurance cards, and tape them in this section. The cards will be handy when calling to get prior approval or have a question. If your private insurance is through an employer you may have an Employer Benefit Administrator (EBA). EBAs can be very helpful answering questions about your insurance. Record their name and contact information. Remember, it is possible your insurance company provides a Care Coordinator. If so, list their name and contact information also. In this section, record information about any other insurance coverage your child may have:

- List each insurance plan covering your child.
- Know if your child is eligible for Medicaid. If yes, know if you met income eligibility guidelines.

### Waiver Information

Is your child eligible for Medicaid because of a Home and Community Based Service (HCBS) Waiver? If so, be sure to ask questions to understand which waiver meets your child's needs. Iowa has seven waivers available for children. Each waiver offers different services. Descriptions of each are available at <https://dhs.iowa.gov/ime/members/medicaid-a-to-z/hcbs/waivers>

In Iowa, your child could be on Medicaid Fee for Service (MFS) or receive Medicaid through a Managed Care companies (MCO). Copy the front and back of your child's **IA Health Link** card and tape it in this section. You should also receive a **Member Handbook from your MCO**. Each MCO also provides "value added" services. These services vary by company and can be useful. They include items such as a free membership to a gym. Make sure to ask about and write down these services. All of the MCOs assign a case manager to your child. Learn who that is and write down their name and phone number. This person can be an important health advocate for your child.

**Medicaid Waiver Programs** can cover items such as diapers and formula for children age four and older. Record the company providing those items, along with contact information. Include notes about how to order supplies.

**Daily Care Plan** This is your child's daily routine and detailed care plan. Break down the day starting with your child's wake-up routine, and what needs to happen. This includes, toileting, medications, teeth-brushing, food, and other details about their likes and dislikes. Include things that soothe your child such as a favorite toy, and how you correct or redirect your child.

### ASK Essential Questions

Have I recorded all of the information necessary to care for my child?

Do I have it gathered in the same place

**Related ASK Resources** available at [askresource.org](http://askresource.org):

Looking for Health Care in Iowa