



Personal Health Record (PHR) Notebook

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Think of a care notebook as a 1-stop shop containing everything that family, doctors, therapists, and care team would need to know about your care. A notebook is simple and easy to carry. Physicians and health care providers keep medical records to better understand a patient's prior care and to help inform their decision for treatment plans. Developing your own system for organizing medical information, or creating a personal health record (PHR), will help you stay on top of doctor's visits, medications, and insurance claims. Providing your own medical records may help you receive safer and quicker treatment if you change doctors, move, or end up in an emergency room.

When deciding how to organize medical paperwork for yourself or another as a caregiver, developing a system that works best for you and is easy to transport, store, and update is vital for your success. A three-ring binder with clear dividers to easily locate topics is portable and should be kept in a specific area of your home. Ensure key family members and caregivers are aware of its location. If you have the capability, make duplicate electronic copies of scanned or photographed documents and save them on your computer to mirror the organization of your paper files, or use a software tool made specifically for medical documents.

Your PHR Notebook should contain:

- The first page of your personal health record should include your name, date of birth, blood type. Record names, medical practices, addresses, telephone numbers, and email (if applicable) of your doctors and pharmacist. Include the emergency contact information of a caregiver, family member, or friend in case of an emergency. Include the name, policy number, address, and telephone number of your health insurance company and a table of contents.
- List providers, including the office medical staff assigned to the doctor as your contact person. This may be a nurse or medical assistant who triages calls and patient portal communications. They may be able to assist you directly or pass the information to the doctor to address directly. Some doctor prefer patients use the patient portal to expedite communication. Include provider's address, telephone number(s) and extensions if available, and fax numbers.



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- Pharmacy address, phone, and fax.
- Emergency Treatment protocol from your Neurologist and stated diagnosis.
- Medications and supplements: Document the drug name, dosage, frequency, start date, end date, and the condition it is treating, plus any side effects experienced.
- Medications you are allergic to and other allergies.
- Immunization records.
- Hospital discharge summaries.
- If you're a caregiver and requesting records for someone other than yourself, facilities will only release them if a direct authorization to disclose records to a third-party form is signed by the patient. Most requests can be fulfilled within 5-10 business days; however, HIPAA (Health Insurance Portability and Accountability Act of 1996) allows providers 30 days to complete a record request, plus a single 30-day extension.
- Let your doctor know you're creating a personal health record. Your doctor, or designated staff, may be able to help you find your medical records online, at hospitals, or other healthcare facilities. Doctor visit summaries and notes should include a disc copy of your chart which you will ask for annually. Make sure you keep the disc updated either from onset to present or from the date of the end of the previous disc. Ask that all studies e.g. EEG, MRI, any scans, be included. The after-visit summary you receive is not as detailed as the doctor's notes. The doctor's actual notes are far more detailed than a visit summary and can make a difference to a new doctor attending your case. Update your chart disc annually.

If several facilities are involved, contact medical records at the facility where an imaging test was performed and request the MRI, EEG or scans to be burned on a disc for your personal records. Sometimes there is a small fee for the cost of a disc. Some discs can be duplicated while you wait. Some discs may require mailing. The importance of having a copy of your most recent scans available is that it allows you to provide them to a new doctor. For example, an ER attending at a facility other than the facility where the scan was done, or a new doctor for a second opinion. Your copy allows a new doctor access to the most recent results which expedites your care. If you have an appointment with a new doctor and copies of your records were ordered to be transferred to their office prior to your appointment but never arrived, your copy avoids delays and the financial burden of having a scan redone. If you or your loved ones have certain lab tests done regularly, this record will enable you to



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track changes from year to year and ask informed questions. Taking your notebook with you to all doctor visits advances your care. This section should include notations of the last appointment and scheduled follow-up appointment. Get in the habit of requesting a copy of the doctor's notes when making a follow-up appointment. Again, these are vastly different and more detailed than a typical visit summary. They are usually sent in the mail. Doctor's notes are included in the disc copy you will be requesting annually. Your health notebook can speak for you when you are unable to remember clearly. Because supplement medical records from other facilities or providers on your team may take weeks to transfer, keeping copies of records as they accrue will help expedite your care.

- A family health history (particularly parents, siblings and grandparents)
- A personal health history (conditions, how they're being treated, and how well they're controlled, as well as important past information such as surgeries, accidents, and hospitalizations). If you can recreate a timeline of your whole medical history this will be helpful. Some keep this electronically as an email file that can be easily accessed.
- Pharmacy printouts that accompanied prescribed medications. In a study, 40 percent of patients were unable to name a single medication.
- Insurance forms related to medical treatment.
- Legal documents such as a living will and medical power of attorney. POA and emergency contacts with a written release of information for the people who may assume your care.
- Create separate sections for labs, specialty, and a daily journal that will read as a timeline
- For students School strategies, IEPs, 504 plans, and contacts.
- The journal should have the date, symptoms, medication changes, daily vitals if you keep these, accidents, and other pertinent information to the patient.
- Copies of articles of interest.