

## Managing Your Medical Information

If you have a serious illness, you'll see multiple doctors: your primary care doctor (usually an internal medicine or family practice physician), a specialist, and perhaps a surgeon. You'll have lab tests and Xray exams and take new medications. You might have a hospital stay or be seen in the emergency room. Each of these encounters and experiences creates important information about you, the state of your health, and your care.

Managing this information is one of the most important things you can do to make sure that your health care is smooth and effective. It's not a difficult task. It just takes attention, some planning, and a little knowledge about what kind of information is important.

### **A place to keep it all**

As soon as possible, designate a notebook as your 'personal health record': your PHR, for short. Think of your PHR as a diary where you record—either by hand or by including copies of other documents—everything significant about your health. Every time you go to see a doctor, have blood drawn, go for an Xray exam, or fill a prescription, take your PHR with you.

Starting now, get in the habit of thinking every day about whether anything happened that you need to record. There will likely be many days when nothing comes to mind. But, if you begin now to make this a daily habit, you're less likely to omit important information.

### **What goes in your PHR?**

- *A list of your medications.* At the top of the first page of your notebook, write down any medications you know you're allergic to. Underneath, record all the medications you're currently taking. Copy the name and dosage from the label on the bottle, exactly as it's written. If you're taking over-the-counter medications, record those here, too. Every time you start or stop a medication, record it. If you stop a medication because you've had a bad reaction to it—a rash or nausea, for instance—make sure you record the reason on this page, too.
- *Your health history.* List your past medical events and surgeries, with dates. Approximate dates are fine. If you list them in reverse chronological order—from the most distant to the most recent—you can simply add new events or surgeries to your list as they occur.
- *Test results.* When you have blood drawn or have an Xray, a CAT or PET scan, or an MRI, record it here. Ask the doctor who discusses the results with you if you can have a copy of them.

- *Pathology reports.* Biopsy results and cell examination (cytology) reports go here. Again, you can ask for copies of these reports to include in your PHR.
- *Hospitalizations.* Record the reason for each hospitalization, your admission and discharge dates, and the treatments or procedures you received. Before discharge, ask for a copy of your history and physical (H & P), scans or other radiology exams, consultants' notes, and the most important lab tests. If you're not sure which tests are most important, ask your nurse or doctor. Each time you're hospitalized, a physician—intern, resident, or your attending—will create a discharge summary, which gives a quick overview of the course of your hospital stay. Your primary care doctor should receive a copy of the discharge summary, and you can ask him or her to make you a copy for your PHR.
- *Consultants' notes.* It's common for you to see several consultants during the course of your illness and recovery. These might include medical specialists, like cardiologists, endocrinologists, or gastroenterologists, and surgical specialists, like breast surgeons or neuro surgeons. Make notes about each visit—what the consultant did and said and what recommendations he or she made to you. If you've seen a consultant while you're in the hospital, ask to have a copy of the notes. If you see a consultant as an outpatient, request that he or she send a letter summarizing your visit to your primary care doctor. Ask your doctor for a copy of the letter.
- *Contact information for all your doctors.* Include current phone numbers and addresses for your doctors.
- *Your own notes.* Make notes about each doctor's visit: what you discussed, what your doctor recommended, and what the two of you decided to do. Also, if you experience new symptoms, make a brief note in your PHR. For instance, record your temperature if you run a fever. Record your blood sugar if you're monitoring it. It's far better to have too many notes than not enough.

### **Using the Internet**

The Internet is an increasingly important source of health-related information. Some of the information you'll find there is reliable—but much of it isn't.

Here are some strategies for using the Internet to find useful information:

- Before you log on, decide what you're looking for. Do you want information about diagnosis, treatment, support groups, managing side effects, clinical trials, national experts, or something else?
- Once you have a goal for your search, stick to it. Resist surfing for hours, jumping from one site to the next.
- If you notice that reading information on the Internet is increasing your anxiety, stop.
- Choose the sites that you visit carefully. Check with your doctor about sites he or she recommends for reliable health information.

**Ask,ask, ask**

An important part of managing your medical information is making sure you know everything you need to. Particularly in the early days of your illness, you may feel intimidated or overwhelmed by the sheer volume of information you're receiving.

To partner effectively with your doctor in your care, you need to understand the information you're receiving. If you don't understand something your doctor says, ask for clarification. If you don't understand the answer, ask again. It's OK to ask your doctor to repeat information until you comprehend it.

Take notes during visits to your doctor. Even if you understand everything you hear, it's easy to forget important details once you leave.

If you've located information on the Internet, bring it with you to your doctor's visit. Discuss it there. Some health-related information on the Internet is trustworthy; some isn't. Ask your doctor to explain anything you don't understand.

Managing your medical information is a critical part of getting good health care. The more you understand about your care and the more information you make available to your doctor and other health care professionals, the better your health care—and your health care experience—will be.

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