

## **Navigating the Health Care System**

When you have a serious illness, you interact with the health care system much more than you did before, often in a variety of new settings. Here are some tips you'll find useful as you move from one to another.

### **Your doctor's office**

- Before your visits: Write down any questions so you remember to ask them all.  
Prioritize your concerns so your most important ones get addressed if time is short.  
Make sure your doctor has what he or she needs: lab tests, reports from any consultants you've seen, etc.  
Bring all your medications—or a current, accurate list
- During your visit: Bring someone with you to take notes  
Consider using a tape recorder, but ask your doctor's permission  
Ask lots of questions: about the differential diagnosis, side effects of any medications, treatment options, etc. If you don't understand the answers, ask more questions until you do.  
Stand up for what you want, but be willing to negotiate  
Get copies of your test results and consult notes  
Make a return appointment before you leave

### **In the emergency room**

Early in your course of treatment, discuss with your doctor when you should go to the emergency room. Some typical reasons include: fever when you're receiving chemotherapy or your counts are low, uncontrollable pain, bleeding, or severe constipation.

Before you leave for the ER:

- Be prepared that you might be admitted to the hospital
- Pack wisely, making sure to take all your medications, your personal health record, and any items you find comforting (pillows, blanket, food, etc.)
- Bring someone with you
- Expect a long wait, so bring something to do (book, knitting, etc.)

In the ER:

Assume nothing. The ER staff doesn't necessarily know that you're there or have been waiting to be seen. They may not be working on your case while the clock ticks away. That medication might not be the correct one. The staff may not know about your allergy to penicillin. The young doctor who seems so nervous just might not know what he or she is doing, especially in July and August when the new doctors have just graduated.

If you feel ignored, speak up.  
Find out if the ER or the ‘floor doctor’ is responsible for you  
Keep someone with you if possible  
Ask about every medicine before it enters your body  
Be extra alert at change of shift time  
Ask questions:  
“What is that medicine for?”  
“What did the tests show?”  
“Are you an intern? A resident? What year?”  
”When will I see the attending physician?”  
”What do you think is wrong with me?”  
”What other diagnoses are you considering?”  
Most of all, *don’t be afraid to speak up!*

### **In the hospital**

Whether your admission to the hospital is planned or unexpected, one of your highest priorities will be knowing who’s responsible for your care. Find out which service you’ll be admitted to: intensive care, surgical, medical, oncology, or hospitalist. Ask who will be making the decisions about your care while you’re in the hospital and whether any specialists will be consulted.

If you are admitted to the hospital from the emergency room:

Find out if a bed is available immediately. If not, ask who’ll be watching over you until one is. If so, are your admission orders written?  
Ask who will be your primary resident or attending physician. This may be different than the doctor who admits you.  
Find out what the plan is for your care. What are the goals for the next 24 hours? What are the goals for your entire stay?

In the hospital:

Know who everyone is who enters your room. If they don’t identify themselves, ASK. Write down the names of the doctors who examine or speak with you.  
Keep someone with you as much as possible  
Insist that everyone wash their hands before touching you or your tubes.  
Ask about every medication before you swallow it. Don’t take a new medication unless your doctor mentioned it to you.  
Ask your doctor if you can take your regular medications—stool softeners, antidepressants, anti-anxiety meds. If so, make sure they get ordered.  
Find out when rounds occur. Ask to have bedside rounds so that your doctors and nurses discuss your care with you present, as opposed to in the hall or a separate room.  
If your nurse says that he or she will call the doctor, make sure it happens.

Make sure your doctors talk to each other. For instance, if a resident or intern mentions a test result, ask what your attending physician thought about it.

Involve your primary care doctor. Call him or her from your hospital bed.

Ask that your attending physician or resident call your primary care doctor with an update on your condition.

When you're being discharged:

Make sure you understand your discharge medications. Compare them to the list of medications you took before being admitted. Are there any new ones? Be sure you know what they're for, how to take them, and for how long. Have any medications been stopped? Make sure this is intentional and not an oversight. Understand why they were stopped. As soon as possible, update the list of medications in your personal health record to reflect any changes.

Ask for a copy of your hospital discharge summary to be sent to your primary care doctor.

Ask for a copy of your history and physical (H & P) and copies of any important lab or radiology tests. Include these in your personal health record.

Whether you're in your doctor's office, the emergency room, or a hospital bed, the most important thing you can do is ask questions. Beginning as soon as you're diagnosed, seek information, clarification, and explanations. If it feels awkward or you're concerned that you're being a pest, keep at it, anyway. You have a right to understand your health care and to make sure that everything that happens to you contributes to your well being.

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