

The Patient's Companion

A pocket guide to understanding your healthcare



Introduction/Goals

Healthcare can be confusing. Tests, treatments, diagnoses, insurance. It's a lot. And it sure doesn't help that despite their best intentions, patients and healthcare workers often seem to be speaking different languages—and sometimes actually are.

Consider this book the Rosetta Stone of healthcare: a tool to help patients communicate their wants and needs in a way their care team can understand.

The Patient's Companion covers common healthcare topics like what to do if you're told you have a chronic (long-term, often incurable) disease or when and how to get a second opinion. (Hint: It's OK if you want to ask someone else!)

Our hope, along with the many teams of patients and healthcare workers who helped us write this, is that if everyone can communicate better, healthcare itself will work better too.

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Our promise to our patients

Promises we as members of your healthcare team will make to you

- We promise to remember you are sick and may be scared.
- We promise to listen to you and make you feel heard.
- We promise to answer whatever questions you have.
- We promise not to use “medical speak” whenever we can.
- We promise to remember that you are the expert about your body and the person with the most information about you.



My promise to my care team

Promises we as patients will make
to the rest of our healthcare team

- I promise to ask questions if I do not understand something.
- I promise to be honest and trust you will not judge me.
- I promise to speak up if I disagree with something you said.
- I promise to follow your advice or be honest if I don't think I can or will.
- I promise to remember you are people too.

Meet Your Care Team

You (the patient) and your loved ones are the center of your healthcare team. Here are some of the other people you may meet at the hospital.



ANESTHESIA

Nurse anesthetists give you anesthesia (drugs that numb pain) and manage your care during surgery, under the supervision of a physician anesthesiologist.



CASE MANAGEMENT TEAM

Social workers and case managers work with your insurance company and help your care team plan for services you will need after you leave the hospital, such as home care and rehabilitation.



CLINICAL TECHNICIANS

These assistants may run medical equipment, collect samples, perform tests, and help your caregivers in other ways.



ENVIRONMENTAL SERVICES

Environmental care associates clean and disinfect your room.



HOSPITALISTS & SPECIALISTS

Hospitalists are doctors who manage your inpatient care. You may also see a *specialist* or consultant who helps your hospitalist with part of your care.



IMAGING TECHNOLOGISTS

When your physician needs to look inside you with a scanner (think X-ray, MRI, or CT scans), these professionals position you for the best pictures.



INTENSIVISTS

These physicians manage your care if you are in an intensive care unit (ICU). They work with specialists, surgeons, and your primary care physician.



NURSE PRACTITIONERS & PHYSICIAN ASSISTANTS

These medical professionals work closely with your attending physician to manage your care in the hospital 24/7.

More of Your Care Team



NURSING ASSISTANTS

These medical professionals help you with basic daily activities like eating and bathing, and other healthcare needs.



NUTRITION

Dietitians use food to manage disease or malnutrition. *Dietary staff* deliver your food at mealtimes.



OCCUPATIONAL & PHYSICAL THERAPISTS

An *occupational* or *physical therapist* can help you relearn to do things on your own through special exercises and training.



PHARMACISTS

Pharmacists advise on medical prescriptions, ensure they are filled correctly, and help you use your medicine safely.



PRIMARY CARE PHYSICIAN

Your *primary care physician* (family doctor) is who you see for checkups or when you're sick.



REGISTERED NURSES

These nurses care for you in the hospital and direct the care that other nursing team members provide.



RESPIRATORY THERAPIST

This specialist helps you breathe better.



SPEECH LANGUAGE PATHOLOGISTS

If you have trouble swallowing while eating or drinking, this therapist can help you strengthen your throat muscles.

Here are some things you should know about me.

My name: _____

My preferred language(s): _____

My sexual orientation: _____

My gender identity: _____

My race/ethnicity: _____

My religion: _____

My family members: _____

“Social drivers of health” are things that can affect your health but have nothing to do with your medical history, such as whether you have access to a computer or have trouble getting to or from the doctor.

You might feel uncomfortable sharing certain things with your care team, but remember: They’re here to help you! And the more information they have, the easier it is for them to do that.

For example: Maybe you’re embarrassed because you don’t have access to a computer. But if your care team knows that, they can just print out any information you need.

These are some things that are really important for your care team to know.

- **Food insecurity:** *“I do not always know where I will get my next meal.”*
- **Housing insecurity:** *“I do not always have a place to sleep inside every night or I often move from place to place.”*
- **Interpersonal safety:** *“I do not always feel safe at home or around people I know.”*
- **Transportation:** *“I do not always have reliable transportation to get me to my doctor’s appointment.”*
- **Computer access:** *“I do not always have access to a computer or the internet.”*
- **Phone access:** *“I do not always have access to a phone.”*
- **Pharmacy access:** *“I do not have a pharmacy close to where I live.”*
- **Designated primary care physician:** *“When I need a doctor, even if I’m just not feeling well, I do not usually see the same person.”*

If any of these are true of you, talk about it with your care team. They can only help fix problems they know about.

How can I help my care team make the right diagnosis?

? Questions for my care team:

- What is my diagnosis? What else could it be?
- Why do you think this is my diagnosis? From test results? From my physical exam?
- How can I have a health problem if I don't feel sick?
- How/where can I learn more about my diagnosis?
- Are there any tests that could confirm the diagnosis or rule out another likely diagnosis?
- What are the risks to the test you want me to have? What happens if I do nothing?
- How urgent (time-sensitive) is the test?
- How or when would we know if this might not be the right diagnosis?
- How can I help my care team know if this is the correct diagnosis?
- When do I need to follow up with you?



I don't feel well.
What do you think I have?

It could be a few things.
Let's run some tests to find out which one it might be.





What to Know: Diagnosis Is a Process

Sometimes it can be difficult to know right away what is wrong. Think about trying to tell whether you have a cold, the flu, or allergies.

Your care team is trying their best to find the answer as quickly as they can. Sometimes that means running tests to rule out some possibilities (“process of elimination”).

The more information you give them, the easier it will be for them to figure out what might be making you sick.

Sometimes your healthcare team uses “medical speak” without realizing you may not understand what they’re saying. It’s OK to ask them to explain any words you aren’t sure of!



The Companion’s Companion: Tips to Help You Help Your Loved One

Your loved one just received a diagnosis of a health problem and wants to make sure it is correct. How can you help? What can you do?

Encourage the patient to keep a diary, or keep one for them. If their symptoms don’t get better or if they change, tell the care team!

Make sure your loved one gets any tests or scans their care team suggests. Those tests give clues to what may be wrong.

I was just told I have a chronic condition.

Now what?

? Questions for my care team:

- What symptoms could I have right now?
- How will this condition affect my health in the future?
Examples: Will I be able to have children? Will I develop new allergies? Will this make it easier for me to get sick with something else?
- What members of my care team do I need now? What members of my care team may I need in the future?
- What medications may I need? What side effects might they have? Can someone update my medication list?
- If I notice a new symptom, do I call my doctor right away?
- What are you going to do to help me (my treatment)? What will my treatment look like?
- How bad is it? Will this affect how long I live?
- How can I contact my care team? And when?



We have the results of your test, and it looks like you have high blood pressure.

OK... I have some questions.
Actually, a lot of questions.





What to Know: Chronic Conditions

“Chronic conditions” is a general term for conditions or diseases that last at least a year and need ongoing medical care and/or affect your daily life.

Some common chronic conditions are high blood pressure (“hypertension”), diabetes (sometimes called “bad blood” or “high blood sugar”), heart disease, or low iron levels in your blood (“anemia”).

Even if you have a chronic condition, you should always see a doctor if you have any of these symptoms: coughing up blood, shortness of breath, chest pains, or signs of a stroke (sudden numbness or weakness in a body part, confusion, difficulty communicating, vision problems, dizziness, trouble walking).



The Companion’s Companion: Tips to Help You Help Your Loved One

Your loved one has just been told they have a chronic condition, now what?

- Remember, one of the most difficult moments for someone is being told they have a serious, possibly lifelong disease.
- Take notes! When you’re with the doctor or at home with your loved one, one of the most helpful things you can do is write down any important information or questions you may want to ask later.
- Keep a diary of symptoms or encourage them to so they can share new information with their doctor:
 - *What is the symptom? How does it feel?*
 - *When did it start?*
 - *How often does it happen?*
 - *Do you notice any patterns before it starts? Does it always happen around the same time? After eating the same foods?*

What is sepsis?

How can I prevent it?

What if I think I might have it?

? Questions for my care team:

- What is sepsis? (See box on the next page.)
- How might I know if I have it? What are the symptoms?
- How can I prevent sepsis?
- What should I do if I think I might have it?
- What should I do if my symptoms worsen or change, or I don't respond to treatment?

Remember: You can get sepsis from any infection, such as the flu, or even something that seems harmless, like a cat scratch or splinter. It's always important to tell your care team if anything out of the ordinary has happened to help them figure out if you have sepsis.



I didn't mention it before, but my cat scratched me yesterday.

Could that be why I don't feel well?

Yes, it could. If the scratch is infected, that might mean you have sepsis.

Let me run some tests.





What to Know: What is Sepsis?

Sepsis (sometimes called “blood poisoning”) is when your body goes haywire trying to fight an infection. This extreme response can be life-threatening, but the sooner your care team finds it, the easier it is for them to treat it.

Sepsis can be difficult to diagnosis because a lot of the symptoms are “nonspecific,” meaning they are similar to symptoms of other diseases. (Think how hard it can be to tell the difference between a cold, the flu, or allergies!)

However, these are the most common ones, so tell your doctor if you have any of them: fever, feeling extra tired (“fatigue”), nausea, or a fast heartbeat.



The Companion’s Companion: Tips to Help You Help Your Loved One

How can you prevent your loved one from getting sepsis—or make sure it’s treated as quickly as possible?

Please encourage them to share any new symptoms, even if they’re not sure what the cause is.

Urinary tract infections (UTIs) are common in elderly patients. However, they are often difficult to diagnose. Family members often notice the symptoms first. If your loved one doesn’t make sense when they speak or seem confused, seek immediate medical treatment, or if they are in the hospital, tell their care team right away.

What's in my medical record?

Why is it important that everything in it is correct?

How can I fix a mistake if I find one?

? Questions for my care team:

- I want to make sure the information in my medical record (“chart”) is correct. How can I get a copy?
- What medications does my chart say I’m taking and how much (“at what dose”)?
- What allergies (such as to food, medication, or the environment) are listed in my chart?
- What does my chart list as my medical history?
Examples: past illness (“diagnosis”), surgery, pregnancy.
- There’s a mistake in my medical record. It says, “. . .,” which is incorrect. How can I make sure the information is fixed?
- Who has access to my chart? How can I give someone access? Keep someone from having access?
- Do you have a patient portal and how can I access it?



It says in your chart you are currently taking benazepril for high blood pressure?

I am not. I’ve also never been diagnosed with high blood pressure. **How can we correct the information in my record?**



What to Know: What Is a Medical Record?

A “medical record” is also called a patient chart. It keeps track of all the information about your health. This includes your medical history, medications you take, what languages you speak, and other things your care team needs to know about you.



It is really important for everything in your chart to be correct. Ask your nurse or doctor for a copy and let them know if you find a mistake.

Many health systems have an electronic medical record you can access from a phone or computer. This is commonly called a “patient portal.”

The Companion’s Companion: Tips to Help You Help Your Loved One

How can you help make sure your loved one’s medical record is correct?

- Always keep notes of any important information and bring it with you to their appointment.
- If you or your loved one finds a mistake, note what it is and who is responsible for fixing it. The next time your loved one is with that care team member, make sure that the mistake has been corrected.

I want to see my doctor, but I'm afraid.

What can I do?

? Questions for my care team:

- I'm afraid of needles but I want my medication. Are there any other options?
- How could my condition or diagnosis affect my family? I don't want to burden them.
- What home health services are available to me after I leave the hospital? I'm afraid I will be on my own.
- I have a question about something that is important, but it isn't exactly the same as my disease ("social drivers of health," see page 8). Who can I talk to about it?
- What kind of financial support is available?



I live alone. I'm afraid of what will happen when I go home.

There are home health services that can help.

We will put you in touch with a case manager.





What to Know: It's Normal to Be Nervous

Many people are nervous to see their doctor for lots of reasons: fear of needles, fear of being unable to pay their bill, fear of hearing bad news.

Talk to your doctor if you're feeling anxious. You shouldn't let feeling afraid keep you from getting the care you need.



The Companion's Companion: Tips to Help You Help Your Loved One

Your loved one is nervous about going to the doctor. That's perfectly normal. However, don't let them avoid going to the doctor for fear of what they might hear.

Not all news is going to be good. But bad news today could be worse news next month.

I would like to get a second opinion.

Is that OK?

? Questions for my care team:

- I'd like to get a second opinion. How do I do that?
- Would a doctor in a different specialty (area of medicine) offer me a different option?
- Will my insurance cover the cost of seeing another doctor?

Remember: You might feel nervous about getting a second opinion, but it's very common in medicine! This is especially true after a big diagnosis like cancer or if your doctor suggests a major operation.



I'd like to get a second opinion.

OK. This is a big decision and it's a good idea to know what all your options are and pick the best one.





What to Know: It's All Right to Get a Second Opinion

Things like surgery or a big diagnosis are major life events. So it's OK to want a second opinion.

Would you buy a car without thinking about all your options? You would do your homework and make sure you choose the best one for you.

Just because two doctors disagree, that doesn't mean one is right and one is wrong. Sometimes, you just need to make your decision based on things like how long it will take you to get better ("recovery time"), what kind of ongoing care you might need, or how much it costs.

Even if two doctors give you the same advice, at least you know that it is probably the right decision.

Remember to tell your doctor if you have seen another doctor about the same thing.



The Companion's Companion: Tips to Help You Help Your Loved One

Your loved one is thinking about getting a second opinion. How can you help?

Remind them that it's OK to get a second opinion.

Bring your notes to their next appointment to give the new care team as much information as possible.

What is an advance directive, and why do I need one?

? Questions for my care team:

- What is an advance directive and why should I have one?
- How do I make an advance directive?
- What happens if I don't have one?
- My loved one lives in a different state. Are the laws the same for both of us?



A living will? Do I really need one of those?

Yes. Advance directives make sure your care team knows what you want even when you can't tell them.





What to Know: There Are a Few Different Kinds of Advance Directives

Living will: A living will is a legal document that describes what types of care you would want if you are unconscious or have a terminal illness.

Durable power of attorney for healthcare (DPA): A DPA names someone to make medical decisions for you if you are unconscious or unable to make decisions on your own.

Physician orders for life-sustaining treatment (POLST): If you are diagnosed with a serious illness, your doctor may fill out a POLST to make sure you get the care you want.

Do not resuscitate order (DNR): Your care team will always try to help if your heart stops or you stop breathing. Tell your doctor if you would prefer for them not to try.

Other advance directives include ventilation (mechanical breathing), tube feeding, palliative (comfort) care, and organ donation. You have the right to decide which, if any, of these things you want.



The Companion's Companion: Tips to Help You Help Your Loved One

Advance directives are important because they help make sure someone's wishes are carried out even when they may not be able to speak for themselves.

Ask your loved one if they have an advance directive, and encourage them to make one if they do not.

Remember: You have a voice. Use it.

Communicating well is one of the hardest things to do in any circumstance. This is especially true in healthcare. We hope this guide helps you feel like talking to your care team is a little easier and that your care team can understand you a little better.

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