

***How to Get Best Care – As an Outpatient  
(when not in the hospital)***



**by Carolyn Oliver, M.D., J.D.**

Helpful advice from both her first book,  
“Cautious Care: A Guide for Patients,”  
and also from her new book which will be published in 2012,  
“Balancing the Doctor-Patient Relationship: Getting What You Need”



## **Outpatient Best-Care Checklist**

This is a list of all of the topics in this chapter. You don't need to read this list now. I just want you to have it in the future so you can run down the list and make sure that you still remember everything.

### **Outpatient Best-Care Checklist**

- \_\_\_ First obstacle to get past in the doctor's office
- \_\_\_ Have more than one illness to discuss?
- \_\_\_ Worsening or changing symptoms after you've seen the doctor
- \_\_\_ Beware of the "it's-all-in-your-head" diagnosis
- \_\_\_ Test results: no news is *not* good news
- \_\_\_ The problem with after-hours phone calls to your out-of-the – office doctor
- \_\_\_ Phone calls to the doctor when he is in the office ("reassuring telephone calls")
- \_\_\_ Breast lump evaluation: the triple assessment protocol
- \_\_\_ Asthma treatment
- \_\_\_ Procedures and operations: think before scheduling
- \_\_\_ Stuck with a certain doctor or clinic?
- \_\_\_ Preventing illness
- \_\_\_ When you have some questions for your doctor: advice on *participating* in your office visit
- \_\_\_ Odds and end: advice that's not from a doctor; vaccine records

## First obstacle to get past in the doctor's office

Be cautious in a doctor's office that has the nurse interview you at the beginning of your office visit, and she writes some things down for the doctor before the doctor comes in. Chances are she will not write down everything you tell her, and she may not use *your own words*—both of which may be important for your correct diagnosis.

Some doctors do this because an x-ray or lab test can be ordered right away, and would need to be done before the doctor makes a diagnosis, and that makes sense. Also, if you have a pretty simple problem like just a sore throat, there may not be any harm in this approach.

But other times, it can be a “shortcut” for a doctor who really should be hearing all of your symptoms himself, but he thinks this is a time-saver. When that is the case, and your doctor doesn't take the time to ask you himself what the problems are, then that's a red flag that he's having to move too quickly to really do the “best” by you.

If you need to test this theory to prove that it's true, next time you're in a doctor's office where the nurse asks what's wrong, and you tell her the story like you usually would—notice how *little* she writes down. And then if the doctor isn't coming in and asking for all the details, make sure you say to him “there's more that I need to tell you.”

Another problem with this approach is that if the nurse listens to you and then writes down things in *her* own words, then that can set the doctor up for an error in diagnosing your illness. Why? Because authorities on making correct diagnoses say that *why* you've come to the doctor that day (what in doctor-jargon is called “the chief complaint”) should be *restricted to what the patient says*, and it's best when it's in the patient's *own words*.<sup>\*</sup> This is important because if the nurse writes down things in “her own words,” *she* is doing the interpreting and diagnosing that the doctor should be doing, and that has the potential of unintentionally leading the doctor down the wrong diagnostic path. Don't think “oh, I bet that really happens rarely.” It is a *common* cause of misdiagnosis. Don't let it happen to you.

(This type of misdiagnosis is caused by “error due to inheriting someone else's thinking,”<sup>\*</sup> and this particular error causes the doctor to lean toward a particular diagnosis “as a result of a judgment *made by [another] caregiver* early in the patient care process.”<sup>\*</sup>)

If you're caught in a situation like this, and you have a medical condition that seems serious or is not getting better, just make certain that you repeat to the doctor the main reason you've come in, and then *all* of the things you said to the nurse, so he's certain to hear them.

It can also be a good idea in offices like this to say *as little as possible* to the nurse about your illness—just enough to give your main symptom and satisfy her. When the doctor comes in, say “I need to tell you more about what's going on,” and then do so.

This works because it's hard to tell the same story twice and remember to put in all the details, and you're giving yourself the best shot at a correct diagnosis when the doctor is hearing all of the small details that may not, from the nurse's viewpoint, have been important enough to write down.

Remember that this advice is especially important if you have a recurring problem or symptoms that just don't seem to be going away. Also remember to follow this advice if you have to be seen in an emergency room, where you almost always have to talk with the nurse first.

And if you're in a situation where you're seeing the doctor repeatedly but you're still not getting better, you may need to write down the history and symptoms of your illness *in your own words*, and give that to the doctor and ask him to make it part of your medical chart. The doctor may then have what he needs to focus on your diagnosis.

(Did you know that you can always "amend" your chart? Yes, HIPAA regulations give you the federal right to add an addition or correction to your medical record.)

\*Campbell, Samuel G., Pat Croskerry, and William F. Bond. "Profiles in Patient Safety: A 'Perfect Storm' in the Emergency Department." *Academic Emergency Medicine* 14(8) (2007): 743-749, *italics added*. The particular diagnostic error described here is called "triage cueing."

## Have more than one illness to discuss?

If you go to a doctor's appointment with more than one problem that you want discussed or solved, it is very important that you *either* bring a list of what you want to discuss with him and give it to him at the very start of your appointment when he first comes in *or* tell him at the start of the interview that you have *x*-number of things to discuss, and here's what they are.

Have an extra copy of the list if you can, so that you can read down it with your doctor.

Having this written list, or telling the doctor at the outset that you have several concerns, is very important for several reasons.

One is that your doctor needs to schedule his time with you wisely, so he needs to know *at the outset* what your expectations are for that visit. There is almost nothing a doctor hates more than finishing up his visit with you, and then you saying "oh, and also ...."

And, if you bring up all of your concerns at the outset, then the doctor will have the opportunity to make an intelligent decision about how the time with you should be spent.

He may not be able to get to all of your concerns that day, and that's okay—you need to be aware that that is a possibility; but at least he knows what they are, and if any are life-threatening or health-threatening, he will be able to pick those off of the list and get to *them* that visit. Give him that opportunity.

You might even say, *at the beginning*, "I have *x*-number of concerns, and I know you might not be able to get to all of them today, but I want to tell you what they are." Then do so.

Then if there's something you especially need that day, tell him which one that is, and then he will also pick out any that might be health-threatening—again, give him all the problems at the outset so he has the data he needs to prioritize. Be prepared that he might ask you to come back another time for the other concerns.

Your doctor will be so appreciative that you are organized in this way, and are not one of the "and also" patients. And you will get better care when your doctor has all the data and can organize his time wisely.

## Worsening or changing symptoms after you've seen the doctor

At the end of every office visit, when the doctor tells you what you have, and what he's going to do, he should *always* add "but if things change, or symptoms get worse, then come back in, or if the office isn't open, go to the emergency room."

Why? Because when you get a symptom or symptoms, then see the doctor, and he examines you and makes a diagnosis, the truth about medical care is that "that's what it looked like *then*." It's a "working diagnosis."

An illness can start out looking like one thing (maybe something basically harmless), and then end up being something else (maybe something that needs urgent attention). *Too much* respect for the doctor's opinion, on what is called the "working diagnosis," can be harmful, and even *deadly* to the patient.

For example, if a child starts with a stomach ache and vomiting, and sees the doctor, the doctor might diagnose a stomach virus, and give something for those symptoms until the virus runs its course. But if the child goes home and starts running a fever and the abdominal pain gets *worse*—then what looked like a stomach virus that morning, could look like appendicitis that afternoon.

And appendicitis that is not adequately treated with surgery can be deadly.

So, *never* think that when you've gotten the diagnosis from the doctor, then that's exactly what it is, regardless of what happens next. If nothing changes and you've got a good doctor, then you're probably fine.

*But if anything changes or gets worse*, or you don't get better on the time-table that the doctor gave, then you *must be* re-examined—for your safety.

Remember, or review what you've learned about misdiagnosed or undiagnosed conditions in the "Misdiagnosed" section, earlier in the book.

"Once a diagnosis has been established, it is often used [by doctors] to explain all newly occurring symptoms *without necessarily considering* that another underlying disease might be present."<sup>\*</sup>

The Kirch and Schafii study quoted just above noted that one of the reasons for misdiagnoses is that a doctor doesn't rethink his position. And that can be a medical error that is sometimes fatal. Since that is a common error that doctors make, *you* need to keep an open mind, and insist on re-evaluation if things change, get worse, or symptoms don't go away.

<sup>\*</sup>Kirch, Wilhelm, and Christine Schafii. "Misdiagnosis at a University Hospital in 4 Medical Eras: Report on 400 Cases." *Medicine* 75(1) (1996): 29-40, *italics added*.

## Beware of the “it’s-all-in-your-head” diagnosis

In so many of the cases of misdiagnosed or undiagnosed illness, the patient is tested and examined by the doctor, and when nothing is found that the doctor can diagnose, he tells the patient “it’s all in your head” (or words to that effect).

Most of the time, it’s *not* all in your head. So when you hear the “it’s all in your head” diagnosis from a doctor, it’s usually best to interpret that as an “I can’t figure out what’s wrong with you” diagnosis.

It’s not always the fault of the doctor that he can’t diagnose what’s wrong. Several things could be going on that are beyond his control.

Most commonly, what happens is that many serious diseases present insidiously—the symptoms come a little at a time. The doctor may not be able to identify the disease as the first symptoms are observed.

So it’s vitally important that your doctor establish an ongoing dialogue with you in cases where he can’t figure out what’s going on. He should say “I can’t really tell what this is right now. We should watch it—many times these things go away. But if they don’t go away, or if you get more symptoms, then we need to re-evaluate you.”

Many symptoms, especially if they are low-key in terms of severity, just go away, and there may never be an explanation as to what caused them. We didn’t invent the human body, and we haven’t spent a lot of research money trying to name and diagnose illnesses that go away on their own.

Other times, those are the first symptoms of disease, but the disease hasn’t progressed far enough along for the doctor to be able to diagnose it. And sometimes your symptoms aren’t the typical ones for a certain disease, so it takes longer to figure it out.

In any case, it’s important for both you *and* your doctor to keep an open mind, and re-assess if things change, become more severe, or just don’t go away.<sup>4,5</sup>

In rarer situations, even if your doctor is a good one, what’s happening could be something rare that he hasn’t seen or even heard of.

In this case, if your symptoms aren’t too severe or urgent, it’s usually okay to wait to see if they persist. If they do, and your doctor still can’t diagnose what’s wrong, then ask him what kind of specialist might be able to look at your symptoms more closely, and then go forward with a specialist.

All of this is not to say that stress (maybe that’s what those doctors are referring to when they say it’s all in your head) can’t cause a lot of symptoms. Stress can and does cause a significant number of physical symptoms and can make you more susceptible to many illnesses.

But most people can tell when the diagnosis of “stress” fits and when it doesn’t. Keep alert and follow your intuition.

“A wealth of research shows that patients thought to have a psychological disorder [“it’s all in your head”] get short shrift from internists and surgeons and gynecologists. As a result, their physical maladies are often never diagnosed or the diagnosis is delayed.”\*

“Misdiagnosis sometimes results from a failure to listen to what the patients say about their symptoms, or dismissing their concerns too hastily [“it’s all in your head”].”<sup>†</sup>

\*Groopman, Jerome. *How Doctors Think*. New York, New York: Houghton Mifflin Company, 2007, p. 39.

†Vincent, C.A., and A. Coulter. “Patient Safety: What about the Patient?” *Quality and Safety in Health Care* 11 (2002): 76-80, *italics added*.

## Test results: no news is *not* good news

You've done your job—you've seen the doctor and had your pap smear done, or your lab work done, or your x-ray done, and now you're waiting for the call to tell you what the results are.

Here's the problem: Many doctors don't have their practices organized in a way that makes it certain:

- *that they get all results back* from all the tests that they send out or order, and/or
- *that they follow up with patients* on all abnormal results.

But you don't know this, so when you don't hear from the doctor's office after tests, you assume that everything's okay—"they would have called if something was wrong."

That assumption can be dangerous.

"There is growing evidence that the failure to follow-up on abnormal test results is a common medical error that can compromise patient safety."\*

To be sure that you get the results from your tests, when you're checking out at the front desk after an office visit, ask what tests were done or ordered. Write them down so that you can follow-up to make sure that you receive an "all clear" on each of the tests.

If you are in the office when the lab results come back, ask for a copy of them right then. If you're getting the results by phone, ask them to fax you a copy "for your records." Either way, just don't put off getting a copy of the tests. It will make life so much easier for you if something should come up later.

One tip: be realistic when approaching your doctor for your lab reports. Most of the time doctors don't want patients to have copies of their lab reports because they don't want to have to explain each and every test (some blood metabolic panels include over twenty different "tests"), and/or explain every minor abnormality. If your request is met with any hesitation, you might say "I just want a copy for my records. If I need to talk about them further, I'll make an appointment."

Not only are there problems with making sure that you receive your abnormal results as an outpatient, but there are also problems with getting results from tests done as an inpatient. Studies have shown that after you have been discharged from the hospital or emergency room, *abnormal results* from tests taken while you were there *may never reach you*.

"Approximately 6% of patients hospitalized in a major academic medical center had ... [important, abnormal] test results return after their discharge *without the knowledge of the responsible physician*."\*

Advising you on how to make sure that you get test results (normal or abnormal) that come back *after* you've been discharged from the hospital or ER—now that's a difficult task. I mean *really* difficult. If you have someone in your hospital room writing down what blood tests are drawn and what other tests are

done—that might be the only way for you to follow-up to make sure that you get the results of those tests. (You can then ask your doctor’s office to track down the results, or call the hospital for a copy of them.)

Please understand how vital it can be to your good health to have these lab or other test results available. Doctors feel so frustrated when you go to the emergency room, or a walk-in clinic, or your regular doctor, and you say “they (wherever) did some blood tests and said everything was fine.” We don’t ever want to hear that. To give you the best care, we want to know *what* tests, and *what* the results were.

\*Sung, Sharon, Valerie Forman-Hoffman, Mark C. Wilson, and Peter Cram. “Direct Reporting of Laboratory Test Results to Patients by Mail to Enhance Patient Safety.” *Journal of General Internal Medicine* 21 (2006): 1075-1078, *italics added*.

## The problem with after-hours phone calls to your out-of-the-office doctor

Although it is very comforting to be able to call your doctor when the office is closed, know that you probably don't have his full attention. He may be sleeping, drinking, or driving, and his full attention is not on you like it is when you are in the office.

So be very cautious when relying on medical advice you get over the telephone. It's a double-edged sword. When you get it, you feel better. But is it really reliable?

The doctor hasn't seen and examined you. He's relying on you to convey medical information. Since you have no medical training, he's most likely offering an opinion based on incomplete information.

In addition, when you call doctors when they're not in the office, they're likely to be less focused—more distracted. To be safe, you must use your intuition in seeking medical care.

Definitely, if you have sudden severe and continuous pain, or you see a condition in a loved one that has worsened and now worries you, go to the emergency room and get a valid examination and opinion.

If you're calling with a quick question, then sometimes that's fine. But if you're calling with a new illness, or a question about something getting worse, or anything that takes you more than a minute to explain, then you really need to take your loved one to the emergency room and not rely on an over-the-phone "it can wait until morning" diagnosis.

Many fatal mistakes have been made by doctors reassuring scared patients that they can wait until morning, no problem—but the doctor didn't get all of the story because he couldn't see the patient, and he was not sharp and focused on asking all of the right questions that might have protected the patient.

Several recent studies have confirmed this point.

In a 2007 study, Katz et al. described 32 cases of telephone-related medical malpractice claims.

"The most common allegation was failed diagnosis (68%); [the] most common injury was death (44%)."\*

"Faulty triage" was an error in 84% of the cases "usually because of incomplete history taking over the phone."\* ("Triage" is deciding the seriousness of the medical situation—whether someone needs immediate attention, or whether it can wait.) The doctors did not "guess right" about whether the illnesses were serious or not *in 84% of those malpractice claims*.

Of the 32 patients described above, *fourteen died*.

"Regarding faulty triage decisions, a dynamic seems to emerge when medical complaints are presented over the phone compared to seeing patients in the office. *Evaluation is more difficult on the phone* because of time pressure, as well as not being able to see the patient during the dialogue. As a consequence, history taking is often rushed and incomplete, letting the patient, rather than the clinician [doctor], do the triage."\*

See notes added below the citations for a case in point and results of another study.

**If you think your loved one is in medical trouble, then call 911 if urgent, or take him to the emergency room where a doctor can see him right away.**

**Don't be a statistic—doctors can't diagnose through the phone, or when they are sleepy or focused on other things.**

\*Katz, Harvey P., Dawn Kaltsounis, Liz Halloran, and Maureen Mondor. "Patient Safety and Telephone Medicine: Some Lessons from Closed Claim Case Review." *Journal of General Internal Medicine* 23(5) (2007): 517-522, *italics added*.

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I've added a few more paragraphs on this problem here. If you've had enough, please feel free to move on to the next section.

A physician described one disastrous outcome of telephone medicine<sup>a</sup>:

"Two years ago a 41 year-old English journalist died from septicemia. Her case haunts me. Two days before the Easter weekend Penny Campbell had an injection for hemorrhoids. During the weekend she became progressively unwell and called the out-of-hours medical service **eight times. None of the doctors she contacted realized how ill she was.** By the next day the die was cast; within 24 hours she was dead."<sup>a</sup>

In 2007 Killip et al. decided to study the safety of after-hours telephone medicine because of the possible dangers.<sup>b</sup>

"Threats to patient safety were suspected for several reasons. Telephone medicine removes visual cues. Clinicians use cues in the office setting, such as general appearance of patients, to decide which patients may be sicker than others. [And] after-hours telephone medicine may be conducted when the doctor is sleepy or distracted and is often without access to patient records. The potential for harm to patients appears to be high."<sup>b</sup>

They found:

"There are many, sometimes potentially serious, threats to patient safety in telephone medicine."<sup>b</sup>

And they concluded:

"After-hours telephone medicine is not as safe as many of us have assumed. Our study demonstrated threats to patient safety. It showed that errors are common, and adverse events are possible."<sup>b</sup>

a. Richards, Tessa. "Who Is at the Helm on Patient Journeys?" *British Medical Journal* 335 (2007): 76, *italics and bold type added*.

b. Killip, Shersten, Carol L. Ireson, Margaret M. Love, Steven T. Fleming, Whitney Katirai, and Katherine Sandford. "Patient Safety in After-Hours Telephone Medicine." *Family Medicine* 39(6) (2007): 404-409.

## Phone calls to the doctor when he is in the office (“reassuring telephone calls”)

When you call a doctor’s office to get a question answered by your doctor, make sure that the answer comes from your doctor, and is not just the opinion of the nurse. Much of the time, if the nurse just answers the question on the spot, then the answer is suspect.

Many doctors allow their nurses or office personnel to answer questions like this because they just don’t feel they have the time to do it themselves.

To make sure that you’re getting the right information, you should ask “would you just check that with the doctor when you have time and give me a call back?” Maybe add “my case is a little different.”

Better safe than sorry. Most good doctors want the questions to go through them first. Just little variations in symptoms or questions can cue a doctor that something is amiss—something that a nurse might not catch.

And realize that the same issues and dangers from “after-hours phone calls to your out-of-office doctor” also pertain here. (You may not be giving the complete medical information needed for him to give the best advice, and he is probably focused primarily on the patients *in* his office.)

I’ve seen tragedies where the patient has called and talked with the doctor in the office, but because the doctor wasn’t actually examining the patient, he didn’t understand the seriousness of the situation, and an absolutely preventable tragedy occurred.

Just be aware of the risk, and you’ll be better off.

If you call a telephone hotline where a medical person asks specific questions from a protocol written by doctors for that purpose, then the advice that you get will be much safer than if the medical person is just “winging it” on his own. Remember, though, that he’s using a book—a manual—just like the person whom you call with a question about why your computer won’t “see” your new printer.

But otherwise, you’re not on safe ground at all.

Under a section that says “The Telephone: False Reassurance?” Goldman and Kirtane wrote that in a case where a patient with chest pain telephoned triage nurses for advice on what to do (three times!), “well-meaning triage nurses seem to have relied on the patient’s willingness to be reassured rather than insisting that the patient come to the emergency department for immediate evaluation.” This patient was subsequently found to have a missed diagnosis of a heart attack.\*

\*Goldman, Lee, and Ajay J. Kirtane. “Triage of Patients with Acute Chest Pain and Possible Cardiac Ischemia: The Elusive Search for Diagnostic Perfection.” *Annals of Internal Medicine* 139(12) (2003): 987-995. The authors believe that, given the potential seriousness of chest pain, “triage systems should recommend immediate in-person evaluation ..., preferably in an emergency department.”

## Breast lump evaluation: the triple assessment protocol

Be aware that breast lumps are treated in a different fashion from doctor to doctor. This inconsistency is very conducive to a patient becoming a victim of a late diagnosis of breast cancer, when there is a much higher rate of dying.

Notably, failure to diagnose breast cancer has been the leading or second most common reason for malpractice suits in many recent years.

Many people believe that if they have a breast lump and the mammogram is normal/negative, then they're fine.

Nothing could be farther from the truth. Mammograms are only 70 to 85% accurate in diagnosing cancer in women with a breast lump.

If you have a breast lump and a normal mammogram or ultrasound, be aware that a third tool is available to help make the right diagnosis, and that tool is a needle biopsy.

When you add the needle biopsy to the mammogram and the clinical breast exam (palpation done by a doctor), experts call this the "triple assessment protocol," and many believe that this is necessary for you to have the *best* chance at an early diagnosis of breast cancer.

So, to protect yourself: if you have a breast lump that has persisted for more than one or two months, *even if you have a negative mammogram*, consider insisting that your doctor use a needle biopsy to make a more accurate diagnosis.

You can go to the Internet and search with the words "breast triple assessment" for more information.

Too many mothers, daughters, wives, sisters and friends have died from breast cancer that could have been diagnosed and treated if it had been caught earlier. Don't let that happen to you.

"We found that *a substantial proportion* of women with a breast problem managed by generalists *did not receive care consistent with a clinical guideline*, particularly younger women with a clinical breast complaint and a normal or benign-appearing mammogram."<sup>\*</sup>

"Problems with breast cancer can include underuse of mammography for early cancer detection, *lack of adherence to standards for diagnosis (such as biopsies and pathology studies)*, inadequate patient counseling regarding treatment options, and underuse of radiation therapy and adjuvant chemotherapy following surgery."<sup>†</sup>

"Mammography screening is far from perfect ... Mammography does not depict all cancers."<sup>‡</sup>

"Every radiologist who has any long-term experience has failed to perceive something of importance that is visible in retrospect ... All radiologists, no matter how skilled or dedicated, cannot avoid periodically missing a clinically important lesion."<sup>‡</sup>

<sup>\*</sup>Haas, Jennifer S., E. Francis Cook, Ann Louise Puopolo, Helen H. Burstin, and Troyen A. Brennan. "Differences in the Quality of Care for Women with an Abnormal Mammogram or Breast Complaint." *Journal of General Internal Medicine* 15 (2000): 321-328, *italics added*.

<sup>†</sup>Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*. Washington, D.C.: National Academy Press, 2001, p.24, *italics added*.

‡Kopans, Daniel B. Editorial: "Mammography Screening Is Saving Thousands of Lives, But Will It Survive Medical Malpractice?"  
*Radiology* 230(1) (2004): 20-24.

## Asthma treatment

Asthma is an old condition that now has very good therapies. The asthmatic patient can, many times, completely control his symptoms with a step-wise use of the new medications.

I hate to see parents who feel so panicked and vulnerable because they often have to rush their child in because of an asthma attack, when the child's asthma could be well-controlled with a little time and good medical management.

"Asthma care is often episodic, with underuse of controller medications and inadequate home management of acute exacerbations. Consequently, many children with asthma live with frequent symptoms and activity limitations, and visits for urgent care are common...Few [doctors] regularly meet with families to monitor asthma control, identify concerns or problems with management, or provide self-management education."\*

If you or your child is an asthma patient who makes frequent trips to the doctor's office or emergency room for out-of-control symptoms, then do some Internet researching so that *you* can understand what classification of asthma you have, and *you* can know what medicines you should be on to keep your asthma under control.

The how-to-do-this-right is pretty complex, and that's why even many doctors don't always have the right answers unless they consult the current charts. But you can find out what you need to know with a few hours of studying the flowcharts and learning to understand the concepts. If you don't try to understand, then you'll forever be at the mercy of busy doctors who will often not have the time to treat you *adequately* so that you can live comfortably and confidently with this illness.

"Effective interventions to improve asthma care have been difficult to disseminate into office practice: many physicians are unwilling or unable to attend training sessions to improve their skills, and most offices do not have a nurse or health educator available to share the work of asthma care."\*

Deaths from asthma, and they still happen, can often be prevented by the use of peak-flow meters, which are very inexpensive (about \$20). *Every* asthma patient should have one on hand—it's a lifesaver, and the only way a serious asthmatic can know exactly how much trouble he's in, and get emergency care if needed, before it's too late.

Asthma patients are particularly sensitive to errors caused by medication mix-ups. Re-read the "Medication: just plain mix-ups" section, and make sure you follow that information very carefully if you are an asthma patient.

Searching on the Internet for the right asthma protocol is a challenge because you want the stepwise approach recommended by the 2007 NHLBI Guidelines, but you also want them in patient-friendly language.

Guiding you through these different asthma websites is beyond the scope of this book, but I have written a protocol for you to find and understand the information you need at [CautiousPatient.org](http://CautiousPatient.org) (just

click on the “Asthma” tab at the top of the page). Your asthma should not be a daily battle or a monthly nightmare. You can get it under control with the *right* management.

\*Garbutt, Jane M., Christina Banister, and Gabrielle Highstein et al. “Telephone Coaching for Parents of Children With Asthma.” *Archives of Pediatric and Adolescent Medicine* 164(7) (2010): 625-630, discussing how a strictly, structured (not casual) telephone coaching method could be effectively used.

## Procedures and operations: think before scheduling

Understand that when you are going to a consult in the office of a doctor who derives a great proportion of his income from procedures or operations, *for some* of those doctors there just seems to be a natural inclination for them to go right to “well, we need to set you up for ...”

It’s almost as if it’s a given, that if you show up in that specialist’s office, then you must want the surgical/procedural option. But usually, they are really supposed to be *evaluating* your condition to see if you *need* a procedure for further diagnosis and/or treatment.

You really need to do your research here before you go right to the scheduling of the procedure. And if you can get a referral from a really trusted source to a specialist that doesn’t always go directly to procedures, then that might be a better place to start.

Too many times, I’ve heard from a friend who has taken himself in to see some specialist, and then phones me after to say “I saw the [*name of specialist*] today and he said the MRI (or hemorrhoids or arthroscopy or other test) was one of the worst he’s ever seen!” And then my friend tells me that he’s already gotten the doctor to schedule the operation (or procedure), so that he can get it fixed right away.

There seems to be some sort of tight connection between “it’s the worst he’s ever seen” to “I’m going to get this taken care of right away.” And something about the “it’s the worst” phrase seems to cause them to lose objectivity about getting a second opinion or doing some checking on their own.

And I know that there are medical ways to solve many of those problems, and I know that when my friend gets done with the surgery—well, things could be fine, but things could be worse. There are possible complications with any procedure or operation. And then when you’re in a post-surgical state, where your body is irreversibly changed, and if you’re not better, then you can’t turn back time from that.

So I try to give my friends a little heads-up warning.

And for you—just be careful. Look at non-surgical alternatives and do your homework before you schedule a procedure or operation.

“If you’re a hammer, everything looks like a nail.” – Old proverb

“The quality of health care provided in the United States varies among hospitals, cities, and states. Whether the care is preventive, acute, or chronic, it frequently does not meet professional standards ... A large part of our quality problem is the amount of *inappropriate care* [overuse, such as unneeded procedures and operations] provided in this country.”\*

\*Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*. Washington, D.C.: National Academy Press, 2001, p. 240, *italics added*.

## Stuck with a certain doctor or clinic?

Some people are in a certain healthcare plan that they're stuck in—it's the only one their employer offers; it's the only one that the government offers; it's the only one in the area; or it's the only one they can afford.

If you are in a tough situation where you *must* use a particular doctor or clinic, and you don't think you are getting the care you need or deserve, then you might need to take a particularly assertive action to get what you need.

Government HIPAA (pronounced "hip'-uh") regulations say that you have a right to see your medical records—so ask your doctor's office for a copy of them and look through them. By reading your records, you should be able to determine if your doctor has at least written down the reason for your visit, the symptoms you described, his assessment (the reason for the symptoms or the diagnosis), and his plan for treating your illness.

As hard as it is to imagine, some doctors don't write down the symptoms and concerns you tell them.\* Maybe they're just moving too quickly to be bothered to write everything down. But *sometimes* it seems that if they don't write your symptoms down in the chart, then they don't have to spend time to do anything about them.

(I've actually seen this happen too frequently. Think of it: if the patient is harmed by the medical care [or lack of it], and wants to bring a malpractice claim, then the doctor just points to the records: "See, I didn't know he had such-and-such-symptoms. He didn't tell me.")

If your doctor is not putting your symptoms into the chart, or if you're not getting the answers that you need or your symptoms still aren't diagnosed, then at your next visit, bring a "Patient-Doctor Encounter Form." Download a form from [CautiousPatient.org](http://CautiousPatient.org), and fill in what you want your doctor to know about your condition that day, and what questions you have for him.

Ask your doctor to make that form you've filled out part of your medical record.

(Federal HIPAA law *requires* doctors to allow patients to amend their charts, so that would be a reasonable request if you're in this situation. To see the HIPAA requirements, visit the [CautiousPatient.org](http://CautiousPatient.org) website. You can also print out the HIPAA info to take to your doctor [if you need to], to show him that HIPAA allows you to amend your chart when it is incorrect or incomplete.)

Once all your symptoms are part of your medical chart, then the doctor is on notice that he needs to pay attention to them. You should get better care then.

"We found discordance between patient self-report and documentation of symptoms in the medical record. This discordance ... may have clinical implications that must be evaluated for potential impact on quality of care, patient safety, and outcomes."\*

\*Pakhomov, Serguei V., Steven J. Jacobsen, Christopher G. Chute, and Veronique L. Roger. "Agreement between Patient-Reported Symptoms and Their Documentation in the Medical Record." *American Journal of Managed Care* 14(8) (2008): 530-539. This study found disagreement "between patient self-report [of symptoms] and documentation of symptoms in the medical record."

## Preventing illness

Do your family a favor and get the preventive medicine tests that you need.

For children, this usually means immunizations and checks for proper growth and development.

For women, it usually means pap smears and mammograms at certain ages and recommended intervals.

For all adults, it means having your blood pressure and cholesterol checked from time to time.

For adults over 50, there are a few other tests that you should start getting.

And for all, the tests that you need often depend upon your own medical history and your family health history.

But again, you can't just leave it up to your doctor to tell you what you need. An interesting but alarming 2003 study concluded that each family physician would need an additional 7.4 hours per working day *just providing preventive medicine* if he were to fully satisfy the recommended preventive guidelines for his patients!\* So you can imagine that you're not getting the complete picture if you just leave it to your doctor to remember to give you all the recommendations.

You'll need to access the right websites to find out the latest guidelines for preventive medicine advice. The [CautiousPatient.org](http://CautiousPatient.org) website will help you with this. Once you know what you need, just take that info in to your doctor, and ask him for those screening or preventive services.

*You* might prevent unnecessary heartache for your family by using preventive medicine:

- to diagnose deadly illnesses while they can still be cured,
- to diagnose other illnesses before there are sad complications, and
- to prevent other illnesses entirely.

So, please get the preventive medicine tests and vaccines that you need! If *you* have to do the research to see what you need, then it may take some of your time; but you and your family are the ones who will profit.

(I know a few of you out there are saying "I just want to pay the doctor to do this for me!" Um . . . good luck with that approach.) (And all this is not to say that there aren't a few doctors who *do* manage to do it all, and do it well. They're just not that easy to find.)

"Poor compliance with recommended schedules of clinical preventive services is a well-documented problem in primary care. The good intentions and usual resources of providers are often insufficient to carry out satisfactory clinical prevention ... One major reason for this may be that ... [the physicians] *fail to involve the person with the most to gain from the clinical prevention effort: the patient.*"<sup>†</sup>

"The increasing role of managed care, with its emphasis on increased productivity [number of patients seen per session], appears at odds with primary care physicians' increasing responsibility for prevention."<sup>‡</sup>

"Preventive services consensus goals are not being met, even for patients who report that their clinic visit was for a checkup or physical examination ... Perhaps the most concerning pattern to emerge from these data is that even for patients who reported visiting the clinic for a checkup or physical examination, the grand mean at which indicated preventive services were prescribed was *only 46%*."<sup>§</sup>

\*Yarnall, Kimberly S.H., Kathryn I. Pollak, Truls Ostbye, Katrina M. Krause, and J. Lloyd Michener. "Primary Care: Is There Enough Time for Prevention?" *American Journal of Public Health* 93(4) (2003): 635-641.

†Dickey, Larry L., and Diana Petitti. "A Patient-Held Minirecord to Promote Adult Preventive Care." *Journal of Family Practice* 34(4) (1992): 457-463, *italics added*.

‡Stafford, Randall S., Demet Saglam, and Nancyanne Causino et al. "Trends in Adult Visits to Primary Care Physicians in the United States." *Archives of Family Medicine* 8 (1999): 26-32.

§Kottke, Thomas E., Leif I. Solberg, Milo L. Brekke, Antonio Cabrera, and Miriam A. Marquez. "Delivery Rates for Preventive Services at 44 Midwestern Clinics." *Mayo Clinic Proceedings* 72(6) (1997): 515-523, *italics added*.

## When you have some questions for your doctor: advice on *participating* in your office visit

Always go to each appointment ready to participate in a dialogue with your doctor. You'll get the best healthcare when you are a *participant* in the visit—you are the expert on you, and the doctor must have the information that only you can give him.

Be sure to ask any questions that you want to, need to, or feel would help you. Embody the attitude you want to see in your physician: kind and respectful. Oh, and also professional—you are the professional on you.

But if you leave the appointment feeling that your questions weren't heard or answered, consider this: your doctor, even if he's a saint, can have the following difficulties with answering questions:

- He may be a good doctor, but may be unable to communicate well “on the patient's level.”
- He may be a good doctor, but just gets irritated when patients question him. (Some would argue whether or not this is a “good doctor,” but we'll give him the benefit of the doubt here.)
- He may be a good doctor, but this just isn't a good day for him personally (family, finances, sleep loss, etc.).
- He may be a good doctor, but just doesn't feel he has the time to answer many questions from patients because of time and production pressures. (This is happening more and more with the bureaucratic hassles doctors have to attend to.)
- He may be a good person, but as a doctor, he just hasn't found the time to keep up with the best practices recommended in medical care.

So, if your doctor is not giving you all the information you need, or not answering all of your questions, then use the other resources we've mentioned to find out more about your illness and treatment.

*Very important:* understand that possibly the *best strategy* to get good care is to show up for your appointment ready to engage your doctor and *participate* in your care.

It's not a safe option anymore to just sit back and be “a good patient.” Effective healthcare requires the input and participation of both doctor *and* patient.

“There are at least two bodies of knowledge that are relevant to the exchanges between doctor and patients—the doctor's and the patient's. Both are experts in their own fields ... Caring for a patient requires both parties to recognize and respect the other's area of expertise.”\*

\*Kennedy, Ian. “Patients Are Experts in Their Own Field: The Interests of Patients and Healthcare Professionals Are Intertwined.” *British Medical Journal* 326 (2003): 1276-1277.

## **Odds and ends: advice that's not from a doctor; vaccine records**

### **Beware of relying on other medical people for serious medical advice.**

Some medical tragedies have occurred because patients have asked for, *and relied on*, medical advice from non-physician medical professionals (nurses, paramedics, etc.).

Other medical personnel absolutely know the medical field in general better than those without any medical background.

But if you have a condition that could be serious, or if you're not getting better, play it safe and see a doctor (or a reliable mid-level practitioner such as a nurse practitioner or a physician assistant).

### **Please write down, and keep a record of, any injections or vaccines you're given, whether you're at your doctor's office, a clinic, or an emergency room.**

This information is so easy for you to get when you're there, and yet so hard to get once you leave.

And it can be so important for your short-term and long-term care to know exactly what injections you were given.

So when you're at the front desk checking out, just ask what medication—name and dosage—you were given. Your future doctors will be so pleased that they don't have to guess, make phone calls, or fill out forms to get this information.

