

HOW TO BE A SMART

PATIENT



Medical information rains down on us, much of it confusing, some of it wrong. It becomes background noise, mostly ignored. This four-part guide will help you map your way through the murk and give you more power over your care. It could alter or even save your life.

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DON'T GET BURIED

You can find what you need—if you stay focused

BY AVERY COMAROW

You'd like to check out a new drug your doctor has suggested. Or you might be wondering about surgery for back pain or how best to deal with a newly diagnosed heart problem. Do you look for help in the cluttered vastness of the Web? In back issues of newspapers or magazines? Maybe there's a new book. . . . The brain shuts down. It's all too much. You can't possibly find the information you need.

Ah, but you can. The prime directive of an info hunt, however, is to know what to look for. Most people don't, says internist Donald Vickery, coauthor of *Take Care of Yourself*, a guide that connects symptoms to illnesses and, through diagrams called decision trees, aids readers in deciding whether they need a medical professional.

Suppose a woman has just been told she has breast cancer. Among the questions Vickery would like her to put to the doctor: What are the qualifiers—are you sure of the diagnosis? What is known and unknown about my condition? Are the lymph nodes involved? "She needs adequate knowledge," says Vickery.

But coming up with such questions, difficult anytime, is more so under an emotional cloud. A "personal decision guide" devised by the Ottawa Health Research Institute (OHRI), which studies how people make medical choices,

might help you collect your thoughts. The form is generic, applicable to almost any medical situation. It can be completed online at decisionaid.ohri.ca/decguide.html or printed out.

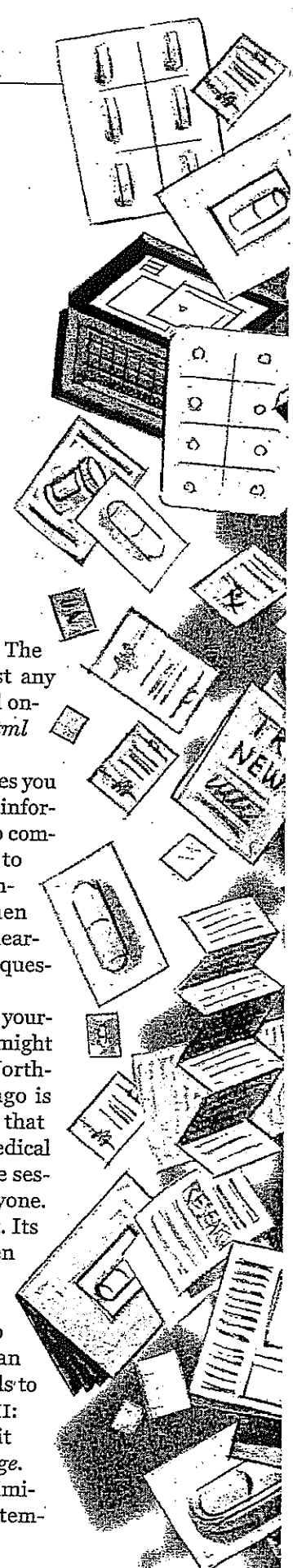
As you step through, the guide nudges you to consider whether you have enough information to understand your situation, to compare various options, and, in the end, to arrive at a conclusion on your own, without being pressured by others. When you're done, where you stand will be clearer. And you'll most likely have specific questions to talk over with your physician.

To fill in information gaps or educate yourself before or after an office visit, you might think about going to the hospital. Northwestern Memorial Hospital in Chicago is among a growing number of facilities that have set up health learning centers. Medical librarians are available for one-on-one sessions, and most centers are open to anyone.

And there is, of course, the Internet. Its raw power is unquestionable but often squandered. Those who are new to the

Internet as an avenue to medical information seem to regard it more or less as an eighth grader does who needs to write a report on World War II: Use that as a search term, hit enter, and *après vous le déluge*. Health searches unleash a similar torrent. No one could system-

**YOU NEED TO
BE SKEPTICAL
ABOUT ANY
CONSUMER
WEBSITE.**



atically wade through the more than 10 million websites and million or so news groups that come up by entering "diabetes" into Google. The natural inclination is to click on a few sites that look promising and give up. That could be why, in one survey, fewer than half the consumers who researched chronic conditions such as heart problems or depression online said they came away better understanding their condition or how to treat it.

Setting limits. At the very least, make search terms restrictive. Suppose you want to find out whether losing weight can help lower your high blood pressure. A Google search on "hypertension" spits out more than 3 million results. Adding "weight" and restricting the search to the previous year cuts them down by about three quarters. And tacking on "benefits" shrinks that number significantly. It's still in six digits, but the search is so much better targeted that several high-quality resources appear near the top.

A better option is to go directly to particular websites. Those intended for consumers can be useful—the good ones, such as the National Institutes of Health's *cancer.gov* and MedlinePlus (*medlineplus.gov*) and for-profit WebMD (*mywebmd.com*), offer the basics for most conditions. But you

need to cast a skeptical eye on any consumer site. If a site has an "about us" tab or link, click on it to see who the sponsors are, and ask yourself whether they might have an agenda other than full and accurate information. Many consumer sites are less than current—check for recent studies from major medical journals. And many don't list their sources of information, which creates uncertainty.

"The greatest sin of consumer sites," says Donald Vickery, "is that they take the attitude, 'I'm just an old-fashioned doctor, and I'm not going to allow you to know what the risks are.'" Maryann Napoli, associate director of the Center for Medical Consumers, a New York-



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WINFRED WATSON, 65, Chicago
The Web helps him manage his hypertension

After I was diagnosed at 62, I needed a doctor closer to home. I went to hospital websites, and Dr. David Baker's name came up at Northwestern because of his special interest in hypertension. I put together a narrative of my history and gave it to his assistant before I saw him so he would have my background. I went to several websites to get an idea of what my condition meant. I wasn't looking for answers. It was more that I was looking for questions I could put to Dr. Baker.

I still do a lot of research. I might see something relevant

on the Web I can bring in to discuss. I often stumble across different websites. It's easy to be overwhelmed. I try to stay with websites connected with institutions known for their credibility and excellence, like Johns Hopkins and the *New England Journal of Medicine*. Online medical dictionaries help me understand what I'm reading. Looking at the professional literature can be worthwhile. It gives me a sense of the latest research, and I can always ask Dr. Baker about something I've read. My blood pressure is good, under 120.

based advocacy group, believes that consumer sites are watered down. "They sin by omission," she says. Consider "watchful waiting." This is an option, involving close monitoring rather than treatment, that is advocated by urologists for some older men whose prostate cancer is localized and slow-growing. The option doesn't exist at NetWellness (*netwellness.org*), a consumer site sponsored by three Ohio universities. MedlinePlus has a thoughtful discussion of watchful waiting, but it's not easy to find.

Napoli and Vickery advise going to professional sites instead. At *eMedicine.com*, a website written by and aimed at physicians, a search brings up a thorough, lucid

discussion of watchful waiting that includes a summary of studies of men who chose that option.

Slogging through the technical language in professional sites can be rough, Napoli readily concedes, but "you can get the gist"—enough to ask a doctor knowledgeable questions. You can always refer to an online medical dictionary like the one at *www.medicinenet.com*. Vickery's secret: Don't look for individual studies; "look for review articles and summaries." One of the best compilations of reviews and summaries can be found at the Cochrane Collaboration (*www.cochrane.org*), a cooperative of medical experts. Full reports are available only to subscribers, but anyone can access the abstracts, which include the reviewers' conclusions and source material. OHRI has begun to convert Cochrane reports into "decision aids"—condition-specific versions of its generic decision guide. They're on OHRI's website.

Once you've figured out which questions to ask a doctor, of course you need to find a good doctor to ask. To track down first-rate medical centers and doctors for serious illnesses, the annual *U.S. News* "America's Best Hospitals" rankings are a start (*www.usnews.com*).

Try to find volume data. Up to a point, the more often hospitals and doctors perform a given procedure, the lower the risk to the patient—and many providers, unfortunately, don't do enough. In New York State during 2002, almost 20 percent of hospitals that inserted heart stents did six or fewer of them, and more than 40 percent of physicians who inserted a stent did it one time. "Hospitals are not doing a very good job with their credentialing process," says Arthur Levin, director of the Center for Medical Consumers. A few other states, such as California, Maryland, and Pennsylvania, make similar data available on the Web. Otherwise, you'll have to ask. And if a hospital or doctor won't tell you? Say thanks, and look elsewhere. ●

FIND A MENTOR

Not just a companion, but a trusted medical guide

BY BERNADINE HEALY, M.D.

In the olden days of medicine, it was said you could cure half the sick by putting them into bed and the other half by getting them up. And the doctor always knew which was which, for he (almost always a "he") was the unchallenged voice of authority. Medical decisions followed a straight course.

Today we know more and can do more, and for almost any illness the paths to be taken are more maze than unbending line. Doctors present options and offer preferences; patients are told the decision is theirs. That's good if you believe in patient empowerment. It's hard to feel empowered, though, if you aren't sure which way to go. Several medical studies have shown that many people faced with important medical decisions wished they'd had some help, even in framing the right questions to ask their doctors.

Cindy Sweeting, 46, calls her bout with cancer 15 months ago a journey to a place she had never been before. "I cannot imagine planning a trip for your life where you don't have a guide who has seen it with their own eyes, or maybe even lived there before," says Sweeting, director of equity research at Templeton Investments in Fort Lauderdale, Fla. The sheer number of choices she had to make in a short period of time was overwhelming. Which doctors to see. Lumpectomy or mastectomy. How to balance work and family with rounds of chemotherapy and radiation treatments. And breast reconstruction: Would it be too much to take

on after months of heavy-duty cancer therapy, or might it be a kind of closure for Sweeting, the last step in her recovery? "It's hard to make these decisions in a vacuum or based only on what you have read," she says.

Mitzvah. She didn't have to. In her sojourn, she sought and found medically knowledgeable mentors who helped her narrow her options. They offered tips and provided perspective perfectly suited to Sweeting's temperament and personal circumstance. Experienced, knowledge-

able, and trusted, they brought her confidence and often an emotional boost.

Mentor was the wizened old man in Greek mythology who guided the son of Odysseus as he set off in search of his father. Mentor was an in-the-back-ground kind of guy. He was there, selflessly, to help with fateful choices. But Mentor had an additional dimension: He was none other than Athena, the goddess of wisdom, who took on the form of Mentor to help Odysseus's son during critical moments of his journey. That image well informs a modern-day medical mentor—wise, experienced, trusted, available, unobtrusive. And every bit as important, a mentor takes on this role out of human kindness and not for personal gain. In a biblical sense, mentoring is a mitzvah, a good deed that is its own reward.

For Sweeting, identifying mentors at different steps along the course of her illness was crucial to her recovery. Suzanne Grimes, a friend from New York City, was a first call. Their friendship went back to their college years. They both had children, close families, and high-octane jobs.

And they shared similar views on how to face difficult times. As a breast cancer survivor herself, Grimes had already taken the difficult journey. She handled it with decisiveness and courage, the way Sweeting wanted to.

When her first biopsy was negative, she confided in Grimes that she was uneasy about the result. Grimes, who knew how nebulous needle biopsies could be, listened carefully and encouraged her to seek another biopsy. When





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CINDY SWEETING, 46, Fort Lauderdale
Reached out to trusted friends

The biopsy of the lump in my breast came back negative, but I was still unsettled. My old college friend from Georgetown, Suzanne Grimes in New York, heard my relief and unease through the telephone. Suzie had had her own brush with breast cancer six years before. In her cool, thoughtful way, she encouraged me to follow my instincts. I went back for a second biopsy, which came back positive.

When you first find out you have cancer, it's overwhelming. You have a general idea of the journey but have never seen it with your own eyes. The smart thing to do is to seek out one or two trusted people who have navigated that place before.

Suzie handled things the way I like to: Get the information; find the right doctors; make an informed decision, and move on. She has a demanding job like mine, and she showed me how she worked through it. I also sought out Jane Pfeiffer, a close friend of my late mother. Jane had just lost her husband to cancer and was a steady guide during my mother's illness. She helped me find the right medical team in my community.

My doctors were great, and my dad, my brothers, my kids, gave me all the love and tenderness anyone could want. But Suzie and Jane were experienced guides. I could let my hair down with them, even when it was temporarily gone.

the diagnosis was handed down, Grimes was there, calm and positive, offering tips on hair and clothes, translating some of the medicalese, and filling Sweeting in on how to balance the cycles of treatments with the demands of her work and the needs of her teenage children.

Multiple mentors. The role of medical mentor is by no means exclusive. It makes sense that there can be different guides for different phases of the journey. Early on, Sweeting called on another mentor, Jane Pfeiffer, who lived nearby. She asked Pfeiffer, a close friend of her late mother, to help her find the right doctors. The 72-year-old, plain-spoken and full of common sense, had had her own experience with cancer. She, too, was a survivor and had just lost her husband to the disease. Through her past roles as a communications executive, she had many connections in the world of medicine. In a matter of hours, she brought Sweeting several contacts, which led her to the Cleveland Clinic in Florida and her cancer treatment team. Pfeiffer would call or visit regularly, always the thoughtful sounding board and cheerleader.

Nor must mentors be limited to your circle of friends. When her treatments were successfully completed, Sweeting was uncertain about proceeding with breast reconstruction. Her real-estate agent at the time happened to mention that his wife was a veteran of breast

cancer treatment and was part of an informal group of about 40 women with similar experiences who lived in their small community of Rio Vista. Sweeting called her and got phone numbers of a few women who had opted for reconstruction.

Sweeting is a private person, not easy putting personal questions to a stranger. That changed. Betsy Keller arrived with food and a bottle of wine, and they sat chatting for quite some time on her front porch. At one point her new friend ripped off her shirt and said,

"Here's what mine looks like." The reconstruction actually looked pretty good to Sweeting. "I can live with that," I thought."

Mentors are a special breed; it's not a job for everyone. One can be loving and kind and be wholly unsuited to mentoring. It calls for a kind of detachment, demanding that mentors keep their own interests and emotions in check. Know-it-alls also need not apply, for mentors are guides and not there to control or make decisions on behalf of the patient. They help lay out the specs of the journey and weigh its risks and rewards. Sometimes it's just a matter of being there, available.

How can you find someone like that, someone with qualities so singular and special? Most times, such a person is already part of your life, if you only ask—and he or she doesn't have to live nearby; there's always the phone or E-mail. As Sweeting learned, formal or informal groups are also there to be tapped—good neighbors, a community center, your religious congregation. The mentor is often someone who had a similar illness but might be a nurse or doctor or someone schooled in health matters.

Sooner or later, we are all patients facing the maze of medical choices. Agonizing over the paths that offer themselves becomes far more manageable if considered with the counsel of a mentor, wise and trusted. ●

WHO'S A MENTOR?

It is no easy thing to be a mentor. A good one is:

Informed and experienced. Previously dealt with similar medical issues.

Trustworthy. Privacy is paramount.

Available. Willingly and easily reachable almost anytime.

A good, gentle listener. Understands the patient's vulnerability and mind-set.

Empathetic but objective. Keeps own emotions in check.

Never dictates. Guides, not steers.

Expects nothing in return. Mentoring is a mitzvah.

GO FOR TWO

No doctor knows everything. Here's how to get another viewpoint

BY JOSH FISCHMAN

It's tough to go up against godlike powers, to confront someone viewed with reverence, who can exacerbate illness or offer cures. It's hard to take on the almighty—to tell a doctor that you want a second opinion.

"Patients often feel their doctors are God. This is someone they've seen and trusted, perhaps delivered their children," says Carla Dionne, executive director of the National Uterine Fibroids Foundation, a patient support group. They worry about making their first physician angry. "People have to get over that hurdle, because it can hurt them," Dionne says. "It's astounding to me, for example, how many women with uterine cancer let their general gynecologists do surgery on them. They don't go to a gynecologist-oncologist."

A second opinion is a fresh set of eyes, a new degree of knowledge, brought to bear on your condition—and the difference in doctors can make a difference in care. In breast cancer patients, one study showed that a second exam by a specialist changed treatment options for 20 percent of the women. And for patients with liver problems, a review of their tests by pathologists specializing in liver disease revealed new information—like the presence of cirrhosis—nearly 30 percent of the time. "If your doc hasn't seen a condition like yours before or has only limited experience with it, a second opinion can be quite useful," says Deepak Bhatt, an interventional cardiologist at the Cleveland Clinic.

But it can be daunting to look for the right expert. There's no yellow pages category called "Best doctors who know the most about your particular situation who are also in your area and who are covered by your insurance plan." Yet by putting together some easily obtainable information—from friends and fami-

lies, from other doctors, and from the Internet—you can figure out four crucial things: when you need this extra help, where to find it, what to do with the advice, and how much it will cost you.

When to ask. If you have a complex condition, like blocked coronary arteries after two bypass operations, then a second opinion is a good idea. It won't change a diagnosis but might give you more treatment options: artery-opening stents, for instance, instead of more surgery. Likewise, get that other

opinion if the treatment your doctor currently recommends has severe side effects or involves major surgery—or if it isn't working. And "if you aren't communicating well with your doctor, look for someone else," adds Monica Morrow, a surgical oncologist at Fox Chase Cancer Center in Philadelphia.

Communication trouble can have serious repercussions. Yong Staranowicz, a 64-year-old from Appleton, Wis., was diagnosed with



lung cancer this past summer. Her oncologist, she says, "was all doom and gloom." So she decided not to have any treatment. But a friend persuaded her to see a lung cancer specialist at the University of Wisconsin's cancer center, Sarita Dubey. "Dr. Dubey explained things a lot better. She told me how chemotherapy could ease my symptoms. I liked her tone. She gave me courage." In fact, Dubey recommended the same chemo as the first doctor did, but—now aware of the benefits—this time Staranowicz decided to do it. She even went back to her initial oncologist, near her house, to get the chemo.

And he didn't get angry that she had consulted someone else. Most doctors don't, despite patient fears, says Bhatt. Adds George Petrossian, a cardiologist at St. Francis Hospital in Roslyn, N.Y., "I value my colleagues' opinions. I don't take them as slights."

Where and who. For a worthwhile opinion, says Morrow, "you want someone who sees a lot of patients with your particular symptoms or disease." You can start with your own doctor and ask for a specialty referral. Just make sure the referral isn't to someone in the same practice—you don't want a rubber stamp by a coworker.

One good place to look, say Dubey and others, is at nearby academic medical centers. They combine clinical care with research, so they are often up on advanced treatments or clinical trials not available at community hospitals. Many give comprehensive evaluations by a team of doctors.

William Parker, chair of obstetrics/gynecology at St. John's Health Center in Santa Monica, Calif., has another trick: Call a local hospital with a good word-of-mouth reputation and ask for the head nurse in, say, the gynecology unit. "Explain your situation. They know the local doctors and who's good. They'll be willing to give you some names," Parker says.

There are other sources. Patient support groups populate the Web. These are



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MARIA DESANTIS, 48, Churchville, Pa.
Wanted a specialized cancer center

I was doing a breast self-check in April 2003 and felt a lump. I went to a general surgeon. He ordered an ultrasound and saw something that made him suggest a lumpectomy, even if it was benign. They analyzed it after the operation. Six days later, I was driving home and he called on my cellphone: I had cancer. I pulled over and started to cry. He kept talking—it was stage 2; it was aggressive; I needed a mastectomy, maybe a double mastectomy.

That night my husband and I decided we needed a second opinion. On the American Cancer Society website, I saw breast-conserving therapy was possible. But when I asked my

surgeon about it, he mock-shook me and said, "I hate the Internet! You're reading too much! Stop it!" I walked out of there and knew I wasn't coming back. A coworker told me about Fox Chase Cancer Center in Philadelphia. Two weeks later I was there. I saw a whole team of specialists—they just did cancer. I knew I was in the right place. They gave me tons of information and didn't hide anything. Their surgeon said the first guy hadn't removed all the tumor, so she wanted to operate again. A pathologist would be in the OR looking at the tissue, and if it looked clean, then I wouldn't need a mastectomy. She got it all.

people with similar illnesses and experiences, and they offer names of doctors and other advice. The problem, of course, is that some advice is just plain terrible. "But you can tell," Dionne says. "Read the message boards of these groups. Are the posts angry? That's not a good sign. Click on the 'about us' link. If it's not obvious who the sponsor of the group is, go away. Good posts refer to medical articles or cite the medical database PubMed—not women's magazines."

What to do. Before seeing the new doctor, make sure he or she sees your old tests. That means the first doctor

should send X-rays, lab tests, and pathology reports. (It's also a good idea to call a day or so before your appointment to make sure the tests got there.) Specialists usually work with specialty pathologists, who can pick up nuances that mean, say, the difference between a lumpectomy and a mastectomy.

It's crucial to *ask* the specialist about options. When patients simply state, "I don't want a bypass," that doesn't require a real response beyond sympathetic murmurs. Turn it into a direct question: "Do I need a bypass? What else is available?"

If the first and second opinions don't agree, then patients need a tiebreaker. And that's not necessarily a third opinion; often that just adds confusion. Take a look at the qualifications and experience of the two doctors. Who inspires more confidence? Which treatment plan are you more likely to follow, and why? These answers will clarify your feelings and the reasons behind them and make it easier to come to a decision.

How to pay. The good news is you have a legal right to a second opinion, under the federal laws that govern most group health plans and Medicare. The bad news is that each insurer can interpret that right differently, some giving you *carte blanche* to consult anyone but reimbursing at a lower rate and some, mainly

HMOs, restricting your choices to their network. Getting prior authorization is always a great idea.

But what if that's initially denied? "What I tell my clients, and this usually works, is that you can get assigned a case manager at the insurance company," says Richard Carter, a healthcare attorney in Alexandria, Va. "That's one level up. And you say something like 'It's been recommended that I get a bone marrow transplant at Duke. But I'd like to see another oncologist first.' That's pretty effective." And effective treatment, by both doctor and insurer, is your goal. ●

TAKE CHARGE

Once you decide what you need, work to make it happen

BY KATHERINE HOBSON

Even the smartest patient can be shocked into silence by the words “the biopsy came back malignant” or “there’s a problem with your heart.” But the biggest challenge, after you’ve absorbed the blow, researched the diagnosis, and decided to move ahead, is how to go about obtaining the care you believe is best. What if the specialist or hospital you want is a thousand miles away and, of course, not in your health plan? What if you can’t get past an implacable assistant? (“Sorry, but he doesn’t have any times open for six weeks.”) There are tactics that can open doors and get the best specialists to pay attention. Part of being a smart patient is learning how to work the system.

Ideally, you’d prepare for this moment well ahead of time, starting with your choice of primary care provider. You’d look for a doctor who has privileges at an academic medical center, even if the doctor’s office is a few miles farther from home than you’d like. It’s a worthwhile trade-off, says Pamela Gallin, ophthalmologist and surgeon at New York-Presbyterian Hospital and author of *How to Survive Your Doctor’s Care*. Such a doctor will have connections to specialists, if the need arises, who are constantly boning up on the latest findings and technology and honing their skills.

Yes, it’s elitist—justifiably. “People don’t realize that it’s a privilege to practice

among good doctors,” says Gallin. Moreover, you are tapping a powerful team of what she calls the “invisible” doctors. “If you come to me as a surgeon,” she says, “you’re getting the anesthesiologist, the pathologist, the radiologist, and any other doctor you’re going to see.” Call up teaching hospitals within a few hours’ drive and ask if they have an affiliation with any community hospitals near you. Pick your doctor from those.

Oh. You say you picked your primary care doctor out of your health insurer’s di-

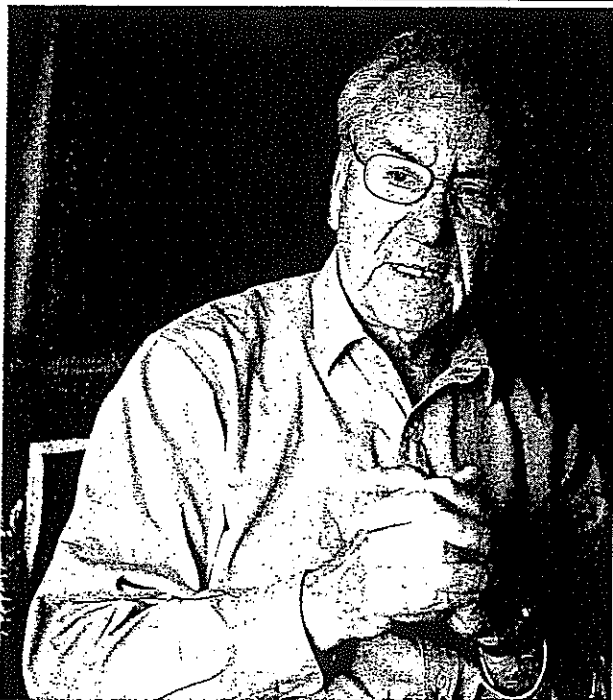
rectory, you’ve never even met the guy, and now you’re confronting a serious diagnosis or treatment? Your instinct may be to grab the first available opening with the first specialist willing to give you one. Slow down—many conditions that have taken years to develop can wait a bit, and even those with a sense of urgency rarely require a decision that day or even that week.

Translation: Don’t let yourself be pushed into choices you’re not ready to make. “We spend a lot of time researching what car to drive, but we’re not willing to spend the time and effort to look for the best treatment for a serious illness,” says Alma Rodriguez, an oncologist at M. D. Anderson Cancer Center in Houston.

Out of network. You may find that the best doctor is at a far-flung hospital most definitely not in your network. Depending on your insurance plan, you might still get some reimbursement, says Kim Calder, manager of health insurance initiatives with the National Multiple Sclerosis Society. If you’re in a managed care plan, lean on your in-network doctor to get you a consultation or at least ask him to chat with the specialist about your case. If your plan is self-insured, with your employer paying out of pocket for care (if you don’t know, ask your benefits manager), you can write a letter of appeal to your employer detailing why this doctor is the best for you.

Getting in to see the physician may call for string pulling. If





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SHELLY WEINIG, 76, New York
Networked his way into great care

I woke up one morning, and I was seeing double. I had three MRIs and they couldn't see anything bad, but I still had double vision. I wore a patch, which helped a little, but I had no depth perception and I couldn't drive. No one could figure out what was going on. It was getting very disturbing. My whole life had turned upside down.

Then I met a friend from my building in the elevator. She asked me about the eye patch I was wearing, and after I made some joke about being a pirate, I told her my problem. She said she had an ophthalmologist friend, Dr. Pamela Gallin, up at Columbia. Dr. Gallin met with me. She sent me to Myles

Behrens, who is a genius at diagnosis. I had something rare—the vein and artery behind my eye were so close together that they were joined by capillaries, and the differential pressure was causing those capillaries to swell. You can bleed into the eye. That or the swelling can cut off the blood supply and cause blindness or a stroke.

They fixed the problem, but one of the eye muscles had been damaged and I still had a bit of double vision. I engineered a pair of glasses with a prism to fix that. I still don't have great depth perception, so now I play tennis only with my wife, because she doesn't try to put the ball through my head.

you were applying for a job, you could send your résumé to human resources, which is what most people do. Or you could ask a friend, or a friend of a friend, to pass it on to someone in the department where you want the job. Which gives you a better shot?

Trying to see a doctor in high demand is the same. You'll get an appointment—eventually—if you call the general line. Network instead. Whom do you know who might have a relative or friend in the physician's office and could put in a word for you? "My friend's kid had a small hole in his heart and wanted to see some of the physicians at Columbia," says Evan Levine, a cardiologist in New York and author of *What Your Doctor Won't (or Can't) Tell You*. "He called [the appoint-

ment number] directly, and it was a four-month wait. I knew a number of people there, and he had an appointment in a week." Fair? Maybe not. But when a medical problem is serious, shouldn't getting the best care be the priority?

Without connections, you'll have to be persistent. Give the scheduler your cell-phone number and offer to be flexible if there's a last-minute cancellation. If you're in the neighborhood, you could drop by to make an appointment in person—it's harder to say no to someone standing right in front of you. (Just be polite.) You can also ask if the physician has partners who may be less renowned but have similar treatment philosophies and success rates. Or find out if the doctor has trained other nearby specialists

or is familiar enough with their work to be able to vouch for them.

Telltale heart. Once you're in front of the doctor, your care is still in your hands as much as it is in the physician's. You need to be assertive, as Shelly Weinig found out. The 76-year-old retired entrepreneur and adjunct professor of engineering at Columbia University woke up one day with double vision. He got a quick appointment with his personal physician and mentioned that he could actually hear his heart beating, very loudly. "Those are the kind of stories I hear from old ladies" is how Weinig recalls the doctor's response. "That galled me," says Weinig. "Don't ridicule me if you don't know what my symptoms mean." He eventually found

HOW TO BE A GOOD PATIENT, TOO

Part of being a smart patient is being a good patient. Show up (on time) for appointments, take medications (as prescribed), and fully disclose your history and habits to your doctor. But there's more.

Start a file. Collect copies

of test results and imaging studies such as MRIs. Note the exact names, dosages, and timing of all your medications.

Call for test results. Don't settle for "If you don't hear, you're fine." Ask for your specific results and the values considered normal, and



write them down. Request a copy.

Be your own scheduler. Patients don't always get reminders about regular screening tests or follow-up appointments. Call to ask when you're due to come in.

Keep your physician informed. If you think a medication is making your

muscles ache or your stomach hurt, say so; side effects are not rare, and you can usually be switched to another drug. Make sure every physician knows about others you saw and tests and drugs that were ordered.

Spread good news. "When things get better, we want to hear about it," says Manhattan pediatrician Michel Cohen. —K.H.

a specialist who diagnosed a network of swelling capillaries behind his eye. Left alone, it could have burst or put pressure on nearby blood vessels, leading not only to loss of vision but also to a possible stroke. The amplified heartbeat was a symptom of this spider's web of blood vessels, called a hemangioma.

YOUR CARE IS IN YOUR HANDS AS MUCH AS IT IS IN THE PHYSICIAN'S.

Even when the diagnosis is clear, the treatment proposed might not be the one best suited to your case. Not all doctors are up to date on the latest research, and every specialty exhibits self-bias: Surgeons think in terms of cutting, radiologists in terms of radiation-based solutions. Even where you live can have an influence. The ongoing Dartmouth Atlas project has found significant treatment differences from region to region and

even within states. In California, for instance, elderly Medicare enrollees in Palm Springs had double the rate of knee replacement surgery in 1999 that comparable Medicare patients did in Stockton. You can use the Dartmouth Atlas to examine statistics for elective procedures in your own community. (Go to www.dartmouthatlas.org and follow the link to Web database tools.)

Be tough. So if you disagree with your doctor's preference because your research has told you it's not the obvious choice, don't automatically give in. "It's perfectly OK to say, 'I've heard some people get a lumpectomy instead of a mastectomy—what do you think of that? What are the pros and cons?'" says Diana Zuckerman, president of the National Research Center for Women & Families. "If the physician gets very defensive and angry, you need a new one," she says. On the other hand, the doctor may take a look at the research you've brought and agree with you. You should keep your mind open, too; the doctor's advocacy for a certain approach might be persuasive. If not, you should

HOLDING DOWN THE TAB

Even if you are lucky enough to have good insurance coverage, chronic or serious illness can impose serious financial pain. Here are some tips to help manage the bills.

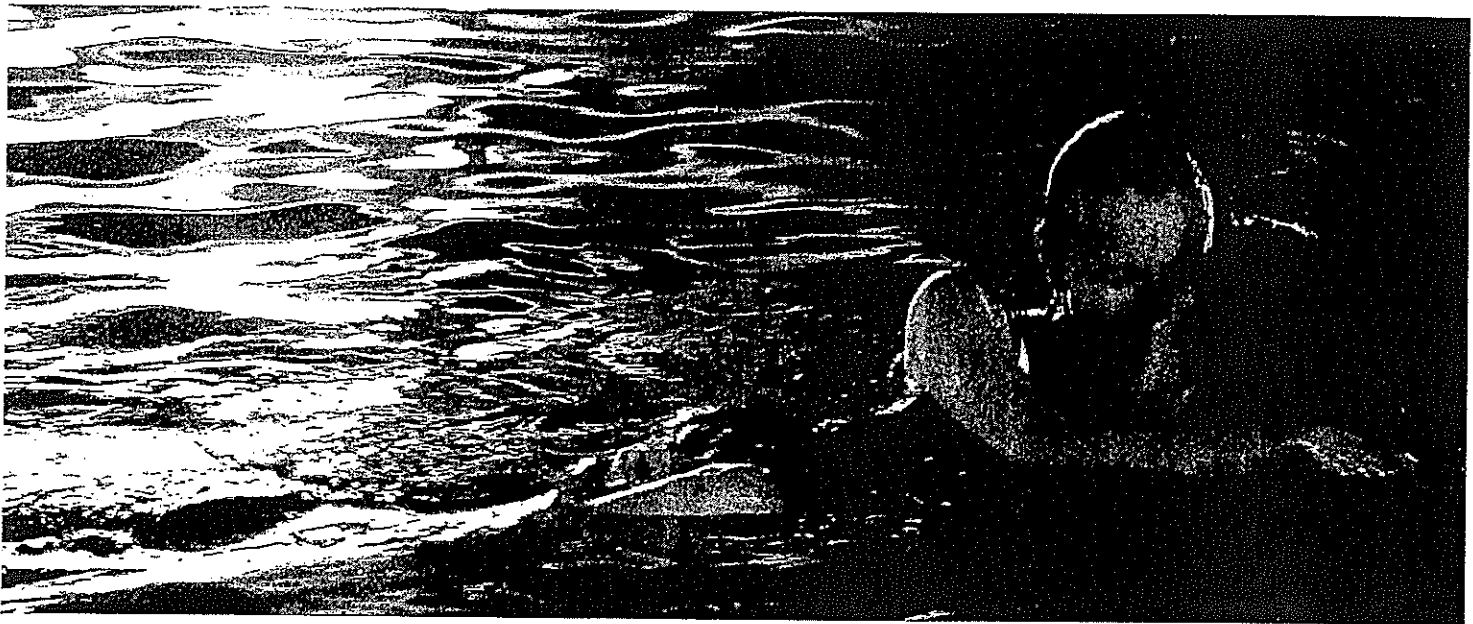
Review your insurance contract. You need to know the procedures, treatments, and facilities covered.

Cut drug costs. If a doctor wants to prescribe a medication that isn't in the insurer's list of approved drugs, or formulary, get an explanation. Ask whether generics are available.

Keep good records. That includes

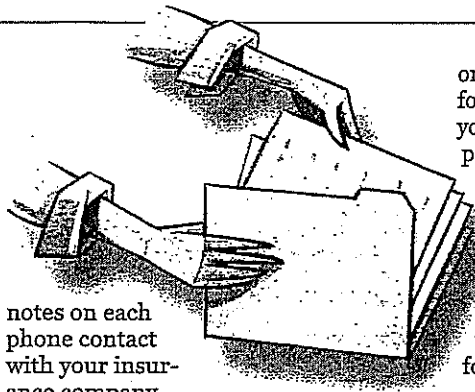
agree to disagree, and get another opinion or find another physician.

Even if you and your doctor are on the same page, your insurance company might not be. Health insurers have formularies, for example—prescription medications the insurer will cover for specific



Cialis is not for everyone. If you take nitrates, often used for chest pain (also known as angina), or alpha-blockers (other than Flomax 0.4 mg once daily), prescribed for prostate problems or high blood pressure, do not take Cialis. Such combinations could cause a sudden, unsafe drop in blood pressure. Don't drink alcohol in excess (to a level of intoxication) with Cialis. This combination may increase your chances of getting dizzy or lowering your blood pressure. Cialis does not protect a man or his partner from sexually transmitted diseases, including HIV.

The most common side effects with Cialis were headache and upset stomach. Backache and muscle ache were



notes on each phone contact with your insurance company.

Ask the insurer to assign a case manager. Often a nurse, this person can preauthorize treatment and cut down

on hassle, which can be considerable for a chronic or catastrophic illness. If you can't get a case manager but happen on a helpful insurance representative, ask for a full name and extension to use whenever you call.

Enlist your doctor, employer, or hospital social worker as an advocate. The muscle or insight might help, says Diane Blum, executive director of CancerCare, an information and support group.

Tap state regulators. Complain to the state insurance department (www.naic.org/state_contacts/sid_websites.htm) if you think you have reason. —K.H.

cy groups often have templates for the letters to make it easier on the doctors.

You can also appeal if a treatment is denied. Most states have an external review process if your initial appeals are rejected, and about half of the decisions favor the patient. This can be done quickly—often within two or three days in an emergency. (Consumers Union and the Kaiser Family Foundation have a state-by-state guide at www.consumersunion.org/health/hmo-review. Contact the state insurance departments listed for the most current information.)

To be your own advocate through a process that seems to stretch out forever from illness to diagnosis to treatment to follow-up is draining. You may not feel well anyway, and the merry-go-round of specialists and opinions adds more anxiety. "I was exhausted," remembers Weing. "I'd been to so many doctors." But your health may depend on your taking charge. "You have to decide you're going to manage your case and decide what you're going to do," he says. "Don't be afraid to question and doubt." ●

conditions. But the approved drugs are rarely identical. Many neurologists, for example, have their own preference among the handful of drugs that treat multiple sclerosis. "You could have insurance plan A that has decided Avonex and Betaseron are great and Copaxone

and Rebif are not so great," says Calder. "Two counties over, it could be just the opposite." But your doctor can, and most will, fight on your behalf for coverage of a particular drug. Ask your doctor to write a letter and appeal if your preferred drug isn't on the formulary, she says. Advoc-

SOMETIME BETWEEN *friday's* MIDNIGHT DIP AND BREAKFAST ON *sunday...*

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† Individual results may vary. Not studied for multiple attempts per dose.*



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also reported, sometimes with delayed onset. Most men weren't bothered by the side effects enough to stop taking Cialis. Although a rare occurrence, men who experience an erection for more than 4 hours (priapism) should seek immediate medical attention. Discuss your medical conditions and medications with your doctor to ensure Cialis is right for you and that you are healthy enough for sexual activity.

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