



Your doctor will ignore you now

He knew something was wrong.
Thirty doctors disagreed.
Luckily, he visited a thirty-first.



"Can you button your shirt?"

"Yes."

"Can you walk without a cane?"

"Yes."

"Can you feed yourself?"

"Yes."

"I don't see anything of concern. You're welcome to see me again in 6 months."

"Is there anything else you can do? Blood tests, perhaps?"

"There's nothing wrong with you. Bye, now."

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THAT WAS MY LAST CONVERSATION

with the top-rated specialist at Los Angeles's top-rated neurology hospital. I had come to him in July 2006 after seeing dozens of "world-renowned" doctors across America.

One had diagnosed carpal-tunnel syndrome and poor ankle reflexes. Another had found a "probably harmless" lesion on the bone that sits in front of my brain stem. ("Don't be concerned, and don't call it a brain tumor," he told me. "But let's watch it and do another MRI in 3 months.") A third doc declared that I had celiac disease, an intolerance to the protein gluten that damages the small intestine. After I cut out bread for 4 months and endured two small-bowel biopsies, he decided I didn't have it. Another doctor ignored the stark abnormalities in my blood test, told me "There is a way to feel better, Adam," and handed me an antidepressant.

Of course, these were the doctors who tried something. Most just accused me of being a hypochondriac and sent me home.

My case was complex: I was a seemingly healthy, 29-year-old man who had survived Hodgkin's disease

Photographs by TIMOTHY ARCHIBALD, set design and prop styling: Shannon Ames/Artist United, hair and makeup: Veronica Sloan



What were the chances that something terrible could strike a guy like me?

during my teenage years, thanks to chemotherapy, radiation, and a stem-cell transplant. Yet my physicians quickly dismissed my disquieting (and very real) symptoms: progressive full-body weakness; joint pain and stiffness; muscle atrophy and twitching; persistent pain in my arms, legs, head, and testicles. After all, what were the chances that another terrible condition—multiple sclerosis, Lou Gehrig’s disease, a pervasive nerve disorder—could strike a guy like me?

Very low, apparently. So low, in fact, that after secondary cancers had been ruled out, no doctor even wanted to look, lest he find something he couldn’t understand or easily label. Never mind the Sloan-Kettering study—available to anyone with Internet access—reporting that survivors of childhood cancers, especially those who had beaten Hodgkin’s, are at risk of serious health problems down the road.

YOUNG, STRONG MEN MOVE FURNITURE, win athletic competitions, build homes, and protect our cities from crime and fire. They don’t get sick. Not seriously. This powerful concept has penetrated doctors’ offices, where it’s very likely that a child, or that child’s middle-aged mom, will receive more meticulous attention, a higher level of communi-

cation, and a kinder bedside manner than the average young guy who walks through the doors.

Young men also aren’t whiners. So if one appears in the exam room, he probably has something obvious (not my case) or something nebulous (often caused by stress and anxiety, two diagnoses that men often don’t want to accept but are present more often than not). So I guess I shouldn’t have been surprised that the 30 doctors I saw didn’t believe me. Or even that my parents had doubts, especially after a few basic cancer scans came back negative. We are taught to respect, admire, and trust our doctors—even confused doctors. That was my attitude for a year. Frustrated but respectful and ultimately deferential.

But when the Los Angeles neurologist (an expert in immunology, too) refused to do blood tests, refused to take seriously the fact that my muscles had lost a third of their volume and that I was losing my balance, and refused to open his mind to any diagnosis other than hypochondria, my frustration escalated into anger. And when I read his report—“The patient believes there is something wrong with him

and will continue to believe this despite my telling him there is no evidence for his concerns”—my anger turned into motivation, both to find out what was wrong and to warn other young men about how the American medical system is rigged against them.

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A FEW MONTHS LATER, AFTER WEEKS OF calling, faxing, and begging, I landed an appointment with one of the world’s top experts on muscle and nerve diseases. He did a variety of blood and nerve tests, muscle biopsies, and physical exams, and confirmed what I’d known all along: Something was seriously wrong.

His diagnosis: a progressive form of chronic inflammatory demyelinating polyneuropathy, or CIDP. It’s an autoimmune disease—my immune system is fighting me from within—that shows up as chronic inflammation of the linings of the peripheral nerves. The symptoms mimic Lou Gehrig’s disease: muscle weakness, numbness, joint pain, problems with pulse and digestion, trouble swallowing—basically everything I’d told every doctor who sent me home without an answer.

No one knows what caused my CIDP. It may have been the Hodgkin’s itself or the chemotherapy and stem-cell transplant that had saved my life. Or maybe it was simply written into the code of my DNA, and I was

5 ways to grab your doctor by the lapels of his lab coat

“Physicians are extremely busy, so they tend to connect certain symptoms with certain problems,” says Cam Patterson, M.D., director of the cardiology division at the University of North Carolina. “You can break through those barriers by being concise and specific.” Wave these red flags to raise your physician’s suspicions.

(Use the word “new.”)

“I have a constant new pain . . .”

“A new pain, particularly one that’s frequent, can be a sign that something is seriously wrong,” says Dr. Patterson. “Stay focused on that issue. You don’t want to confuse matters by talking about more than one problem at a time.”

(Pinpoint the location.)

“ . . . in the tip of my right pinky finger . . .”

The more precise you can be, the easier it will be for your doctor to make a diagnosis. “Giving the exact location is also important because it may indicate that you need to see a specialist,” says Cato T. Laurencin, M.D., Ph.D., orthopedic surgeon-in-chief for the University of Virginia Health System.

(Use strong adjectives.)

“ . . . a stabbing pain, pretty severe . . .”

“Severe,” “blunt,” “numbing,” “stabbing”—these words will grab your doctor by the collar, says Dr. Patterson.

(Rate your symptoms.)

“ . . . maybe a 6 out of 10 . . .”

“Giving your pain a severity score provides your doctor with a concrete idea of how it feels,” says Dr. Laurencin. “Doing this also helps during follow-up visits, because it’ll make it easier for your doctor to judge whether different medications or therapies are working.”

(Tell him what you can’t do.)

“ . . . and I’m having trouble picking my nose now.”

If you used to be able to type for hours and now you can’t because your vision is blurry, say so. Your doctor will immediately understand how debilitating your problem is—and you’ll reinforce the idea that something has changed recently. “If you’ve had to alter your lifestyle,” says Dr. Patterson, “knowing that will add to your physician’s urgency.”

TIA ALBRIGHT

destined to come down with it all along.

Luckily for me, there's a treatment. It's a blood-plasma product called IVIG. It costs \$3,000 a dose, which my insurance covers. Once in my bloodstream, the IVIG overrides my immune system by flooding my body with good antibodies that won't attack my nerves. This gives my burning, tingling, twitching nerves a chance to heal. I'm in the middle of my first course of treatment: 5-hour infusions of IVIG 5 days a week, every 3 weeks. I will continue this course for 3 months, and then my doctor will assess whether it's working. If so, my dosage will be cut. But who knows? I may need it for the rest of my life.

And if it doesn't work? There are other options: cleaning my plasma using a dialysis-like process, and trying new forms of immunotherapy and chemotherapy.

Bottom line: I'm not crazy, and there is reason for hope.

BUT I'M NOT HAPPY, EITHER. My disease is painful and debilitating. I'd been hoping—praying, honestly—that I was indeed a head case.

I'm also not happy that I had to fight for more than a year to get the attention of a doctor. Or that dozens of the nation's "top" doctors, even the one who saved my life when I was a kid, couldn't wrap their brains around the fact that a young man could become very sick with something rare and elusive again. Or, for that matter, that not a single one of those doctors could muster the focus necessary even to *consider* diagnosing it.

During my quest I had to stomach the following (and all too common) brands of medical maniac.

- **The young, pompous Manhattan neurologist who didn't take insurance** but offered discounts if I came to his grand-round sessions to be poked and prodded like a fetal pig by other curious physicians.
- **The wonky academic who refused to look at my brain MRI** ("I'm not a brain surgeon," he boldly admitted), then told me I might have multiple myeloma (a rare blood cancer he also claimed to know nothing about), and finally declared proudly that he was no longer interested in seeing actual patients and that I would have to find another doctor.
- **An old-school oncologist who flatly**

informed me that my symptoms couldn't be related to the cancer I had as a kid, even after I presented him with the Sloan-Kettering research connecting Hodgkin's disease, stem-cell transplants, and nerve problems.

- **A top-rated neurosurgeon—once photographed for the cover of a top U.S. newsweekly**—who gave me all of 2 minutes on the phone after reviewing my MRIs, and told me he was absolutely certain it was safe to biopsy the lesion near my brain stem but had no opinion as to whether it was worth even worrying about.

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MY POINT: YOU'RE PRETTY SCREWED IN America if you come down with something mysterious as a young man, especially if you have a complicated medical history. You meet a host of overly educated, bigheaded doctors who are as bad at communication as they seem to be at assessing blood tests and scan reports. These men and women invariably fail to take responsibility for getting to the heart of what's ailing you. Instead, they focus on less-ambiguous cases.

And yet, I do still believe in Western medicine and the medical profession. But I now understand how important it is to shop for the right doctor—you can't just

Each of us knows better than anyone else what's going on inside our bodies.

go with the person with the most fellowships. More important, I've realized that each of us knows far better than anyone else what's going on inside our bodies. I knew I wasn't well more than a year ago, even though multiple Harvard-educated M.D.'s disagreed. Fortunately, I didn't give up. I flew city to city, read more medical literature than my friend studying to be a surgeon did, and racked up 10 grand in debt. Eventually, I got what I wanted: a definitive diagnosis and a chance to beat it.

The message is depressing but empowering: Trust yourself before you trust any purported medical expert. Demand the attention or treatment you know you need.

In other words, fight like a young, strong man. ■

Not feeling well? Check your symptoms at our A-to-Z Condition Center at MensHealth.com/conditions.