

Eight Ways you can Help Your Doctor Save Your Life

By Joyce Wilcox Graff

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Most people believe that doctors make you better. But each of us needs to work with our doctors, helping them do their best job for us.

HMOs often limit the doctor to 12 minutes per patient. You need to work at making the most of this brief visit.



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Thousands of people in the United States and around the world still have no clear diagnosis for their medical problems. Delayed diagnosis can kill you – it often means permanent disability or death. At the very least, you will spend much valuable time taking the wrong medicine, or following the wrong therapy, making no progress in healing your medical problem, and potentially allowing the condition to worsen.

Doctors are taught in medical school to listen for common conditions, not for rare conditions. “When you hear hoofbeats, think horses, not zebras.” But one person in ten is dealing with some rare disease. There are more than 7000 known “rare” diseases. Taken together, having a rare disease is not rare. Doctors will frequently not think of them. They may not remember the paragraph or two they learned in medical school about this disease. They may never have seen a case – or realized they were seeing a case.

When my son was diagnosed with von Hippel-Lindau disease in 1986 (before the internet was pervasive), I went to the Harvard Medical School library to read all I could find about VHL. I was sitting at a reading table, surrounded by dusty old journals, reading articles in English and German, gathering small bits of information from many places. At a certain point I realized that I was doing what a doctor would have to do to find out about VHL. And the reality is that the doctor simply does not have the time or interest to do the kind of research I was doing.

That was the point at which I realized that we as patients need to make sure that our doctors have easy access to the information needed to manage our condition. That’s why the VHL Family Alliance and so many other rare disease support groups have booklets for patients and their primary care physicians to provide information on how to recognize and manage the condition. If there is not yet a resource like that for your condition, perhaps you can help develop one.

How to Be a Powerful Patient

1) Be There

The first step is that you have to put yourself in the doctor's office. You have to go for those annual examinations. You have to go for help in a timely manner for an infection.

Jim Henson, the creator of the Muppets and Sesame Street, died in 1990 of organ failure due to bacterial pneumonia. By the time he went to the doctor for his cold, the infection was so widespread they were unable to stop it. At the time, I was a busy professional working 60-80 hours a week, and more than once I had said, "I don't have time to go to the doctor." Jim's death was a wake-up call for me – when you need medical help, there is NOTHING more important in your life. No one has time set aside on their calendar for going to the doctor. But we have to MAKE time to go when we need it.

2) Manage Your Fears

We all have fears that keep us from going to the doctor and taking charge of our health. What are yours? Not do you have some, but what are your fears?

“If I go the doctor, they might find something.”

“Maybe this is cancer – maybe I'm going to die – I don't really want to find out.”

“I don't have time to go to the doctor.” (This is usually a cover-up for fear.)

Don't deny your fears, acknowledge them. Be honest with yourself. Examine them. Is there some event in your past that causes these fears? Perhaps you knew someone who “was perfectly healthy” until they went to the doctor, got a nasty diagnosis, and died.

But recognize that that person in fact was NOT perfectly healthy at that point. He was sick, but the symptoms had not yet emerged as a problem. Because that person waited to go to the doctor, the diagnosis was delayed.

3) Never Withhold Clues

Many people believe that when you go to the doctor, the doctor will figure out what's wrong, give you a pill, and fix it.

Not so.

You will have only 5-15 minutes with the doctor. You will need to plan for this meeting, as you would plan for a presentation to the board of directors. You have a very short time to get your message across, and give the doctor the information necessary to make a correct diagnosis. Research has shown that the doctor may even interrupt you after only

18 seconds. You will need to have notes so that you don't get rattled and disoriented, and forget important parts of your message.

Before you get to the doctor's office, think about your complaints and make notes.

- What are your symptoms? (what feels wrong)
- If you have a pain, where is it? What does it feel like (sharp, dull, burning)?
- If you have a fever, take your temperature at home every few hours and keep notes. Be sure to write down when you take fever-reducing medications as well.
- Is there some past event the doctor needs to know about? (you fell last week, or you had cancer in that spot ten years before)
- Is there something in your family history that the doctor needs to know?
- Do you have specific questions? Write them down so you don't forget to ask.

Your doctor cannot see the information you are holding in your head. Even if it is in your record, you may want to call out the highlights of that record. Some patients have records that are inches thick. Don't depend on the fact that the doctor will remember, or will discover the relevant details. Bring out what you consider to be the important relevant details, and make sure that the diagnostic decision being made today will take into account all those relevant bits of information.

On the other hand, make sure your presentation is clear and concise (that is, **SHORT**). Remember that you have a maximum of 3-5 minutes for your presentation, and then doctor has to leave within 10-15 minutes total. Practice what you are going to say, and be sure to have at least an outline written down. Doctors' offices create stress, the shortness of time will create stress, your anxiety about the situation induces stress, -- in other words, things will fly out of your head.

4) Know Your Genes

What medical issues run in your family? Understanding the "genetic risk factors" that run in your family can give you and your doctor some important clues, and strategies for helping you maintain your health.

One person in 300 has some genetic risk factor for cancer. More have a genetic risk factor for another non-cancerous condition, but one that may be critical to maintaining your health. Ask your relatives, take notes, keep that information where you can review it from time to time, and share it with your doctor.

If colon cancer runs in your family, perhaps you should be getting a colonoscopy every few years to watch for early signs of this condition?

If diabetes runs in your family, perhaps you need to watch your weight and blood sugar balance to keep from provoking diabetes.

Here's an example. If you go to the doctor complaining of abdominal pain and bloating, the doctor is going to start at the top of the list of the most popular common reasons people have abdominal pain and bloating – starting with hypochondria and gas. If, however, you share that two of your uncles died of kidney cancer, it puts a different light on these complaints. The doctor is going to do a very different kind of exam, and perhaps order a scan, in order to rule out possible kidney cancer. Found early, kidney cancer is curable. Found late, kidney cancer is a very difficult problem to have.

5) Keep a Log

When you have common complaints for a sustained period of time, the doctor is going to need to see the pattern in order to find a diagnosis. Headache? Pain somewhere? A rash that comes and goes? 5-15 minutes in the doctor's office is not going to get to the bottom of this.

In preparation for the meeting with the doctor, begin keeping a log. Map your pain or discomfort by time of day, time of month, what you eat. Get some perspective on the problem yourself, and ask the doctor to help you analyze what it means. Take a copy for the doctor to keep in your file and review. In the clinic, the doctor will probably be pressed for time. But later, in the office, he or she can pull out your log, review it more closely, and think about it. You will find that this can be a very powerful tool in arriving at a diagnosis.

See Attachment A for a sample Pain Log.

6) Assemble a Team

Assembling a health care team is a little like owning a professional ball team (football, baseball, etc.) You don't have to know how to score a touchdown yourself, but you do need to know how to assemble a group of professionals who can perform the needed functions for the team, work together well with each other and with you, and get the job done – in this case, that job is to maintain your health!

Medical professionals have crowded schedules. They usually have at least one support person (secretary or nurse) who helps them schedule appointments. Make friends with that person, and learn what's the best way to communicate with them.

When you have more than one medical specialist to deal with, communications among those specialists is going to be an issue. It is quite customary for specialists to send a letter to your primary care physician, communicating what tests were performed and what diagnoses were made. You have the right to request a copy of that letter and of any test results or radiology reports. It is a good idea to keep a copy yourself, especially if your medical specialists are at more than one medical center. Within a medical center,

access to a patient's records is usually pretty easy. But records cannot easily be accessed at another center. It can take days or longer to obtain access to those records. If, however, you can walk into the office of Specialist B carrying a copy of the scans performed by Specialist A, it will speed up the conversation enormously.

Read over those reports. Ask your doctor to explain things you do not understand. If something on the report seems not to be consistent with the verbal information you were given, ASK follow-up questions.

Don't be belligerent, even if the doctor's own attitude is brusque. You have a right to ask these questions, and you have a right to get straight answers. Ask politely, respectfully, but persistently. If the doctor says he has to move along to the next patient, ask when you can schedule a follow-up visit, perhaps in his office, to continue with your questions. Be sure to say if you have another appointment scheduled with the next specialist, especially if you are collecting information to share with that person.

7) Take Notes

Take a notebook with your preparation material, the log you have kept to gather insights for your doctor, and to take notes from this meeting.

Especially if the doctor might be delivering news that might cause you stress, there is a danger that your brain will disengage in order to reduce your stress. It's an involuntary phenomenon – you can't choose it, and you can't choose not to let it happen. When your brain feels that you have had enough, it will simply turn off and not take anything else in.

I used to watch this happen with my husband Frank, who had a very difficult medical condition. He had a Ph.D. – this was a brilliant man. We would go to the doctor, the doctor would announce that there was a new tumor, and proceed to talk about his recommendations for what to do about it. I would take notes; Frank would nod in all the right places and seem very attentive.

When we left the doctor's office, Frank would turn to me and say, "The doctor should have talked about ____." "Well," I would say, "actually he did." And I'd get out my notebook and read him my notes. His brain had shut off to protect him from any more stressful information. He absolutely could not remember the topic being discussed.

The best thing to do, especially if the news might be bad, is to take a friend. If you have to go alone, take a tape recorder or notebook yourself. I have never had a doctor yet object to a tape recorder. I have had some of them pull my notebook over and draw me a picture. They usually appreciate that you want to know more details, and that you are recording the valuable information you are receiving.

8) Do Your Homework

Homework?

Yup, homework. Once you have a diagnosis, you should look it up on the internet and find out all you can. Don't take it as gospel, and check the credentials of the site. If you are reading someone's blog, assume this is a patient who knows little more than you do. The level of medical accuracy is likely to be low. If it's a university site, it is probably higher. If it's a peer-reviewed journal, the reliability is high, but the reading level might also be high. If it's a condition-oriented patient support site, check to see whether their material is medically reviewed. One symbol to look for is the HonCode certification of ethical practices among health-oriented sites. You will find the HonCode logo on the vhl.org website.

As you read, ask yourself: Does this diagnosis fit? If you have questions, raise them with your doctors.

If it's the right diagnosis, the description usually feels right, and issues you might have considered unrelated "fall into place." As difficult a diagnosis as VHL can be, many families say to me that it finally makes sense of all they have been doing through for years. A series of tumors, which some doctors may have been attributing to a "run of bad luck" suddenly makes sense as common parts of a wider syndrome.

If the diagnosis just doesn't feel right, discuss it first with the doctor. There may be test results that you don't know about that will help you understand the relevance of this diagnosis. Or you may need to obtain a Second Opinion.

I once had a doctor say to me that if my insurance company needed a second opinion, he could arrange it with one of his colleagues. That's not a second opinion, it's a rubber stamp.

A Second Opinion is when you go to a different doctor, preferably at a different medical institution, and you begin from the beginning and consider the symptoms from a different perspective. See if the second doctor comes to the same conclusions – or not. You may be asked to re-do some of the same tests. There is no harm in that.

Here's one example. A woman was experiencing problems with her inner ear that might have been symptoms of a tiny tumor in the inner ear. Her regular doctor said it "couldn't be" an inner ear tumor because she had had a brain scan to check for brain tumors, and they did not see anything in the inner ear.

However, the inner ear is a very tiny structure. The "slice depth" used on the brain scan was too great to thoroughly check for a tumor of the inner ear. They needed to do a special MRI of the Internal Auditory Canal with very fine slice depth. Slice depth is a term used to tell how far apart the pictures, or "slices" are taken. Picture yourself slicing an orange, and then laying the circles out for inspection. When you look at those MRI or CT pictures, they look essentially like these "slices" laid out for inspection. Depending on the thickness of the slices, there might be a seed hiding inside the flesh of the orange. Or you might have sliced right through a seed. If one of those seeds was a tiny tumor, and the slices are thick, chances are the tumor will not be seen.

The neuro-otologist did a new scan with the right focus and slice depth, found the tumor, removed it, and saved her hearing.

Be a Powerful Patient!

A diagnosis is an essential tool in managing your health. Once you know what's going on, then you and your medical team can determine the best management strategy for keeping you healthy.

Do your part too by contacting other with the same condition. Use the internet to discover patient support groups for your condition. If you can't find one on your own, contact the National Organization for Rare Disorders, <http://www.rarediseases.org> They maintain a directory of people with rare conditions who have authorized release of their names to others with the same condition.

There is strength and comfort in numbers. Finding someone else who understands what you are going through will be an enormous relief.

Please send any comments or questions about this document to

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We would love to hear your stories, too. Did you find these steps helpful?

We look forward to having you with us for the radio show, The Powerful Patient.



Joyce Graff, The Powerful Patient, <http://powerfulpatient.org>

Joyce Graff, host of the radio show Powerful Patient, is Founder and Executive Director of the Cancer Research Fund – VHL Alliance. She has worked with people with von Hippel-Lindau disease since 1962. She compiled the VHL Handbook in 1993, the first practical guidance for patients and physicians on how to monitor VHL and manage one's health. She has updated it every 3-5 years since then. She edits the VHL Family Forum (quarterly since 1993). She served on the Board of Directors of the National Organization for Rare Disorders. In 2007 she was appointed by Dr. John Niederhuber to his Consumer Liaison Group at the National Cancer Institute. She is a popular speaker, and has presented to groups on five continents.

The Cancer Research Fund and the VHL Family Alliance International are dedicated to improving diagnosis, treatment, and quality of life for individuals and families affected by von Hippel-Lindau disease and related tumor conditions. They provide information in 8 languages, fund research,

and help connect people with the best available medical information.

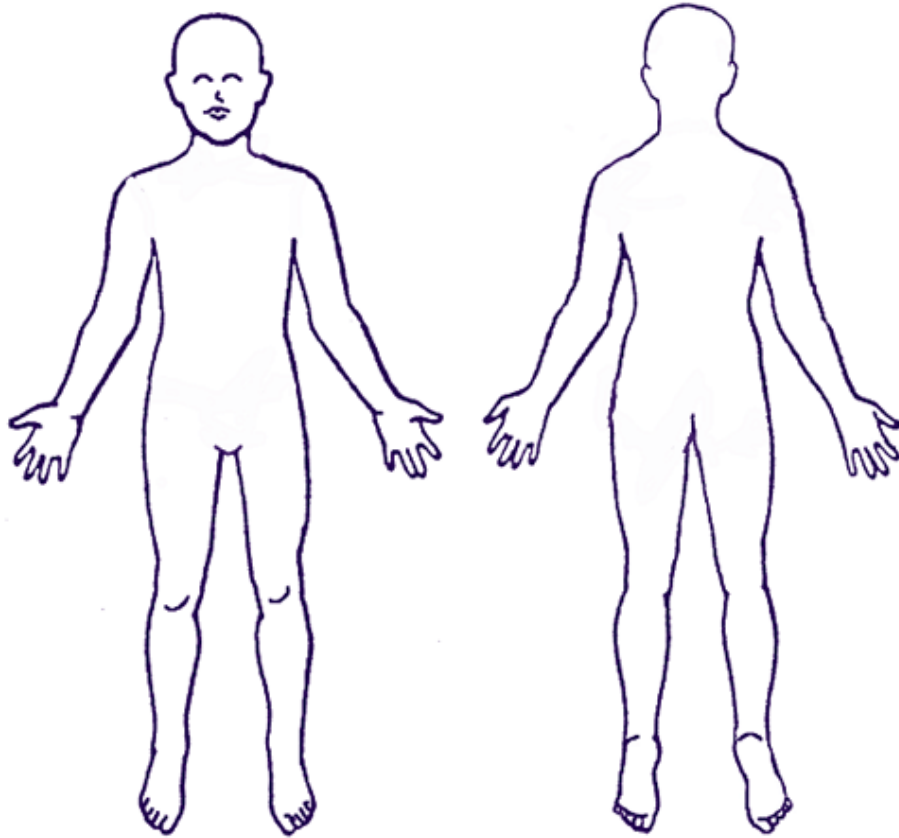
Pain Log

Put an X to show where the pain is.

Note what kind of pain:

- Sharp
- Dull
- Burning
- Aching

Does this pain recur? Is it in the same place or different?
Use numbers on the diagram if the pain moves around.



On a scale from zero to ten, how bad is the pain?

0 1 2 3 4 5 6 7 8 9 10
No pain Worst possible

Date	Time	Pain Rating (0-10)	Medicine I took (if any)	Pain Rating one hour later	What was I doing just before I felt the pain?