



## RESEARCHING YOUR DIAGNOSIS

### VALUE OF HAVING A DIAGNOSIS

Your diagnosis is the name of your disease. It not only validates the symptoms you've been experiencing, it focuses your provider's thoughts about your health and lets your insurers figure how to cover tests and treatments. Having a diagnosis is helpful when talking to friends, family, employers, etc. It's legally important too for things like applying for disability.

### WHAT IF YOU DON'T HAVE A DIAGNOSIS?

Not having a formal diagnosis creates problems. It makes talking about your condition more complicated. No diagnosis means your insurer can only see a collection of signs and symptoms, which are often not enough to cover complex tests and treatments. You end up doing a lot more talking and the chance for misunderstandings goes up.

If you don't yet have a diagnosis, work with your doctor to get one.

### UNDERSTANDING YOUR DIAGNOSIS

You can have more control over what happens next by educating yourself on your diagnosis. There are good online resources (more about that later) that can tell you...

- Causes of the condition (Etiology) - how did you end up with this condition. This might help you decide how you talk to your family or what kind of activities to avoid.
- Signs and Symptoms - Signs are what your doctor can see and measure, like blood pressure. Symptoms are things only you can measure, like pain.
- What to expect over time (Prognosis) - is this condition going to flare on and off, or gradually get worse?
- How is it diagnosed - diagnosis is an ongoing process (there are types and subtypes of some conditions)
- What are the treatments - drugs, physical therapy, psychotherapy, and what you should expect from them
- What kind of doctor should you see about it - you want the most specialized help you can get. Your GYN shouldn't be treating your diabetes.
- What kind of support is available - by communicating with others with your condition you can learn valuable tips and adjust your expectations.

### EMPOWERMENT BEGINS WITH UNDERSTANDING

[Cancer.org](http://Cancer.org) says it well, "Simply having answers to your questions can help you feel more in control and less worried about what lies ahead." Having knowledge makes you less dependent on others for information, increases confidence and gives you more control over what happens next.

### HOW TO FIND INFORMATION

There is no better resource than your **doctor and healthcare team**. But even the best team won't have time to teach you everything. You need to teach yourself.



Here's how you find information:

### **SEARCHING THE INTERNET 201**

We've all Googled stuff. You enter what you want, or what you think you want, or what you think will get you what you want and... it's like a roll of the dice.

#### **Sources you can trust**

The government puts out top quality information about health and medicine in the public interest. They aren't trying to sell you anything. Some institutions hold themselves to an similarly high standard. As a writer and patient advocate [here are the sites I always trust](#):

**MedlinePlus** is operated by the National Institutes of Health's U.S. National Library of Medicine. This website is a reliable source of scientifically-based, peer-reviewed health information. There are no advertisements because it is already paid for by tax dollars.

All the information is written by healthcare professionals (MDs, PhDs, RNs, etc) and it is 100% available in Spanish. If you had one place to go for information, this should be it.

In addition to MedlinePlus, I confidently turn to any division of the [National Institute of Health](#).

**DailyMed** is a source for drug information and is also operated by the National Institutes of Health's U.S. National Library of Medicine, making it very reliable and ad-free. Information is sourced directly from the Food and Drug Administration.

The [Mayo Clinic](#) and [Johns Hopkins](#) are arguably two of the world's leading institutions of medicine and science. Both are consistently ranked among the best medical providers in the country, and both conduct extensive medical and scientific research which keeps them at the forefront of innovation. Both have extensive information on medical procedures. You can search for tests and surgeries and get a lot of reliable info. Both the Mayo Clinic and Johns Hopkins are technically not-for-profit. Nonetheless, it is worth remembering that they are medical institutions that make money by billing for medical services.

#### **How to search for stuff**

Well, I found this awesome [article from TechRepublic](#) from 2011 that taught me more about how to search for stuff than I ever knew. Check it out. Here are some highlights:

#### **The plus operator (+):**

The plus operator tells the search engine to include certain words in the result. Example: [tall +and short](#) will return results that include the word "and".



### **The OR operator (OR) or (|):**

Use this operator to return results with either of two terms. For example [happy joy](#) will return pages with both happy and joy, while [happy | joy](#) will return pages with either happy or joy.

### **The Minus operator (-):**

How many times have you searched for a term and had the search engine return something totally unexpected? Terms with multiple meanings can return a lot of unwanted results. The rarely used but powerful minus operator, equivalent to a Boolean NOT, can remove many unwanted results. For example, when searching for the insect [caterpillar](#), references to the company Caterpillar, Inc. will also be returned. Use [Caterpillar -Inc](#) to exclude references to the company or [Caterpillar -Inc -Cat](#) to further refine the search.

### **Quotations for exact phrases:**

I often remember parts of phrases I have seen on a Web page or part of a quotation I want to track down. Using quotation marks around a phrase will return only those exact words in that order. It's one of the best ways to limit the pages returned. Example: ["Be nice to nerds"](#). Of course, you must have the phrase exactly right — and if your memory is as good as mine, that can be problematic.

### **Adding “ORG”**

It is important to distinguish between information coming from a source that is trying to sell something and a source that is not-for-profit. I also ran searches for multiple diseases where I added “org” to the end of the search bar (“gastroparesis org” “type 1 diabetes org” for example) and the results I got were reliably from “.org” s which indicates not-for-profit.

### **Understanding my...**

I used the search terms “[understanding my](#)” [blank]. I inserted fifteen different diseases from a list of leading causes of death listed by the [Centers for Disease Control](#). I also inserted five rare diseases listed by the [Rare Diseases division of the National Institutes of Health](#). Seventeen times, the very first entry that came up turned out to be very reliable. The other three times, good results were in the top 5 entries.

### **IN CONCLUSION**

When you are diagnosed with a serious illness it seems like you lose a lot of freedom and choice. In a way this is true, but it is also true that you get to decide how much AGENCY you have. Take action. Don't be passive. Empower yourself and you will not be a victim.