

8 RATIONAL TIPS

TO HELP YOU TAKE CHARGE OF YOUR DIAGNOSIS

On any given day, thousands of people wake up to a new world. A well-meaning friend will send them the Welcome to Holland story, and they will find all sorts of inspirational memes urging them on and telling them they are superheroes, that they're "special," and they "got this." What do they "got"?

They got a diagnosis.

They woke up one morning, took a phone call or visited a doctor and they heard a possible reason for the symptoms they have experienced. Maybe they receive a prescription and a plan and then were left alone to figure out how to live with this new information. If they are lucky, their doctor has a brochure they can read obsessively, evaluating everything listed as it pertains to their experience living with the condition.

But, there are the rare diagnoses, the ones that have NO known treatment and no known prognosis. There are no pretty pamphlets, no prescription and no checklist until someone makes one and brings hope to the unknown.

Regardless of the type of diagnosis received, there are a few things that are good to remember and even better things to make a habit.

Here are eight things we think will help you take the reins, for yourself or your loved one now embarking on a new journey into the medically complex world of being newly diagnosed, regardless of the diagnosis you've received.





1. LOOK IT UP! RESEARCH YOUR DIAGNOSIS.

Forget about the dismissive term 'Dr. Google.' That phrase was coined to make people feel like they shouldn't seek out answers, that they should let the medical establishment provide the answers. What if there aren't any? Unless you are patient No. 1, if you have a syndrome with a name, there is information out there somewhere. Go find it. Read up on as much as can about what is happening inside your body. Take a careful look at the sources of information, find credible researchers and authors, and remember that every journey is unique. In most rare diagnoses, you may find a spectrum of symptoms. Not everyone experiences their diagnosis the same, even the most common diagnoses have a severity scale. Become comfortable speaking about it, because chances are when you have a rare diagnosis, YOU will be the expert in the room.

2. SEEK OUT OTHERS WHO HAVE BEEN THROUGH THE SAME OR SIMILAR THINGS.

We mentioned that you are probably not patient No. 1, which doesn't just mean there is research out there, but people living with the same thing you are. There are shoes just like yours and maybe a path you didn't know about because the medical community hasn't been on it; they've been walking just slightly behind.



Waiting for medicine to catch up to you is so much better with friends on your side. You will find that there is an instant comradery, a sharing of a deeply complex and personal understanding that is more than meeting someone you like for the first time. It's meeting someone just like YOU for the first time, you share something under the skin that most people don't share. Look for them.

3. WRITE DOWN YOUR QUESTIONS.

Think of the questions you want to ask your doctor before going into any appointment. Remember: No question is worthless except the one that goes unasked.



Some people are intimidated by doctors; but often, there is simply a limited amount of time you spend with a doctor, a lot to cover, and it's easy to get sidetracked. Write your questions down and reference them in the exam room or office. Your doctor will appreciate your focus.

4. KNOW YOUR COVERAGE.

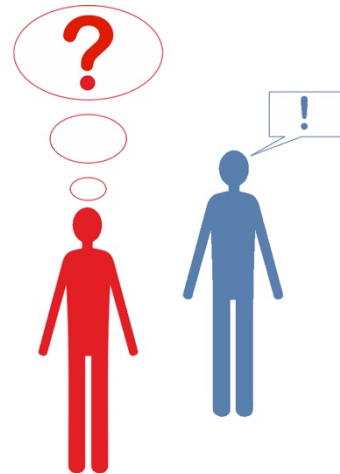


pay out of pocket for your visit.

This may seem to go without saying, but the importance of knowing what your insurance covers matters more than just not having to

Any testing that may be needed may only be able to be done at a certain site, and knowing what is in your coverage area can prevent unnecessary trips. Knowing that you need to see a specialist now becomes less of a burden because you'll know who is in your network. It may just also come in handy if you need another opinion.

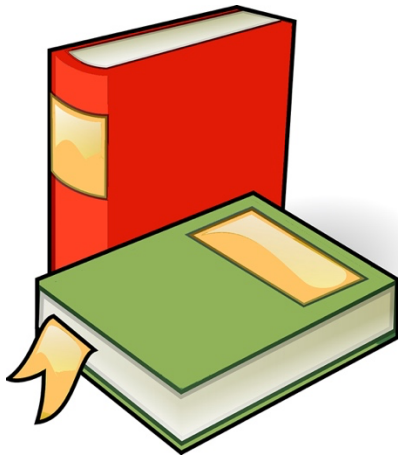
Now that we think about it...



5. DON'T BE AFRAID TO GET ANOTHER OPINION.

Most doctors don't have a discernable problem with a patient getting another professional opinion. Having another set of eyes always helps in a rare condition, and doctors know this. It's also OK to find someone new. Doctors ARE people. If you just don't mesh with your doctor, for whatever reason, it's okay to get a referral to another one.

6. ASK YOUR QUESTIONS, AND IF THE ANSWER DOESN'T MAKE SENSE TO YOU, TELL THE DOCTOR YOU NEED MORE INFORMATION.



You've taken your written questions to your doctor, and you remembered to ask them.

Now you aren't sure you understand the answer. Tell your doctor you need it explained differently, or you need more information. Don't just nod and leave the room because you don't want to admit you didn't understand. Take a moment to write down the explanation when it's fresh in your mind and you know it's correct. Your doctor is there to help find a treatment for your symptoms, explaining the treatment options and why he/she is prescribing it is, literally, why you are both there in the same room.

7. GET YOUR MEDICAL RECORDS AT LEAST ONCE A YEAR. LET THE OFFICE KNOW IF THERE IS A DISPARITY.

For whatever reason, things can get lost in translation; this is especially true with medical records.



It happens more than we like to think, and it CAN make a big difference in your future care. Sometimes you'll find a simple error, such as a typo or misspelling, and notifying the office is enough to get it remedied. Occasionally, entire records for an office visit are incorrect, or records of two separate people can get mixed up. Correcting those errors too long after the fact is nearly impossible. Get your records and read them. If there are errors, reach out immediately for correction.

6. REMEMBER TO LAUGH WELL AND LAUGH LONG.



People respond to trauma in different ways. We may not think of a diagnosis as traumatic initially, but

when it changes our lives, it can certainly be defined as a traumatic event and eventually, we need to accept our new path. When one can finally find humor in some of things we face with a diagnosis, one can now find that acceptance of it. Laughter also has proven health benefits.

BONUS LIST:

Laughter might not be the best medicine, but it is a pretty good pain reliever. According to Mental Health America¹, finding humor in life helps people better deal with the difficulties of life. Aside from a positive mental attitude, there are physical reactions to laughter which include:

1. Our stress hormone levels decrease.
2. Our heart, lungs and muscles are stimulated.
3. There is increased activity in parts of the brain's reward system.
4. Endorphins – the body's natural pain blockers – are released.
5. Our immune system grows stronger.
6. Our mood improves and our anxiety decreases.
7. We have better interactions with others.
8. We have less burnout on the job.

These eight tips are gathered from people who have lived with a rare diagnosis for decades, who have worked to become stellar advocates and happy humans. Happiness is not as elusive as you might think. It can come from understanding as much as you can about your diagnosis and being an equal partner in your healthcare. It comes from finding others who can both commiserate with you and support you. It comes from being able to laugh as much as you cry, and from taking the reins of your own medical needs.

After all, WE got this.