

The Seven Habits of Highly Effective Patients

Advice from a chordoma survivor on how to get the best care possible.

1) Be proactive. You are in charge and will have to be your own expert. Doctors are great, but treat many patients each and every day. You, on the other hand, are worried about only one case – your own! So even though you are not as knowledgeable as your doctors, you can sometimes be better informed than they are. Sometimes you will even be the main conduit of information between the members of your team. Email and/or text messages work for most doctors. Use them!

2) Ask questions. “Why did we decide to change to this medicine again? Can you walk me through this decision?” If done in a pleasant and constructive manner, you will find that doctors slow down, think harder, and concentrate on your care. You may actually get different or better care as a result. This saved my life once or twice.

3) Own your records. Keep a physical copy (CDs or thumb drive) with a copy of your chart, all your test results, and scans, and bring it to every visit or appointment. Murphy’s Law says that the one time you finally get in to see the top specialist is the day when the FedEx with your results goes missing on someone’s desk.

4) Take notes. Keep a notebook with you at all times, and write down everything. Got a new symptom? Something doesn’t seem right? Prepare a list of all your questions before each doctor’s visit, and then write down all the answers as well. Even better is to have a friend or family member come along, and also take notes. In the heat of the moment you may be distracted and miss some important information.

5) Get a second (and a third) opinion. Never stop asking what other options you have. It can literally save your life. Especially for a rare disease, the opinions you get may vary, which doesn’t necessarily mean that any one of them is wrong. Medicine is rapidly advancing, and some differences in doctor’s opinions and recommendations can be part of the natural variation of the frontiers of our knowledge. This may actually be a sign that you have found the true experts, but might be unsettling to some, so remember number 6....

6) Trust your gut. At some point, there is no certainty, and your multiple expert opinions will differ. At this point, the most important factor will be to go with the team that you trust and believe in the most. This will translate into the right frame of mind for all involved, and helps you cope and heal.

7) Be positive – you can beat this. No one succeeds if they expect to fail. If things don’t turn out the way you want, at least you can say you did everything you possibly could have. And never, ever, ever give up. I know one long-term survivor who was told on three separate occasions (separated over a decade in time) that there was no longer anything his team could do for him. Each time he went out and got another opinion, started another treatment, and is still going strong today.