

Getting The Best Healthcare: An insider's guide

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You have a good doctor. You're smart. You're prepared to fight your cancer. But still, you have questions. Should you change to a doctor who specializes exclusively in your disease? Should you get a second opinion? Should you trust what you find on the internet? Navigating our complicated healthcare system is challenging even when you are feeling your best – it can be particularly overwhelming when you are facing a serious illness.

It may seem that there is too much to know and that doctors are just too busy. It may seem that you are at the mercy of the monstrous medical machine and that you have no control. It may seem that way, but it isn't that way. You can grease your wheels through the system with just a few simple steps. In this article I will share my insider knowledge of the healthcare system to help you get the best possible care.

Assemble an expert healthcare team

Doctors have different skills. Finding ones whose skills match your needs is a crucial first step in successfully navigating your healthcare. But how can you know who is an expert? Is a community oncologist good enough or should you go to a well-known cancer center? If you have a rare cancer or an advanced disease stage, you should strongly consider a visit to an oncologist who specializes in your cancer. For those with an early stage of a common cancer it may be less important, but is still worth considering. It is certainly worth discovering if one of your local cancer doctors is an expert in your particular disease. If not, you might consider visiting an out of town specialist for a one-time second opinion.

The National Comprehensive Cancer Network (NCCN) is an extremely valuable resource for finding expert cancer doctors. It is an alliance of twenty-one of the world's leading cancer centers, and its website (Table 1) includes a physician search function, allowing you to input the hospital which interests you, the type of physician that you need, and your specific cancer. It provides contact information for the physicians, making it easy for you to schedule an appointment. If you don't have an NCCN hospital in your area you can still find a well-qualified doctor. Locate the teaching hospital nearest to you (the one with a medical school) and spend some time on its website. Look for the section

called “find a doctor” or “physician referral” and search under oncology, medical oncology, surgical oncology, or radiation oncology, depending on your needs. Most of these websites will allow you to peruse the physician directory, which should include each physician’s special clinical and research interests. Simply look for a physician who is particularly interested in what you have. This physician is more likely to read specialty journals devoted to your type of cancer and to be familiar with the most up to date treatments. He or she is more poised to provide you with the expert advice that is so crucial when fighting your cancer.

What if you located an expert in your particular cancer but that doctor is inconveniently far from your home? You can visit the doctor for a second opinion consultation, yet still pursue your treatment close to home. Simply have the second opinion doctor create a treatment plan and bring it home for your local oncologist or radiation oncologist to implement. Since many patients pursue second opinions before beginning cancer treatment, physicians are usually accepting of such arrangements. On occasion, a local physician will refuse to carry out a treatment plan created by another doctor, and in that case you might need to consider changing oncologists.

If you have no local experts and travel is impossible for you but you’d still like an expert opinion on your case, you might consider an e-consult. The Cleveland Clinic, a well-established and well-respected medical institution provides an expert assessment of your diagnosis and treatment options without the need to see one of their physicians face-to-face (Table 1). After filling out a detailed medical history form, you arrange to have your records and scans sent to the Cleveland Clinic and they assign you to a physician with expertise in your cancer. He or she critically evaluates your case, including your biopsy specimens if appropriate, and within 7-10 days your consultant’s opinion is mailed to you. You can have a copy sent to your doctor, but you are not required to do so. You don’t need a referral and you can even request a consultation on someone else’s behalf as long as you have their permission. The application process takes about an hour and the consult is not covered by insurance. It costs \$565 for the consult and an additional \$180 if your biopsy slides need to be reviewed (prices accurate as of the writing of this article). This service is available in all states except Louisiana, North Dakota, California, and Oregon.

Educate Yourself

You must become the expert on your own disease. This will help insure that you get the best care, help you work effectively with your doctors, and give you the confidence to speak up when things don’t seem right.

Medical information is everywhere – the trick is to sort through the inaccurate, irrelevant and outdated to find the nuggets of information that are most useful to you. In the past, medical textbooks (available in hospital libraries) were a common source of medical information. These are the books that doctors use to study from when they are in training. They offer helpful background information – ‘what exactly is cancer?’ ‘How many people have it?’ – but because of long production times, they are outdated as soon as they hit the shelves.

Popular books can be a useful source of medical information as long as you choose them carefully; stick to ones written by those physicians actively involved in the treatment of your disease. Others, such as those written by patients, can be helpful for learning coping strategies but don't rely on them for information on choosing treatments.

Now, thanks to the internet, everyone has access to unlimited medical information, which is both a blessing and a curse. Searching for accurate information that is relevant to you can be challenging, but it is possible if you follow a few simple guidelines. There are three primary types of medical information that can be found on the internet: original medical research, medical research that has been grouped together and summarized by experts, and information presented by lay people. Each has their advantages but information that has been summarized by experts is often the most helpful. This kind of information can be found in two basic formats: medical review articles and medical websites that are designed to educate patients, doctors or both.

Review articles are targeted to physicians and they generally present the most relevant research on one topic. They can be found on an internet medical research catalog called PubMed (Table 1) which is targeted to physicians but is available to anyone at no charge. Be sure to check the date of publication of any review article – a review of the available treatments 15 years ago will not help you fight your cancer today. The other, and perhaps easier, way to get accurate medical information from the internet is to visit a reputable site that has summarized information and organized it by topic. There are many websites that provide excellent, easy to understand information written specifically for non-physicians (Table 1).

Original research articles are also available on PubMed, but they should be used with caution. It is difficult, even for physicians, to figure out if a particular study was well designed, if the statistics were analyzed correctly, and if it applies to the patient in question. If the study was done on postmenopausal women in their 70s, do the results apply to you if you are premenopausal and 50? Original research is most useful if you are investigating a new or experimental treatment or if your cancer is so rare that reviews have not been published.

Websites created by patients are not necessarily inaccurate, but they can be so it isn't safe to simply believe what you read. These resources are most helpful for learning coping strategies, finding online support groups, or getting ideas for topics to investigate further on more reputable websites.

In addition to learning about the treatment options available to you, you need to learn about the specifics of your own cancer. Be sure to find out your cancer's stage, size, aggressiveness and whether or not it has spread. For many cancers there are other related tests that may affect the treatment decisions – be sure to ask your doctor about them and write down the results. Armed with this information, you will be more able to understand what you read and better able to make thoughtful, effective health decisions.

Communicate Effectively With Your Doctor

It has never been more important to communicate with your doctor than it is right now. Effective communication can not only make your travels through the medical system more pleasant, it may even improve your care.

The challenge is to stick up for yourself without alienating your doctor -- a difficult balancing act in many cases. If you worry too much about being a “good patient” and being liked by your doctor, you might neglect to bring up an important new treatment option that you discovered or admit that you are thinking about getting a second opinion. On the other hand, if you approach every interaction with the doctor as a battle, implying that you know more about the proper treatment than he does, you are likely to be met with hostility rather than the collaboration that is so vital to getting the best care. So how should you walk this tightrope? Essentially, you want to be perceived as knowledgeable and collaborative rather than confrontational and critical. Reflect on the following scenarios. In both cases the patient wants a different anti-nausea medicine than the one the physician has prescribed.

Confrontational Approach:

“My cousin’s doctor gave him a really good medicine when he was sick from chemo – the one that starts with a ‘Z’. This one that you want to give me isn’t as good – I read about it. Maybe you are trying to save money or something, but I want what my cousin got.”

Collaborative Approach:

“I’ve heard about that medicine that starts with a ‘Z’ -- it is supposed to be really good for nausea. Is this one as strong? I really hate being nauseous, so would it be OK if we started with the strongest possible medicine for nausea right from the start?”

If you were the doctor, which scenario would you prefer? Would one of them make you more willing to give your patient what she wants?

If at all possible, try to communicate your needs as requests rather than demands. This appeals to the humanity of the doctor (“please doctor, can you help me?”) rather than engaging his ego (“I know more about this than you do”). I am not suggesting this approach because doctors’ egos shouldn’t be challenged, rather I am suggesting it because it is more likely to get you what you want.

Does it always work? No. If you have tried the gentle, collaborative style of communicating and you still can’t get what you want, it may be time to turn up the heat. If your doctor isn’t listening to your concerns, by all means insist on an explanation. You might even consider bringing a friend or family member, or even a professional advocate, to help you argue your case.

Most difficulties between physician and patient can be worked out with a little patience and consideration of the other’s point of view. But in the rare circumstance when there is an impasse, you might just need to find another doctor.

Organize Your Medical Information

Keeping track of the myriad tests, treatments, scans, and doctor visits involved in treating cancer can be challenging. Designating one place, such as an organized notebook or folder, for all of your medical information can make the job easier and can even help your doctor give you better care (Table 2). Be sure to get copies of your tests, scans, and hospital records to keep in your notebook, and bring it to every doctor visit.

Getting through the healthcare system successfully takes effort. It takes time to find great doctors, perseverance to search for meaningful medical information and self control to advocate for yourself without bruising your doctor's ego. It does take effort, but it is worth it. Traversing the medical system with intention is simply more effective than passively allowing the current to carry you along. You will be more in control. You will become a more knowledgeable participant in your care. And you may even find that you are able to fight your disease more successfully.

Table 1
Helpful Websites

Finding a Doctor

- National Comprehensive Cancer Network
www.nccn.org

Educating yourself

- PubMed
www.pubmed.com
- CancerCare
www.cancercare.org
- American Cancer Society
www.cancer.org
- National Cancer Institute
www.cancer.gov
- Massachusetts General Hospital Cancer Center
www.massgeneral.org/cancer
- National Comprehensive Cancer Network (see above)

E-consults

- Cleveland Clinic e-consults
www.elevelandclinic.org

Table 2
What to Put in Your Health Notebook

Active and inactive medical problems
Current and past treatments
Surgeries
Current and past medications
Drug allergies
Lab tests
Radiology tests
Pathology and other tests
Hospital admission and discharge records
Consultant notes
Notes that you've taken during your doctor visits

Dr. Chiamonte is a private Health Advocate and the founder of Insight Medical Consultants. She has been quoted by CNN, The Wall Street Journal and USA Today as an expert on patient advocacy.

www.InsightMedicalConsultants.com