

CHAPTER 2:

Finding Help

Cancer patients are supposed to be upbeat; we are supposed to relax and trust that our doctors will provide the best possible care. I had never had a serious illness before, so I was naïve about what to expect from the medical establishment. I wanted to feel that I was safe and in good hands, and that I could simply follow my doctors' advice. Unfortunately, that was not my experience.

Our physicians are usually our primary source of information, but the fact is that medicine in the USA is a business. Physicians are paid for their time, so unless a patient is a family member or a VIP, most physicians will not allot a patient any more time than the number of minutes that is the "standard of care." Some doctors are more caring than others, but the for-profit system that we have in the United States rewards oncologists financially if they squeeze in as many patients as possible. A surgical oncologist will want to do surgery; a medical oncologist will want to do chemotherapy; a radiation oncologist will want to do radiation. This is what they know and what they are paid to do; and most oncologists want to get on with it as quickly as possible.

What they will usually not do is spend extra time consulting with specialists and/or looking in the medical literature for newer and better ways to treat their patients. They will generally not become knowledgeable about any kind of treatment outside their specialty, such as nutrition or any type of

complementary medicine. I suspect that most oncologists would be willing to spend the time if they were paid, but insurance in the United States will usually not reimburse for these kinds of activities. In fact, the extra time that an oncologist would have to spend would actually cause them to lose income.

It seemed to me they just wanted me to follow their program, but I knew from even a very quick survey of the literature, that cancer decisions are not easy and simple. The treatment is often unsuccessful, and the side effects can be life threatening. Every patient's case is different, so the "one-size-fits-all" approach on which traditional cancer treatment is based may not be the best way to proceed. I needed all the help I could get to make decisions, but if I wanted to get more than the "standard of care," I found that I was pretty much on my own.

I am listing below the most important things I think a newly-diagnosed breast cancer patient should know. Some of these sources of help may be covered by insurance: in my case Medicare paid for second, third, fourth, fifth, and sixth medical opinions, and would have paid for more if I had needed them. Sometimes insurance will also cover patient advocates and integrative oncologists, and sometimes you will have to pay out of pocket. So far as I know, insurance never covers concierge doctors. The rates for these services vary widely, and some doctors are more affordable than others. However, the one thing that helped me more than anything else was consulting other patients, and that was absolutely free. I had a network of friends and their friends who had had breast cancer, and they gave me valuable advice. I attended a weekly breast cancer support group at the Cancer Support Community (CSC). The CSC has 55 affiliates throughout the United States and abroad, and there is no charge for their services. My local affiliate offers counseling, family services, lectures, complementary modalities like yoga and tai chi, and much more. My other main contact with other patients was online, mainly on breastcancer.org. Because patients post on that site from all over the world, I learned things there that I was able to use in my treatment that I had not found from any of my doctors, from my friends, or from the CSC. Also, the enormous wealth of literature on the Internet, in public-

access journals and in libraries, is available free of charge. Furthermore, you can enhance the quality of care you get by organizing your medical information and learning to ask the right questions, and this costs nothing but time.

Consider a patient advocate

There is a profession called patient advocate or clinical advocate. Unfortunately, I did not know about this profession until my treatment was over, but if I ever have a recurrence, or any other serious illness, this will definitely be the first place I will turn.

As a breast cancer patient, you need to figure out your risk of recurrence with no treatment, and the amount by which each proposed treatment will lower that risk. You also need to know all the short-term and long-term side effects for each proposed treatment, so that you can weigh the risk of recurrence without the treatment against the risk of harm from the treatment. These decisions can be very personal, so nobody should dictate your decisions, but to make them you will need solid information: the statistics for recurrence as well as the statistics for each side effect for each proposed treatment. I asked my doctors these questions, and I got a wide variety of responses. Sometimes I got a paternalistic attitude and a brush-off, and sometimes I got answers. Sometimes I got different answers from different doctors to the same questions, and I did not feel I could trust them. If this happens to you, you might want to hire a patient advocate.

Most people are not equipped to do the research they need on their own. Lay people often have difficulty getting copies of their records and understanding them. They are often unable to get clear and thorough explanations from their doctors. They can't usually read the research, not only because most medical journals require a subscription and a password, but also because lay people do not usually understand medical language or know the ways of hospitals and physicians well enough to extract the information they need.

The terms “patient advocate” and “clinical advocate” are unfortunate because they can mean many things. If you look them up online, you will get different definitions. Some refer to people who help you with health insurance; some are lawyers who will help resolve disputes. The ones I am talking about are usually medical professionals who will work on behalf of patients for a fee. The great thing about advocates is that their allegiance is to you and they will do what you ask. Although the services of patient advocates are rarely covered by insurance, some advocates will accept payment on a sliding scale.

I imagine that different advocates work in different ways, but am going to describe the services of a particular patient advocate I contacted, who is an M.D. specializing in cancer. I do not have permission to use his name because he only accepts referrals. If you need an advocate, you can ask your doctor to refer you, or you can get a referral from the sources listed in Appendix A.

After you arrange for him to have copies of all your medical records, he will read them and explain what is going on, which may not be the same as what you were told. You can raise your questions and concerns. You will brainstorm your case together, and decide which case activities and research questions you want to pursue. Research will usually include a review of the medical literature; and sometimes it will be necessary to consult with the authors of the research or other specialists. Because there is usually a huge lag between the time a research study is finished and when it is published, the advocate will often track down people who are doing cutting-edge research in order to get results that are not yet publicly available. The advocate might also want to contact your physicians. Because of his profession, he can usually get a better response than patients can; his calls tend to be returned promptly, and medical records are quickly sent.

You and he will decide what needs to be done, who will do it, and what the time frame will be. Patients participate at every step of this process; if they are too sick, then family members or friends may help.

After the relevant information is gathered, you and your advocate will

analyze it and develop a plan of action. At that point, it should be obvious what the best options and the next steps are. Some issues that might need to be considered include evaluating the quality of the care you are receiving; whether you need more tests or consultations; whether other treatment possibilities should be considered; quality of life issues, such as pain control; nutrition; and your psychological, spiritual, and family needs.

The advocate will help you develop a plan. Sometimes the plan will be carried out by the medical team you already have; and sometimes you might need to change physicians. If necessary, the advocate can negotiate with your physician on your behalf or recommend a different physician.

Consider an Integrative oncologist

Another patient recommended her integrative oncologist, and he was a life-saver for me. An integrative oncologist is a physician who is trained both in conventional cancer treatments and also in complementary/alternative modalities. My integrative oncologist is a diplomate of the American Boards of Internal Medicine, Hematology and Medical Oncology; board certified in Nutrition; and board certified in Integrative and Holistic Medicine. Although retired now, he stayed with me throughout my treatment and did many of the same things for me that a patient advocate would do. He got copies of all my medical records, and he recommended things that he thought would help. He was aware of what my conventional doctors were doing and not doing, and if something was wrong, he would tell me. Although I never met him because he lives in a different part of the state, we communicated by email; he always answered my questions promptly and thoroughly. He made me feel as though I had someone knowledgeable in my corner. He made me feel less alone and less helpless. After he retired I brought another integrative oncologist on board, because I was convinced that the treatment I was getting was vitally important in preventing a recurrence.

Integrative oncologists believe that there are two parts to cancer treat-

ment. The first part includes some combination of surgery, chemotherapy, radiation, and hormone therapy. This is all that conventional oncology offers; after that is finished, there is no further treatment. Mainstream cancer practice is to wait until there is a recurrence, and then to treat that. If there is no cancer that can be seen on tests, then there is no treatment. The problem is that when there is a recurrence, the cancer is usually no longer curable. My goal, therefore, is to try to prevent a recurrence, and this goal is outside the purview of conventional cancer care.

Integrative oncologists believe there is a second part to cancer care: to change the “terrain,” to make the body less hospitable to cancer, and this is what mainstream medicine does not do. My integrative oncologist worked with me to help me achieve the maximum benefit from my conventional treatments while minimizing side effects. After my treatment was over, he and the new integrative oncologist I consulted after he retired, continued to work to alter my “terrain” to discourage a recurrence. In my case, this involves the use of nutrition, exercise, prescription drugs, and nutraceuticals* for which there is considerable clinical evidence, but which have not yet entered mainstream medical practice. Integrative oncologists will also address stress reduction and the mind-body connection through psychological and spiritual support and complementary modalities such as acupuncture and meditation. Although I will never be able to prove that this approach has kept my cancer at bay, I feel strongly that if there is evidence that something is likely to help, and if there are no significant side effects, then I am going to try it.

Unfortunately, many insurance companies will cover neither the services of integrative oncologists nor of the nutraceuticals, so you will have to check.

It may not be easy to find an integrative oncologist to work with. Some conventional oncologists dismiss integrative oncology as pseudoscience.

* A nutraceutical is a product, usually in the form of a nutritional supplement, which is demonstrated to have a physiological benefit or provide protection against chronic disease.

This means that it's unlikely that your doctor will refer you to a good integrative oncologist. On the other hand, integrative oncology is trendy, so all the cancer centers are now adding smatterings of complementary modalities such as yoga and meditation, often without any real plan, in a way that sometimes does seem like pseudoscience. Although yoga and meditation are nice additions, unless they are part of a unified approach to managing the patient, I would not call it integrative care. To me, integrative medicine is based on a systematic approach that uses conventional and complementary/alternative treatments to mitigate side effects, enhance treatment response, improve the patient's quality of life, reduce life threatening risks and complications, and improve the odds of lasting remission. If remission is not achievable, then the goal would be to increase survival time and improve the quality of whatever life remains. Objective assessments should be performed in order to tailor the treatment to the individual patient.

It is a good idea to bring an integrative oncologist on board as early in your treatment as possible, because integrative oncology can make your treatment more successful. For example, it can help you recover more quickly from surgery and reduce the risk of bodily damage from the side effects of chemotherapy and radiation.

I recommend looking for someone who will give you a battery of tests in order to individualize a program for you. Assessments should address such issues as your levels of oxidation, inflammation, immunity, glycemia, blood coagulation, and stress chemistry, because these are things that have been shown to affect the body's response to cancer.¹ Most of us have cancer cells in our bodies; the issue is whether they remain dormant or grow, and that may be determined by our terrain. The program to change your terrain will likely consist of prescription drugs and nutraceuticals as well as a diet and exercise regimen and various forms of mental hygiene and stress reduction.

Sadly, there are not many oncologists who do this work, possibly because it pays less than conventional oncology. You can find more information about finding integrative oncologists in Appendix B.

Consider a concierge doctor

In the United States, the rich get different health care. Concierge doctors charge a yearly fee or retainer on top of what they collect from the patients' insurance. This allows them to see fewer patients and give better care. Depending on how much they pay, their patients may get house calls or same-day appointments, and the doctor will spend more time with them. Patients are usually given the doctor's cell phone number and email address. Many concierge doctors will act as patient advocates. They will often coordinate their patients' care and go with them to see other doctors. My chemotherapy center was in Beverly Hills, and I would commonly see patients accompanied there by their concierge doctors. Concierge doctors' prices can vary a lot, from affordable to astronomical, and some will accept a number of charity cases for free.

Concierge doctors pose a bit of an ethical problem for me, because as more and more doctors switch to concierge practices, it means that people who cannot pay their fees will have fewer and fewer choices. More people switching to concierge doctors may also take the pressure off the government to improve the system. (In case you are curious about how much money doctors make, you can look at Medscape's *Physician Compensation Report*.)[†]

Get a second opinion, or more

Several people I met had doctors to recommend, and I consulted five surgeons, six medical oncologists, and four radiation oncologists. Although I never got all the information I wanted—sometimes because the answers were simply unknown—I did get a different piece from each one, and that helped me choose the best doctors I could find. I am thankful that Medicare paid for multiple opinions.

Patients shouldn't worry that getting a second opinion will offend their

[†] "Medscape Physician Compensation Report 2015." Medscape. Accessed July 10, 2016. <http://www.medscape.com/features/slideshow/compensation/2015/public/overview#page=3>

doctors. Most of them expect it, and many of them will even offer referrals. If you don't have people you trust to recommend doctors, you can often get them from hospitals and regional cancer centers, as well as institutions such as the National Cancer Institute[‡] and the National Comprehensive Cancer Network.[§] Another way to find experts is through reading scientific journal articles. If you are impressed by articles by particular authors, you can ask whether they are available for consultations.

If the first and second opinions don't agree about your diagnosis or treatment, or if you still don't feel that you are getting the best possible advice, you should go for a third opinion, or more. Your comfort level, the treatment options proposed, and medical expertise should all be considered when making your decision.

Before getting second opinions, you should check what is covered by your insurance plan. Some of them cover or even require second opinions, and some don't; and some will limit you to certain doctors or hospitals.

Check out your hospitals and doctors thoroughly

When patients are facing cancer treatment they are usually frightened and feeling vulnerable. However, it is vital to keep in mind that you are a consumer purchasing a very expensive service. If you have cancer, your life may depend on the choices you make, so you should be more careful than you would be in buying a house or a car.

Some hospitals are much better than others in terms of preventing errors, injuries, accidents, and infections. Hospital safety is not a trivial issue: a study reported in the *Journal of Patient Safety* says that as many as 440,000 patients each year who go to the hospital for care suffer some type of preventable harm that contributes

‡ "Comprehensive Cancer Information." National Cancer Institute. Accessed July 10, 2016. <http://www.cancer.gov>

§ "National Comprehensive Cancer Network." NCCN. Accessed July 10, 2016. <https://www.nccn.org>

to their death.² That would make medical errors the third-leading cause of death in the United States, behind heart disease and cancer.³ Fortunately, you can check out the safety records of hospitals because they are required to report data to the states and the federal government. The Leapfrog Group, an independent healthcare industry watchdog, takes national performance data from the Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), the Centers for Medicare and Medicaid Services (CMS), the American Hospital Association's Annual Survey, and their own Leapfrog Hospital Survey. It analyzes the data and grades hospitals from A to F based on their ability to prevent errors, accidents, injuries and infections. The Hospital Safety Score is the gold standard rating for patient safety, compiled under the guidance of the nation's leading patient safety experts, and you can access it on the website.⁴ You can use it to check up on your hospital, or you can use it to find a hospital with a good safety record.

While patient safety has to do with lack of harm, quality is a different issue. Quality has to do with how efficient and effective the care is, and some hospitals are better at some procedures than at others. In your case, you want to know how good they are at cancer care. One resource is The Commission on Cancer (CoC), a program of the American College of Surgeons. It approves hospitals or facilities that have committed to providing the best in cancer diagnosis and treatment. Its list of accredited programs includes more than 1,500 cancer centers across the United States. It maintains a database of outcomes from these cancer centers, and the data are used to explore trends in cancer care, to create regional and state benchmarks for participating hospitals, and to serve as the basis for quality improvement. CoC-accredited programs can be found in every state, and you can use the Hospital Locator tool on its website to find the programs closest to you.**

¶ "Hospital Safety Score." Accessed July 10, 2016. <http://www.hospitalsafetyscore.org>

** "Cancer Programs." American College of Surgeons. Accessed July 10, 2016. <https://www.facs.org/search/cancer-programs>

The National Cancer Institute (NCI) designates some centers that they consider to be at the forefront of cutting edge treatments. There are currently 68 NCI-Designated Cancer Centers, located in 35 states and the District of Columbia. You can find a list of them on the NCI website.^{††}

While you can compare hospitals for accreditation and designation, unfortunately you can't compare them according to their outcomes, including complications and deaths. Data revealing which hospitals have the best outcomes for particular cancer procedures are not made available to patients. The Cleveland Clinic is the only one I am aware of that makes its detailed outcomes data available to the public, on its website. However, your doctor may be able to access this information on your behalf.

Another way of evaluating hospitals is by using the National Comprehensive Cancer Network (NCCN) guidelines. NCCN, a nonprofit alliance of 26 of the leading cancer centers, has developed clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers.^{‡‡}

The NCCN Clinical Practice Guidelines in Oncology are decision tools that explain the disease and determine the best way to treat a patient, depending on the diagnosis, disease stage, and other factors, such as age. There are currently 60 NCCN Guidelines available free of charge on NCCN.org, covering cancer detection, prevention and risk reduction, work-up and diagnosis, treatment, and supportive care issues. High rates of compliance with the NCCN guidelines are correlated with better patient outcomes. The NCCN collects data showing how well its members adhere to each of the guidelines, but unfortunately it will not release the information on specific centers, so the public has no way of knowing. However, you can ask your hospital whether it is following NCCN guidelines. You can also ask your doctor to find out for you whether your local hospitals adhere to NCCN guidelines.

†† "NCI-Designated Cancer Centers." National Cancer Institute. Accessed July 10, 2016. <http://www.cancer.gov/research/nci-role/cancer-centers>

‡‡ "National Comprehensive Cancer Network." NCCN Network. Accessed July 10, 2016. <https://www.nccn.org/members/network.aspx>

In addition to safety ratings, accreditation or designation, and NCCN guidelines, there are other considerations in choosing a hospital. You should check to make sure that your insurance pays for that hospital, and you will probably prefer a hospital that is conveniently located. One thing that was especially important for me was recommendations from other patients. I found that it was well worth my time to ask around and find as much as I could about other patients' experience at different hospitals.

Even more important than choosing the right hospital, however, is choosing the right doctors. Unfortunately, you can't assume that good hospitals have good doctors. All hospitals have both good and bad doctors, so you will need to check them out yourself. You may have to choose up to four doctors for breast cancer: a surgical oncologist to do the surgery; a plastic surgeon if you have reconstruction; a medical oncologist if you have chemotherapy; and a radiation oncologist if you have radiotherapy.

You should compile a list of doctors to screen. You can get recommendations from health care professionals, from other patients, from family and friends, from cancer centers, and from scientific journal articles. Rule out any who don't accept your health insurance. Find out at which hospital the doctor has admitting privileges, and make sure it's one with a good safety rating and the accreditation or designation you want. Find out whether it follows the NCCN guidelines. Next, consider whether you and the doctor are compatible: Does she listen to you respectfully? Does she fully answer your questions? Does she explain your diagnosis and treatment? An issue that I would not have considered at first, but which turned out to be vitally important, was the doctor's use of technology. I found it very difficult to communicate with doctors who would not use email or who would not check it regularly and respond promptly. Some doctors have a patient portal, a secured website that gives you 24-hour access to your health records, appointments, lab results, prescription refills, and e-mail questions. Cancer treatment is very stressful, and having easy access to your doctor will reduce your stress.

You should also check for board certification and look for red flags. You

can check for board certification through the American Board of Medical Specialties (ABMS) website.^{§§} Red flags include malpractice claims and disciplinary actions. The National Practitioner Databank provides a thorough background check, including information on sanctions by state licensing authorities, malpractice awards, and hospital disciplinary actions. Common reasons for being disciplined include substance abuse and inappropriate sexual behavior as well as negligent medical errors. However, most states let doctors practice while they are on probation. Unfortunately, the National Practitioner Databank is not available to the public; it can only be accessed by doctors, hospitals, managed care organizations, and government agencies.^{¶¶} *Consumer Reports* is trying to change this through their Safe Patient Project.^{***} They believe that it's too difficult for patients to find their doctors' disciplinary records, and that doctors who are on probation should be required to disclose their status to patients. *Consumer Reports* petitioned the California medical board to make the change, but the medical board rejected the idea. However, there are some doctors who believe in transparency: The National Physicians Alliance, an organization of doctors committed to social justice and healthcare reform, is in favor of making the disciplinary reporting system less secretive and more useful to consumers. Meanwhile, perhaps you know a doctor who will access the database on your behalf; if not, patient advocates recommend that you do your own investigation.

A good place to start is docinfo.org, a website run by the Federation of State Medical Boards (FSMB). FSMB represents the 70 state medical and osteopathic regulatory boards within the United States, its territories and the

§§ "Certification Matters | Find Out If Your Doctor Is Board Certified." ABMS. Accessed July 10, 2016. <http://www.certificationmatters.org>

¶¶ ProPublica's Surgeon Scorecard makes public the complication rates for nearly 17,000 surgeons nationwide, but as of this writing none of them are breast surgeons. I contacted them to ask whether they will be expanding to include breast surgeons, but they told me that they don't know yet.

*** "Safe Patient Project." *Consumer Reports*. Accessed July 10, 2016. <http://safepatientproject.org>

District of Columbia. You enter the name of the physician you want to check, and the website will tell you the doctor's education, license, and whether there are actions against him. If there are actions, there will be a link to the state board involved, and you have to click on the link in order to find any information about the actions. However, each state varies on what information it makes available to the public, how often it's updated, and how doctors are disciplined. Some states provide details on disciplinary actions or malpractice awards and some don't. *Consumer Reports* Safe Patient Project and the Informed Patient Institute analyzed the websites of 65 state regulatory boards and ranked them on the completeness of their information and ease of use.⁺⁺⁺

Another source of information is the federal government's new Physician Compare site, which lists physicians enrolled in Medicare by zip code.⁺⁺⁺ It has data on how physicians stack up against specific quality measures requested by Medicare. You do not have to be eligible for Medicare to use this service.

You can check patient online reviews. Experts say there some 40 to 50 websites that rate doctors based on patient reviews. WebMD provides information on its website about Healthgrades.com, RateMDs.com and Vitals.com.^{§§§} All three provide patient ratings of doctors, but only Vitals.com let me read the patients' comments that explained the ratings, which I found very helpful. Use of patient reviews is controversial, and some physicians require patients to sign agreements stating that they won't share their experiences online. I always use these sites. I also use Yelp.com, and my experience has been excellent, often even better than recommendations from friends and

+++ "Seeking Doctor Information Online: A Survey and Ranking of State Medical and Osteopathic Board Websites in 2015." *Consumer Reports*, 29 Mar. 2016. Accessed 10 July 2016. <https://consumersunion.org/wp-content/uploads/2016/03/Final-report-for-posting-3-28-16-6PM-ET.pdf>

+++ "Medicare.gov Physician Compare." Medicare.gov *Physician Compare Home Page*. Accessed July 10, 2016. <https://www.medicare.gov/physiciancompare/search.html>

§§§ "Doctor Rating and Review Sites: Reliable?" WebMD. Accessed July 10, 2016. <http://www.webmd.com/health-insurance/insurance-basics/using-doctor-ratings-sites>

family. However, Yelp has no information about disciplinary actions, and it is not clear whether the others do, either.

In addition, you should ask the doctor how many times he or she has performed the procedure you will be having; this is especially important for procedures that are new or rarely used. You want to be sure your doctor has enough experience to deal with any complications. Ask for references. Doctors should maintain a roster of satisfied patients who are willing to talk about their experience. Follow up with them.

Read everything before you sign

I have heard many sad stories about people who were not careful about permission forms. For example, someone I know specifically told her breast surgeon that even if they found cancer in her sentinel nodes^{§§§} during surgery she did not want any other lymph nodes removed because she was concerned about the serious side effects. (Her decision was also based on recent evidence that removing lymph nodes in many cases does not increase patients' survival.) She trusted that the surgeon would respect her wishes, so she did not alter the consent form which contained the words "possible lymphedectomy" on it. Unfortunately, the surgeon did not respect her wishes, removed all her lymph nodes, and she now has exactly what she feared: lymphedema^{****} with serious pain and limitation in her range of motion.

Do not be pressured into signing anything hastily. If necessary, take the forms home and have someone help you look them over.

§§§ The sentinel nodes are the first place that cancer is likely to spread. In breast cancer, they are usually located in the axillary nodes, under the arm.

**** Swelling caused by a blockage in the lymphatic system

Understand the financial aspect

Make sure your doctor and your hospital accept your insurance. If any part of your procedure will not be covered by insurance, you should have a financial agreement in writing. Make sure you understand and agree with it.

Consult other patients

One of the first things I did after I received my diagnosis was to tell lots of people I had breast cancer, and I gave them permission to share my information with whoever they wished. My thinking was that the more people who were told by others that I had cancer, the fewer I would have to tell. However, I had an unexpected side benefit: People kept contacting me who had had breast cancer, or who knew someone who had, and they were all eager to share information. This led me to new doctors, new treatments, and to a cancer support community.

I also made contact online with other patients all over the world, mainly on breastcancer.org, and this led me to several discoveries that I would not have made any other way. One enabled me to keep my hair even though I was told that my particular chemotherapy regimen had a 100% probability of hair loss, plus a very alarming probability of somewhere between 6 and 17% that the hair loss would be permanent. Another enabled me to reduce the side effects of chemo by fasting. These and other discoveries will be discussed in detail in later chapters.

Organize your information

Many cancer organizations and websites provide very helpful guides to help you through the process of making medical decisions. A guide to making medical decisions and questions to ask can be found in Appendix C. You should use these guides as a basis, and personalize them to fit your needs. Bring the questions to your appointments and write down the answers.

Some patients find it helpful to make an audio recording of the answers, and/or to bring someone who can provide support and help you remember.

It is important to create a file for all your health records, so you will know where everything is when you need it and will not have to madly shuffle through piles of papers when you need something in a hurry. It is also recommended that you start keeping a medical journal. You can find a list of things that should be included in your health file and medical journal in Appendix D.

Search the literature

As soon as I received my diagnosis, I started reading everything I could find: in books, in periodicals, and on the Internet.

As mentioned previously, most professional medical journals are not accessible to lay people, at least not without a subscription. However, there is an exciting new development: open access scientific journals.

PLOS One, founded in 2006 and published by the Public Library of Science, is an open-access peer-reviewed scientific journal that covers research in science and medicine.⁺⁺⁺

Curēus is an online peer-reviewed medical journal founded in 2009 by a Stanford neurosurgeon.⁺⁺⁺ Its goal is to use crowdsourcing to provide better research, faster publication and easier access for everyone.

Open access seems to be the wave of the future, and open access journals are multiplying rapidly. If you Google “open access peer reviewed oncology journals” you will find a wealth of information.

Perhaps the most commonly used resource is PubMed.^{§§§§} Run by the National Center for Biotechnology Information at the National Library of

+++ Accessed July 10, 2016. <http://journals.plos.org/plosone>

+++ Accessed July 10, 2016. <http://www.cureus.com>

§§§§ "Using PubMed." National Center for Biotechnology Information. Accessed July 10, 2016. <http://www.ncbi.nlm.nih.gov/pubmed>.

Medicine (NLM), PubMed provides free access to MEDLINE, which is NLM's database of citations and abstracts. PubMed is a type of search engine for medical literature. Search the list for the article you want, click on the title, and PubMed will display the abstract. If you need the whole article, you can click on a box in the upper right corner of the screen. Sometimes the article will be free, and sometimes you will have to pay.

I believe that medical journals will become increasingly open to the public, because the public will demand it and because the Internet makes access easier. Younger patients in particular are less likely to view doctors as authority figures and guardians of arcane knowledge that ordinary people are incapable of understanding. They expect to be treated as intelligent consumers who need accurate information in order to make informed decisions.