



Finding an Oncologist

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One of the first surprises that many cancer patients find is that they are really choosing a whole team of people, not just one oncologist. There may be a surgical oncologist (specializes in the surgical resection of cancers), medical oncologist (specializes in the use of chemotherapy and other medications in the treatment of cancer), and radiation oncologist (specializes in the treatment of cancer using radiation therapy) all intimately involved in an individual's cancer care. There are also a slew of nurses, nurse practitioners, technicians, dieticians, social workers, and other support staff that are all important members of the team. This may make the task of choosing the right team for your care seem daunting. However, many cancer teams are already assembled, especially at institutions that treat cancer on a regular basis. Physicians who work well together will usually treat the same patients and refer patients to each other. Also, these physicians tend to put together a team with a "personality" similar to their own. You need to think of your physician as the quarterback; the leader of the team, but not more important than any of the other positions on the field. Quarterbacks try to surround themselves with good players, so everything runs smoothly and correctly. The quarterback also needs to choose players that he can trust to do the job correctly so the entire team works efficiently. Fortunately, this decision process may not be as difficult as it seems if you follow some basic guidelines.

- You are in control. The final decisions are yours. You are the most important part of your health care team and you should feel comfortable with the team you choose.
- Chose your quarterback, the rest will usually fall into place. Ask your primary care physician for a recommendation- your primary care physician has sent numerous patients to oncologists. They will typically know the oncologist on a professional level. They will have also had reports from the patients they have sent in the past on the quality of care that they received.
- Comprehensive Cancer Centers typically have a team approach to the treatment of malignancies. You may consider a consultation at such a facility, and ask to meet an entire team of physicians there. This is sometimes called an "interdisciplinary team."
- You may want to speak with people that have a similar diagnosis and have already gone through treatment, and then ask them for a recommendation. Be careful of recommendations or input from people who "know someone who had this problem". They often do not have the story straight and may end up unintentionally scaring you rather than helping you.
- Contact your local American Cancer Society (ACS)- Your local ACS will have a list of the cancer centers and facilities in the area that deal with your diagnosis.
- Nurses can be a great resource. Most have contacts with other nurses who may work with oncologists. They can typically give you the "inside scoop" on what a physician is really like.
- Support groups- Sometimes local support groups can be helpful. You may find people who have already experienced a similar cancer diagnosis.

Internet- The Internet can be a great resource to obtain information and locate facilities in your area. Just remember, many excellent private practice oncologists do not have their own website, so this resource should be used in conjunction with the previous recommendations. In addition, anyone can post anything on the Internet, so use caution with claims on websites. If it sounds too good to be true, it probably is.



Questions to Ask My Doctor

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These questions are things you may want to ask about when visiting your doctor. Not every question will apply to you, nor may you want to know the answers to all of them up front. They are meant to be food for thought when thinking of questions to ask your doctor, either at the initial visit or further along in treatment.

Questions to ask when making an appointment:

- Is this doctor Board certified and licensed in this area (medical, radiation or surgical oncology)?
- Is he or she a member of any professional societies?
- Do you have a multidisciplinary clinic for my type of cancer (this is a clinic where you would see several doctors in one visit)?

Questions about the disease and treatment:

- What type of cancer do I have?
- What stage is my cancer?
- How many patients have you treated with my type of cancer?
- What treatments are considered the gold standard for my cancer and what other options do I have?
- Does this facility have access to all of these treatments?
- If not where are these treatments located?
- Are there other possible treatments that are not available at this facility?
- What are the pros and cons and side effects of these treatment options? What are the expected survival rates with these treatments?
- Are these treatments covered by my insurance plan?
- Will receiving this treatment prevent me from receiving a different type of treatment in the future if I need it?
- Are there clinical trials available for my cancer at this facility?
 - If not, where can I learn about clinical trials?
- Are there any more tests that need to be done before starting treatment?
- What tests will determine how my disease responds to the treatment?
- How often will these tests be done during and after treatment?
- Will you change my treatment if it does not appear to be working?
- How long will the treatment last?
- How often will I see you during and after treatment?
- What signs or symptoms should I bring to your attention to help you observe my treatment and evaluate my response to treatment?

Questions about prognosis and survival:

- Do you expect a cure from these treatments?
- If not, what is the goal of therapy?
- What percentage of patients with my type of tumor live five years or more?

Questions about the team:

- Do you work closely with other members of the cancer care team, such as radiation therapy, surgical and medical oncology, dietician, social work and nursing?
- Do I have access to a dietician at this facility?
- Do I have access to a social worker at this facility?
- Are there any support groups available at this facility?
- What other services are available to help me and my family deal with the disease?

Once a treatment is chosen:

- What are the expected side effects?
- What problems should I report to you? (fever, diarrhea, nausea/vomiting, etc.)
- How do I reach someone for problems in the evening or on the weekends?
- What can I do to prevent or control these side effects?
- Can I drive myself to and from the treatment?
- Do I need to take any special precautions at home (in regards to children, pets)?
- Will I be able to continue my normal activities/can I go to work?
- Will this therapy affect my sex life or my ability to have children?
- Do I need a special diet during or after my treatment?
- Do you have any written materials concerning my treatment?
- Can you recommend any websites concerning my treatment?



Second Opinions

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Many people hear a diagnosis of cancer and think they must make a decision and jump into treatment the next day. While this can be true in certain types of lymphoma and leukemia, for the average patient, a few weeks to get another opinion and weigh your options is realistic. Believe it or not, there is no cookbook to follow when treating a cancer and you can encounter different treatment options for the same patient, even within the same institution. Every patient is different and each case should be decided individually. A second opinion can present different treatment options that were not known about or offered by the first physician or it can act as a quality check to confirm the first suggested treatment. There are many reasons to get a second opinion, including: a rare type of cancer or unknown primary site, you live in a rural area that does not treat many cancers, you have been told "there is nothing we can do", or you just don't feel comfortable with the first doctor you saw.

Second opinions are also a way to educate you about the options. If one doctor says treatment A is the best, but doctor number 2 does not agree, ask them to explain why. Many patients fear offending their doctor by getting a second opinion. A good doctor understands the need to research all of your options, particularly when dealing with something as scary as cancer. If your doctor discourages a second opinion or infers that you can't get better care somewhere else, all the more reason to get another opinion. You do not need the permission of your doctor to get a second opinion, except in the case of needing a referral for an HMO insurance carrier.

The "big cancer center" is not near my home. Getting a second opinion at a major medical center does not mean you have to get your treatment there. In many cases they can provide recommendations for treatment that can be taken to your local doctor. It can be well worth a long drive or overnight visit to get a second opinion on your options.

Educate yourself on the "standard" therapies for your tumor type. The National Comprehensive Cancer Network establishes guidelines for treatment options that are available on their website: www.nccn.org. If you see an oncologist who encourages you to participate in a clinical trial of a new medication compared to a placebo or a drug not typically used in your tumor type, but you know that drug X is effective in your tumor type, you can ask appropriate questions. Clinical trials are extremely important to improving cancer care, but you must weigh the risks and benefits of each option for your situation. In most cases, if you are offered a clinical trial, it should not be your only option and you should also have the option of a "standard therapy".

Many patients think of a second opinion when it comes to treatment with chemotherapy or radiation therapy, but not always when surgery is the treatment of choice. Surgical oncology is a specialty in itself and if you require a big surgery for your cancer, a second opinion from a board-certified surgical oncologist may be in order. In some cases, one surgeon may say a tumor is inoperable, but a more experienced surgeon may say differently. Pathologists also offer second opinions on the actual diagnosis of the tissue taken for biopsy. Many patients do not think to question the actual diagnosis, but if you have a diagnosis of a rare tumor type or an unknown primary site, pathology review may be warranted.

So, how do you find a doctor for a second opinion? The National Cancer Institute designates institutions as "comprehensive cancer centers". To receive this designation, the institution must meet specific criteria

regarding laboratory and clinical research into prevention and treatment of cancer. Visit the NCI website to learn more about the program or view the list of centers: <http://www3.cancer.gov/cancercenters/index.htm>. This may be a good place to find a multidisciplinary center or an expert in unusual tumor types.

Contact your local American Cancer Society chapter. They maintain a list of the cancer centers and facilities in the area and the types of diagnosis they treat. Many advocacy organizations maintain websites that can recommend specialists in the tumor type they are interested in. The NCI's neuro-oncology branch offers second opinions on various types of brain tumors, some can even be done by phone (<http://home.ccr.cancer.gov/nob/default.asp>).

As for finding a pathologist to review slides, there are a few resources available:

The Armed Forces Institute of Pathology (<http://www.afip.org/>) offers expert pathology consultation for both military personnel and civilian cases. Find Cancer Experts is a free, non-profit organization that recommends pathology experts for second opinions based on the tumor type (<http://findcancerexperts.com/>). There is a fee for having slides or tissue reviewed by an expert, but many insurance companies will reimburse part, if not all, of these fees. Fees typically range between 150-250 U.S. dollars.



The First Visit to a Specialist

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When you go to see an oncology specialist, he or she will discuss at length your disease and the treatment options available to you. This can be overwhelming, but there are ways to make it feel more manageable. Many people find that once they leave the office they cannot remember what was said or at least not all that was said. It is a good idea to bring along a supportive friend or family member. You want someone who is a good listener, can take notes, be supportive and not try to influence your decisions. While you are trying to listen to the doctor, they can be taking notes to refer to later and they may be able to think of questions during the appointment that you may not have thought of. You may want to ask for permission to tape the conversation, particularly if you have a large family that will want to know everything that was said.

In preparation for the visit, you may want to read some information on your disease, if you already know what type of cancer you have. You will be better able to ask questions and understand the healthcare team if you have some basic knowledge about the disease. Visit [OncoLink's cancer types menu](#) to read about a particular type of cancer. Other good websites for basic information are the National Cancer Institute and the American Cancer Society. If you do not have access to the Internet, ask a friend or family member to print something from the Internet for you, visit your local library or call the American Cancer Society (800- ACS -2345). As you learn more about the disease, questions may come up. Make a list of these questions and bring them to your appointments, this holds true throughout treatment and follow-up. This way, you are sure not to get home and realize you forgot to ask about something that had been bugging you.

There are a few things to be sure to gather for your appointment:

- Forward all of your recent medical records including operative reports, pathology reports, and radiology reports to your oncologist, or bring copies with you.
- Make sure you have any necessary referrals prior to seeing the doctor.
- Bring all of your recent radiology films including x-rays, mammograms, CAT scans, MRI scans, and ultrasounds to your oncology appointment if these exams were performed at another location. This should include the actual film and the report and can be picked up from the radiology department at the facility that performed the test.
- Bring pathology slides for review if a surgery or biopsy diagnosing cancer was done at another institution. This should include the actual slides and the report from the pathologist and can be picked up or mailed from the pathology department where the surgery or biopsy was performed.
- Make sure the doctor's secretary has received all of the necessary information prior to your visit if you had things mailed to them. It is best to call a day or 2 ahead in case they have not been received and you need to pick things up.
- If you are bringing radiology films to your consultation from an outside location, you may wish to arrive early or drop these films off for review prior to your appointment.
- Bring a [list of all of your medications](#) and any allergies to medications.
- Bring a list of the physicians and addresses that you want reports of the consultation sent.
- Make sure you bring your health insurance identification card if you have one.
- Get all of your questions answered prior to leaving. This is when the question list and the person accompanying you come in handy.

- If you need one, get an appointment for follow-up before you leave.
- Make sure you have the phone number of your doctor's secretary.
- Do not become frustrated if additional blood tests, x-rays, or other procedures are necessary prior to getting a final recommendation. Many centers will want their pathologists and radiologists to review materials or establish a baseline before treatment begins.
- Keep a journal of tests, procedures, and treatments that includes the date, location, and physician involved.



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Chemotherapy History

During some part of their treatment course, many cancer patients receive chemotherapy. Chemotherapy is normally given in “cycles.” Each cycle on average lasts three to four weeks. Patients may receive a number of different chemotherapy agents in combination or at different times during their treatment. It is important that all physicians involved in the patients care are aware of the various drugs being used. There can be important side effects, interactions with medications, and interactions with other therapies. The following chart will help sort out this important information:

Names of Chemotherapy	Date cycle started	Cycle Number	Medical Oncologist	Notes Side Effects



Radiation Therapy History

A considerable number of cancer patients will receive radiation therapy. The amount of radiation therapy given is restricted over a person's lifetime. It is important that your radiation oncologist is aware of any radiation that may have been delivered in the past. Patients should keep a record of when they are treated, location on the body treated, total dose delivered, and the name of the radiation oncologist responsible for delivering the treatments. Utilize the following chart to register any treatments with radiation therapy:

Dates of Radiation	Body Part Treated	Total Dose	Radiation Oncologist	Notes/ Side Effects



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Physician/Appointment List

It is key for cancer patients to keep a record of all physicians involved in their care. Since most patients are treated with more than one therapy for cancer, there may be many physicians involved. Keeping an up to date list allows the patient to reference their physicians quickly. It is also important for all of your physicians to know who else is involved in your care. Notes about your condition can be sent to other physicians if you provide the names and addresses. This allows for care to flow smoothly since all of your physicians are informed regularly on your progress. The following chart can serve as an important guide. This list can be copied and handed to each of your physician to place with your records. Most patients are overwhelmed at the number of appointments that are scheduled for their cancer care. Keeping an appointment note is an easy way to make sure that you don't miss any of your scheduled visits. Make sure to add your next visit to the appointment book before leaving your physicians office and use the notes section to write down any important information discussed at the appointment or questions for your next visit.

Physician Name	Address	Phone/Fax Numbers	Specialty	Next Appointment Date/Time	Notes



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Physician List

It is important for cancer patients to keep a list of all physicians involved in their medical care. Since most patients are treated with combined modality therapy for cancer, there may be multiple healthcare professionals involved in the care of the patient. Keeping a current list of physicians allows the patient to reference their physicians quickly. It is also important for all of your physicians to know who else is involved in your medical care. Notes updating your condition then can be sent to other physicians if you provide the names and addresses of everyone. This allows for care to flow smoothly since all of your physicians are updated regularly on your progress through treatment and follow up. It is important to keep the name, phone number, fax number, address, and name of a nurse contact or secretary for each physicians office. The following chart can serve as an important guide. This list can be copied and handed to each of your physician to place with your records.

Physician Name	Address	Phone/Fax Numbers	Specialty	Nurses Name	Secretary Name



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Past Hospitalizations/Surgeries

Make a list of any hospital admissions and or surgeries. Make sure the date, reason for hospitalization or type of surgery, name of hospital, physician, and complications are included. Thinking about any hospitalizations or surgeries will help you and your physician identify past medical issues. Use the following chart to help sort out this important information. Do not forget to list the following procedures if they have been performed: tonsillectomy, gall bladder removal, appendectomy, and removal of skin cancers. These all count as surgery. Note any complications that you have experienced from the surgery.

Date	Reason for Hospitalization/ Type of Surgery	Name of Hospital	Physician	Complications



Keep a Medication List

It is very important for cancer patients to keep a list of all medications (including vitamins and supplements) they are currently taking. The number of pills can be staggering at times, and it is very easy for patients to become confused. It is important to carry the list at all times so patients can show the doctors and nurses what medications are being taken. Cancer patients may be under the care of a number of different physicians and all of the doctors may not know what others have prescribed. Significant interactions can occur with some medicines that your doctor needs to consider before prescribing any new medication.

If a patient ever goes to the emergency room a list of current medications is extremely helpful to the emergency room staff. Treatment can be instituted promptly if the doctors know all of the current medications the patient is taking. It is not real helpful to say "I'm taking a big blue pill." There are thousands of medications available that can have serious interactions. Keeping a list makes everyone's life easier.

It is important to list the name of each medication, the dose in milligrams, and the frequency that the medication is prescribed. The doctor who prescribed the medication and the date started should also be listed. The following is a sample list that can be copied and kept in a purse or wallet once the blanks have been filled:

Name of Medicine	Dose (mg)	How often taken	Who Prescribed	Date Started	Reason for taking, changing or stopping



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Family History of Cancer

Your physician will ask you about any other family members that have developed cancer. There are many cancers that have genetic links. Take time to think about parents, grandparents, and siblings that may have had a diagnosis of cancer. Also note the approximate age at which these family members were diagnosed with cancer. This information may help your physician decide if genetic testing or counseling should be performed.

Name of Family Member	Relationship	Type of Cancer	Age of Diagnosis



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Radiology Studies List

Many cancer patients will have many radiologic studies done during the work-up and follow-up of a specific cancer. These studies may include X-rays, CT scans, MRI scans, ultrasound studies, and bone scans, just to name a few. It is important to keep a list of all studies that have been performed. These studies may be done at different facilities. It is important for the patient to provide a list of the tests completed and location where the study was performed. This helps each of your physicians to obtain the results of these procedures. Always follow-up on the results of each of your tests with the physician who ordered it. Do not just assume the results are “OK” if you do not hear anything. Utilize the following chart to help keep track of each study that has been performed:

Name of Procedure	Date Completed	Location of Study	Phone Number	Physician Ordering Study	Discussed Results (Yes/No)