

First Steps for the Newly Diagnosed: The Cancer Survival Toolbox

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[Narrator]

Cancer care involves many people with various knowledge and skills. A team effort using several experts is one of the most helpful features of quality cancer care. Who will be on your team depends on the type of cancer you have and other things that make you unique. But in general, your team members are:

- You at the center of the team – knowing you'll have the final voice in making decisions and choices about what happens to you;
- The best doctors you can find – among them, medical and radiation oncologists, radiologists, pathologists, and surgeons – doctors who are smart, up-to-date, skillful, and are people you trust, and with whom you can talk;
- Other knowledgeable and skilled healthcare professionals as they are needed – including oncology nurses, oncology social workers, oncology clinical pharmacists, dieticians, occupational and physical therapists, clergy, and psychologists or psychiatrists.

Since modern cancer care is so complex and involves so many experts, it's best when one member of your healthcare team is designated as the person who coordinates your care. Depending on the type of cancer, this person could be a surgeon, a medical oncologist, your primary care doctor, or an advanced practice nurse.

Joan offers her suggestions for selecting your cancer care team and a care coordinator.

[Joan]

Putting together your team usually starts with choosing the healthcare professional who will assume the main responsibility for coordinating your care. This coordinator helps arrange consultations with specialty doctors and supportive care providers. Your medical records will be assembled and maintained by the people who work with the doctor or nurse coordinating your care. Other people working with the doctor – staff members such as nurses, social workers, receptionists, financial counselors, and laboratory and pharmacy technicians – will play major roles in your care as well.

In terms of choosing doctors for your team, I suggest you give serious thought to what really matters to you. What is truly essential, what is important but negotiable, and what you would like but could do without? For example – how important is your doctor's bedside manner? If you had to choose, is a surgeon's skill more important than his or her bedside manner? These are very personal choices.

Where you live may be one of your first considerations when selecting a doctor. If you live in a small or rural community, your choices may be limited unless you're willing to travel for care. People who live in suburban and small communities could also have limited access to cancer care experts and the technology needed in modern cancer care. In these settings, it is vital that you are confident that the local doctor is qualified and can give you the care you need. You may need to weigh a number of factors in your selection of a cancer care provider – factors like driving distance to a cancer center, access to transportation, and road and weather conditions.

No matter where you live, there are some issues in choosing a doctor that have to be given top priority. First, basic credentials are critical. Most hospitals and cancer care centers offer information about their staff in brochures and on their web sites. Board certification in a specialty means the doctor has training and experience in the specialty area. There are also web sites, such as HealthGrades.com, that grade hospitals, doctors, health plans, and nursing homes, and

charge a fee that allows people to access this data. Professional organizations' web-based tools also offer information about members and help users find specialty doctors. Some of these web site addresses are listed in the online Resource Booklet.

A doctor's competence and experience are important pieces of information. State Medical Boards can provide access to records of lawsuits against doctors and instances where doctors' license to practice medicine have been revoked. It is O.K. to ask about the doctor's experience – how many times have they done this kind of surgery? Used this sort of equipment? Used this kind of therapy? What were the outcomes? Could you talk with a nurse or social worker who works with the doctor? Are there other patients who have the same doctor with whom you could talk?

Make sure the doctor you choose is accepted by your insurance plan. Insurance plans may cover the services of only a select group of doctors and treatment facilities. Using other doctors or facilities may pose problems with paying for care. It is also important to be familiar with your annual deductible amounts and copays. This information can be found in your health insurance benefits plan. Coverage by certain government-funded programs, including Medicare and Medicaid, can sometimes be a problem since not all doctors and treatment facilities accept patients with only these forms of insurance.

[Karen]

The other night, I woke up with back pain. I didn't know if it was related to my colon cancer, my chemo, or if I had pulled a muscle doing yoga. I had diarrhea and didn't know if the back pain could cause that too, or if it was something I ate. I've changed my diet, so maybe the pain and diarrhea could be from the fruits and fiber I've been eating. But I was sitting in the bathroom, thinking the pain was so bad that I should call somebody. I was afraid the pain meant my cancer had spread. I was trying to remember what the side effects of the chemo were. I started to get panicky. Then I thought, 'who do I call?' I wondered if I should call the oncology nurse practitioner, the medical oncologist, or my primary care doctor? I didn't want to wake up the wrong person in the middle of the night!

I ended up taking something for the pain and called my nurse practitioner first thing the next morning. It turned out I was having some irritation of the bowel common with my kind of chemotherapy. I'd been trying to be a "good patient" – not bother the doctors and nurses with questions. But after this experience, I decided that plan hadn't worked for me, and I asked the nurse practitioner for help.

She and I talked to the dietician and we worked out some changes in my diet that helped soothe my bowel tissues. She set up a time for me to talk with a physical therapist, who helped me develop a gentle exercise program and introduced me to a yoga instructor who works with my physical limitations. Most important, she helped me be clear about who I should call when I have problems, concerns, and questions. I was assured that I could call any time, day or night. I feel a lot more confident knowing there's a kind of "safety net" to support me.

[Narrator]

Ask your oncologist or nurse practitioner to make a list of the members of your healthcare team. The first person on the list should be the person to call if a problem comes up. Ask all your doctors and nurse practitioners to give you their business cards, and keep these cards in a central place.

Also, have a telephone number to call for help 24 hours a day, 7 days a week and on all holidays. Most oncology doctors use answering services to take and refer calls to colleagues when they are not available. The person you talk with on these "off hours" may not be your regular healthcare provider, so be prepared to provide some information about your treatment and the medicines you are taking.

In addition to a list of your cancer care team members, it's a good idea to keep a list of all medicines you are taking (both prescribed and over-the-counter). Include the name, the reason you are taking it, dose, how and when you take the medicine, and the name of the doctor who prescribed it. This record can be helpful if you ever have to go to the emergency room or see a new doctor. Also, any time you are discharged from a hospital, ask for a record of the medicines you were given and the medicines you are to take after you leave. Along with your list of medicines, a list of all allergies or sensitivities can be very useful.