

First Steps for the Newly Diagnosed: The Cancer Survival Toolbox

[TRACK 1: INTRODUCTION]

[TRACK 2: SURVIVOR STORIES: GATHERING INFORMATION]

[TRACK 3: SURVIVOR STORIES: YOUR CANCER CARE TEAM]

[TRACK 4: SURVIVOR STORIES: YOUR CANCER CARE PLAN/SECOND OPINIONS]

[TRACK 5: SURVIVOR STORIES: OTHER RESOURCES AND HOW TO FIND THEM]

[TRACK 6: SURVIVOR STORIES: REVIEWING YOUR HEALTHCARE POLICY]

[TRACK 7: SURVIVOR STORIES: ASKING FOR HELP]

[TRACK 8: SURVIVOR STORIES: WHO TO TELL]

[TRACK 9: SURVIVOR STORIES: TELLING YOUR EMPLOYER]

[TRACK 10: SURVIVORSHIP CARE PLANNING]

[TRACK 4: SURVIVOR STORIES: YOUR CANCER CARE PLAN/SECOND OPINIONS]

[Narrator]

When you are diagnosed with cancer, the first decisions are the most important, as they set the course for how your cancer will be managed. Initial decisions that have to be made include the selection of a doctor or doctors, where to go for treatment, which treatment option to select, and whether to try to enroll in a clinical trial.

Often, people with new cancer diagnoses are given several treatment options from which to choose. It's rare that the treatment decision is simple and clear-cut. In trying to determine which treatment option to select, people often ask – “Doctor, if it were you, or your wife or husband, what would you do?” This can be a useful question, but keep in mind that other people's situations can be quite different from yours.

There are multiple resources that can help you make informed, well-thought-out decisions. The National Comprehensive Cancer Network – or NCCN – and the American Cancer Society worked together to develop *Treatment Guidelines for Patients*. These guidelines help patients understand treatment options for many forms of cancer, and are available on the NCCN and American Cancer Society web sites (www.nccn.org. and www.cancer.org).

The decisions you'll make about treatment are very personal. Here are some questions to ask your doctors or nurses, and things to consider as you look at treatment options:

- Ask how successful this treatment has been for others in similar situations.
- Ask about side effects you might have.
- Discuss your health status and any condition that could make side effects more difficult or serious for you.
- Ask about long-term and late side effects. These are health problems that might occur after treatment has ended.
- Ask about what the realistic goals might be for your treatment.
- Ask about changes you can expect in your lifestyle and daily activities.
- Assess your ease of access to the facility providing the treatment. Also, is the facility one that performs this type of care routinely?
- Talk about the type of self-care you or your caregiver will need to take on.
- Talk with your doctor, nurse, social worker, financial counselor, or insurance representative about what to expect in terms of insurance coverage and the costs for which you could be responsible.

Your cancer care team members can help you work through the decision-making process. Another *Toolbox* program, “Making Decisions,” includes more guidance. In addition, a number of cancer-type specific web sites offer treatment decision support tools; these are listed in the online Resource Booklet.

[Linda]

My name is Linda and I'm an oncology social worker. You're most likely to find a social worker like me – with special interests and skills in working with cancer patients and survivors – in cancer care centers and teaching hospitals. I get involved with patients and families during any phase of

cancer care, but am often involved in early discussions with new patients trying to decide where to get treatment.

The decision about where to go for treatment may be easy if you decide to go to the office or clinic used by your chosen doctor or designated by your insurance plan. The “where to go” decision may be harder when there are multiple places you can get care – the oncology doctor’s office, a free-standing radiation therapy center, a community cancer treatment center, or a cancer center that’s part of a teaching hospital.

The complex nature of cancer care demands that treatment facilities have qualified, skilled staff. Good facilities have space for treatment, and the ability to assure safe storage, handling, and administration of medicines. Treatment facilities need equipment to monitor patients’ status during treatment, and to allow staff to respond quickly to emergencies that could arise – for example, allergic reactions or rapid changes in blood pressure. Facilities must also provide privacy and comfort.

[Narrator]

Let’s talk about second opinions. Second opinions can be an important part of making informed decisions about treatment and where to go.

Michael faced the dilemma of getting a second opinion after he was diagnosed with a form of cancer known to offer many challenges.

[Michael]

Last week after church, a group of us went out for breakfast. I told my friends I was going to have surgery soon for a melanoma on my leg. I asked my friends to pray for me – especially since I’ve been concerned because my managed care plan says I need to have the surgery at the local hospital it owns. I’m not sure the general surgeon I’ve been sent to has the experience and skill needed for this type of surgery. I’ve read melanoma is very complicated and unpredictable. I’m thinking I need a surgeon who is really an expert in melanoma surgery.

[Colleen]

I’m Michael’s friend, and I was with him that Sunday morning. I’m a nurse, and although I don’t work as a cancer nurse, I’m aware that melanoma is not something to take lightly. I was surprised Michael was being so passive about these plans for surgery. He’s usually such a take-charge guy. I can only guess he’s really frightened. But, I was terribly upset by the idea of a general surgeon doing this operation. I know neither of the doctors he’s seen are experts in melanoma care, and I know enough to know that this form of cancer requires expert care. So, I really encouraged Michael to ask his primary care doctor to get him a referral for a second opinion. Most doctors are very willing to do this.

I offered to help Michael by making a list of local doctors who specialize in skin cancers. I found there’s a melanoma center at the cancer center 100 miles from here, and he could begin a self-referral process by calling the center or using its web site.

[Narrator]

There is almost nothing worse than making a decision based on too little information. It is important to know that at any time you can ask your doctors for a second opinion to clarify or confirm your cancer diagnosis. A second opinion can also be helpful to confirm your course of treatment. If your doctor does not want to refer you for a second opinion, you can arrange for one yourself. The Bloch Foundation (www.blochcancer.org), a non-profit organization, provides a list of multidisciplinary second opinion services. Contact information is listed in the online Resource

Booklet. An internet search using the terms “second opinion” and “cancer” can yield another list of organizations that offer second opinion services, many of which provide these services free of charge.

If the cost of getting a second opinion is an issue, a social worker or a financial counselor may be able to help. Even if you have to pay out-of-pocket, a second opinion is important, as it can help you have confidence in the doctors and treatment plan you choose.

Sheri, an executive assistant, tells us how important a second opinion can be.

[Sheri]

I was with my mom, in my childhood home, during the last few weeks of her life. While I was there, I noticed this “thing on my lip” – which, given all of stress I was under, I thought was just a cold sore. After Mom died and I was back home, the sore hadn’t healed so I made an appointment to see my primary care doctor. He said it was a basal cell carcinoma and that it should be removed right away. He referred me to a dermatologist, who said the same thing and referred me to a plastic surgeon. During that appointment, I asked the surgeon if he had any pictures of people who have had this kind of surgery – I wondered what I would look like when it was over. He would only tell me that I would look different than I do now. It sounded awful, but not one of the doctors offered another option. He was ready to schedule surgery, but I decided to wait and see if I could get another opinion.

I went back to my primary care doctor to ask that he arrange a second opinion. He refused, saying I’d already had a second opinion from the dermatologist, and a third opinion from the plastic surgeon. I didn’t know what to do – but I did call the woman who was my best friend from the 5th grade on and is now an oncology nurse. Her first question was “What did the biopsy show?” Well – I’d never even had a biopsy. She contacted an oncology nurse in my city, and they helped me arrange for a second opinion at a local cancer center. I saw the cancer doctor, he arranged to have the biopsy performed, and lo and behold, the sore was not even cancer! I was treated with one application of liquid nitrogen and the sore was gone. Just imagine, if I hadn’t had that second opinion, I would have had that extensive surgery – for nothing!

[Narrator]

Another type of second opinion is a multidisciplinary evaluation of your diagnosis and treatment plan, which offers the benefit of more than one doctor’s opinion. The evaluation, sometimes called a “tumor board” or “cancer consultation board or panel,” involves doctors from several cancer specialties. Some panels include social workers, nurses, nutritionists, pharmacists, and others. The group reviews the patient’s history, reports, and pathology slides and X-ray studies. They discuss the case and agree on recommendations.

You may be asked – or even required – to be present to meet with the panel; during this meeting your questions and concerns can often be addressed. Some services provide patients with a recorded copy of their discussion, but if this is not the case, you may want to ask permission to bring your own recording device so that you can re-listen to these conversations and fully understand the advice offered.

If you have arranged for a second opinion or multidisciplinary evaluation, you’ll need to gather your medical records and reports of diagnostic tests, surgery, and treatment you’ve had so far. If someone other than you is going to collect these documents, you’ll need to sign a release form allowing them access to these materials. You’ll need to provide pathology slides and a CD copy of any CT and MRI scans, X-Rays, and other imaging studies you have had. Some second opinion services will help you gather the required documents.

Getting a second opinion does not mean you're unhappy with your doctor, or that you plan to change doctors: getting another opinion is simply a way for you to get a second doctor's advice. It can be an important factor in your ability to make truly informed decisions about your care.

[Joan]

One of the treatment options that's important to many people with cancer is the chance to enroll in a clinical trial. Clinical trials are used to test new treatments before they're made available to the public. Most people who take part in clinical trials will be in Phase III trials, which compare new treatments to treatments currently thought to be the best available for that type of cancer. If the new treatment proves to be better than the current treatment, the new treatment can then be approved by the U.S. Food and Drug Administration – the FDA – for general use.

Some confusion exists about Phase III trials. People sometimes fear if they take part, they could get no treatment at all. In reality, people in Phase III trials get either standard treatment – the treatment they would get if they were not enrolled in the trial – or the new and potentially more effective treatment being studied. People are also sometimes concerned that insurance will not cover the trial costs. Federal law requires most health insurance plans to cover routine patient care costs in clinical trials as long as the patient is eligible for the trial and it is an FDA-approved trial. Plans are not required to cover out-of-network doctors or hospitals if the plan usually doesn't do so. Medicare Part B pays for routine costs, including office visits and tests. Studies show that taking part in a clinical trial costs no more than any other cancer treatment AND adds the values of access to the newest treatment, quality care, and close attention to your condition. If trial-related costs are of concern to you, the study doctor or nurse can answer questions about what is covered and what costs you or your insurance will be expected to pay.

Bob would like to share his story about taking part in a clinical trial:

[Bob]

My wife and I had looked forward to retiring and spent five years traveling the country pulling a 5th wheel trailer. We had a great time, but at some point, we wanted a place to call "home" again. We found a place we like in a small rural town in Texas. I was working in our little hardware store and one day, a gentleman at the store said, "You kind of look yellow today, Bob." I just passed it off – didn't think too much about it. But pretty soon, other people noticed. I went to our local physician. I tried antibiotics and that didn't help, so I went back. That time, it wasn't the doctor I talked to – it was the nurse practitioner. She was concerned and ordered blood tests. To make a long story short, I found out I had cancer of the pancreas.

I went back home to think over the treatment options I'd been given by the local doctors. I really didn't know what it all meant, but the doctor told me "You've got one of the worst cancers you could have." They said I needed to make a decision about treatment right away. My wife and I talked about it, and we talked with our son. Since we were new to this area, this state, we were not well informed about what resources might be out there. My son got on the Internet and the next day he called and said "Get Dad to the Comprehensive Cancer Center" and gave us the number for the center's self-referral program. My wife placed the call. She also got on the internet and pulled up a lot of information about pancreatic cancer. Neighbors were sort of discouraging – they said I'd have a hard time getting into the cancer center. So, we prayed about it. We were relieved when the center called us back just two days later. I was given an appointment for the next week. I was told to gather my medical records. We did that, and off we went.

I had more tests at the cancer center. I had surgery there, and in six days, I was home. A week later, I had my follow-up appointment. In the waiting room, we met another couple – the husband had had the same surgery. They told us about the clinical trial he was in. We'd read a little about clinical trials, and the surgeon had mentioned it before surgery, but he couldn't predict if I'd be qualified to be in the trial until after surgery. After talking with this couple, we decided to go for the

clinical trial if I qualified. At the surgeon's office, they gave me all kinds of booklets and information about what's involved.

If I qualified, I wanted to do it for the simple reason that if it would benefit other people, I wanted to be involved. I did qualify. In this trial, I had to stay near the center for 8 weeks. We couldn't afford a hotel or apartment, but we had the 5th wheel trailer, and we put it in a campground near the center. I got radiation 5 days a week, plus chemotherapy. I got a little weak – but I still did all kinds of things. I washed the truck. I cleaned the trailer up – I washed the trailer, even waxed the trailer with my IV tubing and my bag, my 5FU chemotherapy and pump hanging off my belt – my wife's having a fit all the time. After the 8 weeks were over, I went to the local oncologist closer to home once a week to have my pump refilled. When we got home, I went back to work. I worked at the Ace Hardware, at the local grocery store and gas station, I substitute taught all the time ... the kids at school asked me "What's that thing hanging on you?" (Laughs) I said – "well, that's chemotherapy" and I had to explain a little bit to them. And that's basically it –I've been free and clear on my check-ups ever since.

I'm asked sometimes about the pros and cons of being in a clinical trial. I wanted to be involved – not just to increase my chances of living longer, but also through this study, others would benefit. And the downside ... in my case, I went straight through 8 weeks without stopping for a rest from therapy – so the downside would maybe be the side-effects you have to go through. But I feel very blessed to have had the cancer center, the surgeon, and the trial there for me.

[Joan]

Clinical trial resources are listed in the online Resource Booklet. You can also get information about clinical trials from your cancer care team. Several web sites offer clinical trial matching services. The Coalition of National Cancer Cooperative Groups' web site (www.cancertrialshelp.org) offers practical information you can use to learn about clinical trials, and www.TrialCheck.org is a leading search engine for cancer clinical trials. You can also search for clinical trials at the web sites of advocacy organizations that help people with the specific type of cancer you have.

No one should take part in a clinical trial without full knowledge of what's involved. If enrolling in a trial is suggested to you, you must be given complete information about the trial, and enough time to think about your decision. Before formally enrolling, you will be given a form that spells out the aim and risks and benefits of the trial, and your rights and responsibilities as a participant. An important right is that you can withdraw from the study at any time. You must read the form thoroughly and have your questions answered before you sign the form to indicate your willingness to participate.

Questions to ask your doctor if you are thinking of taking part in a clinical trial are listed in the online Resource Booklet.

[Narrator]

As part of making decisions about treatment, you may find it helpful to collect and organize your medical records, starting as soon as you can after your diagnosis. Getting records later is possible, but it might be harder. State laws allowing people the right to see medical records differ, and it's not always easy to get copies for your files. And, copy fees can be high. The Health Privacy Project provides information about state laws, and can be accessed by phone (202-687-0880) or at www.healthprivacy.org.

The easiest way to get copies of your records is to ask for copies of your test results at the time you speak with your doctor or nurse. Copies of X-Rays, CT, MRI, and PET scans can be placed on CD as well.

By keeping all your records in one place, they will be ready to share with other healthcare providers you may see in the future. Carmen describes how she collected and organized her records.

[Carmen]

After an appointment, I went to the medical records department. I filled out a form and the clerk said the hospital would bill me over \$100 for copying. I couldn't really afford that. But the clerk was helpful. She told me there's no charge for sending reports to doctors, and suggested I call my doctor and ask if she would accept the records and keep them for me to pick up later. So I called and the receptionist told me they would be happy to keep the copied records for me to pick up at my next appointment.

At first, I used an accordion file to organize my health papers, but as time went on and more papers got collected, I ended up with a file box. My friend who's just now starting cancer treatment got a large 3-ring binder and a set of file tabs. She uses the tabs to label sections – one for articles about her form of cancer; one for insurance forms; one for bills; one for X-ray reports; one for pathology and blood study reports; and one for lists of local resources and important phone numbers. It has made medical record keeping so much easier for her. Another friend scans and keeps an electronic copy of all of her health records and related papers on her computer. This makes them convenient to access and easy to forward to her healthcare providers.

Whatever filing system you use, leave room for new pages. My file keeps getting bigger, as new information about my form of cancer and my treatment comes out.