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[Narrator]

When people face something new in their lives – new people, a new job, or... a new diagnosis of cancer – they often look to others to help them learn what to do. In other modules of the *Cancer Survival Toolbox*, you'll find information vital to your being your own best advocate, no matter how long ago your cancer was detected. But, people who are recently diagnosed may have questions, issues, and needs not covered thoroughly in other modules.

In this module, we offer guidance to help you take those first steps toward successfully meeting the challenges that a cancer diagnosis can impose. You may want to listen to this module more than once, as it contains a lot of information that at first can be hard to absorb. Don't worry about writing down names, web site addresses, book titles and other resources mentioned; they are all included in the Resource Booklet that comes with the *Cancer Survival Toolbox*.

Gathering Information

[Narrator]

People say when they first learn they have cancer, it's hard to think clearly. And at the same time, you have to make some of your most important decisions. The decisions you make now will affect your cancer care AND your life when your cancer treatment ends. Having good information can be key to having power and keeping in control.

Carmen, an oncology nurse and a cancer survivor, has helped guide people with new cancer diagnoses for many years. Here's how she suggests getting started on your search for information.

[Carmen]

First, let me say I know you might feel anxious as you hear some of this information. This is completely normal. It's complicated and can be confusing. Your cancer care team can answer questions and decrease any confusion you might have. So, let's get started.

You will hear many new words, and understanding these words will make communicating much easier. I'm going to use some of these words and explain what they mean as we go along. But there just isn't time to cover all the new words you'll be hearing. So, I can't say this strongly enough: Ask for explanations of any words or terms you don't understand. No one expects you to suddenly know all these things. A list of many words and terms and their meanings is included in the Resource Booklet, and also in the section called "Cancer Words" in the NCCS publication "Teamwork: The Cancer Patient's Guide to Talking With Your Doctor."

Cancer often involves a group of cancer cells becoming a *tumor*. The tumor acts like a parasite, robbing normal cells of blood, oxygen, and nutrients. Cancer cells can spread from the original tumor through the bloodstream and lymph system to other parts of the body in the process called *metastasis*. *Metastasis* is also used to mean a second tumor caused by this movement of cancer cells.

It's important for you to know the exact name of the type of cancer you have. Cancer is more than one hundred different diseases, each with distinct traits. It's also important to realize that even if you and I both had the same actual diagnosis, our body make-up, health histories and current health status would make our cancer situations different.

[Narrator]

Many cancers are diagnosed after a doctor takes a sample of cells from the surface of the tumor or performs a biopsy to get a small piece of tissue from a suspicious lump, lesion, or tumor. The forms of cancer that affect bone marrow, blood-forming cells, and lymph tissues – cancers such as leukemia, lymphoma, and multiple myeloma – are diagnosed with special blood and bone marrow tests.

Tissue and blood samples are sent to a laboratory where the *pathologist*, a medical doctor who is an expert on cells and tissues, uses microscopes and techniques to assess structures inside cells and cells grouped together to form tissues. Dr. Grose, a pathologist, explains his role on the cancer care team.

[Dr. Grose]

The first thing I do is see if the sample contains cancer cells or shows evidence of cancer. I look for signs that tell me where in the body the cancer started – the *site of origin*. I try to assess how fast the cells are growing and dividing, and the chance that the cancer cells will spread beyond the site of origin.

Sometimes, a surgeon tries to remove an entire tumor, such as in the procedure called a *lumpectomy* used to remove small breast cancers. In these cases, another part of my job is to check the size of the tumor, and judge whether or not the entire tumor has been removed. This judgment is based on the *tumor margins* – the distance from the end of cancer-containing tissue to the edge of the entire tissue sample. The tumor margin gives doctors guidance as to what the next steps in treatment should be. Very small tumor margins suggest the need for additional surgery to remove the remaining tumor, or post-surgery treatments such as chemotherapy or radiation therapy.

After my analysis, I prepare a *pathology report* that I send to the doctor. This report describes how the cells looked under the microscope, where I believe the cancer started, and my opinion about the way these cells are likely to act in the patient's body.

[Narrator]

A pathologist's first report is often given to the doctor informally, soon after the biopsy or blood sample is studied. The pathologist then completes a final written report, usually within a few days. Sometimes, the pathologist is unable to get all the information that's needed, and tissue samples might be sent to another laboratory where more specialized tests can be performed. In these cases, the pathology report might be delayed several weeks.

The pathology report is the basis of important talks between the patient and his or her doctor or nurse. Carmen describes what this involves.

[Carmen]

Usually, your doctor will discuss the pathology report with you. But it's common in specialty clinics for a nurse specialist to talk with patients about pathology reports. No matter who provides the information, what's important to you is the name of the cancer; the grade; and other signs that may predict the cancer's behavior – sometimes called *prognostic indicators* – that were seen in the pathologist's study of your cells.

The cancer type is important in determining what treatment options exist. Cancers are named by the type of body tissue involved. Cancers that develop from tissues lining internal organs are called *carcinomas*. Cancers that arise from glands are *adenocarcinomas*. Cancers that start in bone, nerve, muscle, and blood vessels in supporting tissues are *sarcomas*. Your doctor or nurse can give you more information about the specific name of the cancer affecting you.

The pathology report includes details about tumor *grade* – a term indicating how aggressive the cancer appears to be. The grading system is used to describe the differences between normal cells and cancer cells. *Well-differentiated* means the cancer cells look and behave in ways that are similar to normal cells, and is thought of as a good prognostic factor – a good sign. At the other extreme are the terms *poorly differentiated* and *undifferentiated*, indicating that the cells are very different from normal cells; these are usually negative prognostic signs. Sometimes, grades are given numbers: Grade 1 is like well-differentiated cells, while Grades 3 and 4 are like “poorly differentiated” and “undifferentiated”.

Prognostic indicators differ among the many forms of cancer. Their value lies in the clues they give about the way the cancer acts and what treatments might be most helpful. For example, hormone status can be a vital piece of information. Some forms of cancer are affected by hormones – hormones that can cause the cancer to grow faster or hormones that slow the growth process. Breast, ovarian, and prostate cancers are among those that can be affected by the presence or absence of hormones. As a result, changing hormone levels – referred to as *hormone manipulation* – might be used to treat these cancers. Talk with your doctor or nurse about the prognostic indicators that are of value in your form of cancer.

If you have questions about your pathology report, or you want to know more about what something in the report means for you and your treatment options, it might be helpful to talk with the pathologist. Your request might be uncommon, but most pathologists will gladly help you and your family get and understand the information you want.

I always suggest patients get copies of all written reports, but this initial pathology report is especially important – it provides direction for almost everything that follows.

You can get more information to help you understand your pathology report from your doctors and nurses, books, magazine articles, and from web sites. Web sites sponsored by cancer-specific groups offer help in understanding pathology reports specific to a particular form of cancer. The organization “BreastCancer.Org” offers a web-based and a printed booklet: *Your Guide to the Breast Cancer Pathology Report. Us Too*, a Prostate Cancer Education and Support Network, has a section on their web site that describes the “biopsy report” – another name for a pathology report – and gives users information helpful in understanding reports from a prostate biopsy.

[Narrator]

Other information gathered to describe your cancer includes the stage of your disease – how far the cancer has spread. The staging workup starts with a physical exam and medical history. Depending on the type of cancer, it could also include blood and urine tests, X-rays, and other studies such as CT scans, MRI, ultrasound, PET scans, and nuclear medicine scans. Cancer stages range from 0 or I to IV; sub-categories further define the stages. Stages define where the cancer fits into the “TNM” staging system outlined in the Resource Booklet. Cancers that start in bone marrow and lymph system have their own stage and grade terms.

Your *prognosis* – the statistical odds of what happens to people with this diagnosis – is arrived at by looking at the type of cancer, the grade and traits of the cancer cells, the stage of disease, the success of treatments for this kind of cancer, and your personal and medical status and how that will affect what forms of treatment you can undergo. Just keep in mind – the prognosis is based on what has happened to all people who have this disease – and not necessarily what WILL happen to YOU.

Your Cancer Care Team

[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, dietitians, 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.

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

[Carmen]

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. You can learn about doctors' schooling and training in *The Directory of Medical Specialists* and *The American Medical Dictionary*, both often kept in local libraries. 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 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 and HMOs usually 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. Coverage by entitlement 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. You can find more information about paying for care in the *Toolbox* module called *Finding Ways to Pay for Care*.

[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.

Your Cancer Care Plan

[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 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 HMO benefits person 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* module, “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 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 HMO 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. It does get a little trickier when an HMO is involved. But, there's a person called an ombudsman in an HMO. That person's job is to help you get what you need from your HMO. I think it's important, if at all possible, that the doctor consulted for a second opinion be a doctor who is NOT a part of the HMO group or the referring doctor's group practice.

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 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. The *Toolbox* module, *Finding Ways to Pay for Care*, also offers some guidance in getting needed services. 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 secretary, 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 HMO 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.

[Carmen]

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. Actually, nearly 90% of trial-related costs are covered by insurance. Medicare pays for routine costs, including office visits and tests. Studies show 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.

[Carmen]

Clinical trial resources are listed in the 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 the Patient and Caregiver Toolkit – a package of practical information and publications you can use to learn about clinical trials. It also offers TrialCheck.Org, a search engine and database 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 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 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 health care providers you may see in the future. Claire describes how she collected and organized her records.

[Claire]

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 used 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; one for lists of local resources and important phone numbers. It made medical record keeping so much easier for her.

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.

Other Resources and How to Find Them

[Pam]

After my diagnosis, I called the cancer center and asked for help getting a consultation. The person at the referral office was very helpful. Up to this point I'd depended on my doctor and nurse practitioner to help me coordinate the needed tests and consults to confirm my diagnosis. But now that I have my diagnosis and am exploring the right treatment plan for me, I have different questions and concerns –

wondering about insurance coverage, concerns with work, dealing with my family and my own emotional issues. How do I find people who are experts?

It was my nurse practitioner who told me about the resource people at the cancer center where I would be going for treatment, including oncology social workers, clinical nurse specialists, patient advocate representatives, case managers, and financial counselors. All these people could help me find my way through the system – I think of this as “navigating” – and manage my cancer care.

[Narrator]

To help those with cancer identify needed resources, many cancer programs use navigators. Some navigators are lay people. Some are nurses or social workers. They are found in a variety of cancer specialty areas – but particularly in those areas where diagnoses and treatment planning are especially complex, such as breast, prostate, and colon cancer programs. In these settings, the nurse navigator works with various doctors to help newly diagnosed patients learn about their diagnoses and understand pathology reports and the treatment options suggested. Nurse and social worker navigators often help set up second opinions and referrals to other available resources, including those in the local community.

Find out if your cancer care center or a local cancer resource facility employs a navigator, and if so, ask to meet with him or her (or someone whose job is similar). Talk about your needs, questions you have, and ways the navigator might help you.

Reviewing Your Healthcare Policy

[Michael]

I’ll never forget that day. It was a week before my scheduled surgery. I got a call from the hospital business office. The financial counselor called to tell me about the deductible and out-of-pocket expenses that would have to be paid when I checked in to the hospital. What a surprise! I had no idea my deductible was so large. I later learned my coverage had changed at the beginning of the year. I guess I had not read all the paperwork that had been sent to me by my employer. My overall coverage dropped from 90% to 75%. After that wake-up call, I got busy reading my insurance policy.

[Claire]

My diagnosis could not have happened at a worse time. Well, there IS no good time, I know. But, my situation was especially hard. I had lost my job due to a large layoff at the company where I had worked for 20 years. This happened 6 months before. I live in a small community. I was having a hard time finding a new job. Then I got sick. I didn’t have insurance. I couldn’t afford to keep my COBRA policy. I never thought this would happen to me.

I met with the oncology social worker at the cancer center. He was so helpful. I learned about disability and disability insurance. I also learned that my state has a catastrophic state insurance plan. I was lucky. I was able to get some help.

[Narrator]

When diagnosed with cancer and looking at treatment options, knowing about your insurance policy can help you avoid frustrations and surprises. Here are some pointers:

- Review your policy, reading it through from beginning to end;
- Learn about deductibles, co-pays, out-of-pocket expenses, and lifetime maximums;
- Learn about the authorization and certification practices of your insurer;
- When you have questions or there are things you don't understand, reach out to experts available to you. These are suggestions of where you might find such experts:
 - * Human Resource people at work;
 - * Financial counselors at your medical treatment center;
 - * Customer service representatives with your insurance company;
 - * Social workers or case managers at the hospital or treatment center;and
 - * Medicare Hotlines (listed in the Resource Booklet).

One additional suggestion about accessing the benefits of your insurance policy: as part of the Major Illness/Catastrophic Illness portion of most health plans, case management services are available. To use this service, all you need to do is call the number on your insurance card, and tell the company you want a case manager. Case managers are often specialists in particular diseases, so it's likely you will be asked to reveal your diagnosis. Most often, an intake person will contact you to get basic information and assign a case manager. The case manager will then contact you and begin working with you to assure your questions are answered and needs are met. Ask your case manager for his or her direct extension, so you can avoid time-consuming menu selections and recordings when you call in the future.

And finally, if you don't have insurance, get help through a social worker and/or financial counselor at your local hospital or cancer treatment center.

Asking for Help

[Pam]

After the doctor said, "I'm sorry, you have cancer", I didn't hear anything else. My heart started pounding and I couldn't breathe. All I could think was, "I'm going to die." But I didn't. It took a few days, but I decided I was going to beat the cancer. And I was going to need help to do that.

[Narrator]

When you first learned you had cancer, you may have felt frightened, angry, or alone. These feelings are very common. But no one needs to face cancer alone. When people with cancer ask for help from others, they often find it easier to cope.

Let's hear how Pam found help and support in her community.

[Pam]

When I saw my doctor for my annual checkup, he wanted me to have a colonoscopy. When he told me the polyp they found in my colon was cancer, I didn't believe it. He told me I needed to see a surgeon, and the surgeon said I needed to have part of my colon removed.

After surgery, my surgeon said I would need a medical oncologist. My cancer had spread to two lymph nodes and I would need chemotherapy. When I heard chemotherapy, all I could think of was how sick my father was when he had chemotherapy for lung cancer. That really scared me.

While I was still in the hospital, Linda, an oncology social worker, came to see me. She helped me realize my fear and anger are normal. Together, we developed a list of resources available in our community that could help me. I've never been one to ask for help, so I did need this gentle push to just ask. Linda explained that my family and friends will want to help, but they may also need ideas about what I'll need and what they can do.

[Narrator]

Knowing what resources are available can be very helpful. To help you get started in putting your list together, Linda shares the list of resources she and Pam developed.

[Linda]

Family is how you define it. It can include your spouse or partner, siblings, children, parents, grandparents, aunts, uncles, cousins, and friends.

Other Friends may include co-workers, people in your faith community or church, and your neighbors. These are people who love and support you.

Cancer support groups are meetings for people with cancer and their families and friends. These groups let you talk about what it's like to have cancer and how to cope. There are different types of groups: face-to-face groups, telephone groups, and online groups. Some groups, like the "I Can Cope" groups sponsored by the American Cancer Society, provide information relating to cancer and cancer treatment and usually start and end in a span of several weeks. Other groups are ongoing, and exist solely to offer

emotional support and to help members cope with common concerns. Some groups are for family members and other caregivers. Find out what groups are available in your community. You might try to attend more than one group if more than one exists to see which seems most helpful. Hospitals, doctors' offices, newspapers, and telephone directories often list contact and schedule information for support groups in the community.

If you're unable to find a support group in your area, or the support group that's available does not meet your needs, there are other options. You can connect with services that offer telephone, on-line, and even talk-radio-based support programs. I'll mention just a few examples here, and more are listed in the Resource Booklet. *CancerCare*, an organization based in New York that offers many types of services including educational programs, individual counseling, and facilitated support groups. CancerCare can be accessed by a toll-free number (1-800-813-4674 – 1-800-813-HOPE) or on-line at www.cancercare.org.

The Lance Armstrong Foundation offers *Livestrong Survivor Care* – a cancer support section on its web site, www.Livestrong.org. Services include one-on-one support, counseling, and referrals to local resources, help with understanding insurance and financial issues, and clinical trials matching. Livestrong cancer support is also accessible at a toll-free number – 1-866-467-7205.

The Wellness Community, www.thewellnesscommunity.org, is an international non-profit organization that provides free support and education to people with cancer and their loved ones. There are over 20 Wellness Centers in the U.S., as well as satellite off-site programs, and online services at its Virtual Wellness Community, which offers online support groups, a resource library, a nutrition center, and its “mind/body room”.

Some grassroots advocacy groups also facilitate support. For example, the Pancreatic Cancer Action Network – PanCAN™ – helps connect pancreatic cancer survivors with others who are more recently diagnosed. Check with an advocacy group that offers services to people with your form of cancer to see if they help connect survivors with one another. You will find a list of advocacy groups in the Resource Booklet. You can also find links to advocacy groups at the National Coalition for Cancer Survivorship web site.

Spiritual support often involves finding meaning in our lives, and now, finding meaning in having cancer. Many people find support and meaning through prayer or with the guidance of a chaplain, pastor, rabbi, other spiritual leader, or a social worker, oncology nurse, or psychologist.

Organizations, such as the National Cancer Institute's Cancer Information Service, the American Cancer Society, and cancer type-specific organizations like the Leukemia and Lymphoma Society, the National Colorectal Cancer Alliance, the National Prostate Cancer Coalition, and the Susan G. Komen Foundation, can provide up-to-date information and connections to other people with the same kind of cancer. A good place

to start is the National Coalition for Cancer Survivorship's web site – www.canceradvocacy.org. Many NCI-designated cancer centers also provide information and help connect patients and survivors to one another.

Another list Pam and I made included ideas about ways family and friends could help. This way, when people ask what they can do, there is a ready-made list to choose from. I usually suggest one person in your circle of friends and family be asked to be the main contact person and in charge of the list.

[Pam]

This was a good idea for me. Having this list eliminated a lot of confusion. Most importantly, I think it helped to spread the tasks that had to be done more evenly among everyone. That way, no one felt over-burdened, yet I felt good knowing things would not be forgotten. Here are some things I put on my list:

- Pick up my children from school on days I have treatment.
- Take my son to soccer practice or my daughter to dance lessons.
- Put my name on the prayer list at your church.
- Cook a meal for my family and bring it in disposable containers.
- Visit for coffee, to share stories and laugh, but call before you visit.
- Help with the housecleaning or yard work when my husband is out of town.
- Send a card or letter.
- Drive me to my doctor's appointment or treatment if my husband is working.

It's been several months since I learned I had cancer. I started attending a support group and it's been so helpful to hear others talk about their fears, to be able to talk about my experience, and to find support and hope. I also went to a weekend-long retreat for people with cancer. It was amazing to find so many other people were going through the same physical and emotional things I was! The support group meetings and the retreat helped me realize I'm not alone, and gave me so many new ideas for coping with my cancer and treatment in really simple and useful ways. I also put my help list into action. It was difficult at first accepting help. But the list made it easier for me. I also think it made it easier for my friends. I could tell they appreciated the suggestions and I'm so grateful for their help.

Talking About Your Diagnosis: Who to Tell

[Michael]

After my diagnosis, it was difficult to say the word "cancer." I wanted to tell my family and friends who knew I'd had a biopsy. When I called them, I said, "What we feared has happened." They immediately knew what I meant.

[Narrator]

Announcing good news is simple. But, sharing bad news is hard to do. It's okay to take your time and wait to tell others until you're ready. And, it is entirely your decision who to tell and how much information to share. The *Cancer Survival Toolbox* "Communicating" module includes many suggestions to improve communication that may be useful both now and in the future.

Linda offers these thoughts about talking to others about your cancer.

[Linda]

Deciding who to tell and what to tell can be difficult. If this is an issue for you, ask yourself this question: "Would I want to know if one of my family members or close friends was diagnosed with cancer?" This might help you decide who to tell.

Often, people are curious about next steps. Will you have radiation? Chemotherapy? Both? They may wonder where and when you'll have surgery. If the time is right for you, answer their questions as best you can, but keep in mind that "I don't know right now" or "I'm still in too much shock to think about that" are good answers, too. And of course, there will be people who ask questions, but whom you don't feel obliged to answer. People who care about your well-being will respect an answer such as: "You know, Greg, I really appreciate your concern, but right now, I'm just not ready to talk about this. I'll let you know when I'm ready."

[Claire]

Telling family, friends and co-workers about my diagnosis and planned treatment wasn't as tough as I thought. But keeping up with phone calls from friends and family members who wanted to know how I was doing was really tiring. My friend Jan offered to send e-mails once a week to keep everyone posted and would include pictures too, if I wanted. Accepting Jan's offer was a great decision! Once a week I give her an update on how I'm feeling, how treatment is going, the highs and the lows and anything else I want to share. Then, Jan sends the next chapter of my journey with cancer to everyone on the e-mail list.

Jamie, a young man in my support group, said he was getting annoyed by so many calls, even though he knew people meant well and just wanted to express their concern. He created a blog to keep everyone informed. The word comes from combining "web" and "log" – and is a personal journal, diary, or bulletin board that anyone can create on the internet. There are some free blog sites; others charge a fee. WWW.blogger.com is one blog site that's free. You can tell your friends and family you have a blog, give them the address, and they can read what you write. You can even include photos, which everyone seems to enjoy. In addition to his blog, Jamie also assured his friends and family he'd call if he needed help or wanted company, and was able to keep the telephone calls to a minimum.

[Narrator]

Most families find being honest and open about their cancer and feelings helps them handle changes that occur. Telling your children about your cancer is another aspect of cancer that is not easy for many people. Of course, the age of the children makes a difference, although even adult children might be quite distressed by the news of a parent's cancer.

[Carmen]

The National Cancer Institute booklet called "*When Somebody in Your Family Has Cancer*" provides guidance and suggestions that can help families cope with a loved one's illness. Likewise, the American Society of Clinical Oncology has a web site devoted to the needs of patients and survivors and their families – the *People Living With Cancer* site – or PLWC – that also offers educational information, guidance, and support to people who are affected by cancer.

One resource I use a lot is the book *When a Parent Has Cancer* by Dr. Wendy Harpham, a cancer survivor, wife, and parent of three young children. In this book, Dr. Harpham describes how she and her family have dealt with her illness in ways that didn't rob the kids of their childhood AND helped the entire family learn and use positive coping skills. Dr. Harpham suggests that families work towards making a "new normal" for family life, including looking at the cancer as a manageable part of daily life.

I know too, it's really crucial to be honest: tell your children you have a serious illness, and doctors and nurses are working to help you get better. Depending on your situation, some honest talk about the possibility of death might also be in order. Give children time to ask questions, and to express their feelings and fears. Make it a point to let your children know their basic needs will always be met. Children should also know they did nothing to cause your cancer.

Share books about cancer that are written for children. *Becky and the Worry Cup* comes with *When a Parent Has Cancer*. Other books that may be helpful include *Sammy's Mommy Has Cancer* by Sherry Kohlenberg (Magination Press, 1993), *Our Mom Has Cancer* by Abigail and Adrienne Ackermann (American Cancer Society, 2001), and *When Mommy Had a Mastectomy* by Nancy Greenfield (Bartleby Press, 2005). As time goes on, and more families are facing cancer, more books will appear. Bookstore customer service people and librarians often have information about new and useful books.

Children need to know that although things are different, your love for them has not changed. It's also important to let other adults in your children's lives know about your cancer – teachers, coaches, neighbors, and parents of your children's friends. That way, these adults may be better prepared to hear and help with concerns you child brings to them or shares with his or her friends.

All children, but especially teenagers, should continue to spend time with friends and take part in their normal activities. Teenagers should be told as much as they want to know about your diagnosis, treatment, and prognosis. A good response to the question, “Are you going to die?” is “I hope not. I’m getting treatment and doing everything I can to get better.” Encourage them to talk about their feelings and concerns. It’s helpful if you are honest about your feelings and your fears.

Suggest ways children can help. Maybe there are things on your “friends and family list” that kids can do. Today’s teens are so at ease with computers – asking them to help share your news by way of e-mail or helping set up and maintain your blog might be a good way they can help lighten your daily burdens.

Talk with your adult children about your cancer, even if you expect they’ll be upset or worry. Tell them about your feelings and wishes in case you don’t recover. Here are some things you may want to consider:

- Ask your adult children to help you make decisions about your healthcare.
- Ask your children to go with you to doctor’s visits so they can hear what the doctor is telling you.
- Talk with your children about what you need from them, whether it is emotional support, help with paying bills, or taking care of the house.
- Make the most of the time you have with your children. Share your feelings – not just love, but also your concerns, your fears, your sadness, and your hopes.

Talking About Your Diagnosis: Telling Your Employer

[Karen]

When I found out I had cancer, my first thought was “I’m going to lose my job”. Then I thought “Oh no, my health insurance!” I had just started my job four months before, and didn’t know how my boss would react to the news that I might need time off.

[Narrator]

When, how, and what you tell your employer is a personal decision. Before you talk to him or her, ask your doctor how your treatment and recovery will affect your ability to do your job, including whether you will need to take time off, and if and when you might expect to return to your “before cancer” work status.

If you need to take time off for treatment, you’ll probably need to think about telling your employer about your diagnosis. Your employer may ask:

- If you’ll be able to continue working
- Whether you’ll be able to continue to do your job as well as before you were diagnosed with cancer
- If you’re taking time off for treatment, whether you’re planning to return

If you believe talking with your employer will cause problems, it may be helpful to talk to a social worker at your cancer center. He or she may be able to help things go more smoothly.

There are federal laws and regulations that may help you and protect your rights while in treatment. The Americans with Disabilities Act, or ADA, can protect you if you look for a new job. An employer cannot make you take a medical exam before you're hired. After you're hired, they can ask medical questions only if they relate to your ability to do your job. Provisions in the Family and Medical Leave Act require that businesses with more than 50 employees allow employees up to twelve weeks of unpaid time off for treatment.

Most employers try to work around their employees' treatments. Still, it's a good idea to keep a record of talks with your employer and people in the human resources or benefits office. Also, keep copies of performance reviews, memos, and letters regarding your employment.

Legal assistance is available if you feel you are treated unfairly at work. The NCCS publication, *Working It Out: Your Employment Rights as a Cancer Survivor*, available free of charge, reviews legal rights, ways to avoid discrimination, discrimination laws, and enforcement of legal rights. Ordering information is included in the Resource Booklet.

Survivorship Care Planning

[Narrator]

Although it may seem too early for you to be thinking about your life after treatment and long-term survivorship, now may be a good time to start putting together your survivorship care plan. This plan should contain the results of diagnostic tests and information about the cancer and the treatment that was used. Eventually, it should list immediate and lasting side effects that you had, and a list of plans for follow-up care. Contact information for questions about the course of treatment should be listed, along with the name and contact information of the doctor who managed your care. You should be familiar with the known long-term and late effects of treatment, signs and symptoms to watch for, and who to contact if they occur. Depending on your specific needs, your survivorship care plan may also include referrals to a fertility specialist, sex therapist, genetic counselor, or a psychiatrist or psychologist who specializes in working with cancer survivors. Financial counselors, insurance information, and estate planning specialists may also be helpful in your particular situation. Eventually, your care plan should also contain resources to help you adopt changes for a healthy lifestyle, such as community resources for fitness, exercise, and stress reduction programs, nutritional counseling, and smoking cessation programs designed for cancer survivors. Check with your cancer care team, physical therapist, local American Cancer Society office, or support group, a YMCA, fitness center, or yoga or Pilates studios for information about

programs you might use. Internet-based searches might also locate programs in your area.

The development of survivorship care plans is a new area. If your cancer care team does not offer you the chance to create such a plan, you can take the lead to make it happen. The *American Journal of Nursing* published the article “The Cancer Survivor’s Prescription for Living” in April 2007. The article contains a care planning model called “A Prescription for Living,” which can be used as is, or revised to more closely fit your needs. The model can be accessed on the *American Journal of Nursing’s* web site – (www.nursingcenter.com/ajncancersurvivors). NCCS also has more information on care planning at <http://www.canceradvocacy.org/care-plans>.

Thank you for taking the time to listen to this module. We hope the information provided helps you cope in the coming days and weeks, and helps you to arrive at a “new normal” lifestyle.