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Transcript: Finding Information

Narrator: Robert O’Gorman

[Lloyd]

I want to keep up with information about cancer research so that if some new kind of treatment for my cancer comes along, I will know about it and be ready to see if I might benefit from it.

[Antonio]

The librarian helped me use the computer and find information about prostate cancer from the National Cancer Institute’s Cancer.gov Web site. I also got a list of drug companies that help cancer survivors pay for the different kinds of medicines that I might need.

[Gloria]

My daughter and I have learned that it is important to get the right kind of information from the right places. I have also learned it is OK to ask for help. It is also OK to say, ‘I’m not ready,’ or, ‘I’m not interested right now,’ when people give me more information than I can handle.

[Narrator]

Welcome to Program Two of The Cancer Survival Toolbox[®], about Finding Information. Cancer survivors -- and, by that we mean people living with a diagnosis of cancer -- know that managing their cancer takes strength, courage, and good information. Many cancer survivors say that the quality of their lives is better because of what they learned about dealing with their cancer. More than a few survivors claim their very survival is due to their wise use of information. After listening to this program, you will know how to find information in your community and from other sources, and judge the quality of the information you find about your cancer and its treatment.

[Narrator]

The moment you think you might have cancer, you start looking for information to help yourself make decisions. Information can help you find answers to your questions. Information can also help you to form, and ask, questions. This program deals with finding and using information so that you can weigh options and make good decisions.

[Narrator]

We will start off by reviewing the many reasons why good information can be so important to you in helping you get the best treatment and knowing what to expect from the treatment you choose. Then, we’ll talk about how to find information, who to ask, and what resources may be available to you in your area. We will also talk about how you should judge good information from information that may not be as good. Finally, we will hear how three cancer survivors faced their challenges, learned to ask important questions, and get the information they needed to make their best choices.

[Narrator]

First, let’s talk about why good information can be so important to you. Many people feel a sense of panic when their doctor tells them that they have cancer. They might feel a need to rush to make a decision and start treatment as soon as possible. One of the first things to know about cancer is that, most of the time, cancer is NOT an emergency. Almost everyone with a new

diagnosis of cancer has time to look for information and make careful, thoughtful decisions. Take time to find the best information and to think it through carefully. Your doctor, nurse, or social worker can give you some guidance on how quickly you will need to make decisions.

[Narrator]

Having and understanding the facts can help you care for yourself better, give you self-confidence, reduce anxiety, and help relieve distressing symptoms. Most people with cancer, and their family members, want to be involved in their care, and to be true partners with the health-care team. To become involved you need to understand the information you find. In many ways, this is like learning a new language -- we could call it the "language of cancer." Information lets you and your family members take your rightful roles as partners on the health-care team. Let's hear what Joan, an oncology nurse, says about how information can be important to you.

Joan, Oncology Nurse: Part I

[Joan]

I've worked with cancer survivors who did not explore their options and regretted not having found enough information earlier in their treatment. This can become a source of stress and sadness. By actively looking for good information before making decisions, you will be able to take comfort in knowing that you have explored all of the options open to you. And, you will know you have made the best decisions for you.

[Narrator]

Now, how should you go about finding and using information? Information can come from so many places, including news presented by the popular media, advice from doctors, nurses, social workers, pharmacists, friends and family members, tips, and certainly, the wisdom you have gained throughout your own lifetime. A good place to start is with your cancer doctors and cancer nurses.

[Joan]

Doctors are usually the first to talk with new cancer survivors about treatment options, to give information about how this cancer is treated, and what treatment offers the best opportunity of success. The doctor should describe what can be expected as "best" and "worst" case results for your treatment options. Be sure to talk about how to manage side effects of treatment before you choose a treatment plan. An "oncology" nurse, a nurse like me who specializes in cancer nursing. We can often be the best source for information about managing side effects of your cancer treatment.

[Narrator]

Advances in cancer treatment are the result of new ideas, and so, you may want to keep looking to see what's new for your type of cancer. For example, you might be given the opportunity to take part in a clinical trial, which is a study that compares a new treatment with a standard, or usual, treatment. Medical researchers run clinical trials to find out if new ways of treating cancer are more effective and have fewer side effects than standard cancer treatments. All new treatments must be proven safe in clinical trials before these treatments can be prescribed for people with cancer.

[Narrator]

Clinical trials are offered by major cancer centers and community cancer programs. They can be sponsored or coordinated by the National Cancer Institute and groups of cancer specialists called "cooperative groups," which are linked to the National Cancer Institute. Also, they can be offered by biotechnology and pharmaceutical companies. Doctors who lead clinical trials are usually leading researchers in their communities and have access to the latest information and medical technologies. Only cancer survivors who want to, and who meet the very strict entry rules, can take part in a clinical trial. If you are asked to enter a clinical trial, or if you are interested in taking part in one, it is important to learn as much as you can about the trial before you make up your mind.

[Narrator]

Once the clinical trial is explained and you agree to be involved, you must sign an "informed consent." The consent form confirms that you know what is expected to happen as a result of being treated using the trial treatment plan. Consent forms for clinical trials are quite long: it is best to take the time to read through the form, and make sure that all of your questions are answered. Know, too, that even if you do decide to take part in a clinical trial, you can always change your mind and drop out of the trial at any time. You would then work with your doctor to see what other treatment would serve you best.

[Narrator]

One thing to keep in mind: many people can help you gather and use information to learn about and compare treatment options, but it may get to be too much. Sometimes, well-meaning doctors, nurses, and social workers give people with cancer what might seem like too many brochures, pamphlets, books, and these days, even Internet web-site addresses. You may think this is just too much information to take in all at one time. Even so, take whatever information is offered, put it where you can easily find it, and take it out as your need and ability to use it grows over time. You can also ask someone you trust, a family member or friend, to gather and sort through information to help you.

[Joan]

The need for good information goes on after treatment starts and even after it ends. Therefore, it's a good idea to keep track of all the information you collect, especially information about your specific treatments and plan of care. Not only are there more decisions to make, but information is also a source of comfort -- easing doubt, fear, worry, and stress. Information helps you to know that other people have gone through this, and that other people have felt the same ways you are feeling. Information helps to relieve the feeling of being alone that people with cancer very often experience.

Joan, Oncology Nurse: Part II

[Narrator]

Where else can you find good information? There are a large number of support systems and associations, both locally and nationwide. You don't have to go it alone. The Resource Guide that accompanies your Toolbox lists valuable telephone numbers. For example, some cities and regions have private cancer resource centers.

[Narrator]

The American Cancer Society, also called the ACS, has offices located in most medium-sized and big cities. The listing in the telephone book is under "A" for American Cancer Society.

[Narrator]

The National Cancer Institute – or NCI -- through its Cancer Information Service provides access to many types of information resources. Of course, the NCI has many printed materials, ranging from simple, easy-to-read pamphlets to in-depth reviews -- called " Cancer Facts." -- covering different cancers, treatments, and supportive care . Cancer Facts are available in a form that is written just for cancer survivors -- usually a simpler and shorter version of the statement is written for health-care professionals. You can get both forms. NCI's printed materials are widely available from treatment facilities, resource libraries, doctor's offices, and regional offices of the Cancer Information Service.

[Narrator]

The NCI's toll-free telephone number -- 1-800-4-C-A-N-C-E-R -- that's 1-800-422-6237 -- connects callers with the nearest office of the Cancer Information Service. Materials you ask for will be mailed to you at no charge. The toll-free number, 1-800-332-8615, allows those who are hearing impaired to access the Cancer Information Service.

[Narrator]

The Internet, a global collection of computers and computer networks, offers what seems like endless information -- from research articles, to treatment information, to emotional support. On the Internet, cancer survivors can get information from anywhere in the world, all with the touch of a few keys on a computer at home, in public libraries, health-resource centers, or community centers. Trained librarians and information specialists can help you use these tools if you don't already know how. The information available through the Internet is growing every day.

[Narrator]

A word of caution: There is a great deal of very good and helpful information available on the Internet. But, there is a lot of false information, too. The Internet reflects real life, and it is important to question your sources. Remember that the most reliable medical information will come from non-profit cancer organizations, research facilities, hospitals, libraries, and government agencies.

[Narrator]

For cancer survivors who do not or cannot use the Internet, it is recommended that they ask a friend with Internet access to help out. When it comes to information about medical treatment, anything that is more than two or three years old is likely to be out of date. Even with information that has been published within the last two or three years, you have to find out if this information is still current today.

[Joan]

I always remind cancer survivors I work with that there's a lot of good information, and a lot of questionable information out there. It's up to you to question how good and reliable the information is, and figure out how much to trust it. To determine the value of a book, tape, or magazine article, look at the author's credentials. Does the author seem to be respected among cancer care professionals? Has the book been reviewed by experts or professional groups? Does the book, tape, or article tell you its source of information? Are there conflicts of interest in the publication or sales of the book, tape, or magazine?

[Narrator]

You will hear about famous people with cancer and how they learned facts about cancer and cancer treatments. As someone who is not famous or in a special position, you may worry that you will not be able to find out all the facts. This is not true. Everyone can find the information they need. If you don't know where to begin to look or if you are not sure you can do it yourself, you probably do have friends or relatives who can help find information. You might find it helpful to hear how other people with cancer have found and used information. Let's listen now to three cancer survivors who have used their skills to look for information. Our first is Antonio, who is 60 years old, was born in Puerto Rico, and now lives in New York City.

Antonio, 60 years old

[Antonio]

After my regular doctor found that I had prostate cancer, I made an appointment to see a cancer doctor. I asked my grown son to go to the appointment with me so he could ask questions and also help me to remember what the doctor said. I had been given some information about treatment for my cancer, but I was not sure I had enough information to decide what to do. I don't know anyone else who has this cancer.

[Antonio]

I have heard a lot about the Internet and I thought maybe I could find some information there, but I do not own a computer. So my son helped me find a library in our neighborhood that has computers that are hooked up to the Internet. I wrote a list of things I wanted to find out about and made an appointment with the librarian who could help with my search. I wanted to find out about different treatments and any side effects. I also wanted to know if I could get help paying for any of the medicines I would need.

[Antonio]

The librarian helped me use the computer and find information about prostate cancer at the National Cancer Institute's Cancer.gov Web site. I also got a list of drug companies that help cancer survivors pay for different kinds of medicines. We found information about how to deal with side effects of cancer treatment at Cancer Care's Web site, and what they call a computer bulletin board with messages from other men who have prostate cancer. I found a Web site for Us-Too, an organization that gives out information and support for men with prostate cancer. I also found the address for a prostate cancer resource center that is close to my home. I found some of this information in Spanish translations that helped me understand better. The librarian printed this information so that I could take it home with me. I went to the Resource Center and picked up some booklets about different kinds of treatment for prostate cancer. I got an appointment with a doctor who specializes in prostate cancer so that I could get a second opinion from an expert of what I should do. Since then, I have read all the information, thought about the doctors' advice, and I talked about things with my wife and son. I think I can now make a decision about my treatment.

[Narrator]

Antonio did a really good job of finding and using resources. He thought about, and made a list of the things he wanted to know. He did not just use one source of information: instead, he found several different places where he found accurate, up-to-date information. He thought that his English language skills might not be good enough for him to understand all of the information that was given to him, so he asked his adult son, whose first language is English, for help. He also found information in Spanish, which was easier for him to understand on his own.

[Narrator]

After hearing Antonio's story, take a few minutes to think about how you can use what Antonio learned about his cancer and the treatment options he had. Why not make a list of the resources that you could use and the people who you might be able to depend upon for help. Do you know what resources your local public library has to offer? Do you, or a family member or friend, have access to the Internet? Is there a bookstore in your community that sells cancer-related books? Is there a cancer information resource center in your town, or in the cancer treatment center? Is there a family member who can go to the doctors' appointments with you?

[Narrator]

You might not need to use your resource list right now, but some time in the future, your list of ideas might be really helpful, since there are important decisions to make all along the way. Now, let's hear from Lloyd, a retired Iowa farmer, who is 67 years old. Lloyd has just finished treatment for lung cancer. Because of his disease, and the kind of treatment he has had, Lloyd has a different set of information needs that he can share with you.

Lloyd, 67 years old

[Lloyd]

When I was diagnosed, I knew that lung cancer can be pretty bad. But I have also learned that maybe the treatment for my kind of cancer is much better now than it was even just a few years ago. My son is an oncology nurse – he specializes in taking care of people with cancer – people like me. So, I am lucky to have a close family member who is really an expert in cancer treatment. He helped me get the very latest information before I decided which treatment to have.

[Lloyd]

I've never been much at reading books, and I don't know anything about computers or this Internet I've heard about. I don't think I have ever been in the library downtown. So, my son helps me find information that I can understand. He has brought me booklets from the National Cancer Institute and the American Cancer Society. My son does have a computer and he is very good at finding things that way. My son found a special lung cancer Web site on the Internet. In the free time that I have now, I have even started to learn to find things on the Internet myself.

[Lloyd]

My son introduced me to the dietitian at the cancer treatment center. She has really helped me with my diet, to find foods, and even recipes, that my wife can fix that I'll want to eat. I'm tired a lot, too. I now know that many people feel this way after cancer. The oncology nurse at the clinic and the physical therapist have helped me to re-think my daily routine – and I have begun to schedule my day in different ways to take advantage of my energy and let me rest when I need to.

[Lloyd]

Even though I have been handed a tough thing, at least with what I've learned, I feel like I have some control over my life again. I have made the decisions about my treatment. I know – or at least know that I can find out - what to expect. Somehow, knowing makes things easier.

[Narrator]

Lloyd's story is quite a bit different from Antonio's, isn't it? But it is interesting that both men seem to have a lot of hope – though they hope for different things. Lloyd knows his prognosis is not a good one, but he is hopeful that he will be comfortable, and that the quality of his life will continue to be good. Like Antonio, Lloyd is clear about the kinds of information he wants to find. He, too, is looking in several places for information: the Internet, his doctors, nurses, and social workers, and the information his son finds in various places. Now let's hear from another cancer survivor, Gloria, who is 47 years old. Gloria went from worrying about her cancer to regaining a sense of control over cancer through information.

Gloria, 47 years old

[Gloria]

I started to look for information when I was about to begin six months of radiation and chemotherapy. The incision from my breast cancer surgery was just about healed. My doctor had told me there would be side effects from the treatments and I wanted to make this as easy on myself as possible. My doctor told me I might lose my hair and maybe I would feel like I have the flu. She also told me that there are some medications that can help with these symptoms, but the medicines can be expensive. My daughter wanted to find out more about what we can do about the side effects. But I wasn't sure I wanted to know more; maybe the more I heard, the more I would worry. I did have some questions, though, about whether there was some kind of financial help I could get if I couldn't work. I also worried and wanted to know about what costs my insurance plan would or would not cover.

[Gloria]

It is important to me that I am not a problem for my kids or my friends. But, I didn't know where to get the answers I needed at first and I needed help. I did read a book my daughter Rae found at the bookstore. It helped me to read that many people think that asking for help is a sign of weakness. I have to admit, I sort of thought this way, too. But, the woman who wrote this book said that asking for help can be a sign of courage and control. She said asking for help gives other people a chance to feel useful, especially if they care about you but don't know what to do to help you. She said asking for help can make everyone feel better. It has made it easier for me to ask for help when I think about it this way.

[Gloria]

When I first started with all of this, I didn't feel I could make these calls and ask questions over the telephone. I asked Rae to make some calls for me. She was happy to do this and said she was relieved I asked her because she wanted to do anything she could to help. While Rae was making those calls, I remembered that I had the telephone number for the social worker who had visited me in the hospital just after my surgery. I thought it would be easier for me to talk to someone in person. I called the social worker and set up an appointment.

[Gloria]

The social worker explained that there are many ways to help with the side effects of treatment. She taught me some simple breathing exercises to help me relax and suggested that I could listen to the audio program of these exercises during my treatments. She also explained how I could find out about financial help if I needed it. The hospital billing office, the insurance case manager, the personnel office at my job, and the social security office are all places I could go for more information.

[Gloria]

My daughter and I have learned that it is important to get the right kind of information from the right places. I have also learned it is OK to ask for help. It is also OK to say, 'I'm not ready,' or, 'I'm not interested right now,' when people give me more information than I can handle.

Conclusion

[Narrator]

Think about the information and stories you have just heard. When you start to look for your own information, think about how to determine how factual and accurate it is. Make a list of the people you know in your community who would be good sources of cancer-related information.

[Narrator]

One simple telephone call to the right person – a doctor, social worker, nurse, librarian, health educator, or pharmacist who specializes in cancer, or to an experienced cancer survivor -- can quickly lead you to helpful sources of information. Local resources combined with the information such as Antonio, Lloyd and his son, or Gloria and her daughter found through telephone calls to national organizations and connecting to sites on the Internet helped with the information they needed to begin to cope with the challenges brought by cancer.

[Narrator]

In summary, every person, regardless of what kind of cancer they have or what kind of treatment they choose, needs certain, basic information. Every person affected by cancer should take these specific steps:

- Take the time to get the information you need: You will need solid information on the best drugs, and doctors and clinics with the best records for success in cancer treatment.
- Put Together the Best Team: You can help pick the experts to be part of your health-care team. Call on other cancer survivors, nurses, social workers and other health-care professionals to be part of the team.
- Pick people you respect and trust, and who will treat you as a part of the whole team.
- Get a Second Opinion: Good doctors welcome second opinions. When you are faced with more than one treatment option, it is good to ask for another viewpoint.
- Look for What's New: There may be openings for cancer survivors willing to try promising new treatments in one of hundreds of clinical trials.
- Don't Go It Alone: Helpful friends, other cancer survivors, and support groups can make the tough times easier, and may even be a factor in helping people with cancer live longer.
- Read the Fine Print: Ask questions and study your insurer's benefits handbook so that you will know what is covered and what is not. Find out about the limits or "caps" of your insurance and work with the health-care team to use your insurance funds wisely.
- Keep Your Care on Track: Records are the key to keeping track of all the information you are collecting, including the information about your treatment and plan of care.

[Narrator]

Your knowledge about your cancer, and how you use this knowledge, can make a difference in how well you live with your cancer, and even how long you live. The decisions that you will make about your plan of care are just too important to let someone else decide for you. Knowledge is the most powerful tool you can have in your own personal Cancer Survival Toolbox. Remember, your best advocate is you. If you have a piece of paper and pencil handy, you may want to write

down some of these toll-free numbers. You can also find many useful phone numbers and Internet addresses in the booklet that's part of this Cancer Survival Toolbox. For more information, you can call the National Cancer Institute's toll-free telephone number at 1-800-4-C-A-N-C-E-R, which is 1-800-422-6237. You can reach the National Coalition for Cancer Survivorship at 1-888-650-9127.

This is the end of Program Two of the Cancer Survival Toolbox, entitled Finding Information. Please continue on to Program Three, entitled Making Decisions About Cancer.