

Table of Contents

Narrator: Robert O'Gorman

Joan, Oncology Nurse: Part I

Jim, 67 years old: Part I

Jim, 67 years old: Part II

Joan, Oncology Nurse: Part II

Bill, 67 years old

Conclusion

Transcript: Making Decisions

Narrator: Robert O' Gorman

[Jim]

The urologist explained my treatment options: surgery to take out the entire prostate or limited surgery with radiation. My wife and I felt like we had to decide on the treatment right away.

[Bill]

I'm used to being in control of my life, taking charge at work and at home. I'm really upset that my cancer has returned, especially because my current treatment options don't seem like they will help me much.

[Jim]

You know, it was kind of tough, but I asked Bob about his cancer. I was so relieved that he wanted to talk about it. And, once I heard how similar his experiences were to mine, I started feeling better.

[Bill]

I recently heard some of my friends talking about the healing effects of what they called complementary and alternative therapies. I searched the Internet for more information, to see if I should give any of these therapies a try.

[Narrator]

Each day, we all make decisions about our lives. Some of these decisions are fairly easy to make, like what time to get up and what clothing to wear. It takes more time to make other, more important decisions -- about school, marriage, children, finances, and death. These decisions involve other people, either because they will be affected by the decision or because their opinion is important. Sometimes, our freedom to make important life decisions is limited by forces beyond our control, perhaps by health insurance.

[Narrator]

And, we all have different abilities for making decisions about our lives. Some people feel they hold the power to decide. Others feel that life is beyond their control and that they have little ability to make any decisions for themselves.

[Narrator]

Our ways of making decisions are often shaped by whether we are male or female, our family background, our culture, our education, and our role or station in life. These patterns are powerful shaping forces that influence why and how we make decisions when a crisis or serious illness occurs. For cancer survivors, which means anyone who is living with a diagnosis of cancer, many factors affect the decision-making processes. Let's listen to what Joan, an oncology nurse, has observed in working with many cancer survivors over the years.

[Joan]

When people are faced with a diagnosis of cancer, their abilities to make decisions about even the simplest daily events may be shaken by the very word "cancer." Too often the word "cancer" is wrongly linked with death. For example, think about a time when a family member or friend had to have medical tests. Think about their relief when the tests came back and showed no cancer. Their response might well have been, "Thank goodness it wasn't cancer."

[Joan]

A diagnosis of cancer can paralyze your usual ability to make decisions about your life and health temporarily or even for a long period of time. You may feel overwhelmed, anxious, angry, or at a loss to make any decision. These feelings are common. When faced with decisions about life, health, or death, many people become uncomfortable because of their emotions or fears. You may want to hide from them or you may choose to face them head on.

[Narrator]

As you know, making decisions is very hard during an emotional crisis, such as a cancer diagnosis. First there is a new language -- the language of cancer -- to learn and understand. Think for a moment about going to sleep in your own home and waking up in another country where people speak a language very different from your own. Now, think about being in that other country and being faced with decisions about cancer: what kind of treatment you need, what you will feel and look like, whether you can go to work, and when you can do the things you used to do. Imagine how frightened and helpless you would feel to wake up in this strange place, having to speak a language you don't know, and needing to make decisions that will affect the rest of your life. Is it any wonder that our emotions and the strange new language of cancer can interfere with making decisions?

[Narrator]

If you find yourself in this situation, you don't have to feel out of control. There are skills you can learn to help you make decisions. While these skills will help you make a decision, they will not tell you which decision to make. No one but you can make the best decision for you.

Welcome to Program Three in the Cancer Survival Toolbox[®], about making decisions about cancer. In this program, we will go through some skills that can help you make better decisions about your life and your cancer. After listening to this program and working through the exercises, you will be better able to:

- Identify how you prefer to make your decisions;
- Find out the benefits of getting a second opinion to help you make decisions;
- Learn how much time you have to make a decision;
- Weigh the PROS and CONS in making a decision about your cancer treatment; and
- Understand that you are an individual, not a cancer statistic.

Joan, Oncology Nurse: Part I

[Joan]

Before we continue, you may wonder, "Why should I make decisions about my cancer?" You may be thinking, "I fully trust my doctor, family or others to make decisions for me, so why should I bother?" Actually, there are many reasons why you should take the lead in making decisions about your cancer. First, the doctor who decides your treatment today may not be the same one who will decide your treatments in the future. Your life may change, you may move, your health insurance may change, or other things beyond your control may change. Leaving decisions about your health completely in someone else's hands could place you in a risky position. Ask yourself the following question: "Am I willing to risk having someone else who may not know all about my life make decisions about me?" Whether your answer is "yes" or "no," please continue with this program to make certain you are comfortable with your answer.

[Joan]

Second, studies about cancer survivors show that those who are active in making decisions about their cancer treatment and cancer care tend to manage the side effects of their treatment better than those who have little or no knowledge about their cancer. These studies also show that when people do things to help themselves during treatment, they have less tiredness, pain, nausea, vomiting, and other side effects from their cancer. Cancer survivors get to know their bodies and how they respond to treatment. This knowledge lets them respond to side effects and manage them in their daily lives.

[Narrator]

To show you why this is important, let's hear how others have responded to their cancer diagnoses and how they prefer to make decisions. Jim is a 67-year-old African American man who recently retired. He lives with his wife, Eve. They have been married for 40 years and have three adult children, two sons, and a daughter. See if you have been in a similar situation. How did you feel and what did you do?

Jim, 67 years old: Part I

[Jim]

I went to see my doctor for an annual checkup. After that he asked me to come back to the office—this time with Eve, to discuss the results of some blood tests. When we went to see him he told us that he noticed a rise in my PSA. He said PSA stands for Prostate Specific Antigen. The PSA test is a blood test that measures the amount of protein in the blood produced by the prostate gland. He was concerned about this change and said that I should get some more tests done by a urologist—a doctor who specializes in treating prostate problems. While these tests included a biopsy which turned out to be positive for cancer.

[Jim]

The urologist explained my treatment options to Eve and me. It came down to two choices: surgery to take out the entire prostate or limited surgery with radiation therapy. These treatments have different side effects, some of which don't last long, like discomfort, pain and fatigue. But, other side effects, like some kinds of sexual problems, might be permanent. We felt like we had to decide on the treatment right away.

[Jim]

So, I asked my urologist what he would do if he were in the same situation. He told me what he would do if he were diagnosed with prostate cancer, and urged me to do the same. So, I thought about it on the ride home from his office. Eve and I talked about my treatment options again. I wanted to do whatever the urologist recommended, to just get the whole thing over with. But, Eve reminded me of our neighbor, Bob, who had also recently been diagnosed with prostate cancer. She said, 'why not talk to Bob, see what he says.' 'I don't know,' I said, 'this is kind of hard to talk about.' But, this was serious, and I could see that Eve was maybe even more scared than I was, so I said I would talk with him.

[Narrator]

Before we hear what Jim did, let's talk more about how people make decisions about health and cancer. There are basically three types of decision-makers: The person who lets others make decisions about their health; The person who makes decisions about their health after talking with others; and, The person who makes their own decisions about their health. Each of these decision-making styles is neither better nor worse than the others. We will talk about them in more detail to help you better identify which of those types of decision-maker you are.

[Joan]

When I start working with a cancer survivor, I try to figure out which kind of decision-maker that person is. That helps me work better with them. The first group is people who let others make decisions about their health and are comfortable with having a doctor or a family member decide. An advantage to this type of decision-making style is that decisions are made rather quickly with little conflict because the person is ready to accept the expert's opinion. One disadvantage is that the doctor may not really know the person's preferences, habits, work, family, and lifestyle activities.

[Joan]

The second group of decision-makers are people who make their own decisions about health after talking it over with other people. They look for all of their possible options to treatment, both standard treatment and treatment in clinical trials. They tend to balance the factor of time with available options in making their decisions. They look at the options provided by their doctors and

decide if those options make sense for them. They choose to make decisions as a partner with their doctors and want a treatment plan that takes into account their habits and daily lifestyle choices. The disadvantage to being this type of decision-maker is that it takes time. This type of decision-maker can go back and forth about decisions until he or she selects the best option for them.

[Joan]

The third type of decision-maker is the person who likes to take complete charge and responsibility for making each and every decision. These people worry over each decision and may express lots of confusion and doubt even when they have made their decision. They choose to make all the decisions and can upset their doctors and others who are caring for them. These persons want as much control as possible over their illness and treatment. They develop plans of action taking into account as many choices as possible. A downside to this style of making decisions is that there is uncertainty about long-term results and this means that it will be hard to make final decisions.

[Narrator]

In our example with Jim, he seemed ready to let his doctor make the cancer treatment decision for him. But, is this the way in which he normally makes decisions? Or, did the news of his diagnosis overwhelm him at first and cause him to change the way he would normally approach a problem? What kind of decision-maker are you? And, might that change if you got unexpected news?

Jim, 67 years old: Part II

[Narrator]

To help you identify how you make decisions about cancer, listen to each of the following statements and then choose one that best suits your style:

- Number 1: I prefer to leave all decisions about my cancer treatment to my doctor.
- Number 2: I prefer that my doctor make the final decision about which cancer treatment will be used, but he or she first seriously considers my opinion.
- Number 3: I prefer that my doctor and I share responsibility for deciding which cancer treatment is best for me.
- Number 4: I prefer to make the final selection of my cancer treatment after seriously considering my doctor's opinion. Or,
- Number 5: I prefer to make the final selection about which cancer treatment I will receive.

[Narrator]

If you chose statements number 1 or number 2, you prefer that your doctor make decisions for you. If you chose statement number 3, you prefer a shared style of making decisions with your doctor. If you chose either statement number 4 or number 5, you prefer to make the decision yourself. Keep this in mind as we continue learning about decision-making skills. Now, let's look more closely at finding out how you can decide about cancer treatment by getting a second opinion and how to identify how much time you have in making a decision. Let's return to our case example with Jim. Do you recognize some of these same feelings? How would you respond in this situation?

[Jim]

We invited our neighbor Bob and his wife over for coffee, to talk. You know, it was kind of tough, but I asked Bob how he was doing, how his cancer was. I was so relieved that he wanted to talk about it. And, once I heard how similar his experiences were to mine, I started feeling better. I wasn't so scared now, and I could see that Bob has been through it all, too. He helped me realize that I have more time to make a decision than I originally thought... more time to make a decision that's right for Eve and me.

[Jim]

Bob said I should get a second opinion about treatment. He suggested that I talk to other guys who have prostate cancer. He said if he had to do it all over again, he would talk to more guys to find out how they handled it. He belongs to a support group now, and he wishes he had known about them before his treatment. He said he wasn't sure if he would have chosen a different treatment. But, he would have felt a lot more comfortable about the decisions he did make. Bob gave me some information about prostate cancer and the name of another urologist, in case I wanted to get a second opinion.

[Jim]

Later that night, Eve and I talked about what Bob said. It helped me to decide to get that second opinion and join a support group. Bob had also suggested that the first thing I should be clear about -- from my first doctor to the second doctor -- is how much time do I really have to make a

decision. Is it almost an emergency? Or, do I have time to get more information, think it over before I need to decide what treatment I want?

[Jim]

I realize now that I was ready to let my first doctor make all the decisions for me at the beginning. But, I wouldn't have been comfortable with that. I always want to be involved in making my own decisions. Eve helped me realize that, by getting me to talk to Bob, I would see that I should get more information before making any decisions.

[Jim]

So, I went to the support group to hear more about prostate cancer, to hear about what decisions other guys made about treatment. It was also interesting to find out how they went on with their lives after a cancer diagnosis. Eve and I talked about all of this information. The second opinion also helped a lot. Now, we feel comfortable about making a decision and in moving forward with my treatment.

[Jim]

It's been a while now, I'm involved in my support group and have become involved in an advocacy organization for black men with prostate cancer. I told my children about my cancer diagnosis and treatment. I want my sons to be aware of the risk of prostate cancer and to get checkups on a regular basis. You know, we all feel lucky that I found out about my diagnosis at an early stage, and that we learned to make important decisions. We feel good about our decisions.

Joan, Oncology Nurse: Part II

[Narrator]

Now that we've heard Jim's story and you have identified your preference in making decisions, let's move on to another important point: weighing the pros and cons in making a decision about cancer treatment. This is useful in not only deciding about treatment, but also in deciding whether to be part of a clinical trial. A clinical trial is a test in which a new cancer treatment is compared to a standard, or usual, treatment for a certain disease. We will look at how to weigh the pros and cons from the viewpoint of three women with ovarian cancer. Are there ways in which your situation is similar to any of the ones these women face? Have you thought about taking part in a clinical trial?

[Joan]

I've been working with Maria, LaVerne, and Rebecca. I've talked with them about opportunities to be part of clinical trials. Maria is a 35-year-old mother with three children in grade school. She lives in a small farming community located 80 miles away from the cancer treatment center. She told me that she is worried about the treatment side effects that can occur, and about the time that she might have to be away from her children. She wonders who will look after her children then. She is also concerned about whether she'll be able to keep up with her other family activities and responsibilities that she takes great pride in.

[Joan]

LaVerne is a 64-year-old widow who lives near the cancer treatment center. She doesn't trust the idea of a clinical trial. To her, the words sound like an "experiment" and she doesn't want to become someone's guinea pig, as she puts it. She worries that she will not live a normal life if she takes part in a clinical trial, that the demands of a clinical trial will take over her life.

[Joan]

Rebecca is a 22-year-old college student who lives with friends off campus. She has made it very clear to us on her health-care team that she will do anything that might cure her disease. She will consider any treatment, whether it is standard therapy or a clinical trial, as long as it fits her individual lifestyle and circumstances.

[Joan]

Each of these women has different needs and goals. So, how do I help them think about making important treatment decisions, like deciding whether to enter a clinical trial? I start with weighing the pros and cons, that is, the benefits and drawbacks. It is a fairly simple exercise and one that can help you with your decisions. Here's what we do: First, get a sheet of paper. At the top of the paper, jot down the most important things in your life. They might include your family, your job, your goals, your hopes, or your dreams for the future. Now, draw a line down the middle of the sheet of paper. On one side, write down the pros of treatment, and on the other side; write down the cons. Look at each of the pros and cons and how they relate to the important things in your life or the dreams that you have yet to fulfill. Now put the sheet of paper away in a drawer and leave it there for at least a day. Take out the sheet of paper, reread it, and think about what you wrote. Make any changes in the pros and cons that you feel are needed. Finally, think about the decisions you must make in light of your list of pros and cons.

[Narrator]

One of the biggest questions that people ask in making their list of pros and cons, and in making decisions about cancer treatment is, "What are my chances if I choose this treatment over

another?" Or, "How much longer can I expect to live if I choose this treatment over another?" Some doctors respond by giving statistics. Others refuse to even discuss them. Whether your doctor provides you with statistical information or not, don't put too much faith in these numbers. Your chances of a cure depend on many things – not only on the type of cancer you have, but at what stage it was discovered, your general health, your family history, any other health conditions, and much, much more.

[Narrator]

Remember that you are an individual, not a cancer statistic. Yes, statistical information can help you to sort out your different treatment options. This information can help you identify the risk of complications that may occur. But, statistics only show what has happened in general in large groups of cancer survivors. They cannot guarantee that a specific person -- you -- will be among those with improved chances for survival. You are a person with hopes, plans, and dreams. You are not a cancer statistic.

[Narrator]

Now, let's talk about cancer treatments that are called "complementary" or "alternative" therapies. Have you ever thought about using any of them? You may have picked up a newspaper or magazine article report on the "benefits" of alternative therapies. Or you may have heard about complementary therapies in your support group or from other cancer survivors. Complementary and alternative therapies are not conventional therapies. They are used either to "complement", that is work along with standard cancer treatment, or as an "alternative" instead of standard cancer treatment. Complementary therapy may include dietary changes, psychotherapy, social support, exercise, massage, and spiritual support that are used along with conventional or standard treatment to help improve quality of life during and after treatment. On the other hand, alternative therapies you may have heard about may include anti-neoplastons, hydrazine sulfate, and other pharmacological approaches that are "outside" of the use of standard therapy for cancer.

Bill, 67 years old

[Narrator]

Whether or not you are currently considering using complementary therapy, let's look at the example of another cancer survivor to illustrate how to make decisions about complementary therapies. Bill is 67 years old. He had had surgery for early stage colon cancer several years ago and now his cancer has returned. He is of German descent, a retired electrical engineer, and has been married for 35 years to his wife Nicole. Bill and his wife have four adult children and three grandchildren who live in other parts of the country.

[Bill]

I've spent my retirement years with my wife, Nicole, sailing and fishing on our boat. I'm used to being in control of my life, taking charge at work and at home. I'm really upset that my cancer has returned, especially because my current treatment options don't seem like they will help me much. The truth is that my chances for long-term survival are pretty low. I don't see why I should start chemotherapy -- the side effects could make me a burden to my wife. I couldn't stand that. There has to be some other way to treat my cancer.

[Bill]

I recently heard some of my friends talking about the healing effects of what they called "complementary" and "alternative" therapies. I searched the Internet for more information, to see if I should give any of these therapies a try. I talked with an herbalist, an alternative nutritionist, and a therapist. It looks like I have two choices: One, to start chemotherapy and use relaxation techniques, a course of high dose vitamin therapy, and drastic nutritional changes along with it. All of that will cost hundreds of dollars a month. Or, my second choice is to go without standard treatment and fly to the Caribbean to find out more about alternative treatments they use there.

[Narrator]

What do you think you would do in this situation? How would you decide? Now, let's do another exercise to examine whether complementary or alternative therapies might be a good choice for you. Go back to your list of "Pros and Cons" about the possibility of taking part in a clinical trial. On the back of that piece of paper, write down your thoughts and feelings about standard cancer therapies for cancer that returns, called recurrent cancer. What is your attitude about treatment for recurrent cancer? Do you consider standard treatment hopeless, like Bill did? Now, draw a line down the middle of the paper to make two columns, one for complementary therapy and one for alternative therapy. Listen carefully to the following nine questions, stop the audio program and think about them. Write down your answers, whether "Yes", "No", or other short answers as we go along.

- First question: think carefully at the suggestions and advice given by people who practice complementary or alternative therapies. Do they have information to back up their claims or do they only tell you about their success stories?
- Second question: Have any recognized medical authorities endorsed these stories about complementary or alternative therapies?
- Question 3: Do the alternative practitioners sell the products that they endorse?
- Question 4: Is the product only available through the alternative practitioner?

- Question 5: Plan out the schedule of vitamins/treatments/nutritional or other interventions that are recommended. Will this schedule fit into your daily lifestyle or will it force you to completely change your daily life?
- Question 6: How much will your complementary or alternative therapy cost?
- Question 7: Who will pay for these therapies?
- Question 8: How long will you be able to cover the costs by yourself, if you would have to do so?
- Question 9: Does the alternative approach cause any short- or long-term effects?

[Narrator]

If you cannot answer all of these questions, you need more information. If you have not already listened to Program 2 of this Cancer Survival Toolbox, you should. That program discusses many different ways to get the information you need to help you make important decisions. For example, you can search the Internet to see if there are any trials on the therapies you are thinking about trying. Then, if you decide to try complementary or alternative therapies, try one therapy at a time rather than starting them all at once. Take things step-by-step. Remember that you can change your mind at any time about using alternative therapy.

Conclusion

[Narrator]

To sum up what we have been talking about, making decisions about your cancer treatment starts by remembering that you have a choice in your attitude about cancer. Learn to identify how you like to make decisions. Consider getting a second opinion to help you make a decision. Learn how much time you have to decide on a treatment plan. Weigh the pros and cons of any decision about cancer treatment. Don't base your decisions only on survival statistics; you are an individual, not a cancer statistic. If any complementary or alternative therapies seem attractive to you, learn all that you can about them before making the decision to try them. If you haven't given much thought to the decision-making process before, you may want to review this program to strengthen your understanding. The principles provided can help you make sound decisions about treatment – decisions that can serve you well after your cancer diagnosis.

This is the end of Program Three in the Cancer Survival Toolbox, entitled Making Decisions About Cancer.