

## [TRACK 2: TYPES OF INFORMATION]

### 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 and the internet, 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.