

## **First Steps for the Newly Diagnosed: The Cancer Survival Toolbox**

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## [TRACK 2: SURVIVOR STORIES: 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.

Joan, an oncology nurse and a cancer survivor, has had a lot of experience guiding people with new cancer diagnoses. Here's how she suggests getting started on your search for information.

[Joan]

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 section called "Cancer Words" in the NCCS publication "Teamwork: The Cancer Patient's Guide to Talking With Your Doctor." "Teamwork" can also help you ask the right questions when choosing a doctor, asking about biopsies, learning about your diagnosis, choosing treatment options and more. In addition, NCCS has developed two tools to encourage communication with your doctors: the "Know Yourself Worksheet" and "Essential Questions to Ask Your Doctor," both available on the NCCS website at ([www.canceradvocacy.org/takecharge](http://www.canceradvocacy.org/takecharge)).

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. Joan describes what this involves.

[Joan]

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 that can cause the cancer to grow at a faster or slower rate. Breast, ovarian, and prostate cancers are among those that can be affected by hormones. Changing hormone levels – referred to as *hormone manipulation* – might be used to treat these cancers. Another type of prognostic indicator, known as *tumor molecular profiling*, may be performed on your tumor to identify which chemotherapy drugs or other targeted therapies are likely to be most effective and which treatments are likely to be ineffective. 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. For example, the National Cancer Institute, or NCI, has a Cancer Fact Sheet on Pathology Reports on their web site. Web sites sponsored by cancer-specific groups often offer help in understanding pathology reports specific to a particular form of cancer. For example, the organization “BreastCancer.org,” which you can find online at [www.BreastCancer.org](http://www.BreastCancer.org), offers information on understanding pathology reports for various types of breast cancer. Similarly, the Prostate Cancer Foundation ([www.pcf.org](http://www.pcf.org)) covers diagnosis, staging, and risk assessment. Other groups have disease-specific information as well.

[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. Cancers that start in the bone marrow or lymph system have their own stage and grade terms.

Staging is done using the “TNM” staging system, which is based on the size and extent of the primary **tumor** (the “T” in TNM); whether the cancer has spread to nearby lymph **nodes** (the “N”); and whether the cancer has spread to other parts of the body – this is called “metastasis” and represents the “M”. The National Cancer Institute has an excellent fact sheet about tumor staging at [www.cancer.gov/cancertopics/factsheet](http://www.cancer.gov/cancertopics/factsheet).

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.