

## **Educating Yourself about Cancer**

Having a serious illness is frightening. And, while cancer is indeed a scary disease, all the things you don't know make it even more so.

Educating yourself about your disease and your treatment options is one of the most important things you can do to lower your stress and increase your ability to partner with your doctors to make good decisions about your health care.

### **What do you need to know?**

Cancer is a complex disease. In addition to originating in different places in the body, cancer has different stages of development, based on the extent of the original tumor and the degree to which it has spread.

Cancer staging is indicated by Roman numerals: I, II, III, and IV. Sometimes, these stages are subdivided, as in stage IIIA or IIIB. Each type of cancer has a unique staging system, but, in general, these are based on:

- The location of your original (primary) tumor
- Tumor size and number of tumors
- Lymph node involvement
- Cell type and tumor grade (how different the cancer cells are from normal cells)
- Spread to other organs of the body.

Staging is important because it helps your doctor plan your treatment and estimate how your disease will respond to that treatment. It also helps you and your doctor identify any clinical trials (research studies) that you could participate in.

Knowing the stage of your disease will help you narrow down the sea of available information to that which is going to be most helpful. And, just as important as the number indicating the stage of your disease are the facts underlying it, like the size and aggressiveness of your tumor, whether you have one or multiple tumors, and whether your cancer has spread from its original location.

These facts about your particular disease come from biopsy and pathology reports, as well as radiology and other tests to look for cancer in other places in your body. Only when you have this information do you have an accurate idea of the *stage* of your disease.

And only information that pertains to the stage of your cancer will be helpful to you. So, from the beginning, be sure to focus only on information that's relevant to your particular cancer and stage.

## Where can you find information?

Information about cancer can be found in a myriad of sources. Some are written for doctors and medical professionals, and some are written for the public.

For professionals:

- Medical texts. Textbooks are good sources for basic information. However, they're quickly out of date, lagging behind medical advances by at least a year, so make sure to check any facts against more recent publications.
- Medical review articles. Most medical journal articles report the results of a single study. It's difficult for even skilled research professionals to gauge the merit of an individual study. Review articles, on the other hand, report all studies that are relevant to a particular form of treatment or type and stage of cancer. If you delve into medical journals, look for a review article focusing on your particular diagnosis. You can search the National Library of Medicine online at [www.ncbi.nlm.nih.gov/pubmed](http://www.ncbi.nlm.nih.gov/pubmed)

For the public:

- Popular books. These present easily-understandable information about cancer and its treatments. However, the lead time for getting a book published is at least a year. While you may find the information about cancer helpful, be wary of relying on any suggestions about treatments. They're likely to be out of date.
- Popular articles. While these are usually more timely, they tend to focus on what sells publications to readers. They usually present information in a summarized and simplified way. They're good for an overview, but don't expect to glean details that can help you understand your particular disease.
- Websites: The Internet is the information source you can rely on anytime, even if it's 2 AM and you just can't sleep. Before you start surfing, though, here are some good guidelines to keep in mind:
  - Don't randomly surf for hours on end. Before you log on, decide what you're looking for: information about diagnosis, treatments, support groups, clinical trials, national experts, managing side effects, or any other subject you want to learn more about. Stick to your chosen topic at each session.
  - If using the Internet is making you anxious, stop! Consider having someone else search for information for you.
  - Choose the websites you use carefully. The Internet is full of information; some of it is reliable, and much of it is outdated or just plain wrong. Here are some websites that always provide information you can count on:
    - [www.cancercare.org](http://www.cancercare.org) CancerCare provides professional support services to anyone affected by cancer. Their programs include counseling, education, financial assistance, and practical help.
    - [www.plwc.org](http://www.plwc.org) People Living With Cancer provides oncologist-approved cancer information from the American Society of Clinical Oncology.

- [www.nccn.org](http://www.nccn.org) The National Comprehensive Cancer Network is a not-for-profit alliance of 21 of the world's leading cancer centers dedicated to improving cancer care.
- [www.chemocare.org](http://www.chemocare.org) Chemo Care is a great source for information on chemotherapy and its side effects.
- [www.pubmed.org](http://www.pubmed.org) Designed for medical professionals, PubMed presents a searchable database of health care publications.
- [www.canceradvocacy.org](http://www.canceradvocacy.org) The National Coalition for Cancer Survivorship is the oldest survivor-led advocacy group in the country, providing award-winning patient information.
- [www.patient.cancerconsultants.org](http://www.patient.cancerconsultants.org) Cancer Consultants provides information for professionals and patients and has a tool for finding a physician near you.
- [www.cancer.gov](http://www.cancer.gov) The National Cancer Institute is a division of the National Institutes of Health, providing up-to-date, accurate information for patients and professionals.
- [www.ralphmoss.com](http://www.ralphmoss.com) The Moss Reports is a fee-for-service site, providing detailed reports on particular cancer diagnoses.

### **Clinical trials**

Advances in cancer treatments occur through clinical trials—carefully designed and conducted studies of new medications and other treatment options. Clinical trials can give you access to treatments that are so new that they're still being studied.

Clinical trials are conducted in phases. Phase I trials establish dosage ranges, side effects, and the effectiveness of new treatments and medications. Researchers generally enroll few patients—and quite slowly, as they study closely how a drug affects the body.

Phase II trials are the next step, enrolling more patients. They focus on whether a new treatment works well enough to test in a Phase III trial, which types of cancer it works best against, what the most effective dosages and regimens are, and, again, what side effects occur.

Phase III trials evaluate the effectiveness of a new treatment, as compared to existing treatments. Trials in this phase are generally quite large, often with thousands of patients participating.

Talk with your doctor about whether enrolling in a clinical trial—and in which phase—is a good idea for you. If the two of you decide it is, here are some websites where you can find information about what trials are being conducted in your area:

- [www.clinicaltrials.gov](http://www.clinicaltrials.gov) provides information on thousands of clinical trials conducted to study the treatment of many diseases.
- [www.centerwatch.org](http://www.centerwatch.org) provides information on industry- and government-sponsored studies
- [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials) provides information on trials that pertain specifically to the treatment of cancer

## **Comparing treatments**

As you learn about treatment options, create a treatment comparison chart to help you make sense of the information you find. This chart may extend over several pages, but it will help you compare the different approaches to treating your particular disease.

For each treatment option, create entries for:

- Survival rates, distinguishing between ‘total survival rates’ and ‘disease-free survival rates.’ The former includes people who are still living with cancer; the latter refers to people who no longer have evidence of disease.
- Inconvenience. Different treatment options may involve travel, lifestyle disruptions, and other inconvenient experiences. As these occur to you, make a note in your chart.
- Side effects.
- Cost. As you note the costs of treatment, be aware that financial assistance is often available.

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[www.InsightMedicalConsultants.com](http://www.InsightMedicalConsultants.com)