

helpful advice for people with cancer and their caregivers

This section includes non-medical advice for the newly diagnosed, metastatic and your caregivers. It has been compiled by many cancer patients, survivors and nurses.

Please read the sections that apply to your medical care and skip those that don't. And please do let us know if you have advice to share. You can send us your advice by email at info@CANCER101.org or by including it on your survey located inside your five-pocket folder. We will add your helpful advice to our Web site as well as add it to the planner when we print it next.

For additional advice, visit CANCER101.org/advice

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SAMPLE

C102 now what?

What to do first when you learn you have cancer

- First, take a deep breath and try not to panic. We know that hearing those words, “you have cancer” is scary. But many cancers are treatable, so try and stay positive until you know all you can about your diagnosis. The more you learn, the less panicked you will feel.
- You may want to avoid researching on the internet until you speak with a specialist about your cancer. Every cancer prognosis is unique because of the person’s age, gender, current health status, family health history, the genetic make-up of the cancer and when the cancer was caught. Make sure you know what you are researching first!
- Try not to panic and rush into treatment decisions before you have had a chance to think about your options, outcomes and associated costs. It’s important to understand the new terminology and explanation your doctor(s) have provided. Make sure you have all your questions answered. There may be more than one option to consider, and a clear head is necessary for decision-making.
- Call your insurance company right away. Tell them about your condition. Ask to have a “case manager” so that you have only one person to talk to for all your questions, getting approvals, bills, reimbursements, etc. If you don’t have insurance, don’t panic. There are financial resources inside the National Cancer Resource tabbed section to help you.
- Ask the nurse with whom you book your appointment what you need to bring with you to the appointment. If you have a pathology report or scans, you will need to bring those. If doctors don’t have all your information, they won’t be able to discuss your cancer and treatment options. Don’t sit in the waiting room for hours only to eventually find out you didn’t bring the essential reports.
- Be prepared for your doctor’s appointments. Use the questions found in this planner, which were provided

by Cancer.Net. If your cancer type is listed in the myCANCER101 tab, make sure to download your supplement and insert it into the planner so you have questions specific to your tumor. If your cancer is not listed in the myCANCER101 tab, go to Cancer.net and you may find cancer-specific questions posted on their Web site. Make sure to write down your own list of questions too. Being prepared before your meet with the doctor is really important.

- Try to bring someone with you who can take notes and ask questions with you. If this is not possible, prepare questions in advance and bring a tape recorder and tape the doctor’s conversation with his or her permission. Or ask a nurse or volunteer at the doctor’s office to take notes for you.
- Learn about your treatment options so you can make good choices. Get a second opinion or even a third from a surgeon and/or oncologist (and a plastic surgeon if needed). Don’t be afraid to ask doctors lots of questions. The more you understand, the less frightening and overwhelming your treatments will be.
- Find a doctor who takes part in a tumor board. A tumor board is an approach to treatment planning in which several doctors with different specialties meet regularly to discuss the medical condition and treatment options of individual patients. A tumor board might be made up of a medical oncologist, who treats cancer with drugs, a surgical oncologist, who treats cancer with surgery, and a radiation oncologist, who treats cancer with radiation.
- Designate a friend or family member to communicate to your friends. You will be receiving many phone calls from well-wishers and repeating your updates will become tiresome. There are also internet options for you to help keep friends and family informed. Find those resources in our National Cancer Resources tabbed section.
- If you work and are concerned about how to talk to your employer, go to cancerandcareers.org. It’s geared toward women, but the great advice it offers is for everyone.

- It's very important for you and your caregiver to understand the cost of your treatment options compared to the benefits of those treatments. For example, some therapies boast that they give patients a "better" prognosis than another treatment option but will require a great deal of money because they are not covered by insurance. Find out what "better" actually means because if studies show that the treatment outcome is only better by six weeks, for example, do you really want to mortgage your home, spend your children's college savings and incur massive amounts of debt?

C103 surgery

Read below if surgery is a treatment option

Before surgery

- Try and pick a surgeon who specializes or is certified in your tumor type. Some general surgeons say they specialize in a particular type of surgery because of the number of patients on whom they have performed the surgery. However, a surgeon certified in a specialty (colon or ovarian, for example) will have had specific training in that specialty and therefore has the expertise required. Also, a certified surgeon is usually more knowledgeable about the latest technology and techniques.
- It is important to ask your surgeon or the coordinating nurse if the anesthesiologists they work with are covered on your insurance plan. Many anesthesiologists do not take insurance and can charge you well over a thousand dollars. For many patients, they only learn about this expense on the actual day of the surgery when they meet their anesthesiologist for the first time.
- If you have time, prepare fresh, healthy meals ahead of time and freeze them. Better yet, ask a friend to bring foods to your home. Friends are always looking for ways to help. Let them cook!

- If you do not want to have a lot of flowers sent to you in the hospital, talk to your friends and relatives ahead of time. You might suggest a donation to a charity, or a helpful favor, such as walking your dog, taking in your mail, or a trip to the market.
- Designate one friend or family member to help organize your needs and delegate them to those who want to help. Having one person manage it all will make it easier for everyone.
- If you can, treat yourself to new pajamas and/or new sheets for your return home after your surgery. If you must go through surgery, you might as well give yourself something special to enjoy! If you can't afford new items, make sure your bed is made up with freshly laundered sheets and your favorite pajamas are ready to wear.
- Ask your surgeon if you will need to purchase special clothing. For example, individuals mastectomies need sports bras that close in the front and oversized soft tee-shirts or button-down shirts because it's difficult to raise their arms. For surgeries in the abdomen or mid-section, cotton nightshirts are more comfortable than pajama bottoms that might rub against your stitches.
- If plastic surgery is an option, ask your plastic surgeon if you can see photographs of surgeries from their other patients. Seeing the different stages of the process can help you feel less anxious. Most patients are happy to help a fellow cancer patient and show them their results. Ask your plastic surgeon if he or she can introduce you to one of their patients with a similar cancer.

After surgery

- The anesthesia takes a while to clear out of your system. You will feel tired and dizzy for a few days after your operation.