



## Cancer Diagnosis: 10 Things You Need to Know

My journey through the complexities of the American medical system began in 1998 when my 2-year old daughter was diagnosed with a fatal, inoperable brain tumor. We were immediately forced to make life-and-death decisions during a time of intense fear and vulnerability, with no experience upon which to draw. I felt adrift in an unknown universe without a lifeline.

A cancer diagnosis thrusts patients and their families into an unfamiliar world of doctors, tests and treatment options. They must simultaneously find information, make decisions under pressure, seek the best medical care, cope with family changes, and deal with insurance, financial, employment, caregiver or school issues.

Here are 10 suggestions to help you as you begin to navigate your cancer journey.

- 1. Gather good information and learn the vocabulary of your illness.** The Internet has made research widely available, but it can be a double-edged sword. Consult only credible websites to educate yourself. My favorite starting points are the National Cancer Institute site ([www.cancer.gov](http://www.cancer.gov)) and the patient website of ASCO - the American Society of Clinical Oncology ([www.cancer.net](http://www.cancer.net)). Do not overload yourself and do not begin looking for information by typing "breast cancer" into your favorite search engine.
- 2. Make sure you understand your diagnosis.** Ask the doctor to discuss the pathology report with you. Make sure you know the name of the cancer, the tumor grade and other signs that may predict the cancer's behavior, sometimes called the prognostic indicators. Make sure to ask for a copy of the written pathology report. You will need this report for second opinions.
- 3. Build a strong cancer team.** Many health care professionals will likely be involved in your care, including surgeons, oncologists, radiation oncologists, oncology nurses, social workers, physical therapists and others. You are at the center of this team. Make sure you are satisfied with your doctors' credentials and experience, particularly if you are not being treated at a major cancer center. Verify that your doctors are accepted by your insurance plan. And don't assume that your team members necessarily communicate regularly or efficiently with each other.
- 4. Develop your cancer treatment plan.** Your early treatment decisions are the most important, including your choice of doctors, where to go for treatment, which treatment option to select and whether to enroll in a clinical trial. There are resources to help you make well-informed decisions, such as the Treatment Decision Tools available on the American Cancer Society website ([www.cancer.org](http://www.cancer.org)). Remember, though, this is ultimately a personal decision and you should do what is best for you and your family.
- 5. Take Names and Take Notes.** I cannot overstate the importance of getting organized early on. It doesn't matter if you use a computer spreadsheet or a small notebook; the key is to develop a system that works for you. Keep accurate and detailed contact information about your providers; prepare written questions for your doctor and make sure you understand his/her answers (bring someone along to help if you can); understand why you are being tested and ask





for results; keep a current list of your medications, allergies, medical history and treatment plan. The ASCO site ([www.cancer.net](http://www.cancer.net)) offers useful tools for organizing your cancer care.

**6. Master the insurance maze.** Insurance concerns are usually high on the list of worries. You must become an informed consumer. Read and understand your policy from beginning to end. Learn about deductions, co-pays, out-of-pocket expenses and lifetime maximums. Understand your insurer's authorization and certification requirements including which providers are covered in your plan. Most health plans offer case management services for a major illness; ask for one.

**7. Conquer the paperwork.** At the beginning of my daughter's illness, I recall weeping one day as I stared at my dining room table, feeling overwhelmed by the piles of unopened mail, bills, insurance forms and research. Aim to keep up with your medical paperwork. Be sure to match bills to insurance claims and to check for errors in billing or diagnostic codes. A knowledgeable friend can organize your medical paperwork to help with this important task.

**8. Ask for and allow yourself to receive help.** Folks want to help when they learn you have cancer, but besides bringing food, most are unsure what to do. Tell them what you need: the soft shoulder of a trusted friend, help with cooking, laundry, children, transportation, or housework. At the same time, it is exhausting to answer well-meaning phone calls and inquiries. Consider using a free website such as Caring Bridge to stay in touch with loved ones during your illness, treatment and recovery. See [www.caringbridge.org](http://www.caringbridge.org).

**9. Don't let money be an obstacle.** There are many resources available through national and local organizations to help patients with financial assistance, air transportation and housing assistance, or medication and treatment costs. Start with your hospital's social workers. An excellent compendium is available on the ASCO site ([www.cancer.net](http://www.cancer.net)) and the Cancer Care site ([www.cancercare.org](http://www.cancercare.org)).

**10. Take care of you.** Healing and recovery encompass more than traditional medical treatments. Patients often seek complementary therapies that support mind, body and spirit. The National Center for Complementary and Alternative Medicine is a good place to start (<http://nccam.nih.gov>). Many specific cancers have their own websites and support groups. In addition, your hospital, local service organization and faith community may offer services.

No cancer journey is the same and no one can predict the outcome. But for those who win the battle and even for some of those who don't, we usually come away with a better understanding of who we are, what really matters and a new perspective on life and our own purpose in it.

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