

Everything I Wish I Had Known... About Cancer Treatment: An Overview

When you receive a diagnosis of cancer, you may ask yourself, "How can this be happening to me?" Fear, shock, anger and denial are common responses. People react with a variety of emotions, ranging from being overwhelmed to barely reacting at all. It's important to remember that your reaction is normal for you and that all reactions are okay.

After diagnosis it's important to gather information on the nature of your disease and the recommended treatment options. Having this knowledge will help you understand how to move forward. You may be anxious to start your treatment immediately after diagnosis. In most cases, you will have time to think about and plan how you will proceed. Your medical team will recommend a course of treatment based on the specifics of your case and on the most current research. Often, and whenever possible, patients will have some treatment choices. Being asked to decide certain aspects of your treatment can feel confusing and scary, and it is important to ask questions at that time.

It may be comforting to include a friend or family member at your appointment(s) and to be present during phone calls. They can help remember what the medical professionals are telling you, and help you ask questions. Also, you may wish to record sessions so that you can listen to them again in the future.

It might be helpful to talk with other women who have experienced similar situations. Groups such as Women LISTEN, Inc. have been valuable resources to women who are just beginning their cancer journey. Groups provide support and information from a patient's perspective and do not replace the expertise and recommendations of your medical team.

Sometimes the details of your diagnosis and/or planned treatments change over time as more tests are completed and more data are available. Your plan of care might change as new research informs treatment protocols. These changes might make you feel uneasy; try to remain calm and focused on the overall plan. If anxiety or frustration arise, talk with your medical team about your concerns. They are working to match you with the best possible treatment plan.

Many women find it helpful to start a binder to hold notes, test results, medical reports and a calendar. Throughout treatment you'll be given many papers that can be kept in the binder for easy access. You will also want to include blank pages to take notes on information you are given and to write down your questions. Organizing the binder with tabs for lab tests, medical reports, doctor visit notes, medications, etc. will allow you to find specific information easily. Be sure to take the binder with you when you travel and to your medical appointments. Some women prefer to use their phone or tablet to track notes, questions and information. To facilitate communication, be sure to authorize your doctors' offices to leave information messages on your phone.

At each stage of treatment, ask your doctors what you can expect and when you should contact them with a concern. If you don't fully understand, ask them to be specific, e.g. contact the office if your temperature reaches a specific level. If you aren't given handouts during treatment teaching sessions, take detailed notes/record the information. This is a great task for someone accompanying you.

Thinking about how much you want to share with others is an important early step. How much do you want your family, friends, co-workers to know about your cancer diagnosis and treatment? Keep in mind close family and friends care about you and want to help. Since trying to stay in touch with everyone could

be challenging, it might be helpful to identify a “point person” to manage communication updates. This is especially helpful in the workplace. Also, <https://caringbridge.com> is a free forum that offers a personal, protected website account to post news updates.

Even if you don’t typically ask for help, you may find that having assistance with day-to-day tasks including meal prep, transportation, housework, child care and pet care is a benefit to your overall wellness plan. Websites, such as <https://mealtrain.com> and <https://giveinkind.com> help organize a team of helpers to provide the practical support you’ll need.

If you work outside the home, you might want to meet with your employer to create a plan to balance work responsibilities and treatment. Also, you will want to evaluate the medical leave options available to you. This may require a discussion with the HR department, your boss, and/or a union representative. Talk with your doctor about your job so that they complete medical leave paperwork, if needed. If you'll be unable to work during treatment, a cancer navigator or social worker can help you assess disability and insurance options. Also, check out <https://everyou.com> if you need headwear, or specialized garments.

Sometimes surgeries and other treatments result in specific concerns. For example, lymphedema is a potential outcome from some surgeries. It is important to ask your doctor for a referral to a trained lymphedema specialist as soon as any symptoms arise. Skin care is vital, especially moisturizing during radiation. Staying well-hydrated is critical to helping your body tolerate cancer treatments. Be sure to contact your dentist soon after your diagnosis. Many procedures, including routine cleaning, cannot be performed while you are undergoing chemotherapy.

Regular exercise will help you maintain stamina, strength and positivity. Ask your physician for the required referral to an Oncology Rehabilitation Program to obtain an individualized, safe program to promote healing and recovery. Many physicians are supportive of integrative medicine including oncology naturopathy to promote nutrition and mitigation of treatment side-effects; acupuncture to relieve fatigue and enhance well-being; oncology massage to relieve stress and muscle pain; and, dietitian services to create a healthy eating plan. Art therapy provides an opportunity to access joy and creativity during a time of uncertainty. Many women find encouragement, strength and solace in their faith communities and spiritual practices.

Mind-body practices such as yoga, tai chi, qigong, reflexology, acupressure and meditation help to promote resilience, reduce anxiety and increase positive thinking. Many women find that guided imagery is beneficial during all aspects of treatment. One practitioner, Belleruth Napastek, offers downloadable mp3 recorded sessions for Successful Surgery, Radiation, Chemotherapy, Insomnia, Ease Pain, Anxiety and Depression. You can listen here: <https://www.cc.nih.gov/patientlibrary/healing-streams> or you can purchase/download: <https://www.hayhouse.com/guided-meditations-to-promote-successful-surgery>

Sleep is necessary for healing. Anxiety and cancer treatments may impact your sleep, and it is important to address insomnia and other sleep disruptions with your medical providers. The self-care options listed above, as well as resting and napping throughout the day, whenever possible, can help restore healthy sleeping. Be sure to check with your medical providers before trying any over-the-counter products. Sometimes stress and anxiety require intervention from a mental health professional, especially if you have pre-existing mental health diagnoses. Counseling is a supportive treatment that promotes healing.

A cancer diagnosis creates ripples that affect those around you. Family and friends may feel sad, fearful and powerless. To the extent possible, communicate with loved ones about your feelings and plans. Spouses and children are particularly vulnerable. Keep in mind the developmental age of your children. Offer them clear, hopeful and reassuring information that is on their level. Try to stick to the typical family routine, as much as possible, and focus on the present. Watch, or ask another adult to watch, your children for signs of depression: eating too much or too little; sleeping too much or too little; dramatic changes in school performance and/or friendships; loss of interest in preferred activities; rebellion or hopelessness. Communicate with your child's school so that the teachers/counselor can watch for academic and/or behavioral changes. If needed, seek support from a pediatrician or counselor. Online support for kids whose parents have a cancer diagnosis is available at <https://www.picklesgroup.org>.

Be mindful when searching online; the amount of information could be overwhelming. Also, online content might be of poor quality and/or not applicable to your specific disease. Always discuss any findings with your doctor. To avoid exposure to negativity, ask someone else to do the research for you. Two websites that offer treatment guidance, for purchase, are <https://www.outcomes4me.com> and <https://www.yerbba.com> (for breast cancer only). Reputable sources and longstanding groups will provide the most valid information and support. Some good websites to visit for beginning research are:

- The American Cancer Society - <https://www.cancer.org>
- The National Cancer Institute - <https://www.cancer.gov>
- Breast Cancer.org - <https://www.breastcancer.org>
- Major cancer centers - M.D. Anderson, Seattle Cancer Care Alliance, Mayo Clinic, Cleveland Clinic

What to do before starting treatment:

- Remember that reactions to a diagnosis vary widely
- Write a list of questions to ask your medical team, including what to expect. Ask for clarification
- Ask a family member or friend to join you for appointments/phone calls; ask them to take notes
- Designate a person to coordinate communication and/or set-up a supportive website
- Make a binder to hold documents and notes
- Develop a plan for transportation to and from treatments, including lodging, if needed
- Discuss with your employer plans for working and/or medical leave during treatment
- Contact your dentist regarding dental work, including cleaning
- Make adaptations at home to accommodate post-surgery limitations
- Ask your physician to refer you for an Oncology Rehabilitation consultation
- Access support for your family members, if needed, especially children living at home
- Contact a Cancer Nurse Navigator, Social Worker and the American Cancer Society for resources
- Determine if you want to get a second opinion or consultation with a Cancer Research Center
- Identify integrative practitioners for your team: naturopath, acupuncturist, mental health therapist, massage therapist, dietician
- Identify additional supportive practices: Spiritual/religious, guided imagery, meditation, yoga, tai chi, qigong, reflexology, acupressure
- Join an in-person or online support group such as Women LISTEN, Inc.
- Most of all, be gentle with yourself

Additional information is available in our **Everything I Wish I Would Have Known...** series on the website.