

Everything You Wish You Had Known...about beginning cancer treatment

A cancer diagnosis thrusts us straight into the middle of things, rushing us towards treatment decisions before we even have a decent grasp on all of those strange terms that tell us what is being treated. Feeling afraid and overwhelmed is absolutely normal.

Download a free worksheet “General Questions to Ask If You Have Cancer” from <https://www.cancer.org/content/dam/cancer-org/cancer-control/en/worksheets/questions-to-ask-about-my-cancer.pdf> .

Try not to panic or become angry if the details of your diagnosis and planned treatment change over time. As more tests are done and more detailed data is available, your doctors can more finely tune your options. New treatments are being approved all the time; studies may open up that you didn't know about earlier. No one test holds all the answers or even an entirely permanent one.

It's helpful to bring another person with you to appointments to help remember details of what's said (yes, even if you're taking notes). Even better yet, most modern phones have voice recording aps (or can download free ones), and that can allow you to record all of those details to go over later.

Get a notebook, load it with a calendar and pens. Add a folder or two. Throughout treatment you'll collect paper and appointments constantly. If you're a device person, aps can handle those needs fine...but you'll still end up acquiring papers. Take notes, constantly: things you're told, questions to ask at the next opportunity, records of how you're doing, and your many scheduled appointments.

Give your doctors' offices permission to leave information messages on your phone.

At each stage of treatment, ask your doctors not only what you can expect but when should you call them. We don't always know what “a fever” or “dehydration” mean in terms of numbers, so it's important to clarify what is and is not something we need to check in about. If you don't get written handouts on this during treatment teaching sessions, take careful notes/record the information so you'll have it when you're wondering.

Think about how "out" you want to be about your cancer to family, friends, co-workers, and strangers.

Keeping in touch with everyone can become a drain on limited energy during treatment. The free site Caring Bridge offers "Personal, Protected Websites for Every Health Journey" at <https://www.caringbridge.org/> that many people with cancer use to manage requests for news updates. You may want to delegate someone to manage communication updates for you if this feels too stressful or takes too much energy.

Can you plan to work during treatment? Should you? A lot depends upon your specific treatment and your job. Some things to consider are exposure to infection risk and the psychic wear and tear of explaining your situation to everyone you encounter...and being subjected to a parade of advice and stories. Looking into your leave options and/or meeting with your boss may help you get a feel for how much juggling you can do of your time and responsibilities. Be open to the possibility of needing to set limits at work because, right now, you're more important.

If it doesn't look as though you'll be able to work, a social worker can help you evaluate your disability and insurance coverage options.

It's important to take care of yourself during treatment. Your oncologist will be focused on killing the tumor and getting you through treatment. But you can also nurture yourself during that process by doing things like seeing

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your dentist (and any other specialists you regularly are treated by) before beginning surgery or chemo, by adapting stress-management tactics like yoga or mediation, by seeing a dietician on how to eat during the disruptions of chemo and during recovery afterward, or by seeing an oncological naturopath or other practitioner for integrative treatments. Exercise is vitally important during treatment, and attending an oncology rehab gym or program can help keep you moving within the limits of your current physical reserves and recover from treatment effects afterward.

Some self-nurturing techniques women have suggested: journaling, massage therapy, acupuncture, Qigong, Tai Chi, reflexology, or acupressure. Take naps. Get a manicure and pedicure before beginning treatment (but if your treatment begins with surgery, keep your nails unpolished for that). Don't look at the mountain. Belleruth Napastek tapes may help with chemo, insomnia, depression. Kids are powerful motivators.

If we go looking online, the volume of information can be unmanageable, much of it poor quality, and overwhelming. You may want to ask someone else to do this for you to avoid exposure to too much negativity. Remember: in browsing online forums, discussions almost inevitably bias to the negative because people who aren't having problems aren't online talking about not having them. A real-life support group like WomenLISTEN can help you keep your expectations reasonable.

What are good quality sites for beginning research?

- The American Cancer Society <https://www.cancer.org/>
- The National Cancer Institute <https://www.cancer.gov/>
- Many of the major cancer centers have good informational pages, and you can locate them using the National Cancer Institute Designated Cancer Center page at <https://www.cancer.gov/research/nci-role/cancer-centers/find>

At some level, we will eventually need to invest trust in an experienced and qualified practitioner. For many treatment paths, asking "which one gives me better survival odds" can help pare down to the nitty-gritty. On the other hand, treatment decisions are entirely up to you, and if there is something you have no intention of doing, no matter how oncologists might pressure you, that's ultimately your right to choose. One way women in our group say that they groundtruth their decisions is: even if things turn out for the worst, can they later say they gave it their best shot?

Many of our group participants state that when they obtained a second opinion, that gave them much greater peace of mind that they were on the correct path...or suggested one that better appealed to them. Seeing out-of-state specialists may also provide access to clinical trials of promising new treatments or testing procedures that aren't available to us here in Alaska. Many women tell us they feel that consulting a specialist in their specific tumor or cancer type was a good investment. Traveling to consult a specialist doesn't mean that your local oncologist can't work with the specialist to deliver some of your chosen treatment here at home—most Anchorage oncologists say they are happy to do this if you ask, even if they don't happen to offer it as an unsolicited suggestion.

All of the major cancer centers in the US have a variety of specialty clinics and most will see new patients on self-referral (you don't have to get your current doctor to refer you, although you will need to arrange to have your records transferred). The National Cancer Institute has a list of recognized centers to help you: <https://www.cancer.gov/research/nci-role/cancer-centers/find> and looking at centers' websites will help you identify which ones have specialty clinics in your field.

Interested in what clinical trials might be open to you? The national clearinghouse, clinicaltrials.gov, can be difficult to navigate. Research Support Services at Prov (907212-6871) can help with your search.

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