

A PRIMER FOR HEALTHCARE CONSUMERS: DIAGNOSIS: CANCER

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1) **I have been diagnosed with cancer – what now?** After diagnosis, pause, take a minute to learn about the illness and treatment protocols. The decisions you make in the beginning are some of the most important.

2) **Should I get a second opinion?** Even if your provider is the best, second opinions can often help refine the diagnosis and broaden the possible treatments. Professionals welcome other opinions and additional information - and everyone is better off if you are confident in your treatment plan. If you can, seek your treatment at a NIH Comprehensive Cancer Care Center (<http://www.nci.nih.gov/cancercenters/centerslist.html>). If you cannot, try to get your second opinion from a CCCC and consult this physician at critical junctures in your treatment.

3) **Should I take someone to the doctor with me?** Doctor visits can be tiring and overwhelming. Most doctors welcome you to bring 'another pair of ears'. If you do, take someone who is not afraid of medical knowledge and who is positive and hopeful – and meet with them before the visit to write down your questions for your providers.

4) **How can I help my doctor design the best treatment plan for me?** Be honest with your provider about your physical and emotional ability and desire for treatment. Many cancer treatments require commitment and stamina – if you have it, show that to your doctor. If you don't, say that too.

5) **How can I best help my doctor while I am in treatment?** Participate fully in your treatment and care decisions – ask questions, find out what your provider is thinking, and participate. The more you know, the better decisions you make and the better you feel about them. That said, at some point, you must find a boat you trust and get in it with both feet. Don't stop asking questions but know that medicine is an art and be satisfied - even if hindsight shows a different tack would have been better – so long as the best possible decision was made at the time.

6) **What should I tell people who ask: "What can I do"?** When people ask this, they want to help but don't know how. It is ok to say nothing and maintain your privacy. But it is also fine to give them a task. Some tasks to consider: organize your bills, negotiate between your providers and your insurance company, act as a second pair of ears in doctor visits, do internet searches on research

breakthroughs or active clinical trials or complimentary healing therapies, cook meals, bring you flowers etc.

7) **Who decides when it is time to give up treatment?** You and your doctor decide when it is time to stop treatment. You always have the option. Often, well-meaning family or caregivers want us to keep at it. Understand this but don't feel pushed to continue treatment if you don't want to.

8) **How do I know if I should keep fighting?** Sometimes a care provider does not feel there is anything more that can be done for you. Often, this will prove true. But, sometimes it will not. It is important to balance honesty with ourselves with our deep desire to live. If you are not comfortable accepting your doctor's conclusion, this is a good time to seek another second opinion. Sometimes there isn't anything else to do. But there may be clinical trials you can enter. These may involve travel, costs not covered by insurance or taking drugs not previously tested on humans. They may not help – but they might prolong or save your life.

9) **How can I be sure that my wishes will be respected when I am too sick to make decisions for myself?** Designate someone you trust to be your power of attorney for health care – the person who makes decisions about your care if you become unable. Be sure you have a full conversation with this person and your doctor about all the possible medical challenges you might face and how you want them resolved.

10) **What if statistics say I'm going to die?** Re: statistics – While they tell you what level of battle you are waging, they do not and cannot say whether you will live or die. Don't focus on them.

11) **How should I get information about my treatment options?** Your primary source of information should be your provider. If you wish to get additional information, there are a number of valuable resources. Start with the folks at 1-800-4CANCER. They will send basic information about your cancer and about ongoing clinical trials that are appropriate for your particular patient. Before you call them, or do any other research, you will need the primary site of the cancer, the cell type(s) and the stage of diagnosis. Without these, you'll not get far.

12) **The internet is a valuable resource** for cancer research. The NCI, NIH, ACS, all have good web sites. Go to www.law.wisc.edu/patientadvocacy and click on "resources" for a list of resources that we like. It is not as daunting as it seems. Then call the Center for Patient Partnerships at (608)265-6267 or us at cpp@law.wisc.edu if you need help sorting out information or finding your way through the maze of cancer care. We are here for you.