

A FIRST AID KIT FOR CANCER CONSUMERS

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1) **Get a second opinion at a Comprehensive Cancer Care Center – NOW.** There is clear evidence that patients treated at these CCCC's do better. Early treatment is the most hopeful and efficacious – so, be sure your first shot is your best.

2) **Don't worry about alienating your doctor by seeking other opinions** and getting more information– a professional welcomes everyone's participation.

3) **Show your care provider that you are invested** and that you 'have it' to go the whole hard way. Sometimes this requires a bit of acting because you don't always feel like you have it – but you know what happens when you whistle a happy tune...

4) **Participate fully in your treatment and care decisions** – ask questions, find out what assumptions are being made, and participate. There is no such thing as too much information – the more you know, the more they'll believe that you 'have it' to go the whole hard way.

5) 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) When a doctor tells you **“there's nothing more we can do for you”** – **put the emphasis on the word 'we'** – and go find someone who can do something for you – or who is willing to try.

7) **You get to decide when it is time to throw in the towel.** You always have that option. So, don't feel pushed to try something else, to carry through with something you elected or to give up. You are the boss, you decide when it is time to stop.

8) **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. You should create a living will and be sure you have it on file at your treating hospital and that you and your doctor and your designated decision maker are all clear on your exact wishes.

9) Re: statistics – They tell you what level of battle you are waging. But, you either live 100% or you die 100% -- so, either way, the **statistics don't mean much** to you.

10) Though people handle life-threatening diagnoses differently, I found it important to **take care of all of the practical things I could** to get as ready as I could to die – in case I did. That way, when I was certain I had done all I could to prepare for that eventuality, I was able to focus all my energy on living.

11) **When people ask what they can do, give them a task** – or, if someone you know has received a diagnosis, think of what they have and try to fill a gap they don't have. Kind of like the "Phone a Friend" option on Who Wants to be a Millionaire... Get those friends out there working for you!!! They can organize your bills, negotiate between your providers and your insurance company, act as a second pair of ears in doctor visits, do internet research on research breakthroughs, active clinical trials, complimentary healing therapies etc.

12) When choosing **a second pair of ears to take to the doctor with you**, take someone who is not afraid of medical knowledge, who is positive and hopeful, and who will engage with you in the thinking process, tell you what they think and support you in whatever you choose. This is an important member of your support team.

13) If you are assigned the **treatment options research** position, 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.

14) **The internet is a valuable resource** for cancer research – the NCI, NIH, ACS, all have websites – then there are dozens of private sites put up by universities, other providers and support groups organized around most every type of cancer imaginable. If you go to a basic medical website and type in the primary site cancer – eg: ovarian cancer – you'll get hundreds of options to peruse. Go to www.law.wisc.edu/patientadvocacy for a list of resources that I like. You will find your own favorites.

15) After diagnosis, pause, **take a minute to learn about the illness and treatment protocols**. Get a second opinion – sooner rather than later – 80% of CA patients get second opinions but the vast majority are too late.