

CAREGIVER RESOURCES

Prepare to Ask Questions

Your job as caregiver, or if you're the patient yourself, is to speak up with questions. In journalism school I learned how to ask questions with the six W's and an H. If you want to have a chance at beating your cancer, or helping your loved one become a survivor, you have to arm yourself with a long list of questions, starting with these: Who, What, When, Where, Why and How, and Who Said So?

You will have specific questions pertaining to the exact type of cancer, or stage of diagnosis, or type of clinical trial, or a hundred other variables. The questions here are important to get you started brainstorming the type of questions you can ask to get deeper clarity.

For more resources, visit CaregiverHope.com.

Who?

Jim Collins, author of the bestseller "Good to Great," is a cancer caregiver himself. His wife survived a radical double mastectomy, he told us at the Lance Armstrong LiveSTRONG Summit in October 2006. He said, based on his research on excellence, that the most important question to answer is Who. Who do you want on your team from all angles? I agree that's the most vital question, but first you have to know What.

Who is my team leader (after me)? The oncologist, the surgeon? Who should I call with medical questions that don't seem related to cancer? Who else should I have on my team, (and does my team want to play on a multi-disciplinary team with the same intentions?) Who is the patient care coordinator assigned to my family, or social worker, or chaplain, or patient advocate, or Healing Touch practitioner, or other integrated-medicine specialists?

Who will be my point-person on the homefront, with my kids, coordinating meals, or housework or yard work, or pet care? Don't assume you have to do it alone. Who should I contact at work? Who can answer my questions on billing, insurance, Social Security, long term disability, respite care, hospice? Who on your team can answer such questions?

What?

What are you facing in terms of your tumor, what is the tumor's pathology? The answers will tell you how urgent the issue, what statistics you're facing in terms of how fast you must act and perhaps, how aggressively. If your doctor tells you, for instance, "You have a brain tumor," that's not enough. If your surgeon tells you based on a biopsy, "It's an astrocytoma," that's not enough. Ask for a copy of the written pathology report, ask someone to explain the specific down-to-the-detail pathology, perhaps even molecular analysis. It may determine a subtle but important variable that helps you decide on your treatment plans. It will, in fact, better define your treatment options.

In addition to asking your doctor, you might as well take advantage of the national organizations who have websites about your specific disease, with brochures and materials written with you, the patient and caregiver, in mind. You might as well enter your specific tumor type in Google or Yahoo and see what you find. But as you sift through websites that come up for that search, you must pay attention to the "who said so." I'll get to that later.

Other "What" questions include what kind of tools and equipment, state of the art, do you work with and will you use it on me? And "What do you mean when you say that?" "What more can you tell me to help me decide?"

When?

When do I have to make a decision about my treatment? If you're brought into the emergency room, unconscious, you don't get a choice, at least not at first. Ask your doctor about the specifics and statistics to help you know when it's time to choose, at least for the next stage of the game. It's imperative to take time, even three days or a week, to seek a second opinion on what -- what options exist beyond the first place you look. Then you can ask, "When will you get back to me with my test results? (and "Why not sooner?" if that seems like too long to wait).

When your child (or your patient, or your family) asks you "When will all this be over?" all you can say is "I don't know. I guess when we're done." Try to find ways to answer that question with specific segments, like "by this Friday, we'll be done with this step. Then we'll rest and get stronger for the next step."

Where?

Where will your treatment take place? How far must you travel, or can you find a specialist in your own city or state who can offer the same treatment approach as “The Experts” who you have visited, spoken to, or somehow connected with to get their opinion. If you ask, you might find it’s feasible for your local specialist to collaborate with The Experts and implement their proven, effective protocol that your local specialist hasn’t heard of until now.

It’s not always financially possible to go somewhere else, but don’t let that fear stop you until you seek out more options, such as “Angel Flight” which offers free flights to cancer patients, and the hotel or long-term housing options from the American Cancer Society or other foundations. Ask your friends or family or coworkers to donate frequent flier miles, if that’s the only way. The “where” you choose should be where you are most comfortable and confident in the approach of the Who. Oncology social workers should be able to help you with “where” to find answers to this and other questions, too.

Another “where” will be “Where in my body is the illness right now? Where is it likely to spread? That brings you back to ask When, which can help you decide further steps.

Where can I find a support group? Where can I go for a brief get-away? Where is the bathroom?

Why?

You can ask “Why me, why now, why did I get this disease?” but don’t expect a clear answer. Ask it now if it will help you choose ways to eat, exercise or live your life differently from a prevention standpoint, or ways to help you cope better with side effects once your treatment begins.

Do ask Why if you don’t understand a doctor’s decision or suggestion or action.

When seeking opinions, you can ask “Why this, and also why not that?” Both why and why not are important to ask and have answered. “Why are you the best doctor to treat me? Why do you believe in this clinical trial, or in not doing more surgery? Why did you become a cancer specialist? Why do you stay?” These why’s will help decide Who.

How?

How often will I need this chemotherapy, or blood transfusions, or other medical treatments? How much radiation will you give me and is that the lifetime dose? How do I know when to call you about scary symptoms or side effects? How can I reach you outside of office hours?

How can I find out about support groups for myself and my family? (Sometimes you have to ask questions in more than one way, and this one's important.) How can I discover other complementary therapies that might help my mind facilitate the healing in my body and spirit?

How can I be sure I am making the right decision? How do I know when enough is enough, in terms of questions, or treatments, or choices?

Who Said So?

Or “who are you to say so?” Who are you in terms of specialty expertise? These questions are important in discerning your answers. Get thee to a specialist, and confirm that any information or advice is coming from a valid source. Don't listen to people who share only horror stories about someone they knew who died. Look for people who know people who've been there, and specifically who they saw, where, when and how often.

Treatment advice (or warnings) about treatment or people or places or medicine from ten, even five or two years ago, may be completely outdated. Beware of who said so and seek out the specialists who, when they say so, have high credibility among their peers, peer-reviewed journals, and even their patients. It's okay to ask for referrals from existing patients.

Please...

Please help me. That's not a question, that's a legitimate statement if you add to that, "Here's how I could really use some help getting through this." Let people be included in your journey. They will be happy to know that their help or their prayers or their shoulder made a difference in the way you become a survivor. You can say it out loud, or you can make a list (like Lotsa Helping Hands or RedToeNail.org or by exploring the resource on the home page), or you can pray or ask for prayers on a prayer chain. Then remember your manners, say:

Thank You.