

What Can You Do For Me?

Well, I'll Tell You!

By Trisha Tester

I am a metastatic breast cancer patient. Although this means that I am almost certainly going to die of this disease (barring a miracle), I am not a victim. I don't like that word, and I would prefer that you never use that word around me. I am a regular person, who happened to be standing in the wrong place at the wrong time, and I got whacked with the cancer stick. I have noticed that people don't always know what to say to me any more, or what to do to help. Most people are loving, caring souls who really do want to help, but really have no clue what I need. To try to help you help me, I have made a list. Please keep in mind that this is purely a subjective list. I have tried to include other viewpoints, but I don't want you to think that all things work for all people. We are wonderfully, excitingly unique human beings. And so, of course, our needs will be different. You will have to judge which suggestions you feel would be appropriate, and what you would be comfortable with.

1. If I want to talk to you about what life will be like after I am dead, DO NOT under any circumstances give me that fake, terrified, cheerful smile and say "Oh don't talk like that. You will be fine." There is every likelihood that I will not be fine, and it is very comforting to me to know that you will tell stories of me to your children (and my children!!), and will always hold me in your heart. It is incredibly comforting to hear that you will include my children, who are much too young to lose their mother, in your life in a much greater way than now, while I am still here for them. You can not depress me, by acknowledging that death is probable, or even imminent. I am all too aware of it. As a matter of fact, if you put on that fake cheer, all you are telling me is that you are not able to be "there" for me for my needs. If that is the case (and I won't fault you if it is), don't even try to pretend. Just give me a quick hug (there is nothing about me that is contagious), and tell me you care, and skedaddle. I don't have the time to waste on fair weather friends.

2. Don't give me the standard offer, "If there's anything I can do for you, please don't hesitate to give me a call." Most of us are used to being strong and capable people, who have taken care of ourselves (and usually others) for decades. It is very uncomfortable to be in a position of not being able to do for ourselves. I would suggest that you drop in for a visit, pick up a broom, and sweep. Ask me if I have any plans for dinner, and just start making it. I won't ask you to do these things. I am not used to asking for help. I am not good at it. If it is an emergency, I will call out for help. But if it is the little day to day nonsense that piles up until it feels like it is going to consume me, I will probably not ask for your help (but I will be eternally grateful if you just come and do it). Be assertive. (But never mean!)

3. Talk about old times often. This has come as a surprise to many people when I have suggested it to them. They say "But Aunt Nellie will think that I think she is about to die if I talk about old times." HELLO!! She is about to die. I am about to die (although I hope it is prolonged by long periods of relative wellness). And I love reminiscing. It helps me to remember fabulous times in my life that I may have forgotten. It brings me a smile. It helps me to remember that even if my life is

cut much shorter than planned, that it has still been a good life. It gives me a better sense of wholeness.

4. (Actually, corollary to 3.) Take some time to organize the photos into albums. I don't know a person alive (well, maybe one) who is really on top of their photos. Put everything else aside, and devote however much time it takes. Get the photos in albums, with captions, and stories. If you have a videocam, just set it up and let it go. If you just have a tape recorder, that would be great too. Not only will your loved one have a superb walk down memory lane, generations to come will bless you. If I had only done this with my mother.....

5. Don't ever, ever feel guilty for enjoying life. When you find yourself having a great time, and you happen to think of me, do not feel bad - not even for a microsecond. Life is short. For all of us, whether we live to be 10 or 105. Enjoy the hell out of it. I would if I were in your shoes. Heck, I do now. My favorite cliché du jour: Your life is a bag of coins to be spent any way you choose. But you can only spend it once. (Spend it wisely, my friends.)

6. Don't be afraid to be afraid. If you are paralyzed with fear (and believe me, I have been there - as has my family!) it's ok to tell me that you are afraid that I am going to die. I am afraid too. Sharing that fear really does in some way make it easier to handle. Denying it seems very very false. I need real. I have no use for false. Once we have shared the fear, amazingly enough, we can set it in back of us again and move on. If we don't do that, it will block our paths at every turn.

7. Chances are that my bills are a pile of unorganized paperwork in a box somewhere. Cancer is an incredibly overwhelmingly expensive proposition. All the charges are mindboggling, and intricate. Insurance companies (in my experience) are incompetent and potentially fraudulent bozos who screw up all the time. I don't know if they could really be that incompetent, or if perhaps they are encouraged to be so, hoping that you will throw up your hands in confusion and pay some of the things that they "forgot" to pay. At any rate, I would be enormously grateful if you would come by some day, without judgement as to what kind of a mess I have made of the pile, and help me straighten it out. Maybe make a few phone calls. Maybe write a few letters. You wouldn't believe what a difference it would make.

8. Say, "I love you" a lot. Depending on who you are, that may come out as "You are the funniest person I have ever met," or "In the history of mankind, there will never be another person as _____ as you," or simply "I love you". But this is your chance. Don't blow it. After a certain point, there is no going back for makeup credit.

9. Be very conservative in what perfumes/colognes you wear. Chemotherapy often makes for incredibly sensitive olfactory senses. Perfumes can be overwhelming and nauseating. And by the same token, be especially sensitive if you are a smoker. (Unless the patient is a smoker - I wouldn't know about that situation.) If you do have to smoke, please go outside. Even if I say it is OK. And hang out outside for an extra 5 or 10 minutes to air out. You wouldn't believe how much vile aroma clings to you.

10. Make plans, not offers. Instead of asking if I want to do lunch sometime, ask me if next Tuesday is free. Then tell me, "Great! I will be by to pick you up at 11 so we can go out to lunch. Maybe we could do a little window-shopping if you are up to it." Of course, you will have to be flexible, in case Tuesday is one of those days that I feel like I have been run over by a Mack truck...

11. When you ask me how I am, please remember that I am much more than my disease. I know that people ask out of concern, but I get a little tired of reciting disease progression/regression, treatment updates, symptoms, etc. Remember that we really did have things we used to talk about BEFORE I got whacked. Those things are still important to me.

12. Please be aware that "looking good" has NOTHING TO DO WITH IT. Don't worry - I even do it myself - tell my friends how good they look as if it meant that the cancer must be under control... No such luck. Until the very very end stages, cancer itself frequently doesn't cause any distress at all. Usually doesn't hurt. Often you can't even feel it (which is why so many of them go undetected for so long.) The treatments, on the other hand, can make you want to die, even when they are saving or (at least prolonging) your life. This doesn't mean I want you to stop telling me I look good. I just want you to realize that it really doesn't mean diddly-squat.

13. I need you to realize that this experience has changed me in several ways. I am still the person I have always been, but I am different, too. For one thing, I am tired. You know how tired you are when you are sick? Imagine having that be your new "normal". Be sensitive to my need to rest often. And don't expect me to be able to go as long or as fast as I used to do. I also don't have the memory I used to. Treatment has taken things from me that I will never get back. Now I feel like I am slogging through marshmallow goop, both physically AND mentally. Another change is in attitude. Some things just don't seem important to me any more. (Hopefully, I don't yell at my kids quite as much.) And other things have become more important. For example, I talk to strangers more often now. When I have something to say, I say it! Don't be surprised if I start dancing in the aisle at the grocery store. It can be a little disconcerting. If I embarrass you, you are free to walk away and pretend you don't know me. But please don't try to limit me. Let me spend the rest of my life doing exactly what I want to do!

14. Don't try to shelter me from the harsh events that happen around me. I have been omitted from too many events, because people well-meaningly felt that I had "enough to handle". Well, I am still alive. Even though I am fighting a war with this disease, I don't want to be shut out of the lives around me. Which includes sharing your pains as well as your joys. My body is failing me, but my spirit wants to support you in whatever way I can, for as long as I can. I don't need protection from truth.
15. Go to the doctor's appointments with me. Sometimes my poor "chemo brain" drops important information. It is very companionable to have someone with me in the various waiting rooms (maybe someday doctors will operate in a timely fashion.....nah, never mind -it'll never happen!). And it's great to have someone to talk to during an infusion drip. It is a good idea to have a pre-written list of questions. Again, a tape recorder can come in handy. And if the doctor is a little short or brusque, dig your heels in and be assertive. Help me to remember that although I am but one file in the doctor's toppling stack of workload, I am the single most qualified protector of MY LIFE. I have every right to as much of the doctor's time as I need. He (in my case she) certainly keeps me waiting long enough!
16. (Actually, corollary to 14.) If I don't like the doctor's advice, or manner, remind me that there are plenty of doctors out there, and I deserve a second (or third....) opinion. Cancer treatment - especially for metastatic disease, is not even close to refined yet. There is so much "art" and doctor's judgement to it, that I should never be coerced into a treatment I don't feel right about.
17. Respect my decision. There may come a time in this journey that I decide to lay down beside the road and stop fighting. If I make this choice, I know that you will be disappointed and dismayed. Maybe even furious. Please remember that it is my battle, and my decision. I know that you love me. I know that you want me to fight. But if that day ever comes, please understand that there is simply no more fight left. I promise you that I will never ever make that decision lightly.
18. If I am walking around bald from chemo, take the plunge. Shave your head! You would be surprised how refreshing it is to stick your head under a faucet on a hot summer day... Don't worry. I will not be in the least surprised if you "pass" on this suggestion. I can say in all honesty, I doubt if I would do it for you!

I hope that these suggestions help you to understand what is TRULY helpful, in dealing with a friend or loved one who is battling a life-threatening illness. Of course, the most important thing you can do is to just be there. Listen. Perhaps your heart will hear what needs to be said or done. Bless you for caring, and may there be miracles enough for all of us!

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