

# MEDICAL STEP 1—WE JUST GOT THE DIAGNOSIS. NOW WHAT?

*Your loved one has cancer.* Very few words in the English language can have an effect on a person like that phrase.

*Your loved one has cancer.* It affects not only the patient but also family members and friends.

*Your loved one has cancer.* A sense of “normal” will come again. For now, wait.

*Your loved one has cancer.*

Others cannot understand your shock unless they’ve been there. If you are with the patient as the news is delivered, you just hold hands or hold each other. Everything around you gets quiet and blurred as you try to get your head around it. You can’t grasp the concept no matter how hard you try. You sit quietly, not knowing what to say. You know that if you open your mouth, out will come uncontrollable sobs, not words.

When we got the news of my husband’s cancer, we sat in the hospital room for half an hour, hands intertwined, tears finding their way down our cheeks. We whispered a little to each other, but I have no memory what we said. I think the word “wow” was softly spoken because of the shock, but we didn’t know enough to even discuss the cancer. All we knew was that cancer was there and we’d find out later how we could fight it. No fighting now, just astonishment.

## More questions than answers

There are more questions right now than answers.

- What kind of cancer does my loved one have?
- How bad is it?
- How long has it been there?
- How soon can you take it out?
- How will we treat it?
- How can this be?

- What do we do now?
- Who else do we need to talk to?
- Can we get a second opinion? Maybe it's not cancer.

There's no need to answer these questions right away. Time and experience will provide the answers.

**Slow down. Write it down. Sit down.**

There are three things you can do now to give you some control in the journey:

- Slow down.
- Write it down.
- Sit down.

## **Slow Down**

Take your time doing everything. No matter how fast you normally do things, don't hurry now. You will realize that rushing is hard to do right now, whether walking, talking, driving, or whatever. You'll need to concentrate more than ever to avoid accidents on the road or in the kitchen.

My brain refused to let me work as fast as normal. I had to concentrate just to make coffee, or I'd forget to put water in the coffee maker before I pressed Start. When clearing the table, if I didn't pay attention, the milk would end up in the cupboard and the oatmeal box in the refrigerator. I had to stop and think before I did anything, and make myself conscious of even little things.

Take your time doing everything, even speaking. You may say something you'll regret if you just blurt things out, especially to those closest to you, including the patient. It's better if you bite your tongue and don't say something that may hurt. Once said, it can't be unsaid. Just take a deep breath.

## **Write It Down**

Write down things that you don't want to forget. Write down:

- Everything the doctor tells you.
- The name of the cancer, and ask for the spelling if you need it.

- Questions that come to mind. You can ask them at a later appointment. Just write down the questions.
- Any feelings you have. These will come in waves and extremes. Don't think about your feelings. Just feel them and write them down.
- People you need to call. You can look up their phone numbers later. Just write down their names.
- Whatever you need to do right away, like cancel the babysitter tonight or reschedule the plumber for next week. Just write it down as you think of it.
- Things that you planned on doing "someday," and make plans to do them. It will give you a few moments of hope and escape. If you do have the opportunity to fulfill one of your dreams, don't put it off. Do it! But for now, write them down.

Writing down everything is the only way to remember, because you won't be able to rely on your brain for a while. Don't beat yourself up over it; that's just the way it is. No one will be upset or disappointed that you're human. Your life just came crashing down, and what used to be normal will never be normal again.

When Bryan was diagnosed, we decided to watch the movie "The Bucket List," starring Jack Nicholson and Morgan Freeman. It's about two senior citizens who decide to accomplish some of the things they had planned to do before they died. Bryan and I created our own Bucket List, things that we would do when Bryan's cancer went into remission. It gave us something else to think about, happy memories that we planned to create, and a momentary lapse of reality when we needed it.

## Sit Down

Don't try to do everything you usually do. Take time to just sit, think, and talk with those who love you. Right now, you just need to *be ...* just be. Your mind is having a hard time digesting the news, so don't push it. The battle ahead is the most important thing in your life right now.

You also will be doing a lot of waiting: for doctor's appointments, in the emergency room, and for pending test results. You may as well get used to it.

This may be the time to make sure your finances are organized. Bryan had always handled our bills and payments, so he took the time to show me where he had budget information and receipts. Since I would be paying the

bills while he was fighting cancer, it helped me to know where everything was located.

Here are a few more suggestions to help you through the journey:

- Put things away in the same place every time. It's easy to just drop things when you're done with them, like most people do all the time, but you may not remember where you left them.

**Keep your keys handy and the gas tank full.**

- You *must* find your car keys in a hurry if you need to go to the emergency room. Spending time looking for them is not an option. You may want to put a hook inside the door and hang them up every time you come home, so they'll be visible and handy the next time you need them. Also, put your purse or wallet nearby so you can grab it on the way out.
- Keep your car's gas tank full in case you need to leave in a hurry.
- Let others know what you're going through. Read "Relationship Step 1—Whom do we tell? And how?" for specific ideas. You'd be surprised how many people care and want to help you.
- Don't be afraid to ask for help. "Relationship Step 5—Asking for and receiving help" will show you how and when to ask, and how to accept help. This may relieve you of some tasks, such as keeping the house clean or the lawn mowed. Offer loved ones the gift of helping you.
- One of the most useful things you can do now is to stay organized. Your life feels out of control, and knowing where things are is the first step to being in control. Don't try to organize your closets or dresser drawers; that would be too much to tackle. Just keep all your info and paperwork on cancer in one location so they're easier to find. And putting things away will make your life less cluttered in more ways than one.
- Do small, mindless tasks that you can control. One caregiver took this opportunity to alphabetize her spices, something that she could handle without help.

**Prepare a tote bag.**

Get a bag ready to take to appointments or the emergency room, which you may find yourself visiting frequently. It's better to prepare now rather than as you're running out the door, trying to remember what you need to take.

Here is a list of things to put in a tote bag and keep by the door:

- The patient's health care identification card and photo ID. Most health care providers will not give any medical care unless you have a valid health care ID and a photo ID such as a driver's license.
- A list of the patient's medications and doses.
- A list of contacts and telephone numbers. Include your doctors as well as family, close friends, and your pastor or other religious leader. This is easier to carry than a Rolodex or a Day-Timer, and quicker than a cell phone.
- Cell phone charger. You can dig it out if you need it at home.
- A sweater. Since bacteria grow more slowly in a cooler temperature, hospitals keep the rooms uncomfortably cold. The patient can get blankets, but the caregiver generally cannot.
- A note pad and pen to write down everything that happens. If you have a notebook as explained in "Information Step 1—What do I do with all the paperwork and information we get?" keep that in the tote bag.
- A water bottle for the caregiver.
- An energy bar or other snacks.
- Magazine, book, or crossword/Sudoku books and pen to pass the time.
- Some cash, in case you need to buy snacks or a meal from a vending machine while you're waiting.

Your life has just changed dramatically. Take your time getting used to the idea and adjusting. You've just started a journey that many others have taken or are in the midst of. You can manage your journey one step at a time.

## APPENDIX A—HINTS FOR PATIENTS

1. Learn all you can about your cancer. Knowledge is power, so arm yourself for the fight.
2. Confide in a trusted friend or loved one, not necessarily your caregiver.
3. Get a loose-leaf notebook to hold all your bills, brochures, notes from every appointment, and questions to ask your doctor.
4. Take someone with you to appointments to write down all that is said.
5. Eat what you can when you can to keep up your strength.
6. If you are nauseated or getting chemotherapy, don't eat your favorite foods. Save them for when your stomach won't reject them.
7. Sleep when you can.
8. Laugh as much as possible. Watch funny movies or sitcoms on television.
9. Take advantage of a chance to get out for some fresh air.
10. Accept only visitors you want. You don't need to see everyone.
11. Follow all your oncologist's instructions and keep every appointment.
12. Get in touch with your spirituality. Read your Bible, pray, or meditate.

13. Never give up! You're worth fighting for, so keep fighting.
14. Write your feelings in a journal. Don't keep everything inside.
15. Ask for help. It shows wisdom, not weakness.
16. Advance health directives are a form of control, not a sign of surrender.

## APPENDIX B—HINTS FOR CAREGIVERS

1. “If you find it in your heart to care for somebody else, you will have succeeded.” Maya Angelou<sup>19</sup>
2. Get help. Don’t try to do it all by yourself. Accept help if offered.
3. Prepare a loose-leaf notebook with tabs for notes, bills, meds (info from the pharmacist), medical info (from the web), questions to ask the doctor, and encouragement from friends or family.
4. Make a list of things friends can do and tell them when they ask.
5. Tell friends and family what is happening.
6. Confide in a trusted friend or loved one.
7. Find ways to laugh. Watch comedy movies or sitcoms on television.
8. Encourage the patient to eat, but don’t force it.
9. Have the patient’s favorite snacks within reach.
10. Get enough rest. Learn to nap if you can’t sleep all night.
11. Find “me time” when possible. Ask a friend to stay with the patient while you shop, drive around, or just sit in your car.
12. Exercise produces energy. Try to work out a few minutes each day.
13. Spend time every day reading your Bible, praying, or meditating.

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<sup>19</sup> [http://brainyquotes.com/quotes/authors/m/maya\\_angelou\\_2.html](http://brainyquotes.com/quotes/authors/m/maya_angelou_2.html)

14. Keep the gas tank full and a tote bag by the door with a sweater, water bottle, paper and pen, cash, and cell phone cord for a run to the ER.
15. Regulate visitors. You don't need to let everyone come, especially if it may upset the patient.
16. Find a way to safely express your anger, depression, grief, or other emotions.
17. Filter bad news to the patient with care. Let others know if you have not told your loved one bad news such as Uncle Joe's passing, so they don't accidentally spill the beans.
18. Advance health directives are a form of control, not a sign of surrender for the patient. Encourage the patient to have his or her directives in place, and you do the same.

## APPENDIX C—HINTS FOR FAMILY AND FRIENDS

1. Keep in contact. Don't cut off communication.
2. Send written encouragement, such as cards, letters, and e-mails. A phone call is nice, but something written can be read whenever support is needed.
3. Offer specific help, such as, "I'd like to bring dinner. What day would be best?" or, "I feel like cleaning. May I come and vacuum for you?" If you just say, "Let me know what I can do," the patient and caregiver won't know what you're willing to do and won't ask.
4. Find out what the patient can eat, and bring it.
5. Provide food that can be frozen and reheated, so it won't spoil before it can be eaten. Give reheating instructions.
6. Ask what the caregiver and patient need and want.
7. Call before visiting. Don't just drop in unannounced.
8. If you really mean that your loved one can call you any time, day or night, tell him or her so and offer your cell phone number.
9. Understand that you may show up at an inconvenient or awkward time and may be asked to leave, even if you called first. Don't take it personally.
10. Laugh with the patient and caregiver. Take a funny movie or a game and spend time.

11. Don't tell the patient and caregiver how strong they are, making them feel they can't show emotion around you.
12. Let the patient and caregiver talk. Let them cry. Learn to listen.
13. Allow the patient, caregiver, or other loved one to grieve in your presence.
14. Don't spread what you hear.
15. If you have a close relationship with the patient, offer to sit with him or her while the caregiver goes shopping or just gets away for some much-needed "me time."