Tips for Caregivers

An excerpt from:

Cancer *for* Two

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Support Group

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Introduction

My name is Dave Balch; my wife, Chris, went through nine months of breast cancer and I was her primary caregiver through three surgeries, chemotherapy, and radiation.

I'm proud to say that I went with her to over 60 appointments and drove most of the 6400 miles involved. I bathed her when she needed me to, washed, dried, and styled her hair, bought the food, made the meals, scheduled and coordinated all of her medical visits, filled the prescriptions, re-filled the prescriptions, kept track of what she should take and when, etc. in addition to running my home business and taking care of two horses, two dogs, two cats, and a really mean parrot that Chris has had since 1957.

I looked at it this way:

"It was her job to get better.
It was my job to do everything else."

If you find yourself in this unfortunate situation, remember these two things:

1. **Your role is critical to the patient, both physically and mentally.** Here's why. The patient's attitude is arguably one of the most important factors in how well the patient deals with her predicament, and no one is in a better position to influence that attitude than the caregiver. Your role is critical. You are important.

2. **This will undoubtedly be one of the most meaningful and rewarding experiences of your life.** It certainly was for me. Keep that in mind, and it will help you through the dark times.

Tips

I was lucky in that, working at home, it was relatively easy for me to juggle my schedule in order to go to appointments and to do as much as I did. Many, if not most, caregivers will not have that flexibility due to job-related responsibilities. These caregivers may therefore not be able to be the full-time caregivers they would like to be.

There are still a number of things that you can do as a part-time caregiver that will be very helpful to the patient. I have culled a number of things from my experience that apply equally to full- and part-time caregivers. (Since my experience was with breast cancer, some of these ideas may not apply in your situation.)

1. Your number one priority should be to remove or reduce every shred of stress from the patient so that she can spend all of her energy fighting the disease. Everything you do should revolve around that basic principle, *but "removing as much stress as possible" does not mean "do everything for her."*

   It all depends on your patient and what is stressful to her; having someone else do certain things for her may actually *in*crease her stress instead of reduce it. In our case, I wanted to do all of the driving so she could sleep, but she wanted to do some of the driving so she could feel like she had control over *something*; my insistence on driving caused her more stress than it saved her, so she did enough of the driving to satisfy that need, then I took over.

2. Take advantage of the free services at www.ThePatientPartnerProject.org to post progress reports for your family and friends. You can even have the system automatically send an email to those whom you specify whenever you post an update; this way you can keep everyone informed without having to make tedious, repetitive phone calls and you can do it when it is most convenient for you.

   It is critically important that you keep everyone informed, and using this free service will allow you to do that while reducing your stress and the demands on your time.

   The system is easy to use and offered free of charge, no matter how much you use it. Try it!

3. Allow the patient to express herself without comment, recrimination, or criticism – you don't have to "fix" everything.

4. Try to find humor wherever you can, especially self-deprecating humor.

5. **"Don't go there 'til you get there"** – there are some things over which you will have no control, so try not to even think about how you will deal with these

things until you have to. In many cases, the things you feared will never come to pass anyway.

The perfect example was my fear of danger and difficulty getting to daily radiation appointments because of winter weather. By remembering “Don’t go there ‘til you get there,” I realized that there was no point in worrying about it until the time came. As it turned out, the weather never materialized and had virtually no affect during the radiation treatment period. Had I worried and fretted about that when I first realized the potential, I would have been wasting energy: there was nothing I could do about it anyway, and there was the very real possibility that it wouldn’t be a problem in the first place.

Focus on the things that you can control, not on things you cannot control. It’s easy to say, but hard to do.

6. Everything seems worse when you’re tired. The same is true for the patient, who will be tired a lot of the time. Try to remember this so that when you are feeling overwhelmed and discouraged, you can chalk some of it up to being tired. And, by reminding yourself that everything is worse when you’re tired, you are also giving yourself hope by realizing that you will feel better after you’ve gotten some rest.

7. Don’t do anything that will generate additional stress unless it is absolutely necessary. For example, this is not the time to decide to sell your home and move, which is a very stressful undertaking.

8. Give yourself and your patient something to look forward to, such as a vacation when the treatments are over. Spend time planning and talking about it. The anticipation will give you energy when you need it the most.

9. When your patient asks for something, not only should you do it, but tell her “I would be happy to do that for you.” *And mean it.*

10. Take time to take care of yourself, including exercise and time away from the situation. You need your physical and emotional strength, so if you need to get away and go to a movie, do it. You *need* it, and you *deserve* it. As they say during the airline safety speech, "Put on your own oxygen mask before helping others with theirs.”

11. Be protective, but not overly protective. Part of the suffering for the patient is the loss of control over her life, so if she wants to do something and it won’t be harmful to her medical condition, let her; it will help her feel better about herself.

12. Tell her often how great she looks, *and mean it.*

13. Tell her often how brave she is, *and mean it*.

14. Don't always trust how you feel; stress and anxiety can do strange things to your priorities and confidence, including feelings of overwhelm, hopelessness, and fear.

15. Don't take things personally. Her reactions and emotions are based on how your patient is feeling, which is pretty lousy a lot of the time. If she gets overly emotional or snaps at you about something, it is probably due more to the way she feels than to anything else.

16. Her desires may seem impractical, but you do them for *her* rather than for the reason she says. For example, Chris would ask me to change the dog’s water even though it looked pretty clean to me. It didn’t really need changing in my opinion and my first reaction was annoyance at having to do something (anything) that wasn’t necessary in my view, but *it made her feel better* so that was the reason I did it.

17. She may feel ugly or unattractive, so do what you can to help her feel pretty, such as a manicures, pedicures, or special makeup.

18. You must be an advocate for your patient. If you don't like the care she’s get-

ting, *speak up*! If you don’t understand something, *ask*! If you don’t like the answers you’re getting or the way you are being treated, *go somewhere else*!

19. Remember that you can handle more than you think you can. Things will come up that you don’t think you can handle, but you will *because you have to*. Don’t spend time thinking about how you can’t handle something, just do whatever it is; you will surprise yourself.

20. **“Juggling your life will become your way of life”** A very difficult aspect of your situation is how disruptive it is. Your usual routine is out the window, and even your day-to-day schedule will be somewhat chaotic due to your patient’s ever-changing and often unpredictable medical condition, doctor appointments, tests, phone calls, errands, filling prescriptions, finding medications or other products… the list is endless. You can’t do anything about it, so do yourself a favor and accept the fact that chaos and unpredictability are your new lifestyle for the time being.

21. Remember the pain of the current situation is only temporary. You're miserable for a while, and then it's over. Life WILL get back to some sort of normalcy. After all we went through, what we remember most is all of the things we laughed about.

22. You don't have to share *everything* with your patient. For example, my worry about the weather during radiation treatments that I mentioned earlier; why say anything about it? It could only upset her, nothing could be done about it at the time, and it may never happen.

23. People will offer to help in various ways, some of them will *insist*. Remember this about that:

    - *It is not your responsibility to satisfy their need to help*. It is wonderful that they want to help and tell them that you appreciate it, but if what they are offering is not something you want or need, tell them "No, thank you."

      Well-meaning people can actually *increase* your stress rather than reduce it by insisting that you let them help: don't accept help you don't want or need. Be polite, but firm. I cannot overemphasize how important this is to your peace of mind and stress level.

      Don't be lulled into the trap of feeling guilty because you are not allowing them to do something they want ("need") to do. *Protect yourself from well-meaning but needy people*; you have your own needs to meet and they are far more important than theirs, especially now. It doesn't matter what your reasons are; if you don't want their help you don't have to accept it, and you don't have to explain why.

- Rather than simply saying "No," another way you can protect yourself is to thank them and say that you'll call when you need their help.

  For example, several people *insisted* on driving Chris to some of her daily radiation treatments and wouldn't take "No" for an answer. Chris wanted to drive herself to those treatments, and when she couldn't she wanted me to do it. So we simply told them we'd call them but, of course, never did. We truly appreciated their willingness to help and told them so. We simply chose not to take them up on it.

- The other side of this coin is that if people are offering help that you *do* need or want, *accept it.*

  We got many offers from friends who wanted to make food for us. My first inclination was to say "No," because I didn't want to be a burden to them and I didn't want to seem like I needed it. Guess what? I *did* need it. This was our time to accept the help that we needed, and providing meals was about the best thing that anyone could do for us in our particular situation.

As far as being a burden, I took some of my own advice about that: *"It's not my job to protect them from making an offer that they don't really mean, and it's not my responsibility if they choose to do something they don't really want to do."* We had several friends that went overboard in this particular area, but the food was great, they really wanted to do it, and they weren't pushy about it. One couple even went to one of our favorite restaurants on their way back home from the city and picked up some great meals, which lasted several days. God bless 'em!

24. Sometimes, due to lack of time or emotional energy you just won't feel like talking on the phone, even to caring and well-meaning people. If you don't feel like answering the phone, *don't*. This is your time to take care of yourself, not others; just because someone wants to talk to *you* does not obligate you to talk to *them*, so let them leave a voice message and return the call when you feel more like talking.

    If they are looking for updates on your situation, use the free posting services at www.ThePatientPartnerProject.org and encourage them to register to receive notices when you post an update. (See item #2 above.)

25. Take every opportunity to protect yourself from anything and everything that will cause you even the slightest additional stress or anxiety.

    For example, if you are expecting an important call, screen your calls to save yourself from a conversation you don't feel like having. If you are unable to screen your calls and you answer a call for which you simply don't have time, tell them politely but firmly that you are expecting another call and you must leave the line open. Well-meaning people who truly care want to know what is going on, but your first responsibility is to your patient and yourself and relieving yourself of any additional demands on your time.

    One simple thing you can do to protect yourself from unnecessary stress is to avoid watching the news on television. Most of what you hear is about murders, accidents, and deaths which is very difficult to hear when you are stressed to the limit; I found that it made me very anxious. *Then I realized that turning it off was an option*, and as soon as I did I felt much better!

This booklet is an excerpt from *Cancer for Two*,
a component of *The Patient/Partner Project*

About…

Cancer for Two

> *"Every family with a cancer patient needs this book because we all walk the same footsteps. ...what you have done is create an immediate and complete 'support group' in a book. If I were an oncologist, I would make sure all of my patients had it. The book is fantastic: it needs to be out there!"*
>
> ~ Robert Kotler, MD, FACS
> Clinical Instructor, UCLA
> Author, "Secrets of a Beverly Hills Cosmetic Surgeon"

Dave Balch supported his wife during her successful nine-month battle with breast cancer. You will laugh, cry, and learn important support skills in this moving chronicle of their journey together.

More than just a memoir, *Cancer for Two* is a *solution*, offering specific advice and examples.

If you are a cancer patient or partner (or know one), this book will give you comfort, advice, guidance, and understanding of breast cancer and how to support the patient with humor and love. You will discover:

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- The importance of the caregiver's role
- An amazing attitude in the face of serious illness
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- How to find humor in serious situations
- 16 reasons why cancer was a "gift"
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