



CANCER RESOURCE CENTER
OF THE FINGER LAKES

PRACTICAL ADVICE WHEN THE DIAGNOSIS IS CANCER

From the director of a cancer resource center who is also
a cancer survivor. Sales support the work of the resource center.

When Your Life Is Touched by Cancer

Practical Advice and Insights
for Patients, Professionals
and Those Who Care



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Excerpts from Bob Riter's book, *When Your Life is Touched by Cancer: Practical Advice and Insights for Patients, Professionals, and Those Who Care*. ©2014, Hunter House Publishing.



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Advice for People Newly Diagnosed with Cancer

The first few days following a cancer diagnosis are like riding on top of a speeding train. You're hanging on for dear life and can't quite see what's ahead. Although every situation is somewhat different, this is what I generally suggest:

Focus on one step at a time. If you are having a biopsy next week, focus on that biopsy and do not let your mind wander to what might happen next.

Take someone with you to medical appointments. They can take notes and help you remember what was said.

Do not hesitate to ask your doctor to repeat something.

Family members, friends, and complete strangers will give you advice. Be wary when they say, "You should do..." Though well-intentioned, they do not know what is best for you.

You control who to tell about your cancer diagnosis and when to tell them.

Remember that cancer treatments change rapidly. What you hear from people who were treated in the past is out of date.

Understand that cancer is not a single disease. What you hear about cancer in other people probably does not apply to your cancer.

Survival statistics are averages. They can be helpful if you want a general idea of the prognosis for people with your disease, but they can't predict what will happen to you as an individual.

Do not hesitate to get a second opinion if you think it might be helpful. Your doctor won't mind. (If your doctor does mind, you should get another doctor).

A new cancer diagnosis is rarely a medical emergency. You generally have several days or

even weeks to explore your options. (Some situations do require immediate attention - ask your doctor how long it is safe to wait before beginning treatment).

Do not begin a radical "cancer curing" diet or major lifestyle changes before or during treatment. Just eat sensibly and nutritiously, exercise moderately, and get plenty of rest. You can make whatever lifestyle and diet changes you want after treatment is over.

Nearly everyone undergoing cancer treatment experiences fatigue. It is probably the most common and least publicized side effect. Conserve your energy for activities that are most important to you.

Nothing goes in a straight line. You will feel better one day; then you will feel worse; then you will feel better. Do not be discouraged by the down days.

Being diagnosed with cancer is life-changing for many and life-disruptive for nearly everyone. It is difficult at first, but once the decisions are made and treatment begins, most people gradually regain their rhythms. Cancer isn't fun, but treatment often ends up being more manageable than people expect. It's a club that no one wants to join, but trust me, you're in good company

Cancer and Positive Thinking

Whenever someone is diagnosed with cancer, people feel compelled to say, "You gotta stay positive!" (This is usually said with an enthusiastic pump of the arm.)

I'm a pretty positive guy and I'm all in favor of positive thinking, but I cringe whenever I hear those words.

First of all, telling someone to be positive has never transformed anyone into actually being positive. I've yet to hear someone respond, "You're absolutely right. I've never thought about being positive, but now that you mention it, I see the wisdom in it. I will become positive and change my outlook on life." That just doesn't happen, at least not in my world.

My real concern is for people with cancer who may blame themselves for not being positive enough. How does one make sense of a recurrence if positive thinking is supposed to help? I hope no one sees their recurrence as the result of not thinking enough positive thoughts. People with cancer don't need another reason to beat themselves up.

Don't get me wrong—I think it's great to have a positive attitude when dealing with cancer. I did, and I'm sure it was helpful in my recovery.

If my cancer returns, I will again be positive. If there's only a five percent chance of survival, I figure that I'm going to be in that five percent.

But attitude is largely a function of personality, and you are who you are. Positive people enjoy having other positive people and positive energy around them. People who aren't so positive don't necessarily want or benefit from cheerleaders in the room.

And even the sunniest, most positive people will have down days when dealing with cancer. It's a scary, life-changing event and filled with uncertainty. Rather than telling them to be

positive, acknowledge and share in their sadness on those days. Doing so makes an honest connection.

Cancer is no different than every other aspect of life. We need to face it in our own way and on our own terms.

And our dearest friends and family members will accept those terms, and support us and love us no matter what.

Communicating with Your Doctor

I'm always struck that some people diagnosed with cancer want to know absolutely everything about their disease while others just want to be told when to show up for treatment. Some people complain that their doctors give them too much information while others complain that their doctors give them too little.

Every doctor I've known will truthfully answer whatever questions are asked. The more difficult issue for doctors is what information to offer in the absence of questions. This is especially relevant when patients are first diagnosed. Many people experience a brain freeze when they hear the words, "You have cancer," and are unable to ask any questions at all

The basic information - diagnosis and suggested treatment - has to be shared, of course. But there's SO much information that could be discussed related to a cancer diagnosis. For example, should patients be told the survival statistics for their type of cancer? Some patients diagnosed with a serious cancer want to know their chances of survival because it helps them plan their lives.

Others don't want to know because they want only positive thinking around them. There's no right or wrong in this. What is important is for the doctor and patient to have a shared understanding of what works best for the patient.

Some doctors, of course, are better at sensing the patient's wishes than others. I encourage patients to tell their doctors how much or how little they want to know.

Another important time for clear communication is when a patient has metastatic or advanced cancer. Many of these patients can live for years with a good quality of life by receiving chemotherapy on an ongoing basis. At some point in time, though, cancer cells mutate and become resistant to the current treatment and another treatment has to be initiated. When there are no more treatments to offer, the focus turns to comfort care, often through hospice.

Some people want to try every treatment option in order to extend their lives as long as possible. Others would rather focus on quality of life and not go through another round of chemotherapy. What's important is for the patient to control these decisions.

Ending active treatment is a very personal decision and depends on the patient's condition and the treatment options at a specific point in time. But I encourage patients to share their general mindset with their oncologist.

It's OK to say, "If I only have a few months to live, I'd rather spend those months in hospice." By saying that you're comfortable with hospice, it may allow the doctor to introduce hospice as a reasonable option earlier than he or she would have otherwise. It's also OK to say, "My daughter is getting married next summer and I want to do everything possible to be at that wedding."

Like so much in life, the more that we share our wishes, the more likely it is that we'll get what we truly want.

The After-Treatment Blahs

For many people the months following cancer treatment are more difficult than the treatment itself.

During treatment, your "job" is to be in treatment. You're busy with appointments and you see the same doctors and nurses almost every week. At the same time, friends bring you

meals, family members take on extra duties, and you're left to focus on getting better.

Then you have your last radiation therapy treatment or chemotherapy session. You get hugs and congratulatory handshakes. There's an expectation that everything in your life will suddenly revert back to normal.

Let me pop that bubble: everything doesn't return to normal right away. You might even wonder, "Is my new normal the same as my old normal?" Your body is tired. Your brain is muddled. You're worried that the cancer will come back. And you miss the safe cocoon of your chemo nurses and radiation therapists.

What makes it especially hard is that the people around you sometimes expect you to bounce back almost immediately. While they were happy to help you during treatment, they now see you as recovered and expect you to carry your old load.

The post-treatment blahs are so common that I try to prepare people for them in advance. This is what I suggest:

Expect a post-treatment slump. Rather than being a time of celebration, the last treatment is sometimes the beginning of a funk. If you expect that funk, it won't be so difficult.

Realize that recovery is not a straight line. You'll feel better one day but worse the next. That's normal.

Expect recovery to take several months. Some people say that the recovery phase takes as long as the treatment phase. It took me a full year following chemotherapy to really feel like myself again.

Expect to be acutely aware of every ache and pain and immediately think the worst. Every headache is an ominous sign of a brain tumor instead of just a normal headache. Every cough is a lung metastasis instead of a normal cold. These worries become even more pronounced before doctor visits and tests. You scan your body for the slightest indication of anything bad. Everyone goes through this.

Realize that cancer will continue to be front and center in your life for several more months. It's what you think about in the morning, at night, and throughout the day. But this fades with time. The second year after treatment is much easier than the first year after treatment.

Expect your family and friends to have less time to sit with you and listen to your concerns about living with cancer. They're eager to get back to normal as quickly as possible. There's a good chance that you still want to process what you've been through. Joining a support group or speaking with a therapist can be especially helpful during this transition phase.

Most of all, be patient with those around you and especially with yourself.

What to Say—and Not Say

Most people find it awkward when first talking with a friend or acquaintance who has just been diagnosed with cancer. Even though nearly everyone is well-intentioned, many say things that hurt or mystify more than they comfort.

Based on my own experiences and my conversations with others with cancer, here are some suggestions:

What not to say

Don't worry. You'll be fine. Everyone's natural instinct is to reassure the newly diagnosed that everything will be OK. While encouraging words are welcome, most people just diagnosed with cancer will be worried. Rather than dismissing those worries, acknowledge them. Honest conversation is likely to follow.

That's too bad about your cancer, but I could be hit by a bus tomorrow. No one in the history of civilization has ever found comfort in these words, but people say it all the time.

Do you smoke? People with lung cancer get asked this routinely. This is blaming, not supporting. People seem to ask this question for their own peace of mind. "You smoked and got lung cancer. I don't smoke, therefore I don't have to worry."

You have to see this doctor or have this treatment or begin this cancer-fighting diet. If people want your advice, they'll ask for it.

Tell me how I can help. This comment often comes from the heart, but it puts the burden on the person with cancer to think of and assign tasks. It's far better just to do things. Bring meals, take care of the kids for an evening, walk the dog, write cards of support, or call and say, "I'm heading to the supermarket. What can I pick up for you?"

What to say

I'm so sorry. This is a good and honest response.

How are you doing with all of this? A simple question like this lets the person with cancer take the lead and opens the door for conversation.

Would you like to grab a cup of coffee and talk?

I'm keeping you in my thoughts and prayers. Positive energy always helps, in whatever form works for you and the person with cancer.

One friend describes two layers of response whenever she tells someone that she has cancer. The first layer is immediate, honest and from the gut. "Oh no. I'm so sorry." The second layer is when the person begins saying those things they *think* they should say. "You'll be fine. You'll be playing tennis in a month." She wishes that people would stop talking after the "I'm so sorry."

As with other difficult conversations, the specific words are less important than the tangible presence of friends and loved ones. It's OK if the words get a bit tangled—it's the heart that matters.

Advocating for a Loved One

I've often written that it is helpful for a person with cancer to have an advocate present during doctor's appointments and hospital stays. I'd like to devote this column to the nuts and bolts of what this really means.

The most important role for the advocate is to understand and be supportive of the patient and the patient's wishes.

Above all, a good advocate needs to be a good listener. Listen to the patient. And listen to the health professionals.

Most problems occur when loved ones confuse their own wishes and agenda with those of the patient. This isn't done maliciously. More often, it's based on assumptions of what's best for the patient without actually asking the patient.

It's entirely normal for loved ones to have their own agendas. But understand that the patient's agenda and loved ones' agendas aren't necessarily one and the same.

It can be helpful for patients and their loved ones to separately write down their wishes and priorities. Afterwards, compare the lists to see where they overlap and where they differ. This provides clarity and also a springboard for discussion.

Ultimately, though, advocates need to realize that it is the patient and the patient's wishes that take precedence. Here are a few additional suggestions for advocates:

- Talk with the patient before appointments to write down questions the patient wants to ask.
- Let the patient speak for him or herself.
- Take notes.
- Let the health care team do its work.
- Report changes in the patient's status to the health professionals, especially ones that

aren't obvious. For example, "Sarah seems to have much less energy than she did last month."

- Understand the reality of the situation and maintain reasonable expectations.
- Think of yourself as part of the care team. Ask both the patient and the professionals how you can be helpful.
- Be a bridge-builder. Connect with providers, other patients and family members.
- Think of ways to help with non-medical issues, e.g., household chores that free up the patient's time and energy.

Some people don't think of themselves as advocates because they aren't loud and pushy. In fact, the best advocates are quiet forces who support mostly by their steadfast presence. I heard one patient refer to his advocate as his "designated listener." What a perfect description. We should all have designated listeners.

Groundhog Friends

I'm often asked how to be a friend to someone with cancer.

I generally answer this question by encouraging them to be good listeners and to be present for their friend in every sense of the word.

The best friends are what I describe as "groundhog friends."

Remember the movie *Groundhog Day* with Bill Murray? The same day kept reappearing. That isn't a good trait for one's day, but it's a terrific trait for a friend of someone with cancer.

When you're first diagnosed, many people call, send notes, and help in a variety of ways. That's great and those kindnesses are appreciated.

But cancer is more a marathon than a sprint. The challenging time is when the initial outpouring of support slows and you still have four months of chemotherapy looming ahead.

A groundhog friend checks on you throughout the course of your treatment.

A groundhog friend keeps sending notes of support.

A groundhog friend keeps popping up to do things that make your life easier.

A groundhog friend isn't offended by your crankiness on those inevitable bad days.

A groundhog friend doesn't change the subject when you have bad news to share.

A groundhog friend keeps filling your freezer with food.

A groundhog friend brings in other friends when you're in the mood and keeps them away when you aren't.

Above all, a groundhog friend keeps reappearing, day after day

Helping Friends with Cancer

Nearly everyone has had a friend, neighbor, co-worker or acquaintance diagnosed with cancer. Most people want to be helpful, but may fear being intrusive or simply getting in the way of the immediate family. In general, what those of us with cancer most appreciate from our friends are help with practical matters and the maintenance, as much as possible, of a sense of being normal.

Here are a few suggestions:

Do

- Send cards of support and encouragement. (E-mail just isn't the same).
- Offer to walk their dogs.
- Cut their grass or shovel their walk.
- Fill their birdfeeders.
- Offer to bring mutual friends over to watch a sporting event or other favorite tv show.
- Offer to watch their kids for an evening or weekend.
- Drop off meals that can be frozen.
- Take their trash cans to the curb.
- Offer to drive them to appointments.
- Offer to organize other friends who may want to help by cooking or driving.
- Send small gifts.
- Take the initiative for staying in touch. The person with cancer is often short of both time and energy.
- Send another card.
- Extend small kindnesses.
- Make a donation in their honor to an organization they value.

Don't

- Provide unsolicited advice about how they should treat their cancer.
- Assume that your friend is a different person because they've been diagnosed with cancer.
- Be afraid of talking about normal stuff. People with cancer usually enjoy taking a break from cancer.
- Stay too long when visiting. If the patient is looking tired, let them rest.
- Ask, "How can I help?" That puts the burden on the patient to think of things. It's better to call and offer something concrete such as, "I'm heading to the grocery store this afternoon. Can I pick up something for you?"
- Be nosy. It's fine to ask how the person is doing, but don't pry for details. If they want to tell you, they will.

A person who recently went through cancer treatment told me that the friends he valued the most were those who found the "sweet spot." That is, they acknowledged his cancer but still treated him like he was still the same person. It's a balancing act that may take some fine-tuning and practice, but it's worth the effort.