



CANCER RESOURCE CENTER

OF THE FINGER LAKES

Welcome to the Cancer Resource Center!

We understand that this is a difficult time for you and your family. We are here to offer assistance throughout your diagnosis, treatment, recovery, and beyond. The welcome folder describes some of the services and support we provide to individuals and families affected by cancer. Please don't hesitate to contact us if you have questions about any information contained in this folder.

Our staff is happy to talk with you one-on-one to answer questions and to provide information and resources available both locally and nationally. We meet with couples and families as well and we always respect the confidentiality of everyone we meet with. We share information only when given permission to do so.

CRC has a lending library of books and other materials that covers a wide range of cancer-related topics as well as a boutique featuring free wigs, hats, scarves, and other items that can be useful during some types of treatment.

Our many support groups for individuals with cancer and their loved ones play an important role in providing assistance and connection to others with similar experiences. Our Financial Advocacy program can help provide assistance with financial concerns if needed.

Our website (www.crcfl.net) includes many additional resources that may be of assistance to you and your family. We encourage you to visit it. If you do not have a computer, we will be happy to assist you in finding cancer-related information that we can mail to you.

Our staff and volunteers are here to help you in any way we can. COVID-19 has not stopped CRC from delivering services to our community. To maintain safe health for our staff and visitors, all staff are working some days in the office and some days remotely. We have staff available by phone, email or face to face encounters on platforms such as Zoom or Facetime, or in our office by appointment. You can reach us by phone at (607) 277-0960 or email us at info@crcfl.net

Our Cancer Resource Center community truly believes that “***No one should face cancer alone,***” and we look forward to providing support to you and your loved ones.

Cancer Resource Center of the Finger Lakes
612 W. State Street
Ithaca NY 14850

(607) 277-0960
info@crcfl.net
www.crcfl.net

The mission of the Cancer Resource Center is to create and sustain a community of support for people living with and affected by cancer.

CRC Statement of Inclusion

The Cancer Resource Center seeks to serve all people living with or affected by cancer. Our goal is to create an inclusive, welcoming community in which the perspectives and needs of all those we serve are heard and respected.

Basic Cancer Terms

Cancer has its own language that is unfamiliar to most people when they are newly diagnosed. Our volunteers and staff are happy to help you understand the terms listed below or any other terminology that you may encounter.

Basics

Benign: Not cancer.

Cancer: Abnormal, uncontrolled growth of cells of any organ of the body. Cancer is not one disease, but over 100 different diseases. (Breast cancer, for example, is a different disease than colon cancer).

Malignant: Another term for cancer.

Tumor: An abnormal mass of tissue. Tumors may be benign (not cancer), or malignant (cancer).

Metastasis: The spread of cancer from one part of the body to another.

Pathology

Stage: The extent of a cancer in the body. It is based on the size of the tumor and whether it has spread. Stage 1 is early stage and Stage 4 is the most advanced stage.

Grade: how abnormal the cancer cells look under a microscope and how quickly the tumor is likely to grow and spread. High grade tumors tend to be more aggressive than low grade tumors.

Margins: When a tumor is removed, it's examined to determine if the borders of the tumor are cancer-free. If there are cancer cells on the border, more surgery may be required.

Tests

CT Scan: a series of X-ray that are combined by computer into images of the bones and soft tissues inside your body. CT scan images provide much more information than do plain X-rays.

MRI: Another imaging device that is especially useful in viewing the brain, spine, the soft tissue of joints, and some other parts of the body. MRIs do not use X-Rays.

PET Scan: Unlike CT and MRI which look at *structures* (i.e., the architecture of the body), PET looks for cancerous *activity*. Cancer cells often "light up" on a PET Scan because they metabolize glucose differently than do normal cells. PET scans are often used to see if cancer has spread to other parts of the body.

Ultrasound (Sonogram): Uses sound waves to identify tumors and other structures within the body.

Tumor Markers: blood tests that *may* indicate the presence of certain cancers in the body. The PSA test for prostate cancer is a tumor marker. Not all types of cancers have tumor markers.

Treatment Terms

Chemotherapy: Treatment with drugs that kill cancer cells.

Radiation Therapy: The use of radiation from x-rays and other sources to kill cancer cells and shrink tumors.

Hormone Therapy: Treatment that blocks, removes or adds hormones to slow or stop the growth of certain cancers (such as prostate and breast cancer). Tamoxifen and Lupron are examples of hormonal therapies.

Targeted therapies: Newer drugs that specifically target cancer cells while doing minimal damage to normal cells. Herceptin is an example of a targeted therapy.

First Line Treatment: the initial treatment that is used to treat a patient's cancer.

Second Line Treatment: a treatment that is started when the first-line treatment stops being effective. (There are also third-line treatments and so on).

Source: Adapted from the National Cancer Institute Dictionary of Cancer Terms.



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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



Bob Riter

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.

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.

Looking for support?

Virtually Together Group

Zooms the 2nd Tuesday of each month 5:30-7pm. Open to cancer patients, survivors, loved ones, any gender, and those affected by any type/stage of cancer.



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Mindful Mondays

Zooms every Monday 10-10:30am. Open to cancer patients, survivors, loved ones, any gender, and those affected by any type/stage of cancer.

Caregiver Group

Zooms the 2nd Tuesday of each month 5:30-7pm. Open to family, friends, and caregivers of those with cancer.

Lymphedema Group

Zooms & Meets the 5th Tuesday of each month 5:30-7pm
For people affected by lymphedema.

Women's Friday Group

Zooms every Friday 12-2pm. For women with any type of cancer, at any stage of treatment or recovery.

Living Well with Cancer Workshop

Zooms the 3rd Tuesday of each month 5:30-7pm. A monthly educational program on a topic related to cancer and/or general well-being. Open to the public.

Colorectal Group

Zooms the 1st Tuesday of each month 5:30-7pm. For people with any type of Colorectal cancer, at any stage of treatment or recovery.

Cornell Cancer Group

Zooms the 2nd Wednesday of each month 11:45-12:45pm. Open to faculty, staff, students and retirees with any type of cancer, at any stage of treatment or recovery.

Pat's Group: Living with Cancer as a Chronic Disease

Zooms the 1st & 3rd Thursday of each month 12-1:30pm. For people with more advanced cancers. Caregivers welcome.

Women's Wednesday Group

Zooms every Wed. 1-2:30pm. For women with any type of cancer, at any stage of treatment or recovery.

Men's Breakfast Club

Meets every Friday 8-9am at the Royal Court Restaurant. For men with any type of cancer, at any stage of treatment or recovery.

No pre-registration required.

Prostate Group

Zooms the 2nd Thursday of each month 7-8:30pm. Offers support, education programs and discussions related to prostate cancer. Open to men & their caregivers.

Gentle Yoga class

Zooms Tuesdays 10-11am. A blend of stretching, relaxation, healing visualization, and meditation in a supportive group environment. (free to those with cancer)

Beth's Group:

Adults Under the Age of 50
Zooms & Meets the 4th Tuesday of each month 5:30-7pm. For people at any stage of treatment or recovery. Partners welcome.

Pre-registration required. Contact CRC for more information and to join:

info@crcfl.net 607-277-0960 crcfl.net 612 W. State St., Ithaca, NY



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Cancer Support Services
Finger Lakes Region of
New York State



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@CancerResourceCenter

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For many more resources available to residents of specific counties in the Finger Lakes area,
please see

Cancer Support Services Guides for:
Cayuga, Chemung, Cortland, Schuyler, Seneca, Tioga, and Tompkins counties.

The Cancer Resource Center of the Finger Lakes

...because no one should face cancer alone

No one is prepared to hear the words, “You have cancer.” It’s like entering a world where you don’t understand the language or even know which questions to ask.

Everyone feels lost at first.

This guide is designed to help you identify potential resources. It provides the answers to the questions we are asked about most often here at the Cancer Resource Center.

The Cancer Resource Center of the Finger Lakes (CRC) is a local non-profit organization serving individuals in and around Tompkins County who have been affected by cancer. We are not affiliated with, nor do we receive funding from, the American Cancer Society.

We recognize that every person and every cancer is different, so we begin by listening. Many people come to us when they are first diagnosed. Others come because they are concerned about a loved one with cancer. We answer questions, suggest resources, and share what we’ve learned from others who have come through our doors.

Our programs include one-on-one assistance, support groups, financial advocacy, financial assistance, transportation assistance, a boutique, and wellness programs. We are happy to track down additional resources for you, just contact us with your questions.



Advice for People Newly Diagnosed with Cancer

by Bob Riter

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. 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).
- Family members, friends, and complete strangers will give you advice. Be wary when they say, "You should do..." Though well-intentioned, they may 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. Lung cancer and breast cancer are very different diseases. There are even 14 different types of breast cancer. 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.
- 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.

*Bob Riter joined the staff of the Cancer Resource Center as Associate Director in 2000 and was the Executive Director from September of 2010 - September of 2017. Bob contributed regular articles about cancer for the Ithaca Journal. Bob's columns are available online at www.crcfl.net or in his book, *When Your Life is Touched by Cancer: Practical Advice and Insights for Patients, Professionals, and Those Who Care* (©Hunter House Publishers, 2014).*

Resources for Financial Assistance

<p>Cancer Resource Center 612 West State Street Ithaca, NY 14850 607-277-0960 http://www.crcfl.net/</p>	<ul style="list-style-type: none"> Trained volunteers are available to assist individuals navigate their financial concerns related to a cancer diagnosis. We can help identify resources, organize paperwork, assist completing applications for benefits, and advocate on a client's behalf.
<p>Social Services-Home Energy Assistance Program (HEAP) 320 W State St, Ithaca, NY 14850 (607) 274-5680</p> <p>To apply: Online: myBenefits.ny.gov HEAP application or to your HEAP Local District Contact.</p>	<ul style="list-style-type: none"> The Home Energy Assistance Program (HEAP) helps low-income people pay the cost of heating their homes. If you are eligible, you may receive one regular HEAP benefit per program year and could also be eligible for emergency HEAP benefits if you are in danger of running out of fuel or having your utility service shut off.
<p>Social Services-Supplemental Nutrition Assistance Program (SNAP) 320 W State St, Ithaca, NY 14850 (607) 274-5680</p>	<ul style="list-style-type: none"> Nutrition Assistance/SNAP provides nutrition benefits to supplement the food budget of needy families so they can purchase healthy food and move towards self-sufficiency. To get SNAP benefits, you must apply in the state in which you currently live and you must meet certain requirements, including resource and income limits
<p>21st Century CARE 888-850-1622 www.21stcenturycare.org</p>	<ul style="list-style-type: none"> Provides patients immediate financial assistance for incidental expenses related to active cancer treatments
<p>Embrace Your Sisters 585-624-9690 www.embraceyoursisters.org</p>	<ul style="list-style-type: none"> Based in Canandaigua, NY, provides emergency financial support to people with breast cancer in the greater Finger Lakes area
<p>Hope for Young Adults with Cancer http://www.hope4yawc.org/</p>	<ul style="list-style-type: none"> Provides financial support to young adults battling cancer as well as those who have been in remission for up to 5 years after their treatment. Links to other similar organizations

Catholic Charities / Samaritan Center 324 West Buffalo Street Ithaca, NY 14850 607-272-5062 www.catholiccharitiestt.org	<ul style="list-style-type: none"> • The Samaritan Center provides urgent, short-term financial assistance to families and individuals in immediate crisis. • Emergency financial assistance is offered in Tompkins County only; funds are limited and determined on a case-by-case basis. • Referrals for other types of assistance are provided.
Leukemia and Lymphoma Society Western and Central NY Chapter 4043 Maple Road Suite 105 Amherst, NY 14226 716-834-2578 LLS Information Specialists: 800-955-4572 http://www.lls.org/	<ul style="list-style-type: none"> • National organization with local chapters, which offer various supports for people with blood cancers. • Financial assistance available towards the cost of insurance and prescription co-payments. • There is also some financial assistance for travel expenses for those with a significant need.
My Benefits NY www.mybenefits.ny.gov/mybenefits/begin	<ul style="list-style-type: none"> • Check website to identify potential program eligibility

Assistance with Medication Costs

Ithaca Free Clinic 521 West Seneca Street Ithaca, NY 14850 Clinic: 607-330-1254 http://ithacahealth.org/	<ul style="list-style-type: none"> • The Ithaca Free Clinic is a medical center where patients can receive both conventional medical care offered by physicians and nurse practitioners and alternative care from holistic professionals. • The clinic serves the uninsured, free of charge. • The clinic offers appointments, and also has walk in hours, call for details.
CancerCare Copay Assistance Foundation 800-813-4673 www.cancercare.org/copayfoundation	<ul style="list-style-type: none"> • Helps cover deductibles and co-pays for chemotherapy or targeted treatment for certain cancer diagnoses.

HealthWell Foundation 800-675-8416 www.healthwellfoundation.org	<ul style="list-style-type: none"> Assistance for Rx copays, health insurance premiums, deductibles and coinsurance, pediatric treatment costs, and travel costs
Merck Co-Pay Assistance Program 855-257-3932 www.merckaccessprogram-keytruda.com/hcp/the-merck-copay-assistance-program/	<ul style="list-style-type: none"> Covers cost of Keytruda infusions up to \$25,000/year. Patient pays first \$25 of co-pay of each infusion.
NeedyMeds P.O. Box 219 Gloucester, MA 01931 Helpline: 800-503-6897 http://www.needymeds.org/	<ul style="list-style-type: none"> Anyone is eligible, regardless of age or income
Novartis Patient Assistance Now www.patientassistancenow.com	<ul style="list-style-type: none"> Drug cost assistance
Partnership for Prescription Assistance 888-477-2669 https://www.pparx.org/	<ul style="list-style-type: none"> Acts as a single point of access for individuals without or with limited prescription drug coverage to receive information about financial assistance programs to get prescription drugs for free or at very low cost. Search engine resources available through various biopharmaceutical industry programs.
Patient Access Network Foundation (PAN) 866-316-7263 panfoundation.org/index.php/en/patients/assistance-programs	<ul style="list-style-type: none"> Assistance for prescription drug costs

<p>Patient Advocate Foundation Co-Pay Relief Program 866-512-3861 https://www.copays.org/</p>	<ul style="list-style-type: none"> ● Provides financial assistance to financially and medically qualified patients for co-payments, deductibles, or prescription medications. ● Program does have eligibility requirements. ● Application available online, or by calling.
<p>ProAct Prescription Discount Card proactrxsavings.com Cards are available online, at participating local pharmacies, or by calling 2-1-1</p>	<ul style="list-style-type: none"> ● Offers a free discount card that reduces the cost of prescription drugs. Present your card at participating pharmacies and save. ● Anyone is eligible, regardless of age or income who is without or has limited prescription drug coverage.
<p>RxAssist Patient Assistance Program www.rxassist.org</p>	<ul style="list-style-type: none"> ● Information about free and low cost medication programs and ways to manage your medication costs.
<p>ScriptSave Well Rx wellrx.com</p>	<ul style="list-style-type: none"> ● Cards are available online and at participating local pharmacies. ● Offers a free discount card that reduces the cost of prescription drugs. ● Present your card at participating pharmacies listed online. ● Anyone is eligible, regardless of age or income.
<p>The Assistance Fund (TAF) 855-845-3663 tafcares.org</p>	<ul style="list-style-type: none"> ● Financial assistance for copays, coinsurance, deductibles, etc.

Assistance with Insurance and Legal Issues

<p>American Cancer Society Helpline: 800-227-2345 www.cancer.org</p>	<ul style="list-style-type: none"> • Can help find specific resources in your region for day-to-day living such as rent, utilities, and transportation. • They also have a health insurance information team that helps people understand their choices to change or purchase new insurance.
<p>Cancer Legal Advocacy and Serv Project Legal Services of Central NY Multiple Locations 877-777-6152 https://www.lscny.org/</p>	<ul style="list-style-type: none"> • A project of Legal Services of Central New York which provides legal assistance to individuals and their families living with cancer in Central New York. They can provide information and referral.
<p>Health Care Bureau NYS Office of Attorney General Helpline: 800-428-9071 https://ag.ny.gov/bureau/health-care-bureau</p>	<ul style="list-style-type: none"> • The Bureau protects – and advocates – for the rights of consumers regarding health care throughout the state. They safeguard consumers against illegal practices in the health care market and assist consumers with resolution of health care complaints.
<p>Health Insurance Navigators Human Service Coalition State Street #133 Suite 275 Ithaca, NY 14850 607-273-8686 or 211 www.hsctc.org/</p>	<ul style="list-style-type: none"> • A free and confidential program to assist individuals find quality health insurance in NY, renew insurance, compare insurance plans and programs, or change insurance. • Call to schedule an appointment with a navigator.
<p>Law NY Legal Assistance of Western NY 902 Tabor St. Suite 1 Ithaca, NY 14850 607-273-3667 OR 800-724-4170 www.lawny.org</p>	<ul style="list-style-type: none"> • Free legal help with public benefits such as shelter denials, cash assistance, Medicaid, Social Security and SSI, low-income based housing, employment rights, consumer defense issues, survivors of domestic violence, divorces and wills, and elder care directives.

Patient Advocate Foundation Co-pay Relief Program 866-512-3861 www.copays.org	<ul style="list-style-type: none"> • Provides patients with arbitration, mediation, and negotiation to settle issues with access to care, medical debt, and job retention related to their illness. • Case managers work with patients, caregivers or their medical personnel free of charge.
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Wigs, Makeup and Mastectomy Products

The Boutique Cancer Resource Center 612 West State Street Ithaca, NY 14850 607-277-0960 http://www.crcfl.net	<ul style="list-style-type: none"> • Maintains an inventory of wigs, hats, scarves, turbans, and mastectomy products. • Staff provide personal assistance with wig fittings and selection. • Items are free of charge to individuals with cancer.
Paula Young 800-364-9060 https://www.paulayoung.com/	<ul style="list-style-type: none"> • A company that has a selection of hairpieces and wig styles for women who want to look their best and feel confident. They offer a variety of products that can be ordered online, by phone, or by mail.

Beds, Wheelchairs and Other Equipment

Finger Lakes Independence Ctr 215 Fifth Street Ithaca, NY 14850 607-272-2433 http://www.fliconline.org	<ul style="list-style-type: none"> • The Center provides durable medical equipment (such as walkers, wheelchairs, rails, etc.) available for a short term loan. • The Center also has a “Try It Room” with items that can help with daily living. The room also loans assistive technology and devices for a one month period.
Ithaca ReUse Center 214 Elmira Rd Ithaca, NY 14850 (607) 257-9699 https://ithacareuse.org/	<ul style="list-style-type: none"> • Works toward a resilient and waste-free world that values people and resources. Join us in reducing waste sent to landfills, and giving quality materials and people new chances, all while making a local impact.

Nutritional Assistance

The Cancer Resource Center occasionally receives donations of Jevity, Glucerna, and Ensure. Contact our office for current availability at 607-277-0960.

The Oley Foundation provides resources and information for people dependent on tube feeding or IV nutrition. Contact them at 518-262-5079.

The Partnership for Prescription Assistance is a clearinghouse for assistance with nutritional supplements. You may qualify for assistance from the manufacturer of the products. Contact the program at 888-477-2669. <https://www.pparx.org/>

Cancer Support for All Ages

Children:

In the local area, children with cancer are most often treated outside of Tompkins County. However, there are some local programs that can assist children and families.

Camp Good Days (www.campgooddays.org) provides residential camping programs and year-round recreational and activities for children with cancer, children with a parent or sibling with cancer, and children who have lost a parent or sibling to cancer.

Camp Kesem is dedicated to supporting children impacted by a parent's cancer. At no cost to families Kesem's innovative and fun-filled programs provide children with peers who understand their unique needs and create long-lasting impact. www.campkesem.org

Cancer Resource Center of the Finger Lakes (www.crcfl.net) provides support to parents in talking with their child about cancer and connects them with additional resources in the community. Our program, **CRC Cares About Families**, helps families in need pay for counseling sessions for their children. Insurance co-pays can also be covered.

Young Adults:

Cancer can be especially difficult for young adults because they are just establishing themselves in their relationships and their careers.

Cancer Resource Center of the Finger Lakes offers a support group for young adults.

Hope for Young Adults with Cancer (<http://www.hope4yawc.org/>) is an organization that provides financial support to young adults battling cancer as well as those who have been in remission for up to 5 years after their treatment. This organization has an application process for financial assistance for the necessities of everyday life.

Stupid Cancer (www.stupidcancer.org) is an organization whose mission is to empower, support, and improve health outcomes for the young adult cancer community. Their website provides age-appropriate resources and social networking for young adults with cancer.

The Young Survival Coalition (www.youngsurvival.org) is an international organization focusing on the critical issues women ages 40 and under who are diagnosed with breast cancer.

Older Adults:

Cancer Resource Center of the Finger Lakes (www.crcfl.net) offers a variety of [support groups](#) for adults.

CancerCare https://www.cancer.org/support_groups Online Support Groups take place using a password-protected message board format (not live chat) and are led by professional oncology social workers who offer support and guidance.

Cancer.net

<https://www.cancer.net/coping-with-cancer/finding-social-support-and-information/online-communities-support> Provides emotional support, there are several options to get the help you need. Joining an online community makes it easier to connect with others, even if they live far away.

National Cancer Institute

<https://www.cancer.gov/about-cancer/coping/adjusting-to-cancer/support-groups> Offers online support groups meetings for people with cancer and anyone touched by the disease.

Transportation

<p>Angel Flight Northeast 492 Sutton Street North Andover, MA 01845 978-794-6868 or 800-549-9980 www.angelflightne.org</p>	<ul style="list-style-type: none"> • A non-profit organization that provides air transportation in private aircraft by volunteer pilots so that children and adults may access life- saving medical care free of charge. • The Northeast service area covers 9 states: Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Vermont.
<p>Wings: Flights of Hope P.O. Box 872 Orchard Park, NY 14127 866-619-4647 or 716-667-0816 www.wingsflight.org</p>	<ul style="list-style-type: none"> • A non-profit organization that helps people in need of free air transportation for medical and humanitarian purposes. • Wings Flights of Hope flies out of Buffalo, NY to various locations throughout the North East section of the US.

Angel Wheels (a part of Mercy Medical) https://www.mercymedical.org/	<ul style="list-style-type: none"> • A non-profit charity, dedicated to providing non-emergency, long-distance ground transportation to financially disadvantaged, ambulatory patients who are traveling for treatment. • Assistance can only be completed online.
Road to Recovery Program Cancer Resource Center/ American Cancer Society (800-227-2345)	<ul style="list-style-type: none"> • The Cancer Resource Center is working in collaboration with the American Cancer Society: Road to Recovery Program to provide rides to take patients to treatments and cancer related medical appointments. Requests must be made well in advance. • This program is especially helpful for people who need to travel into or out of Tompkins County. (Gadabout and FISH only travel within the county).
Cornell Campus to Campus Bus C2C Service Hotline: 607-254-8747 www.c2cbus.com	<ul style="list-style-type: none"> • The Campus to Campus bus makes three round trips daily to New York City and is very convenient for appointments at the major medical centers in the city. • Cancer patients and a support person are eligible for free seats, if space is available. • To check seat availability and make a reservation contact the Cancer Resource Center (607-277-0960).
Medicaid Transportation Management 855-852-3287 https://www.medanswering.com/	<ul style="list-style-type: none"> • Arrange long distance trips out of town when medically necessary. Long distance trips out of town may take more time to arrange and need to be scheduled at least one week (7 days) in advance. • To book a ride please contact the number listed.
Medical Answering Services https://goo.gl/NgZqk6	<ul style="list-style-type: none"> • Provides information on transportation options to and from medical appointments within your community, all of which are covered by Medicaid.

An excellent source for additional information is 211 in your area.

Updated July 2020

Peer to Peer



Would you like to connect with someone affected by cancer who has experienced a similar situation to yours?

Our free confidential service connects patients and caregivers with mentors who provide the perspective of "someone who's been there."

This program is open to all patients and caregivers touched by any type of cancer.

Looking for support?

Please contact the Cancer Resource Center at 607-277-0960 or visit our website www.crcfl.net for an application to be paired with a mentor.

Want to become a mentor?

You should:

- Be mentally and physically able to take on the mentorship role. It's not about you – it's about the person you're helping.
- Adhere to the guideline of not giving medical advice. It's ok to say what you did. It's not ok to say what someone else should do.
- Be emotionally prepared to participate in a mentoring relationship.
- Maintain confidentiality.
- Be willing to be an active match for 6 months.

Mentors listen, extend emotional support, and offer practical advice. They do not provide medical advice.

The Cancer Resource Center will provide training focusing on listening skills, the mentorship role, confidentiality, problem solving, and how to handle difficult situations.

Please contact us if you are interested in becoming a mentor.



**CANCER
RESOURCE
CENTER**

OF THE FINGER LAKES

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