

**FRANKLY**  
SPEAKING  
ABOUT CANCER

# Liver Cancer



People with cancer who *actively* participate in *their care* along with their health care team will improve the *quality* of their lives and may *enhance* the possibility of recovery.

THIRD EDITION

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CANCER SUPPORT  
COMMUNITY



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# Prologue

This booklet is here to help you. Here you will find information about what liver cancer is, how it is diagnosed, treatments available, tips to help you talk to your doctor, and information to help manage the emotional impact of cancer. This booklet also includes information about credible organizations and resources that can help you.

*I was devastated when I was first diagnosed with stage IV liver cancer. As a nurse, I knew the prognosis was not good. What I didn't know was that there were a lot of treatment options available to me. Luckily, I have a very diligent husband who uncovered all of these options and I was quickly seen by a liver surgeon on a transplant team and by oncologists. Now I am more than a two year survivor with a hopeful future because I know I have treatment options.*

— Helen, liver cancer survivor

# 1

## *Empower Yourself*

You are the expert in your cancer experience in relation to how you feel, what is important to you, and what you want.

Being empowered is about regaining a sense of control and confidence after receiving a cancer diagnosis. Learning about your diagnosis, treatment options, and how to communicate with your health care team can help you take control.

## THE IMPACT OF CANCER

A sense of emotional distress from cancer can include feelings of vulnerability, anger, sadness, depression and anxiety. These are all normal responses for people who receive a diagnosis of cancer, and for members of their family.

Living with cancer and undergoing treatment can also affect practical elements of your life that cause stress including:

- changes in family roles
- a depletion of financial resources
- a decrease in self-esteem

Fortunately there are actions you can take to get information, seek support, and learn how to cope with your emotions. These actions can help you regain a sense of control and maintain hope.



### MANAGING THE COSTS OF CARE



For information on how to manage the costs of cancer care, order the free booklet *Frankly Speaking*

*About Cancer: Coping with the Cost of Care* at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or call 1-888-793-9355.

# 10 Actions You Can Take to Improve Your Quality of Life

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1. **Pace yourself.** Try to focus on resolving only today's problems. Allow your mind to rest by not thinking too far into the future and avoid imagining worst-case scenarios. Taking one small step at a time can help give you a greater level of control.
2. **Ask for support.** Be open with your family and friends about how you feel and how they can support you. Ask a broad range of people. Some of your loved ones will be better suited to help you in some ways over others. Offer specific examples, such as: driving you to appointments, researching sources for financial support, or just listening when you want to talk. It is also good practice to take an advocate with you to medical appointments to take notes and help you remember instructions. Your nurse or oncology social worker can also offer information and support.
3. **Communicate with your health care team.** Prepare a list of questions for each appointment. If you don't understand something, ask for clarification until you do understand. If you do not develop a good relationship with your doctor, consider finding another. In general, it is useful to get a second opinion on your diagnosis and treatment to feel more confident about next steps.
4. **Retain as much control of your life as is reasonable.** Having cancer can make it difficult for you to feel in charge of your life and your care. Work with your doctor, nurse, and caregiver to develop a plan that gives you as much control over your life as you desire and can comfortably handle.
5. **Acknowledge and express your feelings.** A diagnosis of cancer can trigger many strong emotions. Take time to listen to yourself. Find constructive ways to express your feelings through writing, talking, physical activity or other hobbies. Consider professional support if you feel that depression or anxiety is getting in the way of your ability to function well.
6. **Seek support from other cancer survivors.** Often, people find a sense of comfort when they communicate with others affected by liver and other cancers. Ask your doctor, nurse, or social worker for local support groups. You can also contact Cancer Support Community for ways to connect one-on-one, in groups, or online with others.
7. **Learn relaxation techniques.** "Relaxation" refers to a calm, controlled physical state that will enhance your well-being. It may take some effort to find time and to learn to relax. Stress reduction is an important part of regaining your health. Consider music that makes you

happy, read a book, or take a walk. Yoga, tai-chi, or meditation programs are also helpful. Take time to enjoy the moment.

8. **Do what you enjoy.** It is important to not let stress crowd out opportunities for joy. Try to find humor in the unexpected moments of each day. Consider activities that you enjoy and can do comfortably.
9. **Maintain intimacy.** Don't give up physical closeness and intimacy—they are an essential part of life. If you are experiencing physical and emotional problems that make intimacy difficult, remember that solving problems involves communication and openness between you and your loved ones.
10. **Maintain a spirit of hope.** Hope is desirable and reasonable. There are millions of people who have fought cancer. Even if your cancer recovery is complicated, you can set small goals and enjoy daily pleasures. You may want to redefine how and when you experience hope by focusing on your spiritual beliefs, cultural customs, and family connections.

*Patients and families coping with liver cancer often have to face the challenges of treatment decision making, side effect management, and prognosis alone. Liver cancer because it is often diagnosed late may have the added complexity of having to plan for treatment while simultaneously addressing a number of quality of life issues. The role of education and support is crucial in helping patients and loved ones cope so that there is good quality of life and to enhance the chances of longer survival and remission.*

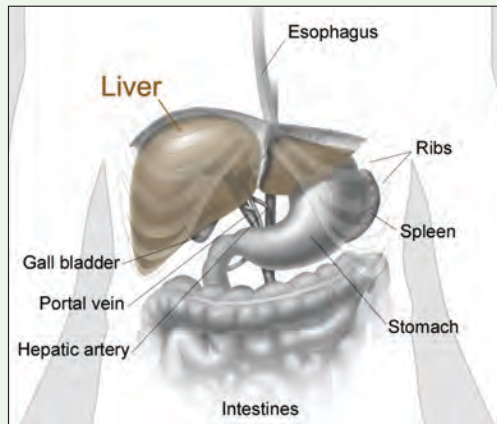
—Dr. Peggy Rios, Cancer Support Community  
Greater Miami

# 2

## *What is Liver Cancer?*

The liver is one of the largest organs in the body. It is located on the right side of the abdomen and is protected by the rib cage. The liver has three important functions: it filters and removes waste and toxins from the blood; it makes bile which breaks down fats in the digestive process; and converts food into protein and other nutrients needed by the body.

The liver is divided into two lobes (right and left) and it receives its blood supply from two major blood vessels, the portal vein and the hepatic artery.



**Source:** National Cancer Institute (NCI), Don Bliss (artist)



Cancer is the growth of abnormal cells that divide and multiply without any control or regulation. As cancer cells begin to divide rapidly, a mass or tumor is formed. When a tumor grows, it destroys the surrounding tissue and takes critical supplies of oxygen and nutrients away from healthy cells for its own growth. Cancer cells have the ability to spread (or metastasize) by traveling along the network of blood and lymphatic vessels throughout the body.

The development of cancer cells in the liver may be related to previous damage to the liver. For example, an infection from hepatitis B or C virus, fatty liver, cirrhosis, family history of liver cancer or other risk factors. It is also more common for men and people over 60 years of age to be diagnosed with liver cancer.

Even when people have known risk factors for developing liver cancer, they may not develop the disease. It is, however, worth discussing risk factors with your doctor and family so screening tests can be included in regular physical exams.

### Primary liver cancer

When cancer begins in the liver, it is called primary liver cancer. In 2013, approximately 30,600 Americans will be diagnosed with primary liver cancer, increasing with the number of detected hepatitis C cases. It is a much larger problem globally, where it is the most common cancer diagnosed in men worldwide. Hepatocellular carcinoma (HCC), which develops in the functional cells of the liver called the hepatocytes, accounts for 90% of all liver cancers diagnosed.

### Secondary liver cancer

Secondary liver cancer is very different from primary liver cancer. This cancer begins in another part of the body and then spreads (or metastasizes) to the liver. Its treatment is different for each patient.

## WHAT ARE THE SYMPTOMS OF PRIMARY LIVER CANCER?

As cancer cells multiply, warning signs may begin to appear. These may include an increase in size and decrease in functionality of the liver. Other diseases in the liver can also cause the same symptoms, so it is important for a doctor to assess what is happening. Unfortunately, most liver cancer patients feel no symptoms until the disease is more advanced.

*For your information, the following symptoms are the most common health problems experienced by people with liver cancer or liver disease. This list does not contain all possible symptoms:*

- A hard lump or swelling found on the right side of the abdomen, just below the ribs
- Pain or discomfort on the upper right side of the abdomen or by the right shoulder blade
- Jaundice—yellowing of the skin or the whites of the eyes or dark-colored urine
- Nausea, loss of appetite or feeling full shortly after you begin to eat
- Unexplained weight loss
- Fatigue

- Swollen abdomen, bleeding—the symptoms of cirrhosis
- Enlarged, tender liver upon physical exam



### MORE ABOUT RISK FACTORS

- **Hepatitis B or C virus** — Hepatitis B or C viruses infect the liver chronically (the virus does not go away). They can be passed from person to person through the blood or sexual contact. Blood tests will show if either virus is present since people with hepatitis B or C may not feel any symptoms.

People who have not been infected with hepatitis B can receive a vaccine to protect themselves. The development of a vaccine for hepatitis C is still being researched.

- **Cirrhosis** — Develops when liver cells are damaged and replaced with scar tissue. Alcohol abuse, certain drugs and chemicals, and certain viruses or parasites could cause scarring.
- **A family history** — People who have a family history of liver cancer may be more at risk for the disease.

# 3

## *Getting a Proper Diagnosis*

If you experience any of the common liver cancer symptoms, or you believe that you might be at risk for developing liver cancer, your primary care doctor should refer you to a *gastroenterologist* (a doctor who specializes in diseases of the digestive organs) or a *hepatologist* (a doctor who specifically treats liver diseases).

If liver cancer is diagnosed, you can expect to be evaluated by a team of specialists including a *medical oncologist* (a doctor who treats cancer). Since liver cancer is a challenging disease, consider a National Cancer Institute-designated comprehensive cancer center or an academic medical center associated with a university for high quality care.

## GETTING A SECOND OPINION

It is always a good idea to consider a second opinion. Getting a second opinion can provide you with additional information, additional treatment options, or access to a different medical facility. It may also give you confidence that you are already on the right course. Some insurance companies require a second opinion and others will cover the cost if you request one.

Your doctor will often be able to provide you with the names of physicians or hospitals that can provide a second opinion. It is important to know that any “good” doctor will not be offended if you seek a second opinion because it is encouraged that all patients do. Think of getting a second opinion as a routine part of your care.



### CONSIDER A SECOND OPINION

- If you feel uncertain about your diagnosis or treatment options.
- If you were diagnosed in a small hospital and would like to speak to someone with more experience in treating liver cancer.
- If you are interested in a clinical trial.
- If you just want to be sure that you're on the right course.

# Finding an Experienced Doctor

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It is very important to find a doctor who is experienced with treating liver cancer, who answers all of your questions, and who makes you feel comfortable. Never be afraid to ask your doctor important questions such as:

1. How much experience do you have in treating liver cancer?
2. How many patients with liver cancer do you see per month, and per year?
3. Are you board-certified in this specialty?
4. Do the doctors at your clinic/hospital participate in clinical trials?
5. Do you accept my insurance?
6. Will you refer me to an oncology nurse and/or oncology social worker to help me with education and support?
7. What other support services are available for me and my family?
8. How can I contact my treatment team with questions? (Can I use email or phone, or do you prefer only office visits?)



## SEARCHABLE DATABASES

To find a doctor who specializes in the treatment of liver cancer, visit:

- **The National Cancer Institute**  
[www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility](http://www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility)
- **Cancer.net**  
[www.cancer.net/all-about-cancer/newly-diagnosed/find-oncologist/find-oncologist-database](http://www.cancer.net/all-about-cancer/newly-diagnosed/find-oncologist/find-oncologist-database)
- **American Board of Medical Specialties**  
[www.certificationmatters.org/is-your-doctor-board-certified/search-now.aspx](http://www.certificationmatters.org/is-your-doctor-board-certified/search-now.aspx)

## WHAT DIAGNOSTIC TESTS SHOULD YOU EXPECT?

A combination of tests that examine both the liver and the blood (and possibly surrounding organs and bones) would be used to determine whether liver cancer is present, and if so, to determine the exact stage and type of liver cancer so treatment options can be assessed.

*The following diagnostic tests may be used in addition to a physical exam and history assessment:*

- **Serum alpha feto-protein (AFP) test** shows if there is an increased level of this protein in the blood, which may indicate the presence of a tumor. However, AFP may also be elevated by a different cancer or non-cancerous condition, so other tests are offered.
- **Blood tests** are done to assess liver function, kidney function, and measure a complete blood cell count.
- **Laparoscopy** is a surgical procedure which allows the physician to view the abdominal organs through a laparoscope (a small camera).
- **Biopsy** involves the removal of cells or tissues from the suspected tumor. A biopsy can be taken during a laparoscopy or with a thin needle inserted into the liver during an ultrasound or CT scan. A doctor looks at the tissue under a microscope to determine if cancer cells are present.
- **Computerized Tomography scan (CT or CAT scan)** is an x-ray taken from various angles with the help of a computer. A dye (for contrast) may be swallowed as a liquid or injected through a vein to make the organs show up more clearly.
- **Ultrasound** takes a picture called a sonogram created by bouncing sound waves off organs in the abdominal cavity, to see if anything abnormal exists.
- **Magnetic Resonance Imaging (MRI)** is a detailed picture of the organs in the body, created using a magnet, radio waves and a computer.
- **Chest X-ray and Bone Scan** tests determine if cancer has spread to the lungs or bones.

## WHAT IS “STAGING” FOR LIVER CANCER?

Staging is the process of finding out how widespread a cancer is. The stage of liver cancer is one of the most important factors in considering treatment options.

Staging is a standardized way for the cancer care team to summarize information about the primary tumor size (T), number of lymph nodes that contain tumor (N) and if it has spread (metastasized) to another part of the body (M). These factors comprise the TNM Staging system. Numbers that appear after T, N, and M provide more details about each of these factors. The numbers 0-4 are used to indicate increasing severity (0 being less severe than 4).

Liver cancer is unique in that it occurs mostly in people who have some liver damage. The degree of liver damage plays a very important role in determining what treatment options are possible for an individual patient.

*As a result, several other liver cancer staging systems have been developed that take into account a variety of factors including:*

- liver function
- tumor spread
- tumor invasion into blood vessels (which is very common in liver cancer)
- and the overall health of the individual.

Currently, most cancer treatment centers use a team approach in evaluating patients with liver cancer. The multi-disciplinary team reviews all of the information and determines if the patient is eligible for liver transplantation, surgical resection, intrahepatic or regional therapy, systemic targeted therapy, or a clinical trial.

# 4 *Treatment Options*

When selecting treatment options, the size of the tumor(s), the spread of cancer to other parts of the body, the potential to remove the tumor surgically, the functional capacity of the liver and the general physical condition of the individual are all taken into consideration. Treatment may include one or a combination of the following therapies: surgery, local or regional therapies, systemic therapies, or radiation.

Once you have your medical team in place, the most important thing you can do is to strive for open and honest communication. If your team knows your concerns, you will feel more at ease and confident that your needs will be met. This chapter provides an overview of these options.



## SURGERY

Surgery is done when the cancer has not spread to neighboring lymph nodes or any other part of the body. Your doctor will also consider the number and location of tumors within the liver. Surgery has the potential to cure very early stages of liver cancer.

*There are two major types of surgery used to treat liver cancer that can be removed (resectable):*

- **Partial hepatectomy** – removal of part of the liver where the cancer is present. This can involve the removal of one or more of the eight liver segments, or an entire lobe. The liver tissue remaining after a partial hepatectomy must be healthy enough to continue to perform the liver’s functions for the body. The extent of cirrhosis is also an important consideration.
- **Total hepatectomy and liver transplant** – the entire liver is removed and replaced by a healthy liver from a donor. As a standard, a donated liver that is a match must be found for this surgery to be performed. Transplantation is done when the cancer is only in the liver, has not invaded major blood vessels in the liver, and is smaller than 5 centimeters. Sometimes other procedures are performed to control the cancer while a patient waits for a donor liver to become available.

# Questions to Ask About Your Treatment Options

Making a decision about treatment can be difficult. Here are some questions you may want to ask your doctor as you gather information to make an informed choice and prepare for the treatment process.

1. What is the goal of my treatment? Is it to cure the cancer, control it (keep the cancer from spreading or slow its growth), or to relieve my symptoms?
2. In your opinion, why is this the best treatment for me?
3. What are the benefits of the treatment?
4. What are the risks?
5. Are there other ways to treat my cancer or are there clinical trials I should consider?
6. How often will I have a treatment?
7. How long does each treatment last?
8. How can I manage or prepare for side effects associated with this treatment?
9. Where can I go for emotional support?



## HELP WITH MAKING TREATMENT DECISIONS



**Open to Options™** is a free telephone or in-person counseling program provided

by trained professionals at the Cancer Support Community. It empowers you to:

- Communicate your concerns clearly
- Create a list of questions for your doctor or health care team that will help you address your specific needs
- Organize your questions for specialists to help you get the most helpful answers from the right people

Call 1-888-793-9355 to schedule an appointment or visit

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

## LOCAL OR REGIONAL THERAPIES

*Unresectable liver cancer* (liver cancer that cannot be removed) requires other therapies instead of surgery. These treatments are usually performed by a doctor called an *interventional radiologist*. The patient often stays overnight in the hospital after the procedure. They are used for patients with small tumors that are not resectable or sometimes when a patient is waiting for a transplant.

*Standard local or regional therapies for unresectable liver cancer include:*

- **Ablation** – any treatment that destroys tissue. One of the newer forms of treatment for liver cancer is *radiofrequency ablation*. A probe is placed into the tumor through an incision in the body and tiny electrodes on the probe destroy cancer cells with heat. Other ablation therapies freeze cancer cells or use alcohol to destroy them.
- **Embolization** – a treatment to block the tumor’s blood supply.
  - **Chemoembolization** first delivers a high dose of chemotherapy directly into the tumor through a catheter in an artery and then uses special particles to seal off the tumor and cut off its blood supply. This procedure is also called *TACE (transcatheter arterial chemoembolization)*.
  - **Radioembolization** (*selective internal radiation therapy*) uses radioactive beads that are injected through a thin catheter threaded into the liver, through an artery, and deposited close to the tumor site where they destroy the DNA of the cancer cells.

If a new tumor develops in the liver after an initial treatment with local or regional therapy is complete (a *cancer recurrence*), these therapies may be performed again.

## SYSTEMIC THERAPIES

An exciting new development in the treatment of unresectable or *advanced liver cancer* is the approval of sorafenib or Nexavar®. Unlike chemotherapy, which kills all rapidly dividing cells, sorafenib is a targeted therapy that selectively focuses on a specific molecule or process in tumor cell development.

The FDA approval of sorafenib was based on a clinical trial that showed longer survival for liver cancer patients who were treated with the drug. Sorafenib is an oral medication and is part of a category of drugs that target *vascular endothelial growth factor* or *VEGF*.

VEGF is a protein that allows a tumor to grow its own blood vessels. Sorafenib blocks VEGF, as well as other proteins that play an important role in the growth of new blood vessels and in the signaling process in the tumor cell that promotes cancer cell growth and multiplication.

## RADIATION

Another option for tumors that cannot be surgically removed is treatment with high-energy rays or radiation therapy. Radiation can be given externally from special equipment that positions the patient and delivers doses of radiation from the outside of the body to very precisely target internal cancer cells. The primary goal of this treatment is the relief of symptoms. Internal radiation using radioactive beads injected through an artery, *radioembolization*, is discussed with information about “Local and Regional Therapies.”



### MORE INFORMATION ABOUT TREATMENT OPTIONS

More information about treatment options for metastatic cancers can be found at the National Cancer Institute website, [www.cancer.gov](http://www.cancer.gov) and the American Cancer Society website, [www.cancer.org](http://www.cancer.org).

## CLINICAL TRIALS: THE SEARCH FOR NEW TREATMENTS

Because doctors are still trying to find more effective treatments for liver cancer, clinical trials are an important option to consider. Clinical trials are research studies that test whether a new treatment is safe and effective against cancer. Clinical trials also test whether a new treatment is better at treating specific cancers than the best practices available today (also known as the “standard of care”).

Participating in a clinical trial may give you the opportunity to be among the first to benefit from the most advanced treatment available. Clinical trials are conducted by the National Cancer Institute (NCI), cancer centers, medical universities, and pharmaceutical companies around the world.

They are conducted with the highest level of regulation and review to make sure participants are safe.

If you are interested in a clinical trial, ask your health care team about studies that you might qualify for.



### HOW TO FIND CANCER CLINICAL TRIALS

- **The National Cancer Institute’s** clinical trials registry is one of the most comprehensive cancer clinical trials registries available. Visit [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials) or call 1.800.422.6237
- **The Cancer Support Community’s** clinical trials search engine through EmergingMed: [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or call 1.800.814.8927
- **National Institutes of Health’s** search engine: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- **American Cancer Society’s** matching service and personal support hotline: [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials) or call 1.800.303.5691

For many of these search engines, you can search by trial type and stage of cancer, the treatment modality, and by geographic location. If you find a trial that you may want to participate in, ask your doctor for more information.

# 5

## *Managing Treatment Side Effects*

Everyone responds differently to treatment. You may feel no side effects, while someone else experiences many uncomfortable symptoms. Knowing what side effects to expect can help you prepare to deal with them. More importantly, being better informed may enable you, your doctor, and your nurse to proactively manage or possibly prevent side effects so that they won't decrease your quality of life or disrupt your treatment.

Consider also preparing for treatment by getting your support system ready. It is important to discuss any side effects you experience with your health care team so that they can help you minimize the effect.

## PALLIATIVE CARE

Palliative care is a medical specialty that focuses on preserving quality of life for those living with a chronic or life-threatening disease. Palliative care can be incorporated into one's treatment plan at any point, including right after diagnosis.

Palliative care can provide relief from pain and other disease-related symptoms and help manage side effects. It is often used in combination with other cancer treatments.

The palliative care team can also offer emotional support. Many hospitals have a palliative care service or a team of health care providers dedicated to this medical specialty. To learn more about palliative care, talk to your doctor or nurse.

*Make sure to let the doctors know your comfort zone. If you're experiencing pain, tell them how intense it is. The doctors don't want us to be in pain, if we don't have to be.*

— Ken, cancer survivor

## SIDE EFFECTS OF SURGERY

Your body will need time to recover from surgery. Initially, you will have pain or discomfort and you will receive medication to control the pain after surgery. Be sure to talk openly to your nurse or doctor about your pain. You will be asked to rate your pain on a scale of 0 (no pain) to 10 (worst pain imaginable). Let your health care team know if your pain is not well-controlled.

- It is important to remember that acetaminophen (Tylenol®), a common pain reliever, can damage the liver. You should *not* take acetaminophen unless the doctor treating your liver cancer instructs you to take it.
- You may also have abdominal discomfort—a feeling of fullness. Walking can help decrease the discomfort and return your bowel function to normal. Talk to your health care team about an exercise routine prior to engaging in any activity.

- The incision from your surgery will take time to heal. Your nurse will teach you how to take care of the incision when you return home. If you notice any redness or discharge at the surgical site, call your doctor right away.
- You may feel tired or weak after surgery. Take short naps (20-30 minutes), prioritize the things that are most important for you to accomplish and assign the rest of your tasks to family or friends.
- *Immunosuppressants*, drugs that decrease the response of your immune system to the new liver, will be given to reduce the potential for rejection. Ask your nurse or pharmacist about the side effects of the specific immunosuppressants you are taking.
- If you have a transplant, you will remain on antibiotics and immunosuppressants for a period of time after your transplant to protect you from infection.

If you have a liver transplant, you will first go to an intensive care unit after your surgery to recover.

- You will remain in the hospital for several weeks and may have a drain placed to help reduce fluid around the surgery site. Your doctor will be carefully assessing your condition to be sure that your body is accepting the new liver.

*Call your doctor right away if you experience a fever, redness or discharge at your surgery site, bleeding, or signs of liver failure—yellowing of the skin or whites of the eyes, dark urine, or confusion—after surgery.*



## SIDE EFFECTS OF LOCAL AND REGIONAL THERAPY

*Ablation* and *embolization* have short-term side effects that occur for a brief period of time after the procedure. Many of these side effects can last up to two weeks after the procedure.

- You will receive medication for abdominal pain or cramping and a prescription for pain medication to take at home. Take your medication as directed and let your health care team know if the pain is not well controlled.
  - A low grade fever (less than 101 degrees Fahrenheit) is common for up to 5 days after the procedure.
  - You will also receive medication to *prevent* nausea. Take it as directed—don't wait for nausea to occur before taking it.
  - Fatigue is also a very common side effect. Get adequate amounts of rest and increase your activity slowly.
- Other possible side effects include decreased appetite, constipation, and abdominal bloating.

*Call your doctor if you experience severe pain, a high fever or swelling at the puncture site after you return home from local or regional therapies.*

## SIDE EFFECTS OF SYSTEMIC THERAPIES

Treatments like sorafenib (Nexavar®) cause side effects such as fatigue, diarrhea, high blood pressure, and skin reactions. Sorafenib can interfere with wound healing and may be stopped if problems occur.

### Diarrhea

Keep the following in mind if you experience diarrhea:

- Tell your health care team if you are experiencing diarrhea. Take anti-diarrhea medicine if prescribed by your doctor.
- Stay hydrated. Room temperature fluids, like water, sports drinks, clear broth or ginger ale without fizz are best.
- Eat 5 or 6 small meals a day, rather than 3 large meals.
- Eat low fiber foods and avoid spicy or fatty foods and milk products.
- Wipe gently after each bowel movement; baby wipes may be most comfortable.

### High Blood Pressure

Your blood pressure will be monitored carefully. If it is high, you may be treated with medication.

*Call your doctor if you experience chest pain, light-headedness, high fever, bleeding or severe abdominal pain after receiving a targeted therapy. Also call if you develop swelling and blisters on your hands or feet.*

### Skin Reactions

Skin reactions can include rash, dry skin, itching, and peeling skin on the hands and feet. The hands and feet are most often affected, but a rash can occur anywhere.

- Apply moisturizing lotion to hands and feet before starting Nexavar®, and daily thereafter.
- Let your doctor know about any skin reaction you experience.

## SIDE EFFECTS OF CHEMOTHERAPY

- Use a mild, soap-free and fragrance-free cleanser, and moisturize your skin well.
- During treatment, talk to your doctor before you change your laundry detergent, lotion, or deodorant. Making these changes mid-treatment can cause your skin to become itchy and red.
- If your skin is itchy, take quick, lukewarm showers or try an oatmeal bath.
- Always use sunscreen.
- Ask your doctor if you should use a steroid cream on your rash.
- Avoid infection and call your doctor if you see blistering, bleeding or oozing.

Each chemotherapy agent causes a unique set of side effects. Your oncology nurse will discuss the side effects you can expect based on your treatment plan. If you are taking chemotherapy drugs as part of a clinical trial, the research nurse will discuss any side effects you should anticipate for the specific drugs you are taking. Ask for information about the best way to manage those side effects.

## SIDE EFFECTS OF RADIATION THERAPY

If you receive external radiation therapy, you may experience nausea, vomiting or diarrhea among other possible side effects. Radiation also causes fatigue and can reduce your blood counts, leading to:

- low white blood cells, which increase your risk for infection
- low platelets, which increase your risk for bleeding
- low red blood cells, which may make you feel tired and short of breath.

Radiation therapy can cause skin changes that include redness, dry or peeling skin, itching, blisters, and swelling.

- Your radiation oncologist and nurse will talk to you about skin care. Be gentle with your skin. Don't use any lotions or creams unless the radiation treatment team recommends them.
- Don't put anything hot like a heating pad, or cold like an ice pack, on the area being treated.
- Wear soft clothes and use soft sheets made of fabrics like cotton.

*Call your nurse or doctor if your skin blisters or swells, you have diarrhea for more than 24 hours, or you are too nauseated to drink liquids after receiving external radiation therapy. Let your health care team know if you have a fever or any signs of infection, bleeding or are short of breath.*

# General Tips to Help Manage Side Effects

- Prioritize your activities and pace yourself.
- Identify the time of day when you have higher energy, and do your goals or tasks for the day then.
- Good nutrition maintains energy, strengthens the immune system and can decrease side effects.
- Adequate fluid intake avoids dehydration, prevents constipation, and decreases fatigue.
- Try to get some physical activity every day. Exercise combats fatigue, helps maintain physical function, promotes restful sleep, and can elevate your mood.
- Maintain good personal hygiene, like washing your hands. Good hygiene decreases the risk of infection.
- Try mind-body activities such as yoga, meditation and guided imagery to help to reduce stress and increase energy.
- Participation in a support group can help you understand and manage your feelings and provide an opportunity for you to connect with others facing cancer.



## LEARN MORE ABOUT SIDE EFFECTS MANAGEMENT



Useful tips to better manage common side effects such as fatigue, nausea, skin rashes, and low blood counts can be found in the Cancer

Support Community's booklet: *Frankly Speaking About Cancer: Treatments & Side Effects*. Order a free booklet at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or call 1-888-793-9355.

# 6 *Quality of Life*

Because the cancer experience exposes you to the fragility of life, it gives you an opportunity to reprioritize things that are important to you, do things you've left undone, and offers you a new perspective on how to live for each present moment. You may learn to find a “new normal” that can help you focus on today.

*Life is no less beautiful, and everything you have to offer is no less diminished because you have cancer. Try to find opportunities to grow closer to family or friends. Get support, don't be afraid to lean on others.*

— Terri, cancer survivor

## HOW MUCH EMOTIONAL DISTRESS IS NORMAL?

Some signs or symptoms might indicate that professional help is required to manage feelings of distress.

Talk to your doctor or nurse if you experience the following:

- Sadness or worry so severe that you miss or postpone your treatment appointments
- Fear that leads to panic or an overwhelming sense of dread
- An inability to make any decisions or difficulty concentrating
- Sleeping less than 4 hours per night or having no appetite for a period of weeks
- Extreme irritability or anger
- Feeling despair or hopelessness
- Constant thoughts about cancer or death
- Feeling worthless or suicidal thoughts

## THE VALUE OF SUPPORT

There has been extensive research on the benefits of support groups as a way to cope with cancer and improve quality of life. Studies show learning to express a wide range of emotions within a support group or through individual therapy can lead to:

- Decreased feelings of hostility
- Greater self-confidence and assertion
- Greater access to support, empathy, interest, and humor
- Better physical functioning
- An improved overall quality of life

If you are unable to attend, or not interested in a traditional support group, consider online support groups, chat rooms or other means to connect with valuable sources of support. Connecting with other survivors is an important way to feel connected and hopeful while gaining practical guidance.

## THE MIND-BODY-SPIRIT CONNECTION

The medical community is increasingly aware of how the mind and body work together in our overall health. Making the mind-body connection can make a significant difference for people with cancer. Complementary and alternative medical techniques for relaxation, such as yoga, meditation, acupuncture or massage, can be used by people living with cancer who wish to relieve symptoms or side effects, and reduce their stress.

Here are some examples of mind-body practices:

- **Guided Imagery** – a simple, effective way to transform your emotional state while incorporating deep breathing and meditation. The feelings you experience are governed by the thoughts and images on which you focus. Think of something positive and your emotions will be led in that direction.
- **Yoga** – a mindful movement practice that includes stretching and strengthening poses, breathing exercises and meditation practices.
- **Qigong and Tai Chi** – both are Chinese practices using physical movements that are believed to promote the flow of “qi” or life force and thought to promote internal harmony, good health and vitality.
- **Mindfulness Meditation** – a self-directed practice for relaxing the body and calming the mind. Meditation can be done while sitting quietly or while moving mindfully, such as a walking meditation.

If you use alternative medical techniques, such as dietary supplements or herbs, it is important to tell your doctor, to ensure safety while undergoing cancer treatment.



### COMPLEMENTARY AND ALTERNATIVE MEDICINE

The National Center for Complementary and Alternative Medicine ([www.nccam.nih.gov](http://www.nccam.nih.gov)) is a valuable source of information about the safety of these practices.



## MAKING PLANS

It is a good idea for all adults, no matter their health situation, to prepare for the future by having their affairs in order. The following legal documents are tools to help you do that:

- A **will** is a legal document that designates who will receive your money and belongings and who will be responsible for your children (in the absence of another parent). If there is no will in place, an agent of the state may become responsible for these decisions.
- A **living will** is a legal document to let your doctor know what kind of medical care you want at the end of your life if you can't speak for yourself.
- A **durable power of attorney** is a person who will make health care decisions for you if you are unable to make them yourself.
- A **do not resuscitate (DNR) order** is an order for your doctor if you determine that you would not like heroic measures to be taken in the event of cardiac or respiratory arrest.
- An **ethical will** is a way to share your values, blessings, life's lessons, hopes and dreams for the future with your family, friends, and community. Many people find this an important part of their planning as it can bring them a sense of purpose and satisfaction.

Choose someone you feel very comfortable with to make plans like these. If you make these plans, you will help your family and loved ones by not leaving them with very difficult decisions at a time when they are emotionally overwhelmed. You will be reducing confusion and helping everyone around you feel more comfortable that the medical decisions made are yours.

## IF CANCER RETURNS

Sometimes cancer returns or is advanced and cure is not an option. Yet, there are still many opportunities for joy. It is important that you continue to seek support in your efforts to live well. At some point, you may need to weigh the advantages of continuing active treatment to control the cancer pain or relieve symptoms.

The decision about how to proceed should be based on your personal goals and your doctors' recommendations. Pain or symptoms that decrease your quality of life should be addressed. Your health care team should be as active in ensuring your comfort as they were in the treatment of the cancer.

*I know a liver cancer diagnosis is dire. But between the moment you are told you have this to the last moment, there is a lot, a lot that the patient and the family goes through. Even if it is just months, it is still a lot to go through and the patient and the family need a lot of support.*

— Ernestine "Mikki," caregiver

## HOSPICE CARE

Is a coordinated program to provide symptom management and support to patients and their loved ones when a patient has only a few more weeks or months to live. Hospice involves care provided by doctors, nurses, social workers, chaplains and volunteers, with care delivered in a hospice setting, or in the patient's home.

For more information about hospice, go to [www.hospicenet.org](http://www.hospicenet.org).

## FINDING HOPE

People affected by cancer hope for many things: peace in relationships; good communication with doctors; a way to come to terms with cancer; and certainly for the recovery of physical and emotional health. Hope is found throughout the cancer experience in a variety of ways—and science is offering new hope for the best possible treatments available today and in the future.

By being empowered you can balance optimism and hope with a realistic understanding of your experiences. You can more effectively deal with information, regain a sense of control, and find hope that you are not alone.

*A few good things can come from being smacked in the face with your own mortality: your priorities put in proper order, and deep, meaningful and helpful friendships with fellow ‘warriors.’ These things can make you stronger than you ever thought possible.*

— Alan, online support group participant,  
Cancer Support Community



CANCER SUPPORT HELPLINE®

CANCER SUPPORT  
HELPLINE  
888-793-9355

Whether you are newly diagnosed with cancer or a long-time cancer survivor or caring for someone with cancer, CSC’s Toll-Free Cancer Support Helpline is open Monday-Friday from 9 a.m. – 8 p.m. ET. Call 1.888.793.9355 for support. If you receive a recording, please leave your name and contact number and one of our counselors will call you as soon as possible.

# 7 *Resources*

## **Liver Cancer Specific Information & Support**

### **American Liver Foundation**

800-465-4837

[www.liverfoundation.org](http://www.liverfoundation.org)

### **The Asian Liver Center at Stanford University**

888-311-3331

<http://liver.stanford.edu/>

### **CanLiv: The Hepatobiliary Cancers Foundation**

[www.canliv.org](http://www.canliv.org)

### **Cancer Support Community**

888-793-9355

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

## **General Cancer Information & Support**

### **American Cancer Society**

800-227-2345

[www.cancer.org](http://www.cancer.org)

### **CancerCare**

800-813-4673

[www.cancercare.org](http://www.cancercare.org)

### **Cancer.net**

800-651-3038

[www.cancer.net](http://www.cancer.net)

### **Cancer Support Community**

888-793-9355

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

### **National Cancer Institute**

800-422-6237

[www.cancer.gov](http://www.cancer.gov)

## Financial & Legal Support

### Cancer and Careers

646-929-8032

[www.cancerandcareers.org](http://www.cancerandcareers.org)

### Cancer Legal Resources Center

866-843-2572

[www.cancerlegalresourcecenter.org](http://www.cancerlegalresourcecenter.org)

### Co-Pay Relief Program

866-512-3861

[www.copays.org](http://www.copays.org)

### Healthcare.gov

800-318-2596

[www.healthcare.gov](http://www.healthcare.gov)

### LIVESTRONG

855.220.7777

[www.livestrong.org](http://www.livestrong.org)

### NeedyMeds

800-503-6897

[www.needymeds.org](http://www.needymeds.org)

### Patient Access Network Foundation

866-316-7263

[www.panfoundation.org](http://www.panfoundation.org)

### Patient Advocate Foundation

800-532-5274

[www.patientadvocate.org](http://www.patientadvocate.org)

## Clinical Trials

### CSC's Emerging Med Search

800-814-8927

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

### National Cancer Institute's Clinical Trials Registry

800-422-6237

[www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

## Caregiver Support & Complementary Support

### Caregiver Action Network

202-772-5050

[www.caregiveraction.org](http://www.caregiveraction.org)

### Family Caregiver Alliance National Center on Caregiving

800.445.8106

[www.caregiver.org](http://www.caregiver.org)

### National Center for Complementary and Alternative Medicine

888-644-6226

[www.nccam.nih.gov](http://www.nccam.nih.gov)

# CSC's Resources for Support

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Cancer Support Community's resources and programs below are available at no charge.

## CANCER SUPPORT HELPLINE®



Whether you are newly diagnosed with cancer, a long-time cancer survivor, or caring for someone with cancer, CSC's TOLL-FREE Cancer Support Helpline (1-888-793-9355) is staffed by licensed CSC Call Counselors available to assist you Monday-Friday from 9 am-8 pm ET. Our Call Counselors have been trained to answer your questions and link you to valuable information.

## CANCER EXPERIENCE REGISTRY



The Cancer Experience Registry is designed to help people impacted by cancer, particularly those living with multiple myeloma, to share their story, to learn about the experiences of others and to help transform the cancer experience. People who participate are connected to a network of support and resources. Findings from the Registry help us all better understand the social and emotional needs of people living with cancer and improve the ways in which care is delivered. Join today at [CancerExperienceRegistry.org](http://CancerExperienceRegistry.org).

## OPEN TO OPTIONS™



Free one-on-one treatment decision counseling is available with licensed mental health professionals who help patients process information and formulate a list of specific questions for the oncologist. Appointments can be made by calling 1-888-793-9355, visiting [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org), or by contacting an affiliate providing this service.

## AFFILIATE NETWORK SERVICES

Over 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, yoga, nutrition and mind-body programs for people affected by cancer. For a full list of affiliate locations, visit [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org) or call 1-888-793-9355.

## THE LIVING ROOM, ONLINE

"The Living Room" offers much of the same programming available at each CSC affiliate, online. You will find web-based support groups, discussion boards and social networking, a "build your own website" service, and educational materials for patients and caregivers. Join today at [www.cancersupportcommunity.org](http://www.cancersupportcommunity.org).

*These services are made available with generous contributions from CSC supporters.*

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## GRAPHIC DESIGN

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## THE CANCER SUPPORT COMMUNITY

[www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)

The mission of the Cancer Support Community (CSC) is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of 55 licensed affiliates, over 100 satellite locations and a vibrant online community, touching more than one million people each year.

## CANLIV –

## THE HEPATOBILIARY CANCERS FOUNDATION

[www.canliv.org](http://www.canliv.org)

CanLiv's vision is to be the catalyst that brings together patients and their families affected by hepatobiliary cancers, with doctors, researchers and partners, to create a community of stakeholders that will work together to advance research and improve patient outcomes by:

- Providing accurate, current Patient Resources to assist patients and their families in understanding their cancer diagnosis and finding the best possible treatment options.
- Engaging and uniting the cancer research and patient communities to drive the science that will improve hepatobiliary cancer patients' outcomes.
- Sponsoring an annual Biliary Cancer Translational Research Symposium.



Cancer Support Community and CanLiv provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professional to answer questions and learn more.

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THIS PROGRAM WAS MADE POSSIBLE WITH UNRESTRICTED EDUCATIONAL GRANTS FROM:



People with cancer who *actively* participate in *their care* along with their health care team will improve the *quality* of their lives and may *enhance* the possibility of recovery. People with cancer who *actively* participate in *their care* along with their health care team will improve the *quality* of their lives and may *enhance* the possibility of recovery.