



LIVER CANCER



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**GILDA'S
CLUB**

If you or a loved one is diagnosed with Liver Cancer, also called Hepatocellular Carcinoma (HCC), you may have many questions and will need to make several decisions. This booklet gives an overview of liver cancer diagnosis and treatment, addresses caregiver concerns, and helps you cope with the different impacts of liver cancer. We hope this resource will help you learn more about your treatment options, improve communication with your care team, and empower you to take control of your diagnosis.



What is Liver Cancer?

Liver cancer is a cancer that forms from the tissues of the liver. The liver is one of the largest organs in the body. It is on the right side of the body protected by the rib cage. The liver has three important functions:

1

To filter waste
and toxins
from the blood

2

To make bile,
which aids in
digestion

3

To store
energy

Secondary liver cancer is more common than **primary liver cancer**. This means the cancer has spread from a primary site and did not start in the liver. Liver cancer is rarely diagnosed early which can change treatment options. You may hear many words used to talk about liver cancer. Some keywords to know are:

1. **JAUNDICE** (JAWN-dis) – the yellowing of the skin or the whites of the eyes and dark-colored urine
2. **ASCITES** (uh-SY-teez) – abnormal buildup of fluid in the abdomen. This may cause swelling. In later stage cancers, tumor cells may be found in this fluid. This can also occur in people with non-cancerous liver diseases.
3. **ESOPHAGEAL VARICES** (ee-SAH-fuh-JEE-ul VER-uh-seez) – abnormally enlarged blood vessels (most often veins) in the esophagus (throat). These can develop when blood to the liver is obstructed by a clot or scar tissue.
4. **CIRRHOSIS** (seh-ROH-sis) – a disease where liver cells are damaged and replaced by scar tissue
5. **HEPATITIS** (HEH-puh-TY-tis) – a group of viruses that affect the liver. It can also refer to general inflammation of the liver. This can be caused by some treatments used for liver cancer
6. **PRIMARY SITE OR PRIMARY CANCER** – the original site or organ where cancer began
7. **METASTASIS** (meh-TAS-tuh-sis) – when cancer spreads to other parts of the body from the primary location
8. **TUMOR** (TOO-mer) – a swelling of part of the body due to abnormal tissue growth. Tumors can be benign (non-cancerous) or malignant (cancerous)
9. **PARACENTESIS** (PAYR-uh-sen-TEE-sis) – a procedure where a thin needle or tube is put into the abdomen to remove fluid.
10. **PARTIAL HEPATECTOMY** (HEH-puh-TEK-toh-mee) or Liver Resection (ree-SEK-shun) – the removal of a piece of the liver affected by cancer
11. **LIVER TRANSPLANT** – the removal and replacement of the entire liver with a donated organ



Diagnosis & Staging

Risk Factors

Risk factors are things that can increase the chance of developing a disease. Certain cancer risk factors, such as smoking or diet, can be changed. Other cancer risk factors, like a person's age or family history, cannot be changed. Having one or many risk factors does not mean that a person will get the disease. Liver cancer risk can be reduced by protecting yourself from hepatitis and cirrhosis. The following are risk factors for developing liver cancer:

- 1. VIRAL HEPATITIS** – Hepatitis is one of the largest risk factors. Hepatitis viruses infect the liver and include hepatitis A, B, and C (HAV, HBV, HCV). Hepatitis is contracted in several ways. Prevention is possible through:
 - a. Vaccination (for HAV & HBV)
 - b. Safe sex practices (i.e., the use of condoms)
 - c. Avoiding intravenous (IV; into the vein) drug use
 - d. HCV can be treated and cured with proper medication
- 2. CIRRHOSIS** – Cirrhosis is a disease where liver cells are damaged and replaced by scar tissue from inflammation. People with cirrhosis have an increased risk of liver cancer. Many (but not all) people who develop liver cancer already have some evidence of cirrhosis. There are several possible causes of cirrhosis. Most cases occur in people who misuse alcohol or have a preexisting hepatitis infection
- 3. SEX ASSIGNED AT BIRTH** – Liver cancer is much more common in people assigned male at birth than those assigned female
- 4. AGE** – In the U.S., adult primary liver cancer occurs most often in people over the age of 65
- 5. RACE AND ETHNICITY** – In the U.S., non-Hispanic American Indian/Alaskan Native people have the highest rates of liver cancer, followed by Hispanics and Latinos, Asian Americans and Pacific Islanders, non-Hispanic Black or African American people, and whites



6. **INHERITED METABOLIC DISEASE** –

Certain genetic diseases can lead to cirrhosis. For example, people with hemochromatosis (HEE-moh-kroh-muh-TOH-sis; a condition where the body stores more iron than it needs) are more likely to develop cirrhosis because of the high levels of iron in their liver

7. **DIABETES** – Diabetes can also increase the risk of liver cancer, usually in people who have other risk factors such as heavy alcohol use and/or hepatitis

8. **OBESITY** – Obesity may increase the risk of liver cancer due to the increased risk of fatty liver disease and/or cirrhosis

9. **ANABOLIC STEROIDS** – These are male hormones used by some athletes to increase strength. Long-term use of steroids can increase the risk of liver cancer. Cortisone-like steroids such as hydrocortisone, prednisone, and dexamethasone **DO NOT** carry this same risk

10. **ARSENIC** – regular exposure to drinking water contaminated with arsenic, such as

that from some wells, can increase the risk of liver cancer. This is more common in parts of East Asia, but may be a concern in some areas of the U.S.

11. **NONALCOHOLIC FATTY LIVER DISEASE** – buildup of fat in the liver not related to the misuse of alcohol

12. **EXPOSURE TO AFLATOXINS** – Aflatoxins are poisons produced by molds that grow in some crops, like grains, corn, and nuts. Despite regulations, these food products can become contaminated and could be eaten by anyone

13. **EXCESSIVE ALCOHOL CONSUMPTION** – Drinking more than a moderate amount of alcohol daily over many years can lead to irreversible liver damage and increase your risk of cirrhosis and liver cancer

For more information on liver cancer risk factors, visit:

www.CancerSupportCommunity.org/Liver-Cancer

Signs and Symptoms of Liver Cancer

Many of the signs and symptoms of liver cancer are like those of other cancers. Common signs and symptoms of liver cancer may include:

1. A hard lump or swelling on the right side of the abdomen, just below the ribs
2. Pain or discomfort on the upper side of the abdomen
3. Pain by the right side of the shoulder blade
4. Jaundice
5. Nausea, loss of appetite, or feeling full shortly after you begin to eat
6. Unexplained and unintentional weight loss
7. Fatigue
8. Swollen abdomen, bleeding (symptoms of cirrhosis)
9. White, chalky stools

If you have any of these symptoms or other concerns, speak with a health care provider.

Liver Cancer Diagnosis

Liver cancer is sometimes referred to as a “silent disease.” This is because early liver cancer rarely causes symptoms. Diagnosis typically begins with a physical exam. During the physical exam, the doctor will feel your abdomen to check the liver, spleen, and other organs for lumps or changes to size and shape. The doctor will also check for any fluid buildup in your abdomen as well as signs of jaundice. Further testing may be recommended and include:

1. **BLOOD TESTS** – Samples of blood are used to check for liver problems. Your doctor may request tests like:
 - a. **Complete blood count (CBC)** that shows how many of each type of blood cell you have
 - b. **Basic or Comprehensive Metabolic Panel (BMP/CMP)** that gives information about your metabolism and how your body turns food into energy
 - c. **Liver (Hepatic) Function Panel** which shows how well the liver is working
 - d. **Alpha Fetoprotein (ALF-uh FEE-toh-PROH-teen) Test (AFP)** – This test shows how much of this protein is in the blood. Too much of this protein may mean you have a tumor. High AFP can also be caused by other cancers and non-cancerous conditions.
2. **LAPAROSCOPY** – This procedure allows your doctor to view your organs through a small cut in the abdomen using a small camera called a laparoscope
3. **CT SCAN** – Stands for “computed tomography” and is a type of X-ray machine that takes detailed pictures of the liver, other organs, and blood vessels in the abdomen. This can allow doctors to see tumors in the liver or other areas of the body
4. **ULTRASOUND** – Sound waves and a computer are used to create a picture

of your liver and other organs in the abdomen. This can show tumors or abnormalities

5. **MRI** – Stands for “magnetic resonance imaging” and uses magnets and radio waves to create pictures of areas in the body. A special dye or coloring called “contrast” may be injected to help doctors see any blockages that could be caused by a tumor
6. **ANGIOGRAM** – A doctor injects dye into an artery so that the blood vessels of the liver can be seen in X-ray images. This can reveal a tumor in the liver
7. **BIOPSY** – A small piece of the liver is taken and studied under a microscope. This can be taken through “fine needle aspiration” (inserting a thin needle into the liver). The doctor may choose to do a “core biopsy” instead, which uses a thicker needle or tube and small camera

Staging

If your test results indicate that you have liver cancer, your doctor will then need to stage your cancer. Staging is finding out how widespread cancer is. The stage of liver cancer is one of the most important factors in considering treatment options.

Staging is a standard way for the cancer care team to summarize the 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 make up the “**TNM Staging System.**” Numbers or letters that appear after T, N, and M provide more details about each of these factors:

1. Numbers 0-4 show severity (0 being the least severe and 4 being the most severe)
2. The letter “X” means “cannot be assessed” because information is not available

Liver cancer is unique in that it occurs mostly in people who have some liver damage. The degree of liver damage is very important when deciding treatment. Because of this, it is more common that liver cancer is staged using the **“Barcelona Clinic Liver Cancer (BCLC) Staging System.”** This system is used to predict chances of recovery and plan treatment based on:

1. Whether the cancer has spread within the liver or to other parts of the body
2. How well the liver is working
3. The general health and wellness of the person
4. The symptoms caused by the cancer

BCLC uses 5 stages:

1. Stage 0: very early
2. Stage A: early
3. Stage B: intermediate
4. Stage C: advanced
5. Stage D: end-stage

For adults diagnosed with liver cancer, treatment options also group certain stages:

1. Liver cancer staged 0, or A can often be removed by surgery
2. Stage B liver cancer is commonly treated with treatments directed to the liver only – such as radiation or chemoembolization
3. Stage C liver cancer has spread to the blood supply to the liver or outside of the liver. Stage C liver cancer cannot be safely removed by surgery
4. Metastatic liver cancer has spread to other parts of the body and cannot be removed by surgery alone. This indicates Stage D liver cancer. This means that the liver has had significant damage. People with Stage D liver cancer are often too sick to proceed with cancer treatment. In this case, your health care team may discuss palliative care as the next step in your treatment. Palliative care focuses on your comfort and quality of life. We'll explain more about this treatment option later.

Understanding the stage of your liver cancer can help you to actively participate in your treatment alongside your health care team.

Questions to ask your health care team

There's a lot to know about a liver cancer diagnosis. Here are some questions you and your caregiver may want to consider asking:

- What is the exact name of the kind of cancer I have?
- What is the type, subtype (if there is one), and stage?
- Where did the cancer start?
- Where is it located now?
- [If you had a prior cancer] Is this the same type of cancer I had before?
- Are there other tests, scans, or biopsies that should be done to help decide what treatment I should have?
- Do you have a suggestion for where to go or someone to see for a second opinion?
- Which treatment do you recommend and why?

For each treatment you consider, ask:

- What is the goal of this treatment?
- Where will treatment take place?
- How often will I go there and how long will it take?
- What are the possible side effects and how are they managed? Is there anything I can do before my treatment that can help?

Consider your treatment goals and discuss them with your caregiver(s) and health care team when asking these questions.

Choosing Your Treatment Team

Cancer treatment is complicated and changes all the time with new discoveries. You deserve a healthcare team you can trust to take the best care of you. Look for doctors who have experience treating liver cancer. Choosing the right doctor and team is especially important for liver cancer due to the uniqueness of the disease.

It is very important to seek an oncologist that has treated HCC before. HCC is a very distinct cancer and is treated differently from other cancers. Some treatments for liver cancer can harm the liver in the cases of primary HCC so finding an experienced physician is important.

Most cancer treatment centers use a team approach in evaluating people with liver cancer. This helps professionals focus on the person (and family), not just the cancer. Teams can include specialized doctors, nurses, and other health care professionals. This is called “multidisciplinary care.”

Your multidisciplinary team may include:

Physicians:

- Medical oncologist - who specializes in liver cancer
- Surgical oncologist - this could be a general surgeon or transplant surgeon depending on your treatment
- Radiation oncologist – a doctor who has special training in using radiation to treat cancer
- Gastroenterologist – a doctor who has special training in diagnosing and treating disorders of the digestive system
- Interventional radiologist – a radiologist who uses imaging (like ultrasounds) to guide procedures inside your body
- Hepatologist – a doctor who has special training in treating liver diseases

Nurses and Nurse Navigators:

- Oncology Nurse – serves in many roles, including giving chemotherapy, medications and other treatments, identifying your needs, communicating with other team members, providing education and support.
- Nurse Navigator – helps you through the care system, from diagnosis through treatment, and in recovery.

Mid-level Providers/Practitioners:

Nurse Practitioners (NPs) or Physician Assistants (PAs) – Your oncologist may work with oncology NPs, or PAs. These providers support your oncologist.

Nutritionist/Dietitian:

Liver cancer can affect eating, digestion, and metabolism. A registered dietitian (RD) can recommend foods to help you eat comfortably and get the nutrients you need.

Palliative Care Specialist or Team – assists you with prevention and treatment of pain and other symptoms associated with cancer and/or its treatment, focusing on quality of life (may also be called supportive care).

Social Worker – helps you and your loved ones find resources to cope with cancer, cope with treatment, and pay for care.

Chaplain – provide you with spiritual support. Chaplains assist people from every faith and background, including people with no religious faith or affiliation.

Mental Health Professionals:

provide you with support for your mental and emotional wellbeing. Cancer is a lot to deal with. Having someone to talk to can impact how you look at things. It may help you find or maintain the energy you need to get through treatment and take the best possible care of yourself. It is a good idea to seek support early on so you have somewhere to turn when you should need or want it.

Questions to Ask Doctors You are Considering

- How many patients with liver cancer have you treated?
- How do you stay up to date on the latest treatments? (Look for someone who attends scientific meetings, reads medical journals, or actively researches liver cancer.)
- Do you work with other specialists as part of your team?
- What other support services do you offer to people with liver cancer?
- Do you offer treatment through clinical trials?

Communicate with Your Team

The next step is to make sure you work with your team in a way that is most helpful to you. Here are some tips for communicating with your health care team:

- Keep a running list of questions to bring to office visits
- Bring a friend or family member to appointments to help listen and take notes
- Ask about the best way to get your questions answered. Is it better to call, email, use a patient portal, or bring a list to appointments? Do you need to schedule a separate appointment to ask all of your questions?
- Find out who to contact with questions and concerns between visits. Write down their contact information
- Ask questions until you are sure you understand. You deserve to get your questions answered in a way that makes sense to you. It's okay to ask the same question again. Tell your doctor if you need something described in a different language or format (for example, a picture or video)
- Tell your team about:
 - Any side effects or symptoms you notice
 - Current and past concerns about your mental, emotional, and physical health
 - Any natural treatments you are taking – including herbs, vitamins, supplements, or other complementary treatments
 - Medicines prescribed by any other doctor for other health conditions
- Make sure your treatment goals and preferences are known and honored

You are a valued member of your health care team. Knowing that you can give your health care team open and honest feedback is critical to treatment success, whatever that means for you, and can be essential to your physical and emotional health.

Get a Second Opinion

If you are unsure of your doctor or hospital for any reason at any time, get a second opinion. Many people with cancer get a second or even third opinion from another oncologist or cancer center. Many doctors even encourage it.

Talking with other doctors can help you make a decision or confirm your current treatment plan. Another hospital or doctor may offer a different treatment or more useful support services. They may be a better fit for you in other ways. Do not worry about hurt feelings. You can always return to the first doctor if you want.

A second opinion may:

- Help you feel more confident that you are getting the best possible care
- Be especially helpful if one treatment stops working and you're looking for the next one to try
- Give you some new suggestions for treatment and management of side effects

If possible, try to get a second opinion from a doctor at a National Cancer Institute (NCI) designated cancer center or university hospital, especially if you have advanced or metastatic cancer.

Treatment Planning

As you discuss treatment you will be asked to make decisions. You might help choose the type of treatment, the timing of treatment, or the order of treatments. You may have the option to try a clinical trial. Making these choices is called treatment planning.

Good communication with your doctors will make treatment planning easier. Talk with them about your needs and preferences. Work to understand what they are saying about the stage and location of the cancer, and why one treatment might be more effective than another. Ask questions.

Treatment planning takes into account:



The stage and location
of the cancer



Your
symptoms



The side effects
of treatments



Your goals for the
treatment



Your personal
preferences



Open to Options®

If you are facing a cancer treatment decision, the Cancer Support Community's Open to Options® program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options® specialists can help you create a written list of specific questions about your treatment plan for your doctor. **Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.**

Treatment Options

Treatment for liver cancer will depend on the stage of your cancer, the presence of other conditions like cirrhosis, your general health, and your preferences.

Try to learn about the options and work with your health care team to make decisions that are right for you.

Surgery

Surgery is usually the first treatment for liver cancer. The goal is to remove as much of the cancer as possible. For early-stage cancers, only portions of the liver may need to be removed (resected). More advanced cancers may require full liver removal and the transplantation of a donor organ. The most common surgeries for liver cancer include:

Surgeries to remove the tumor

1. Minor liver resection: also called a partial hepatectomy, segmental resection, or wedge resection. This is when the cancer

and a small portion of healthy liver tissue around the tumor is removed

2. Major liver resection: also called a right or left hepatectomy or lobectomy. This procedure removes the entire right or left lobe of the liver
3. Multiple liver resections: multiple tumors may be resected at the same time. This can be performed as a part of a major or minor liver resection
4. Two-stage liver resection: If it is too dangerous to remove multiple tumors at one time, your doctor may do the resection in two stages. The first operation removes part of the tumor. Then, your liver "regenerates" (grows toward original size) for a few weeks to create more healthy tissue. This way, you will have enough healthy liver for a second resection

For these procedures to be effective, the tumor(s) must be small and liver function should be good. These options also depend on the location of your cancer within the liver. You can have up to two-thirds of your liver removed as long as the remainder is healthy. If the remaining liver is healthy, the liver will grow back to its original size! These procedures are minimally invasive and can be performed laparoscopically (using a series of smaller incisions and special instruments), and in some cases robotically.

Total Hepatectomy and Liver Transplantation

The entire liver is removed and replaced by a healthy part of, or a whole, liver from a donor. 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 you wait for a donor liver to become available.

Localized Treatments

Localized treatments for liver cancer are those that are administered directly to the cancer cells or the area surrounding cancer cells. Localized treatment options for liver cancer include:



Heating cancer cells: also called “radiofrequency ablation,” this procedure uses electric current to heat and destroy cancer cells. Using an imaging test (like ultrasound) as a guide, the doctor inserts one or more thin needles into small incisions in your abdomen. When the needles reach the tumor, they’re heated with an electric current. This destroys the cancer cells. Other procedures to heat cancer cells might use microwaves or lasers.



Freezing cancer cells: also called “cryoablation,” uses extreme cold to destroy cancer cells. During the procedure, your doctor will place an instrument called a “cryoprobe” filled with liquid nitrogen directly onto liver tumors. Ultrasound images are used to guide the cryoprobe and monitor the freezing of the cells.



Percutaneous Ethanol Injection: simply explained as the injection of ethanol (alcohol) into the tumor. Pure alcohol is injected directly into tumors either through the skin or during surgery. Alcohol causes cancer cells to die.



Chemoembolization: the injection of chemotherapy (strong anti-cancer) drugs directly into the liver, killing cancer cells.



Radioembolization: placing small spheres (beads) that contain radiation are placed directly into the liver where they deliver radiation to the tumor, killing cancer cells.

Radiation Therapy

Radiation therapy uses high-powered energy from sources such as X-rays and protons to destroy cancer cells and shrink tumors. Doctors carefully direct the energy to the tumor and avoid healthy tissue.

Radiation therapy might be an option if other treatments aren’t possible or if they haven’t helped. For advanced liver cancer, radiation therapy may help to control symptoms. The common types of radiation therapy for liver cancer include:

- **External Beam Radiation:** during this procedure you lie on a table and a machine directs energy beams to the site of a liver tumor
- **Stereotactic Body Radiotherapy:** a specialized type of radiation therapy. This involves focusing many beams of radiation simultaneously at the site of a liver tumor

Targeted Therapy

Targeted therapy focuses on specific abnormalities present within cancer cells. By blocking these abnormalities, targeted drug treatments can cause cancer cells to die. Many targeted drugs are available for treating advanced liver cancer. Some targeted therapies only work in people whose cancer cells have certain genetic mutations. Your cancer cells may be tested in a laboratory to see if these drugs can help you. Targeted therapies for liver cancer include:

- **Tyrosine Kinase Inhibitors (TKIs)** – These drugs block several kinase proteins which allow tumor cells to grow or allow blood supply to tumors to increase. Blocking these proteins can help stop the growth of cancer cells.

- Monoclonal antibodies – Also called “angiogenesis inhibitors,” these drugs are man-made versions of immune system proteins (antibodies) that attach to a specific target on cancer cells. These affect the tumor’s ability to form new blood vessels, a process called angiogenesis. These treatments target the vascular endothelial growth factor (VEGF).

Immunotherapy

Immunotherapy uses your immune system to fight cancer. Your body’s disease-fighting immune system may not attack your cancer because the cancer cells produce proteins that blind the immune system cells. Immunotherapy works by interfering with that process.

Immunotherapy treatments are generally only offered to people with advanced liver cancer. The drugs used to treat liver cancer are considered checkpoint inhibitors. They include:

- PD-1/PD-L1 inhibitors – These drugs target a protein on immune cells called PD-1. This protein can prevent the immune system from attacking cancer cells. By blocking it, the drugs help the immune system fight cancer. Rash and skin changes along with fatigue and diarrhea are the common side effects with this therapy.
- CTLA-4 inhibitors – These drugs block a different protein that keeps immune cells from attacking cancer cells. Given through a vein or an IV, they are sometimes used at the same time as a PD-1 inhibitor. Possible side effects include cough, decreased appetite, diarrhea, fatigue, fever, nausea, pain in the muscles or joints, and skin problems (rashes, itching). It is very important to report any side effects to your doctor right away. In rare cases, CTLA-4 inhibitors can cause severe reactions, even months after treatment.

Chemotherapy

Chemotherapy is sometimes used to treat advanced liver cancer but is not as common as other treatments. Chemotherapy uses drugs to kill rapidly growing cells. This includes cancer cells. Chemotherapy can be administered through a vein (intravenously; IV), as a pill (orally), or both.



It is recommended that you use one pharmacy for all medication if possible. You should bring all the medications you are taking to every doctor’s visit and inform your care team of any changes. There is always the possibility of medication interactions and using the same pharmacy is another layer of protection against any possible mistakes that could be harmful.

Key things to know about clinical trials

You may consider participating in a clinical trial. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. It's important to know that:

- ✔ You will always receive the best available treatment during a cancer clinical trial. Even if you don't receive the experimental medication, you will still receive treatment.

- ✔ Clinical trials test new treatments, new combinations of treatments, or better ways of using existing treatments

- ✔ The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe

- ✔ If you join a clinical trial, you can leave at any time

- ✔ Not every doctor has access to the same trials

- ✔ Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay covers "standard" treatment costs. Be sure to ask about the costs to you.

- ✔ There are phase 1, phase 2, and phase 3 clinical trials; make sure you understand the goals and before joining a clinical trial

- ✔ Some clinical trials may make you ineligible for a future trial or treatment, so make sure to ask questions about this. See the resources below for help finding clinical trials that might be right for you.

In addition to talking with your doctor, you can look up clinical trials online if you know the type and stage of your cancer.

Learn more here: [**www.CancerSupportCommunity.org/Find-Clinical-Trial**](http://www.CancerSupportCommunity.org/Find-Clinical-Trial)

Supportive and Palliative Care

Palliative care is specialized medical care that focuses on providing relief from pain and other symptoms of a serious illness. Palliative care is different from end-of-life care or hospice. You can see a palliative care doctor at any point during your treatment. Palliative care specialists work with you, your loved ones, and your other doctors to provide an extra layer of support that complements your ongoing care. Palliative care teams are often involved in the care of patients with cancer, including those getting aggressive treatment.

Managing Symptoms and Side Effects

How you feel can affect your mood, outlook, and quality of life. It is hard to stay positive when you are tired, in pain, or uncomfortable. Managing symptoms and side effects can make you feel better physically and emotionally. It helps to learn about the side effects of treatment before you begin so you will know what to expect. When you know more, you can work with your health care team to manage your quality of life during and after treatment.

Here are a few examples of common symptoms and side effects of liver cancer and treatment:

- **FEVER** is an increase in body temperature above normal (98.6°F or 37°C). Fever can be a sign of potential infection. It is important to record temperatures, especially if rising, and report to your doctor. Speak with your doctor about when a fever is too high and when to seek emergency medical attention.
- **PAIN** may be short term, long term, or come and go throughout the treatment process. You may also have abdominal discomfort - a feeling of fullness or bloating. Walking or applying heat to the abdomen can help decrease discomfort. It is important to keep a log of where the pain is, how severe, what makes it worse or better, and if medicine helps. You should not take over the counter medication, including acetaminophen (Tylenol®) or ibuprofen (Advil®, Motrin®) unless approved by your care team. You should let them know right away if pain is not controlled, changes, or worsens suddenly.
- **NAUSEA AND VOMITING** - Nausea and vomiting are very common. There are medicines that can be taken before and after symptoms appear. Some people find it helpful to eat smaller meals, focus on bland foods, and drink more liquids. Relaxation exercises like mindfulness or meditation can also help. If side effects persist or are hard to manage, talk with your health care team. They can recommend medicines that might help. Your doctor may suggest lowering the dose of your treatment if needed. Ask to see a palliative care specialist and/or speak with a dietitian about ways to manage these side effects.
- **DIARRHEA** is several watery stools a day. This is a common side effect of many treatments. It's very important to drink lots of fluids, as you are losing a lot of fluid and nutrients. Eating foods like bananas, toast, and rice may help. Medicines can work well against diarrhea too.
- **FATIGUE** is a feeling of tiredness that does not always go away with rest. It may be hard to accept that you cannot do as much as before. Try to pay attention to when you have energy. Notice the times of day and how long your energy lasts. Plan activities, work, or chores around those times. Make time to be active and to rest. Accept your limitations and ask for help when you need it.
- **LOSS OF APPETITE** is when you don't feel hungry or have the desire to eat food. Feeling full after eating a small amount of food is also common. This is often the most bothersome and challenging problem for patients and their families. It can be related to nausea or other digestive discomfort, changes in taste, a feeling of fullness, fatigue, or changes to the mouth and throat like sores. Eating small, frequent "snacks" instead of trying to eat a big meal can be helpful.
- In some cases, loss of appetite may be a symptom of **CANCER CACHEXIA**. Cachexia is a condition many people with cancer

experience and includes loss of appetite, unintentional weight loss, and fatigue. Cachexia can become severe quickly, if you are experiencing symptoms, speak with your doctor. Learn more about cancer cachexia at

www.CancerSupportCommunity.org/Cancer-Cachexia.

- **INFECTION** is caused by the growth of germs in the body. These may be bacteria, viruses, yeast, fungi, or other microorganisms. The risk of infection is increased after liver transplant because of the use of immunosuppressive medicines. These medicines reduce the risk of rejection (or implant failure) but may make it easier for you to become infected by other things.
- **JAUNDICE** is the yellowing of the skin, whites of the eyes, or dark colored urine. If you experience jaundice during or after treatment, it is important to tell your doctor.

Everyone's body is different, and cancer related symptoms and/or side effects of treatment can vary. It is important that you tell your doctor or nurse right away about any new or worsening problems, even if they are considered "common." Mild symptoms may quickly become severe.

There are many medications and strategies that can help prevent or manage these and other symptoms.

Learn more about the side effects of cancer treatment and how to manage them at **www.CancerSupportCommunity.org/Managing-Side-Effects**.

Cost of Care

Cancer treatment can be costly, even with health insurance. Keeping up with these costs might be overwhelming. Many people facing cancer say that financial worries about cancer costs are a big source of stress. There are resources that can help. Visit **www.CancerSupportCommunity.org/Cost** or speak with your social worker and health care team for more information on managing health care costs.

Coping with the Stigma of Liver Cancer

Many people living with liver cancer feel that they must explain the cause of their condition to others. You may feel that you are unfairly "judged" because of the perceived links between liver cancer and alcohol or drug misuse. The feeling that society has these thoughts about you, even when they go unsaid, is called "stigma." It is unfortunate that these ideas are often based on stereotypes and promoted by the media.



What You Can Do

Dealing with a liver cancer diagnosis and treatment can be difficult to manage. The added feelings of stigma, shame, and blame will not help you heal. Focus on identifying what you can do to find support after a liver cancer diagnosis.



Talking About Stigma

In some cases, you may feel like you are being treated differently because of your diagnosis. You deserve good care regardless of your medical condition or possible history with alcohol or drug use. If your care team does ask about your history, they may be asking because it could impact treatment options.

It is important to find a care team that you trust and can be open and honest with. They should treat you with dignity and respect. If this is not happening, advocate for yourself. Talk to your care team about your concerns. You do not need to continue working with a care team if you are being mistreated. Consider seeing a different provider if you are uncomfortable.

To change the narrative, consider the following:

- Talk to them about the emotional impact of their questions
- Advocate for yourself by sharing information about liver cancer from trusted resources like those listed at the end of this booklet
- Remind them that you can never know exactly why you got liver cancer, but you do need their support and empathy

Regardless of if you have a history of drug or alcohol use or not, questions about these topics and others' assumptions can be frustrating. All these feelings are valid.

Seeking Support

The stigma of living with liver cancer can contribute to many negative emotional impacts. This can include distress, grief, stress, depression, and/or anxiety.

- **DISTRESS** is an unpleasant state that can affect how you think, feel and act. This may include emotions like fear, sadness, anger, and worry.
- **GRIEF** is the emotional response to loss. Grief can arise from loss of many different things, such as the loss of a person, loss of health, or loss of control.

- **STRESS** is how the body responds to pressure like specific events, trauma, and illness. Stress can cause changes in both our physical and emotional well-being. Everyone responds to stress differently.
- **DEPRESSION** is a diagnosed condition. It can cause a persistent feeling of sadness or loss of interest in things you once enjoyed.
- **ANXIETY** is a feeling of uneasiness, worry, or fear that usually occurs because of stress. Anxiety can have physical sensations as well, such as feeling tense or like your heart is racing.

These symptoms should be taken as seriously as cancer itself.

Cancer care teams are prepared to help you and your loved ones after a cancer diagnosis. Throughout your care, they may check in with you specifically about your mental health. Your care team can connect you with social workers, psychologists, and other mental health specialists. These professionals can help you talk through your feelings, understand what you are experiencing, and develop coping skills. Coping skills are things you can do in the moment and over time to feel more in control when you are feeling stressed, anxious, or uncomfortable.

Some people may think that only someone experiencing severe mental health challenges should seek help. This is not true. Everyone deserves to have good mental health. You do not need to wait for your mental health to reach a certain severity before getting help. Learn more about Mental Health and Cancer at www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns

The stigma of liver cancer is especially unique because liver cancer is often associated with lifestyle or personal choices. These include smoking, drinking alcohol, and other conditions, like HCV, which can be transmitted sexually or through IV drug use, and alcohol related cirrhosis. Stigma can affect how you feel about yourself or how you think others feel about you. Anyone can be diagnosed with liver cancer.

Stigma can be especially harmful as it can discourage people from seeking medical help. This may be because they fear discrimination from health care professionals, friends, family, or others. Stigma often delays diagnosis and, in turn, leads to poorer outcomes. Even early diagnosis and treatment of liver cirrhosis or hepatitis infections can greatly reduce the risk of developing liver cancer.

What Will the Future Hold?

It's difficult for anyone to think that there may be a limited amount of time to live. If you haven't already thought about it, a cancer diagnosis can force you to think about "what if?"

Now is when you should talk about your wishes, and advance directives, or "living will" with your team and your family. Having these discussions is hard, but much harder if you wait until the situation becomes urgent. Social workers and/or palliative care specialists can inform you of what forms you might need.

Liver cancer can come back after treatment. This is called recurrence. Liver cancer may come back in the liver or in other parts of the body. You may be eligible to undergo another treatment, or you may not.

There may also be a time when treatment stops working, or you may choose to stop treatment – what happens next? Your team will likely talk about hospice care, which is often the best next step. Care for you does not stop, but changes from treating cancer to a focus on quality of life for you and your family.

Support for Liver Cancer Caregivers

Liver cancer affects not only those with the disease, but also the people who care for them. Caregiving for a person with liver cancer can be stressful and frustrating. You may feel angry, guilty, alone, afraid, or sad.

If you are caring for a person with liver cancer:

Find support

Share your feelings with others. Look for caregiver support groups, either in person or online. Ask the patient's cancer center if they have a support program for caregivers.

Look for extra help

Ask friends and family if they can help. If they offer, give them specific tasks. Consider homecare or companion assistance if needed. Speak with your loved one's care team or social worker about options.

Take Breaks

Carve out time for yourself. Spend time with people important to you and take time for activities you enjoy. Don't feel guilty about making time for yourself – it is important for your own health.

Learn about Financial Assistance

You may have high out-of-pocket costs from parking, transportation, and food as part of your caregiving duties. There are also costs and impacts related to lost time at work. Ask the hospital where the person with cancer is receiving treatment if they can provide help with financial counseling for caregivers.

Learn about the Family Medical Leave Act (FMLA)

You may qualify to take up to 12 weeks of unpaid, job-protected leave to care for a seriously ill family member in the U.S. In Canada, you may qualify for up to 28 weeks of compassionate care leave. Other countries may have similar programs available for caregivers.



LIVER CANCER INFORMATION AND SUPPORT

Cancer Support Community

1-888-793-9355

<https://CancerSupportCommunity.org>

American Cancer Society

800-227-2345

<https://Cancer.org>

Global Liver Institute

800-845-5910

<https://GlobalLiver.org/>

American Liver Foundation

1-800-465-4837

<https://LiverFoundation.org/>

American Cancer Society - Liver Cancer

<https://Cancer.org/Cancer/Types/Liver-Cancer.html>

Blue Faery

<https://BlueFaery.org/>

American Transplant Foundation

<https://AmericanTransplantFoundation.org/>

CANCER SUPPORT COMMUNITY RESOURCES

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon-Thurs 11am-8pm ET and Fri 11am-6pm ET.

Open to Options® — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

Services at Local CSCs and Gilda's Clubs

— With the help of 190 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now at www.MyLifeLine.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

Photos are stock images posed by models.

The Cancer Support Community and its partners 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 professionals to answer questions and learn more.

This publication is available to download and print yourself at www.CancerSupportCommunity.org/Liver-Cancer. For print copies of this publication or other information about coping with cancer, visit www.Orders.CancerSupportCommunity.org

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Frankly Speaking About Cancer:
Liver Cancer Program Partner

