GLOBAL LIVER INSTITUTE

NEWLY DIAGNOSED

LIVER CANCER GUIDE



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LIVER CANCER BASICS

Understanding Your Liver

The liver is one of the largest and hardest-working organs in your body. It is located on the upper right side of your abdomen, just beneath your ribs, and it plays a vital role in keeping you healthy every day.

The liver performs more than 500 essential functions, including:

- Producing bile, a fluid that helps digest fats from the foods you eat.
- Storing sugars (glucose) to provide your body with energy when needed.
- Filtering your blood to remove waste products, toxins, and other harmful substances.

Most of the liver is made up of specialized cells called hepatocytes. These cells perform many of the liver's important functions, such as processing nutrients, breaking down fats, proteins, and carbohydrates, producing bile, and removing harmful substances from the body.

Because the liver is involved in so many important processes, maintaining liver health is essential for your overall well-being.

What Is Primary Liver Cancer

Primary liver cancer is cancer that starts in the liver. It develops when normal liver cells change and begin to grow uncontrollably, forming a tumor.

There are several types of primary liver cancer. The type depends on which cells in the liver become cancerous. Understanding the type of liver cancer you have is important because it helps your healthcare team recommend the most appropriate treatment options.

Sometimes, cancer begins in another part of the body and later spreads to the liver. This is called secondary liver cancer or metastatic liver cancer. Although this cancer is found in the liver, it is named after where it started. For example, colorectal cancer is the most common cancer to spread to the liver, but cancers of the breast, lung, pancreas, and stomach can also spread there.[1]

Hepatocellular Carcinoma

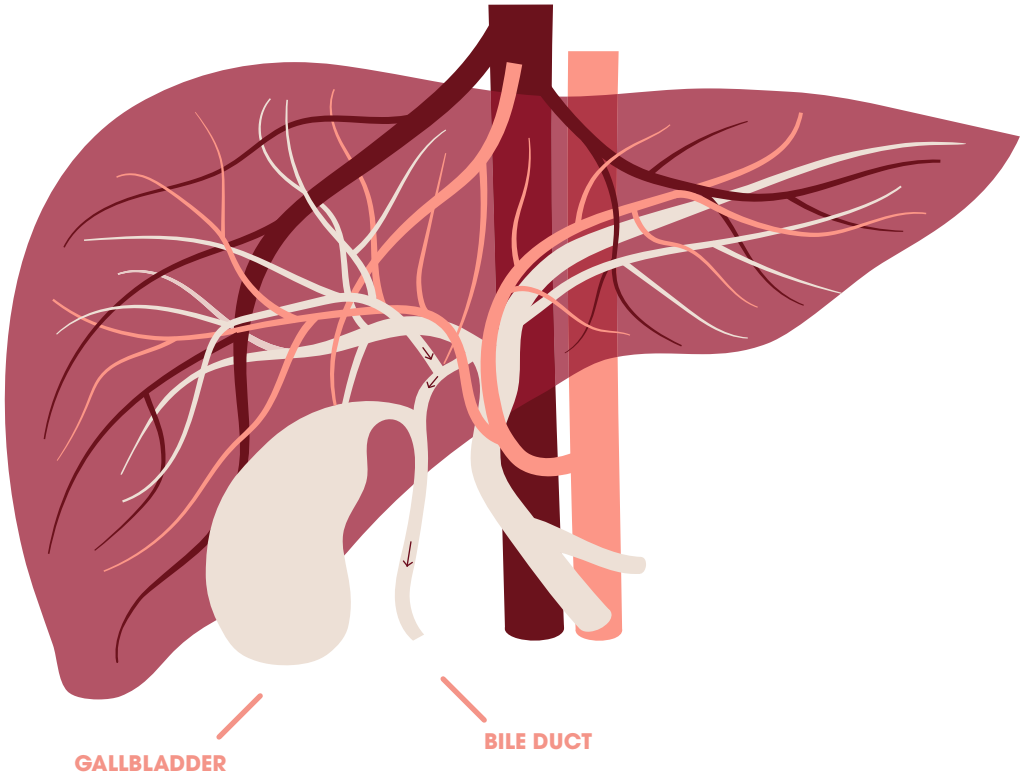
Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer in adults. It is the sixth most common cancer worldwide.[2] HCC is often linked to long-term liver disease, including cirrhosis, chronic hepatitis B or hepatitis C infection, and metabolic dysfunction-associated steatotic liver disease (MASLD). While anyone can develop HCC, it is diagnosed more often in men and in people over the age of 60.[3]

Cholangiocarcinoma

Cholangiocarcinoma (CCA), also known as bile duct cancer, accounts for about 10-15% of liver cancers.[4] It develops in the bile ducts, the small tubes that carry bile from the liver to the small intestine to help digest food.

CCA is classified based on where it develops:

- **Intrahepatic cholangiocarcinoma** begins in the bile ducts located inside the liver. This is the least common form of CCA.
- **Hilar cholangiocarcinoma**, sometimes called perihilar cholangiocarcinoma, develops where the bile ducts exit the liver.
- **Distal cholangiocarcinoma** develops in the bile closer to the small intestine.[5]



Learning which type of CCA you have can help you and your healthcare team better understand your diagnosis and determine the treatment approach that is right for you.

What do liver cancer symptoms look like?

Liver cancer symptoms can vary from person to person. Some people experience only a few symptoms, while others may notice several. The type and severity of symptoms often depend on the size of the tumor(s), location, and how well the liver is functioning.

One of the challenges with liver cancer is that it often causes few or no symptoms in its early stages. This is because the liver has very few pain-sensing nerves, allowing a tumor to grow without causing discomfort. Symptoms are more likely to appear as the cancer grows, affects liver function, or stretches the outer lining of the liver.[6]

Common signs and symptoms of liver cancer include:



Loss of appetite



Yellowing of the skin or eyes (jaundice)



Unexplained weight loss



Light colored stool



Pain or discomfort in the upper right side of the abdomen



Swelling or bloating of the abdomen



A lump or feeling of fullness under the right side of the ribs



Fatigue or unusual tiredness



Nausea or vomiting



Dark-colored urine



Itchy skin



Fever without a known cause



UNDERSTANDING LIVER DISEASE PROGRESSION AND CANCER RISK

Most primary liver cancers develop after years of ongoing liver damage and inflammation. Over time, repeated injury can cause scar tissue to build up in the liver, increasing the risk of developing liver cancer.

How Liver Disease Progresses

Some long-term liver conditions can cause ongoing inflammation and damage to the liver. Over time, this damage may lead to ***fibrosis***, or scarring of the liver. When scarring becomes severe, it is called cirrhosis.

Cirrhosis is the strongest risk factor for hepatocellular carcinoma (HCC), the most common type of primary liver cancer, although liver cancer can also develop in people who do not have cirrhosis. For example, certain chronic hepatitis B infections and some cases of metabolic dysfunction-associated steatotic liver disease (MASLD) can lead to HCC without cirrhosis.[6]

Cirrhosis does not mean that liver cancer or liver failure will necessarily develop. However, as liver scarring becomes more severe, the liver may have more difficulty performing its normal functions. Cirrhosis can also affect which liver cancer treatments are safe or appropriate, making it important for your healthcare team to consider both the cancer and the health of your liver when developing a treatment plan.

Because liver cancer often develops in people with advanced liver disease, regular screening is recommended for people who are at higher risk. Screening can help detect liver cancer before symptoms appear, when treatment options are often more effective.

Risk Factors for Hepatocellular Carcinoma

Hepatocellular carcinoma (HCC) is the most common type of primary liver cancer.

Risk factors include:

- Cirrhosis from any cause
- Chronic hepatitis B infection
- Chronic hepatitis C infection
- Metabolic dysfunction-associated steatotic liver disease (MASLD)
- Metabolic dysfunction-associated steatohepatitis (MASH)
- Alcohol-associated liver disease (ALD)
- Type 2 diabetes
- Obesity
- Tobacco use
- Exposure to aflatoxins (toxins produced by certain molds found in contaminated foods)
- Hereditary liver diseases[7]

Risk Factors for Cholangiocarcinoma

Cholangiocarcinoma (CCA) develops in the bile ducts that carry bile from the liver to the small intestine. Although it is less common than HCC, several conditions can increase the risk of developing CCA.

Risk factors include:

- Primary sclerosing cholangitis (PSC)
- Bile duct cysts (choledochal cysts)
- Parasitic liver fluke infections (more common in certain regions of Asia)
- Hepatolithiasis (stones within the bile ducts)
- Exposure to certain environmental or industrial toxins

Other factors that may increase the risk include:

- Cirrhosis
- Chronic hepatitis B infection
- Chronic hepatitis C infection
- Inflammatory bowel disease (particularly ulcerative colitis)
- Type 2 diabetes
- Obesity
- Heavy alcohol use
- Tobacco use[8]

Having one or more of these risk factors does not mean you will develop liver cancer, but it may increase your risk. Your healthcare provider can help determine whether regular liver cancer screening is right for you.



LIVER CANCER SCREENINGS

Who Should Be Screened for Liver Cancer?

Regular liver cancer screening is not recommended for everyone. It is generally recommended only for individuals who have a higher risk of developing liver cancer.

Liver cancer surveillance is recommended for many people with cirrhosis and for some people with chronic hepatitis B, even if they do not have cirrhosis. Your healthcare provider can assess your individual risk and overall health to determine whether regular surveillance is appropriate for you.

For CCA, routine screening is not recommended for the general public. However, people with certain rare conditions, such as primary sclerosing cholangitis (PSC), Caroli disease, or other types of choledochal cysts, may require specialized monitoring because of their increased risk.

Your screening plan should be based on your personal medical history. Talk with your healthcare provider about whether liver cancer screening is right for you.

Screening Tests

Screening for Hepatocellular Carcinoma

An abdominal ultrasound is a type of imaging test that uses sound waves to create an image of the liver. It is a non-invasive, outpatient procedure and typically used as the first-line approach for detecting liver cancer. Abdominal ultrasounds can be used to identify whether there are tumors in the liver or to note lesions (cirrhosis).

For most people who need hepatocellular carcinoma (HCC) surveillance, the usual approach is a liver ultrasound and an alpha-fetoprotein (AFP) blood test every six months. An ultrasound looks for changes or suspicious areas in the liver, while the AFP blood test provides additional information that may help your healthcare team assess your risk.

It is important to know that AFP is not a stand-alone test for liver cancer. A normal AFP level does not rule out cancer, and an elevated AFP level does not necessarily mean that cancer is present.

If an ultrasound does not provide a clear enough view of the liver, your healthcare team may recommend a different imaging test.

Screening for Cholangiocarcinoma

Most people do not need routine testing to screen for cholangiocarcinoma. However, if you have **primary sclerosing cholangitis (PSC)**, your healthcare team may recommend regular monitoring because your risk of CCA is higher. This may include yearly imaging of the liver and bile ducts, usually with MRI/MRCP, and sometimes a CA 19-9 blood test.

Blood tests include liver function tests (LFTs), which can show signs of bile duct blockage or liver damage, and tumor marker tests, such as CA 19-9 and CEA. While these markers may be elevated in some people with CCA, they cannot diagnose cancer on their own.

Imaging tests help healthcare providers look for tumors and evaluate the bile ducts. An ultrasound is often the first test performed, while an MRI or a CT scan provides more detailed images to help confirm the diagnosis and determine the extent of the cancer.[11]

Your surveillance plan should be based on your individual health history and risk. Talk with your liver specialist about which tests and schedule are right for you.

Where can I get screened?

If you think you may be at risk for liver cancer, start by talking with your primary care provider or liver specialist. Many screening tests are performed as outpatient procedures and do not require a hospital stay. Depending on your medical history, your primary care provider may refer you to a:



Hepatologist (liver specialist)



Gastroenterologist



Oncologist



Imaging center or laboratory

Your healthcare team will help determine which screening tests are appropriate for you and how often they should be performed.



GETTING YOUR DIAGNOSIS

If a screening test or imaging scan shows an abnormality in your liver, your healthcare team may recommend additional tests to find out what is causing the abnormality and whether it is liver cancer.

The tests you need will depend on your individual situation. Your healthcare team may recommend:

- **Imaging tests** to look more closely at the liver and any tumors
- **A biopsy** to examine a sample of liver tissue for cancer cells, when needed
- **Blood tests** to assess your overall health and how well your liver and other organs are functioning
- **Biomarker or molecular testing** to learn more about the cancer and identify potential treatment options

You may not need every test. Your healthcare team will recommend the tests that provide the information needed to confirm your diagnosis and plan your care.

Biopsy

A **biopsy** involves removing a small sample of tissue so it can be examined under a microscope for cancer cells.

Not everyone with liver cancer needs a biopsy. In some cases, doctors can diagnose hepatocellular carcinoma (HCC) using specific non-invasive tests such as imaging tests, particularly when a person has an increased risk of developing HCC. Your healthcare team will determine whether a biopsy is appropriate for you.

There are several ways a liver biopsy may be performed:

- **Percutaneous biopsy:** A thin needle is inserted through the skin and into the liver to collect a tissue sample. This is the most common type of liver biopsy.
- **Surgical or laparoscopic biopsy:** A surgeon makes one or more small incisions to collect a tissue sample. A laparoscope, a small camera, may be used to help guide the procedure.[12]
- **Transvenous biopsy:** A catheter is inserted through a vein, usually in the neck, and guided to the liver to collect a tissue sample. This approach may be considered for people who have an increased risk of bleeding or other reasons that make a percutaneous biopsy less suitable.

Your healthcare team can explain which approach, if any, is appropriate for you and what to expect before and after the procedure.



Imaging Tests

If a screening test finds a concerning area, your team may order a special CT or MRI that takes images before and after contrast several times. In some people at high risk of HCC, the appearance on these scans can establish the diagnosis without a biopsy. In other situations, a biopsy may be needed.

- **Computed tomography (CT or CAT) scan:** A CT scan uses X-rays to create detailed images of the liver and other parts of the body. A contrast dye is given before or during the scan to make certain areas easier to see.
- **Magnetic resonance imaging (MRI):** An MRI uses magnets and radio waves to create detailed images of the liver and other soft tissues. Contrast is often needed during an MRI to provide additional information about a tumor.[13]

Further Testing

Once liver cancer has been diagnosed, your healthcare team may recommend additional tests to better understand the cancer and your overall health. These results can help your care team determine which treatment options may be appropriate for you.

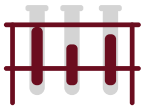
Testing may also help your healthcare team understand how well your liver, kidneys, blood, and other organs are functioning before treatment begins.



Biomarker Testing

Biomarkers are biological features or substances that can provide information about a cancer. Biomarker testing may involve analyzing a blood sample, tumor tissue, or another type of sample.[14] Depending on the type and stage of liver cancer, biomarker or molecular testing may help your healthcare team better understand your cancer and identify treatment options, including certain targeted therapies or immunotherapies.[15]

Biomarker testing is not needed for every person with liver cancer. Ask your healthcare team whether testing is appropriate for your type of liver cancer and how the results could affect your treatment options.



Blood tests

Blood tests provide important information about your overall health and how well your liver and other organs are functioning. This information can help your healthcare team determine which treatments may be safest and most appropriate for you.

Your healthcare team may order several types of blood tests, including:

- **Blood-clotting tests**: Measure how well your blood is able to clot. Because the liver produces proteins that help with blood clotting, these tests can provide information about liver health and bleeding risk.
- **Kidney function tests**: Measure substances such as BUN and creatinine to show how well your kidneys are working. Kidney health can be important when planning certain treatments.
- **Complete Blood Count (CBC)**: Measures your red blood cells, white blood cells, and platelets to provide a snapshot of your overall health and blood cell levels.
- **Blood chemistry tests**: Measure substances such as glucose, calcium, and electrolytes to provide information about your overall health and how well your organs are functioning.

UNDERSTANDING YOUR DIAGNOSIS

Receiving a liver cancer diagnosis can bring a lot of questions. Understanding the type and stage of your cancer can help you and your healthcare team make informed decisions about your care.

How Is Liver Cancer Staging Determined?

Your stage helps your healthcare team understand the extent of your cancer and identify treatment options that may be appropriate for you.

There is not one staging system used for all liver cancers. The staging system used depends on the type of liver cancer you have.

For hepatocellular carcinoma (HCC), healthcare teams may use the **Barcelona Clinic Liver Cancer (BCLC) staging system** to classify the cancer and help guide treatment. The BCLC system considers the extent of the tumor, whether the cancer has spread, your overall health, and how well your liver is functioning. **The Tumor, Node, Metastasis (TNM)** staging system may also be used.

Cholangiocarcinoma (CCA), also known as bile duct cancer, is generally staged using the **TNM staging system**. The specific staging criteria can vary depending on where the cancer began, such as inside or outside the liver.



Cancer characteristics to expect at each stage

Barcelona Clinic Liver Cancer Staging System (BCLC)
The BCLC staging system classifies HCC into five stages: 0, A, B, C, and D. Staging considers the size and extent of the tumor, how well the liver is functioning, and overall health.

STAGE 0 | Very Early HCC
- The nodule is less than or equal to 2 cm
- Preserved liver function, PS 0

STAGE A | Early HCC
- Single or less than or equal to 3 modules, each less than or equal to 3 cm
- Preserved liver function, PS 0

STAGE B | Intermediate HCC
- More than 1 nodule in the liver
- More than 3 nodules, or up to 3 nodules with at least 1 being larger than 3 cm
- Preserved liver function, PS 0

STAGE C | Advanced HCC
- Tumors have spread into the blood vessels, lymph nodes, or surrounding organs
- Preserved liver function, PS 0-2

STAGE D | End-Stage HCC
- The tumors have spread into the blood vessels, lymph nodes, or surrounding organs
- End-stage liver function, PS 3-4

Note: During stages 0, A, and B, removal of cancer is possible depending on your health status and the health of your liver.

Tumor Node Metastasis Staging System (TNM)

For bile duct cancer, the **TNM staging system** describes how far the cancer has grown and whether it has spread. **T** describes the size and extent of the main tumor, **N** indicates whether nearby lymph nodes contain cancer, and **M** indicates whether the cancer has spread to distant parts of the body.

Because bile duct cancer can begin in different parts of the bile ducts, the specific staging criteria vary depending on where the cancer started. Your healthcare team can explain your stage and what it means for your treatment options.

TUMORS

T (Tumor): The size and number of tumors and whether they have grown into nearby structures

NODES

N (Node): Indicates whether the cancer has spread to local lymph nodes. The N category relies on a number-based system:
- **(N0)**: No nearby lymph nodes involved
- **(N1)**: Cancer has spread to 1 to 3 regional lymph nodes
- **(N2)**: Cancer has spread to 4 or more regional lymph nodes

METASTASES

M (Metastasis): Denotes if the cancer has spread to distant organs
- **(M0)**: No distant metastasis
- **(M1)**: Distant metastasis is present[16]

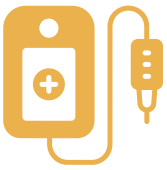


UNDERSTANDING LIVER CANCER TREATMENT

What is available depending on the stage of cancer?

There is no single treatment that is right for everyone with liver cancer. Your treatment plan depends on several factors, including the type and stage of your cancer, your liver function, overall health, and your preferences.

Your care team may recommend one treatment or a combination of treatments. Treatment may include medications, procedures, radiation, surgery, or supportive care.[17]

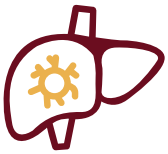


Systemic Therapy

Systemic therapy uses medicines that travel through the bloodstream to treat cancer throughout the body.[18] Depending on your type of liver cancer, systemic therapies may include:

- **Chemotherapy:** Is a cancer treatment designed to kill cancer cells and prevent tumors from growing that is often paired with other treatments. Chemotherapy can cause severe side-effects like nausea, exhaustion, increased risk of infection, and more.[19]
  - Used for: CCA
- **Immunotherapy:** Helps your immune system recognize and attack cancer cells. Immunotherapy may be used alone or in combination with other treatments.[20]
  - Used for: HCC, CCA
- **Targeted therapy:** Uses medicines designed to target specific features of cancer cells. Molecular or biomarker testing may help determine whether a treatment is appropriate.[21]
  - Used for: CCA

For HCC that cannot be treated effectively with surgery or liver-directed treatment, options may include immunotherapy-based combinations or medicines that block signals helping tumors grow. Conventional chemotherapy is not routinely used for HCC. For advanced CCA, chemotherapy often forms the backbone of treatment and may be combined with immunotherapy; molecular test results may guide later targeted treatments. Side effects vary by medicine and person, and your team can help prevent and manage them.



Locoregional Therapy

Liver-directed treatments focus on tumors in or near the liver. Which procedures are useful depends on the cancer type, the number and location of tumors, liver function, and the treatment goal. Your multidisciplinary team may combine these with other treatments or use them at different times.

- **Ablation:** Uses heat, cold, or other techniques to destroy a tumor without removing the entire liver. Common types include radiofrequency ablation and microwave ablation.[22]
  - Used for: HCC; may be considered in select cases of CCA
- **Radioembolization:** Delivers tiny radioactive particles directly to a liver tumor through its blood supply. This can help deliver radiation to the tumor while limiting exposure to surrounding tissue.[23, 24, 27]
  - Used for: HCC; CCA
- **Radiation therapy:** Uses high-energy radiation to destroy or control cancer cells. It may be delivered from outside the body or, in some cases, from inside the body.[25]
  - Used for: HCC; CCA
- **Transarterial Chemoembolization (TACE):** Delivers chemotherapy directly to a tumor through its blood supply and blocks blood flow to the tumor. TACE may be used when surgery is not the best option.[26,27]
  - Used for: HCC; may be considered in select cases of CCA



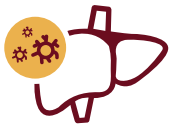
Surgery

For some people with hepatocellular carcinoma or cholangiocarcinoma, surgery to remove the cancer may offer a chance for a cure. The type of surgery recommended depends on factors such as where the tumor is located, how extensive it is, and how well the liver is functioning.

For selected people with HCC, a liver transplant may be an option. At specialized centers and under strict eligibility criteria, liver transplantation may also be considered for some people with perihilar CCA, which develops where the bile ducts join near the liver.

Distal CCA, which develops farther down the bile duct, generally requires a different type of surgery. This may involve removing part of the bile duct and pancreas, along with nearby tissues and lymph nodes.

Your healthcare team can help determine whether surgery or liver transplantation may be appropriate based on your cancer, liver health, and overall health.



- **Liver resection (hepatectomy):** Removes the part of the liver containing the cancer. The remaining liver can continue to perform its functions.[28]
  - Used for: HCC, CCA



- **Liver transplant:** Replaces the diseased liver with a healthy liver from a donor. Transplant may be an option for some people with HCC, CCA, or other liver cancers, depending on the type and extent of cancer and other health factors.[29]

Palliative Care

Palliative care is care that is designed to help manage pain and symptoms associated with liver cancer and liver cancer treatments. Palliative care can begin at the time of diagnosis. Which pain management option is best will be different for every person. Talking with your care team will help connect you to palliative care services that can complement your current treatments.

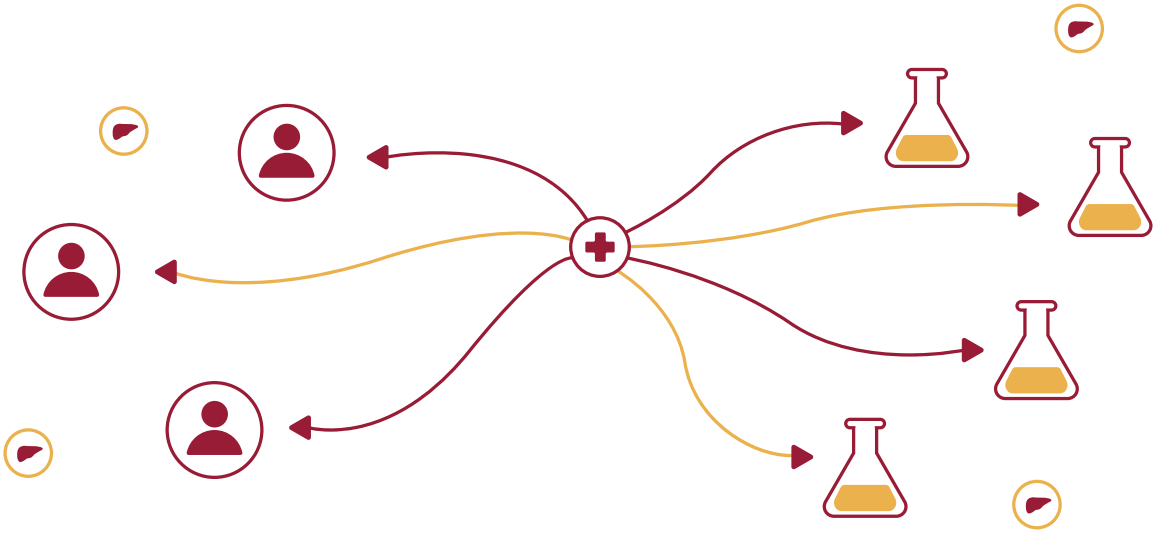
Hospice Care

In some cases, an individual may decide that curative treatment is no longer the right path for them. Hospice care is specialized end-of-life care that focuses on comfort, quality of life, and support rather than curing the illness. It usually begins when curative treatments are stopped and is provided at home or in nursing facilities to make patients as comfortable as possible.

Clinical trials

Every day, new progress is made in the treatment and diagnosis of liver cancer. Clinical trials play a key role in furthering those discoveries to better treat, prevent, diagnose, and understand liver cancer. There are two main types of clinical studies: clinical trials and observational studies. Clinical trials give patients who are willing to try new treatments access to drugs and other treatments that are not yet available to the broader public. They allow researchers to determine if a new test or treatment is safe and effective. Observational studies simply record changes over time in a person's liver cancer case, without any further added interventions.

To find out if a clinical study is right for you, talk with your care team or trusted patient advocacy groups. You can also search for a clinical trial at **ClinicalTrials.gov** and find studies focused on your form of liver cancer, or in your location.





YOUR HEALTHCARE TEAM

A multidisciplinary care team is a group of healthcare providers from different specialties who work together to support your care. This team may include hepatologists, oncologists, primary care providers, and other specialists. Open communication and coordination among your providers are important to help ensure you receive the best possible care.

Your primary care provider is often your first point of contact and can help connect you with specialists while managing your overall health. During liver cancer treatment, your hepatologist or oncologist will usually play a leading role in your care, as they have specific knowledge about your condition and treatment options. Providers on your care team may order tests, explain results, refer you to other specialists, prescribe treatments, and help you manage and understand your case and treatment plan.

Many different types of healthcare providers may be involved in your care. Your team may include some of the following professionals:

- **Hepatologist:** A doctor who specializes in liver diseases and conditions affecting the liver and related organs.
- **Gastroenterologist:** A doctor who specializes in the digestive system, including the liver, gallbladder, pancreas, stomach, and intestines.
- **Infectious Disease Specialist:** A doctor who treats infections, including viral infections such as hepatitis B or hepatitis C that can affect the liver.
- **Interventional Radiologist:** A doctor who uses imaging to guide minimally invasive procedures, including certain liver cancer treatments that may be performed without major surgery.
- **Mental Health Professional:** Provides support for emotional and mental well-being. This may include a psychologist, psychiatrist, or other trained professional.
- **Nurse:** Provides hands-on care, monitors your health, administers medications, helps manage symptoms and side effects, and answers questions about your care.
- **Nurse Navigator:** Helps you understand and navigate the healthcare system, coordinate appointments and care, connect with resources, and address barriers to treatment.
- **Nurse Practitioner (NP):** A healthcare professional who can assess your health, manage symptoms and side effects, order tests, prescribe medications, and provide ongoing care.
- **Nutrition Professional:** Provides guidance on nutrition and eating habits to support your health during and after treatment.
- **Oncologist:** A doctor who specializes in cancer care. Depending on your treatment needs, this may include a medical oncologist (medications), surgical oncologist (surgery), or radiation oncologist (radiation therapy).
- **Palliative Care Specialist:** Helps manage symptoms, pain, side effects, and other physical or emotional concerns. Palliative care can be provided alongside cancer treatment.
- **Pharmacist:** Helps manage your medications, including explaining how to take them, identifying potential side effects, and checking for interactions between medications, supplements, and foods.
- **Radiologist:** A doctor who specializes in medical imaging and interprets scans such as CT scans and MRIs to help diagnose and monitor cancer.
- **Social Worker:** Helps patients and families access practical and emotional support, including financial assistance, transportation, counseling, and community resources.[30]



HOW CAN I PREPARE FOR MY APPOINTMENTS?

Communication

When you are facing a complex medical condition like liver cancer, clear communication and keeping track of important information are essential. It is important to have an open and honest relationship with your healthcare team. Always feel comfortable asking questions if something is unclear or if you need more information. Understanding your care and treatment plan can help you make informed decisions and feel more confident throughout your journey.



How Can I Discuss Health History?

The health history of you and your family members can be an important resource for care providers who are trying to better understand your disease.

Because family members share genetics and often behaviors, family health history can help providers understand all the factors that impact your health. Family health history is a living record of all the diseases and health conditions in your family. Your family health history will change as your family changes; it's important to document and keep your family health history up-to-date with any major changes. Communicating family health history to your care team is an important early step in building a relationship with your providers.[31]

Personal health history is also very important to share with your care team. Personal health history should include:



- ***Current medications, any side effects***
- ***Current symptoms***
- ***Lifestyle habits/changes***
- ***Pre-existing diagnoses***
- ***Relevant previous diagnoses and procedures***

Your Case File

Keeping a personal case file can help you stay organized, better understand your care, and communicate more easily with your healthcare team. Your case file can be a binder, notebook, or digital folder where you store important information about your health and treatment. This may include your personal health summary, appointment notes, test results, imaging reports, medications, treatment plans, and recommendations from your providers. Organizing these records in chronological order can make it easier to track changes over time and support continuity of care.

Taking notes during appointments or keeping a record of conversations with your healthcare team can also help you remember important information and feel more confident when making treatment decisions. If permitted, recording appointments may also help ensure you have accurate information to review later.

You may also find it helpful to bring a caregiver, trusted friend, or family member to appointments. They can provide emotional support, help you ask questions, and assist with note-taking or keep track of important details discussed during your visit.

Care Summaries

Your providers may also provide you with care summaries or After-Visit-Summaries after any kind of medical care. These can be helpful to supplement your own documentation and include in your case file. Care summaries can summarize clinical visits, providers, and more. You can ask your provider to create a care summary for you.

Care summaries should include the following:

- Updated medication list
- Updated vital sign measurements
- Documentation on the reason(s) for your visit
- Procedures
- Instructions from clinical discussions that happened during your visit
- Updates to a problem list
- Immunizations administered
- Medications administered
- Recommended patient decision aids
- Laboratory and diagnostic test orders
- Test and laboratory results
- Summary of topics discussed during your visit

Care summaries can also provide logistical information such as:

- Provider's office contact information
- Date and time of visit
- Location of visit
- Time and location of future appointments and testing (if scheduled)
- Recommended appointment timelines
- List of other appointments and tests that you are due for scheduling
  - With contact information for scheduling appointments[32]

NEWLY DIAGNOSED WORKSHEET

Information about your liver cancer.
It is important to keep track of the key information about your liver cancer diagnosis. This information will help you make important decisions about your care.

Diagnosis Date: _____

Liver Cancer Stage at Time of Diagnosis: _____

My Liver Cancer is

- ○ Local
- ○ Spread to surrounding structures

Number of Tumor(s): _____ **Tumor Size(s):** _____

Current Liver Function (CTP Score): _____

Procedural History:

Test	Date	Result	Follow-up Testing
Biopsy			
CT Scans			
MRI			
Other Tests			

Biopsy Results:

- Number of biopsies performed: _____
- Number of biopsies containing cancer cells: _____

My Care Team:

Provider Name	Specialty	Contact Information

Medication History:

Medication Name	Dosage	Dates Prescribed	Instructions

Treatment Plan:

Current Treatment	Treatment Goal	Frequency
	◯ Curative ◯ Extend Time ◯ Comfort Care	



HOW CAN I ADVOCATE FOR MYSELF?

Remember, you do not have to wait until your next scheduled appointment to contact your healthcare team if you experience new, worsening, or concerning symptoms. Arriving at appointments with questions and concerns prepared can help you make the most of your time with your provider and better understand your care options.

For individuals facing complex health conditions, seeking a second opinion can also provide valuable insight and reassurance. Consulting another healthcare provider or specialist may help confirm a diagnosis, explore additional treatment options, and ensure that your care plan is tailored to your health needs and goals.

Questions To Ask Your Doctor

1. What type of liver cancer do I have?
2. What is the stage of my cancer and what is my tumor grade?
3. How do my stage and tumor grade impact my treatment and outlook?
4. Can you walk me through my pathology report and lab results?
5. What follow-up tests will I need before starting treatment?
6. How often should I have these tests, and what will they tell us?
7. What treatment options are available to me, and how soon will I begin treatment?
8. What are the potential benefits and risks of each treatment option?
9. How successful are these treatments based on my cancer stage?
10. What are my cancer treatment goals?
11. What side effects might I experience from my medications, and how can I manage them?
12. How might treatment affect my daily life, and what lifestyle changes should I prepare for?
13. Who will be my health care team, and what are their roles?
14. What support services are available to me and my care partners?

Advanced liver cancer

1. What treatment options are available, and what is the outlook?
2. What is the goal of treatment–slowing growth or managing symptoms?
3. Are there any clinical trials I might qualify for, and how do I find out more about them?
4. What if I decide not to seek further treatment?
5. What palliative care options are available to me?
6. What support options are available to me?

LIVING WITH LIVER CANCER:

COPING AND SUPPORT

Receiving a liver cancer diagnosis can be overwhelming and may affect any aspects of your life, including your physical health, emotional well-being, finances, relationships, and daily routines. It is important to remember that support and resources are available to help you and your loved ones navigate the challenges that can arise throughout your care journey.

Visit our Liver Central resource page to explore tools, support services, and educational materials designed to help patients and caregivers manage the emotional, financial, and practical aspects of living with liver cancer.



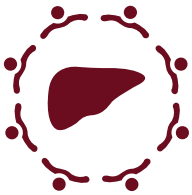


Mental Health Support

Living with liver cancer can affect more than your physical health. Many people experience feelings of depression, anxiety, stress, uncertainty, or fear following a diagnosis and during treatment. These emotions are common, and support is available.

Mental health professionals, including therapists, psychologists, psychiatrists, and counselors, can be valuable members of your care team. Addressing your emotional well-being is an important part of your overall health and quality of life.

Mental health care looks different for everyone. For some, it may include individual or group counseling, while others may benefit from medication, mindfulness practices, support groups, or regular physical activity. Finding the right combination of support can help you cope with challenges, build resilience, and improve your overall well-being throughout your liver cancer journey.



Support Groups

Cancer support groups can be a valuable source of emotional support, practical advice, and connection with others who understand what you are experiencing. Support groups vary in their focus and format. Some are designed specifically for people living with liver cancer, while others are open to individuals with any type of cancer, caregivers, or those navigating specific challenges related to treatment and survivorship.

One can find support groups through one's healthcare team, cancer centers, patient advocacy organizations, and trusted online resources. Support groups may meet in person or online, offering flexible options to connect with others who understand the challenges of a liver cancer diagnosis.

When choosing a support group, asking questions like how big is this group, how often do they meet, who leads meetings, how involved do I need to be, and who can I bring with me as support will help you determine if a support group is right for you.[33]



ACKNOWLEDGEMENT

We extend our heartfelt thanks to the liver cancer community, including patients, caregivers, healthcare professionals, researchers, and advocates, whose experiences and expertise help shape better resources and support for those affected by liver cancer. Through the Global Liver Institute's Liver Cancers Council, we bring together diverse voices to advance education, awareness, early detection, access to care, and patient-centered support. We recognize that every patient's journey is unique, from understanding risk and navigating a new diagnosis to exploring treatment options and living beyond treatment. By working together, we can help ensure that patients and families feel informed, supported, and empowered at every step of their liver cancer journey.

October 2026

Global Liver Institute 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.

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