



Elm & Carlton Streets | Buffalo, New York 14263 www.RoswellPark.org 1-800-ROSWELL (1-800-767-9355)

A National Cancer Institute-Designated Comprehensive Cancer Center | A National Comprehensive Cancer Network Member Blue Distinction® Center for Cancer Care | A Blue Distinction® Center for Transplants

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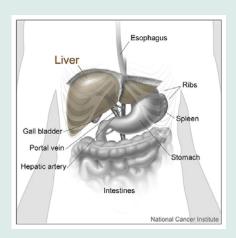


PATIENT EDUCATION

Welcome to the Gastrointestinal (GI) Oncology Center at Roswell Park Comprehensive Cancer Center. Experts in each type of GI cancer work together and create a treatment plan that fights your cancer while keeping your preferences in mind. Our goal is to work with you to make your journey as comfortable as possible. Thank you for placing your trust and confidence in our team.

Primary liver cancer begins in the liver. If a cancer begins somewhere else and spreads (metastasizes) to the liver it is called secondary liver cancer. This booklet provides an overview of primary liver cancers and their treatment options. We encourage you to take an active part in your care decisions. Your preferences will always be respected and considered in your care plan.

Remember, we are here for questions at any time. Please do not hesitate to talk to your nurse, your doctor, or any staff members who are assisting you.



NOTES

OTHER RESOURCES

ROSWELL PARK GENERAL INFORMATION

1-800-ROSWELL (1-800-767-9355)

Cancer Coach Program

716-845-8659 www.cancerwellnesscenter.org

American Liver Foundation

1-800-GO-LIVER (1-800-465-4837) www.liverfoundation.org

CancerCare

1-800-813-HOPE (1-800-813-4673) www.cancercare.org

National Cancer Institute

1-800-4-CANCER www.cancer.gov

American Cancer Society

1-800-227-2345 Buffalo Resources: 716-689-6982 www.cancer.org

Hospice Buffalo

716-686-8000 www.hospicebuffalo.com

THE LIVER

The liver sits in the upper right portion of your abdomen, beneath your ribs and above your stomach. If you are looking down at your own stomach, it is on your right side. It is the largest organ inside your body. The liver performs many functions necessary for good health.

WHAT THE LIVER DOES

- Filters harmful substances out of the blood
- Makes bile, a fluid that helps you digest fats
- Stores sugar and releases it when your body needs energy
- Makes new proteins such as globin (Globin is needed to make hemoglobin, the substance in red blood cells that carries oxygen to your body's cells)
- Stores iron, vitamins, and minerals

WHAT IS LIVER CANCER?

Cancer in any part of our bodies happens when cells become abnormal and then reproduce without order or control. New cells form when you do not need them. Old cells do not die when they should. This buildup of cells can become a tumor.

A risk factor is anything that increases a person's chance of developing cancer. Risk factors for liver cancer include sex (male), race (Asian/Pacific Islanders, American/Alaskan natives, Hispanics), habits (use of anabolic steroids, long term drinking, eating foods contaminated with aflatoxin*, obesity, and medical conditions such as chronic hepatitis B, chronic hepatitis C, diabetes, or cirrhosis of the liver. Cirrhosis is usually due to alcohol abuse or chronic hepatitis B or C.

More than 33,000 new cases of liver cancer are diagnosed in the United States each year. Some people with several risk factors never develop cancer, while others who have no known risk factors do.

^{*} Aflatoxin is a poison from a fungus that can grow on nuts and grains that are not stored properly. In developed countries, commercial crops are routinely screened for aflatoxin. Food supplies that test over the regulatory limit are considered unsafe for human consumption and destroyed.

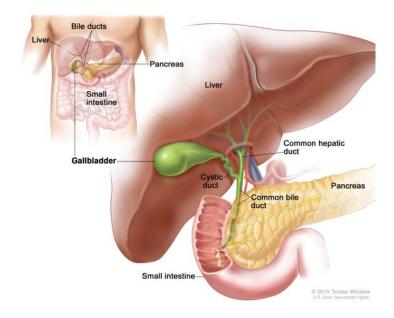
There are two kinds of tumors in the liver:

- Benign tumors are not cancer. They are usually not life-threatening and can be followed or removed in surgery.
- Malignant tumors are cancer, and they are harder to treat. Cancer cells can invade nearby tissues, spread to other parts of the body (metastases), and may be life threatening. Cancer may require surgery, chemotherapy, local ablation/embolization, radiation, or a combination of therapies.

There are two main types of primary liver cancer:

- Hepatocellular carcinoma (HCC) is the most common kind of liver cancer. This cancer begins in the main type of cells in the liver, known as hepatocytes. Other types of cells in the liver can develop cancer, but are much less common.
- Bile duct cancer, also known as biliary cancer or cholangiocarcinoma, is a cancerous growth that begins in the cells of the bile ducts.
 The biliary ducts are found both inside and outside of the liver.
 Bile helps you digest fats.

This brochure only discusses hepatocellular cancer.



Rehabilitation Services

This team includes physical therapists and occupational therapists that implement plans to improve a patient's mobility, restore function, increase ability to perform daily activities (bathing and dressing), maximize comfort level, and manage fatigue. Phone: **716-845-3271**

Social Work and Case Management

The Department of Social Work and Case Management combines the skills and resources of licensed social workers and registered nurses. They work with you, your family, and your medical team on the many challenges a cancer diagnosis can bring - transportation and lodging, transitioning from hospital to home, language/interpreter services, emotional support and counseling, and disability and financial assistance issues.

Social Work: 716-845-8022

Case Management: 716-845-5735

Pastoral Care

The Pastoral Care Department is an interfaith department. Our pastoral care staff works with your health care team. Interfaith chaplains are here when and if you need them. They provide a listening ear, guidance, and support.

Phone: **716-845-8051**

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CARING FOR THE WHOLE YOU

Dealing with a cancer diagnosis and treatment can bring new challenges. Roswell Park offers many services to help you and your loved ones.

The Resource Center for Patients and Families

Stop in our Resource Center on the first floor, inside the Sunflower Café. There, you'll find a warm, welcoming staff, free publications on cancer information and support, computers with WiFi and printers, a lending library (laptops, DVDs, CDs), and more. The Resource Center also offers a complimentary wig, hat, and scarf boutique for cancer patients experiencing hair loss from their treatment. Phone: 716-845-8659

Supportive and Palliative Care and Cancer-Related Pain Management Teams

Cancer and cancer treatment can cause fatigue, nausea and vomiting, pain, limited mobility, and other side effects. The Supportive and Palliative Care team focuses on symptom control and pain management with regard for the emotional, social, and spiritual needs of patients and their families. The Pain Management team includes pain specialists with backgrounds in anesthesiology, psychology, nursing, physical therapy, occupational therapy, and social work that provide medication and non-medication pain control options to relieve cancer-related pain.

Supportive and Palliative Care: 716-845-8214.

Pain Management: 716-845-4595

Nutritional Guidance

Registered dietitians are an important part of the GI team. They check your nutritional status, help you meet your nutrition needs, and manage side effects that affect your ability to eat. If your treatment is interfering with your ability or desire to eat, ask your doctor about a referral for a personal meeting with one of our dietitians. Phone: 716-845-2398

STAGING CANCER

If your doctor suspects you have liver cancer, you will have some tests to determine if it is cancer, and if so, how far the cancer has progressed. These tests will help determine the exact "stage" of your cancer. Stages are a way of defining how much a cancer has grown, if it has spread to other organs, and how it affects the rest of your body.

At present, experts in this field have concluded that no single staging system could be used to stage all liver cancer patients accurately. The Barcelona Clinic Liver Cancer (BCLC) Staging System is one staging system currently in use. This system is used to discuss a patient's chance of recovery and to plan treatment, based on the following:

- Whether the cancer has spread within the liver or to other parts of the body
- How well the liver is working
- The general health and wellness of the patient
- The symptoms caused by the cancer

There are 5 stages in the BCLC system:

• Stage 0: Very early

• Stage A: Early

• Stage B: Intermediate

• Stage C: Advanced

• Stage D: End-stage

Treatment to cure the cancer is given for stages 0, A, and B. Treatment to relieve symptoms and improve a patient's quality of life is given for stages C and D. Treatments given in stages C and D are not likely to cure the cancer because the patient's overall health is poor, or the cancer is more advanced, or both.

A NOTE ABOUT CIRRHOSIS

Cirrhosis, or scarring of the liver, is a common risk factor for liver cancer. The scarring may be the result of injury or disease. Therefore, some patients will have liver cancer and cirrhosis. If you have both conditions, there may be fewer treatment options available to you, and the liver cancer may be more difficult to treat.

The *Child Pugh Score* classifies patients as having class A, B, or C cirrhosis of the liver. Physicians use it to help determine if a patient is a good candidate for surgery.

The National Comprehensive Cancer Network (NCCN) Treatment Guidelines do not use a particular staging system, but divides patients into 4 groups:

- 1. Disease that can be treated with surgery (operable disease)
- 2. Disease that cannot be treated with surgery (inoperable disease)
- 3. Disease that is localized (has not spread) but patient is not a good candidate for surgery (inoperable because of performance status or comorbidity)
- 4. Disease has spread to distant sites in the body (metastatic disease)

TESTS TO DIAGNOSE AND STAGE LIVER CANCER

If liver cancer is suspected, your doctor is likely to order any or all of the following tests:

- History and Physical Exam: History and physical exam: A care provider takes a history of your health habits, past illnesses, and family medical history. He or she checks your general health and looks for any signs of disease that may affect your care plan.
- Blood Tests: Serum tumor marker (AFP) tests and liver function tests
 (LFTs) involve taking a small blood sample from you and measuring
 how much of certain substances, like alpha-fetoprotein (AFP) are in that
 sample. High levels of certain substances may indicate a problem with
 vour liver.

QUALITY OF LIFE QUESTIONS

- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- Will this treatment affect my ability to become pregnant or father a child?
- What long-term side effects may be associated with my treatment?
- If I'm worried about the costs of my cancer care, who can help me?
- Where can I find emotional support?
- Who should I call for questions or problems?

HOW TO MANAGE SIDE EFFECTS OF TREATMENTS

Some treatments may have mild, moderate, or more severe side effects. Here are some tips for managing your health and managing any discomfort during treatment.

- Get plenty of rest. Do not overexert yourself.
- Drink 2-3 quarts of water/fluids per day unless your doctor has restricted your fluids.
- Eat a healthy and balanced diet.
- Brochures about how to manage specific side effects are available from your nurse and in the Resource Center for Patients and Families (see description on page 16).
- Stay active. Work with your doctor to determine the physical activities best for you.
- Maintain good hygiene. Wash your hands thoroughly and often.
 Ask friends and family not to visit you if they are sick.
- Mouth care is very important. Follow instructions about dental care and how to brush your teeth. Avoid smoking, alcohol, and mouthwashes that contain alcohol.
- Find a support group. Roswell Park and local organizations
 offer a number of support groups for cancer patients, survivors,
 and families. Ask a member of your care team or see our calendar.
 You can also join the Roswell Park online community at
 www.cancerconnect.org/roswellpark

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HEPATITIS AND LIVER CANCER

In people who have chronic hepatitis B or hepatitis C, the virus repeatedly attacks the liver. Over time, this can lead to progressive liver damage and liver cancer. Worldwide, chronic infection with hepatitis causes 8 out of 10 primary liver cancers.

People with chronic hepatitis B (HBV) are 100 times more likely to develop liver cancer than people who are not infected with HBV. The good news is that the U.S. Food and Drug Administration approved a hepatitis B vaccine as the first "anti-cancer vaccine". There are also effective therapies that can help control and manage chronic hepatitis B infections.

At this time, there is no vaccine to help prevent liver cancers caused by chronic hepatitis C infections. Recently, however, effective therapies to treat hepatitis C have become available. Your doctor will advise you on the need for hepatitis medications, if appropriate.

QUESTIONS TO ASK THE DOCTOR

Before you can make important care decisions, you need to understand your cancer, the risks and benefits of each treatment option, and how cancer and your treatments may affect your life. Regular communication is important in making informed decisions. Consider asking these questions when meeting with your doctor or care team.

DIAGNOSIS AND TREATMENT QUESTIONS

- What type of cancer do I have?
- Can you explain my pathology report (or laboratory test results) to me?
- What stage is my cancer? What does this mean?
- What is the prognosis (likely course of my disease)?
- Which treatment plan do you recommend? Why?
- What is the goal of treatment? Is it to eliminate the cancer, help me feel better, or both?
- What are the side effects? How will you prevent or relieve these side effects?
- Who will be part of my treatment team? What does each member do?

- Ultrasound Exams: High-energy sound waves (ultrasound) are bounced
 off internal tissues or organs, making echo sounds. A computer uses
 these sounds to form a picture of the inside of your body called a
 sonogram. Ultrasound can show liver tumors.
- Computed Tomography (CT): A CT scan is a diagnostic test that uses special x-rays and computer enhancement to take multiple cross-sectional images of your body. CT images are many times more sensitive than the image from a standard x-ray. Liver tumors can be diagnosed by their classic CT features. A CT scan may also be used to guide a doctor who is performing a biopsy.
- **Biopsy:** A doctor takes a sample of your cells or tissues. The sample is viewed under a microscope to see if cancer cells are present and to confirm a cancer diagnosis.
- CT/Ultrasound-guided biopsy: Both ultrasound and CT scans, described above, can be used to help guide a radiologist (a doctor who specializes in obtaining and reading medical images) when he or she wants to take a small sample (biopsy) of suspicious or abnormal tissue. This procedure is performed in the Radiology Department on the 2nd floor of the hospital.
- Magnetic Resonance Imaging (MRI): An MRI scan is created by an imaging machine that uses a large magnet, a computer, and radio waves to create detailed images of the inside of your body.
- Laparoscopy: While you are under general anesthesia, the surgeon makes small cuts (incisions) in your abdomen. The surgeon inserts a thin, lighted tube (laparoscope) into the abdomen and looks at your organs.
 The surgeon may remove lymph nodes or other tissue samples for biopsy (examination, usually under a microscope).

YOUR LIVER CANCER CARE TEAM

Roswell Park offers the benefits of being cared for by a collaborative team of surgeons, medical oncologists, radiation oncologists, nurses, and other experts. Their individual roles and responsibilities include:

Physician (MD): She or he diagnoses and treats illness and is usually the leader of your health care team. Physicians generally have the responsibility for making clinical decisions and carrying out many of those decisions. A **Fellow** is a physician who has completed residency and training in general medicine or surgery and is now training in a specialty.

- Oncologist: An oncologist is a physician with specialized knowledge
 in diagnosing and treating cancer and relieving symptoms. A
 medical oncologist is a specialist in the use of medications, such as
 chemotherapy, to achieve these goals and is the primary care provider
 for your cancer. A surgical oncologist performs surgery and a radiation
 oncologist specializes in radiation therapies
- Gastroenterologist: A physician with 2-3 years of specialized training in internal medicine and another 2-3 years of training in problems of the digestive tract
- Gastroenterologist/Endoscopy specialist: a gastroenterologist with additional specialized training in performing endoscopy (a minimally invasive medical procedure in which a flexible lighted tube is used to examine the inside of the body for diagnostic purposes or to perform endoscopic therapy (see description below)
- Interventional radiologist: a board-certified physician with additional advanced training in performing minimally invasive, targeted treatments using imaging to guide them. Treatments they may offer for liver cancer include chemoembolization, biopsy, ablation, and radioembolization

LIVER TRANSPLANTS

A liver transplant is a potentially curative treatment for liver cancer and has the benefit of treating the underlying cirrhosis, but there is a lack of readily available livers for transplant. Our doctors follow strict national guidelines about which patients are eligible for a liver transplant. Qualifying for a transplant may mean being added to the list of people waiting for a new liver. If a liver transplant is an option for you, you and your doctor should have an open discussion about the risks and benefits.

Some patients can receive a piece of a healthy liver from a living donor (usually a close relative). However, this procedure also carries some health risks for the donor.

OVERVIEW OF CURRENT TREATMENT OPTIONS

Treatment	When it Can be Used
Liver Transplant	 One lesion smaller than 5 cm or 3 lesions that are each less than 3 cm The cancer has not invaded the blood vessels The cancer has not spread outside the liver
Surgery	Mostly limited to 1 lesion, smaller than 5 cm
Radiofrequency ablation	No more than 3 lesions, each smaller than 4 cm
Chemoembolization	 Multiple lesions that cannot be treated with ablation or surgery May be used as a bridge to transplant Bilirubin must be less than 2 mg/dl, the main portal vein must not blocked, and there must be no ascites (excess fluid in the abdomen)
Sorafenib (targeted therapy)	Advanced cancer (cancer that has spread into blood vessels and/or outside the liver and cannot be treated with surgery)

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DRUG THERAPIES

If targeted therapy or chemotherapy are options for you, your doctor, and/or pharmacist will discuss possible drug therapies with you.

Targeted Therapy

No two cancer patients are exactly alike. The same is true for cancers. Each tumor is genetically different. These differences can mean that one patient's body may respond positively to treatment while another does not.

Traditional chemotherapy drugs identify cancer cells by their rapid rate of reproduction. Targeted therapies identify and attack cancer cells by identifying specific genetic abnormalities of these cells. The most frequently used targeted therapy for liver cancer is sorafenib (Nexavar®).

Chemotherapy

Due to the unique features of primary liver cancer, and the liver itself, existing chemotherapy regimens have not been very effective. There are clinical trials underway that are looking at new ways to use chemotherapy such as combining it with another treatment such as embolization or a targeted therapy drug.

CLINICAL TRIALS

Clinical trials are research studies that involve people. They are the final step in a long process that begins with research in a lab. Clinical trials are key to developing new methods to treat cancer. Most treatments we use today are the results of past clinical trials. Clinical trials may offer promising new therapies. These therapies are being tested to help create new, improved ways to prevent, detect, diagnose, and treat cancer and treatment side effects. If you take part in a clinical trial (also called a clinical or research study), you will play an important role in this process. Your participation will have a future benefit for many other patients and their families. Some patients may be eligible for clinical trials, if they meet certain criteria. Talk with your doctor and discuss whether a clinical trial is right for you.

Nurse Practitioner (NP) are advanced practice nurses who can prescribe medications and other treatments, order and interpret lab tests and x-rays, care for patients, and teach patients and families about their care. NPs practice independently, within their scope of practice.

Physician Assistant (PA) complete physical exams on patients, and diagnose and treat illnesses under the supervision of a physician. They order and read tests, write prescriptions, and assist in surgery. They teach patients and families about their care.

Clinical pharmacists (PharmD) prepare the medications and chemotherapy agents that are prescribed by physicians and given by nurses. They help patients and families understand the medications prescribed.

Oncology nurses (RN) complete patient assessments, give prescribed medications and treatments and help patients and families understand them, and communicate changes and abnormal findings to the provider (MD. NP. or PA).

All of the positions listed above require licensing by the State of New York.

YOUR TREATMENT OPTIONS

Your team will review the results of your diagnostic tests and develop a treatment plan just for you. Your treatment plan will be based on:

- the size and location of your liver cancer
- whether the cancer has spread outside the liver and invaded nearby lymph nodes, blood vessels, and other organs
- how well your liver is working
- your age and general health

Your treatment plan will likely include one or more of these approaches:

- surgery
- radiation
- medical therapy (chemotherapy or targeted therapy)
- chemoembolization or radioembolization
- ablation (radiofrequency, alcohol, or microwave)
- nanoknife
- clinical trial

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TREATMENT OPTIONS BY STAGE

Barcelona Clinic Liver Cancer stages 0, A, and B (potentially curative treatments are available)	Barcelona Clinic Liver Cancer stages C and D (curative options are not available)
Partial liver resection (also called partial hepatectomy)	Embolization therapy or chemoembolization
Total liver resection and liver transplant	Targeted therapy
Ablation of the tumor using one of	Radiation therapy
the following methods:radiofrequency ablationmicrowave therapypercutaneous ethanol (alcohol)	Clinical trial of targeted therapy after chemoembolization or combined with chemotherapy
injectioncryoablation	Clinical trial of a new targeted therapy
electroporation therapy	3-D conformal radiation therapy, stereotactic body radiation therapy, or proton-beam radiation therapy
	Clinical trial of stereotactic body radiation therapy with or without targeted therapy

Clinical trials may be available at any stage. It is a myth that they are only for people who have advanced cancer that is not responding to treatment. (see Clinical Trials section on page 12)

SURGERY

You may have one of these types of surgery:

- Liver resection: The surgeon removes any tumors from your liver. He or she may also remove the part of the liver containing the tumors. If the rest of the liver is healthy, up to 70 percent of the organ can be removed. The part of the liver that remains will likely grow back to normal.
- Ablation: This surgical procedure destroys the tumor without removing
 it. This is a good option for patients who cannot undergo traditional
 surgery. There are several different kinds of ablation techniques including
 microwave, nanoknife, alcohol, and radiofrequency.

Selecting one technique over another is based on the size of the tumor(s) and its location (how close it is to blood vessels)

RADIATION THERAPY

Radiation therapy may be used to treat cancer or to ease cancer symptoms in the liver or another part of the body. If radiation therapy would be helpful for you, your care provider will explain the different radiation techniques and discuss what may be best for you.

Doctors use two types of radiation therapy to treat liver cancer:

- External radiation therapy, which aims radiation in a precise way at a patient's chest and abdomen, above the liver.
- Internal radiation therapy uses tiny radioactive beads in the blood vessels that feed the liver tumor. The doctor injects the beads through a catheter that is placed in the blood vessel(s). The radiation destroys the blood supply to the liver tumor. This treatment is called selective internal radiation therapy, or SIRT.