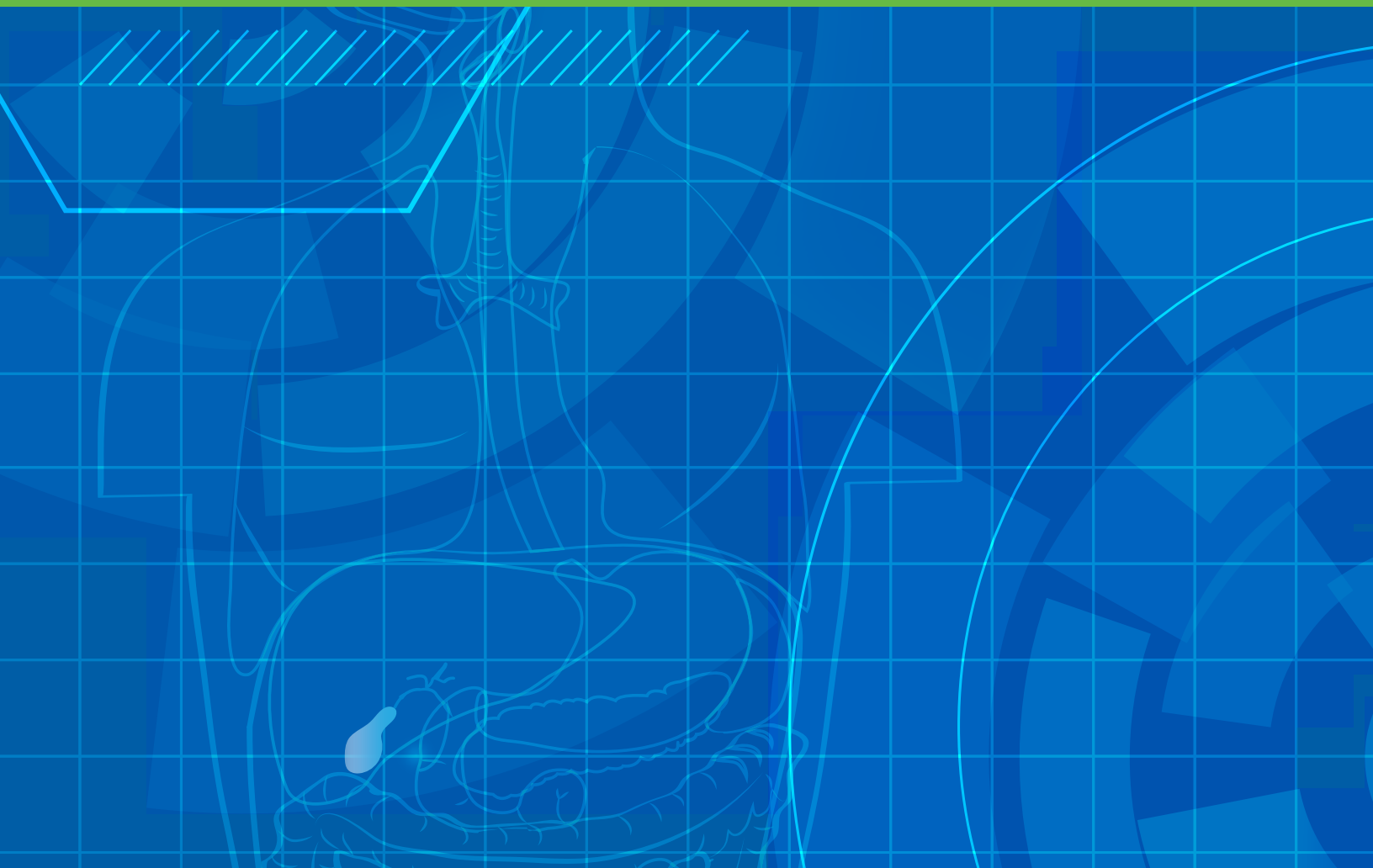


UNDERSTANDING BILIARY CANCER

Patient Education Guide



**PATIENT
EDUCATION**

Questions and Emergencies

Contact Information for GI Center
Hours: 8:00 a.m. – 5:00 p.m., Monday – Friday
Phone: 716-845-4005

- If you need assistance after hours, or on weekends or holidays, call the GI Center. Someone will answer your call even if the center is closed.
- The Assessment and Treatment Center (ATC) is open 24/7, 365 days a year. This service is available for current patients, and provides access to Roswell Park clinicians after hours.
This is not a walk-in clinic.
Please call the GI Center or Roswell Park's main number **716-845-2300**.
- In an emergency, please call 911 or go to a hospital emergency department.
- Bring your Roswell Park "green card" (ID card) with you and let the ER staff know the last time you were treated at Roswell Park.
- If you go to the ER or are admitted to the hospital, have someone notify your Roswell physician.

Welcome to the Gastrointestinal (GI) Center at Roswell Park. Experts in each type of GI cancer work together and create a treatment plan that treats your cancer while maintaining the best quality of life possible. Our goal is to help you understand all potential therapies for your cancer so that you can make the best treatment decisions. Thank you for placing your trust and confidence in our team.

Biliary tract cancers begin somewhere in the biliary system, which includes:

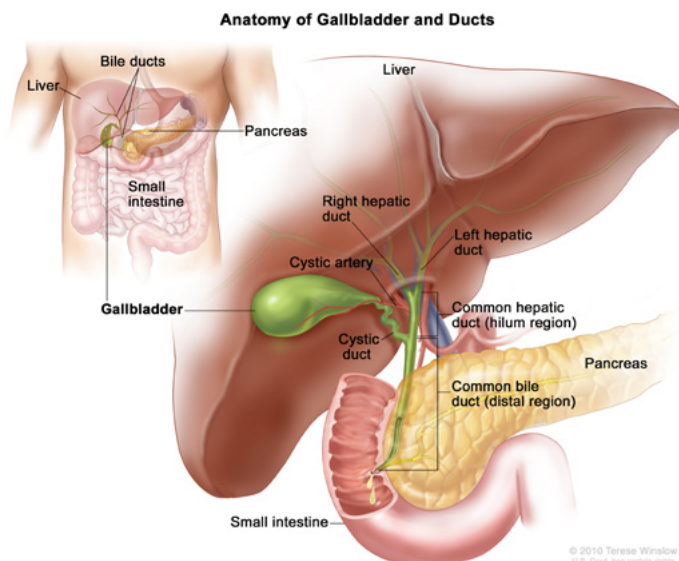
- bile ducts within the liver
- the gallbladder
- the bile duct outside the liver

Almost all cancers affecting the biliary system are primary cancers—very few cancers beginning somewhere else spread to the biliary system.

This booklet provides an overview of biliary tract cancers and 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 your questions at any time.

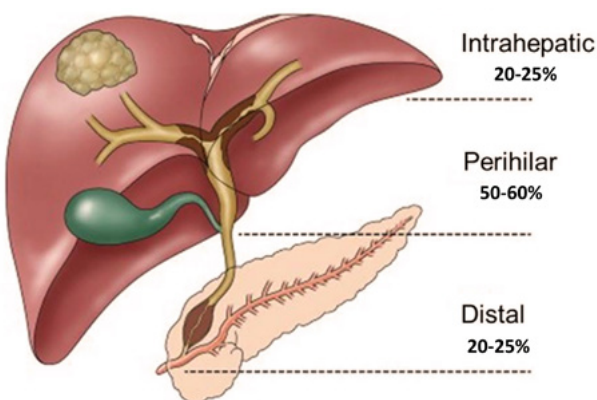
The Biliary System

The liver sits in the upper right portion of your abdomen, beneath your ribs and above your stomach. It performs many necessary functions—one of which is to make bile. Bile is needed to digest food—particularly fat. The biliary system is similar to a tree—small branches collect bile made by liver cells. The small branches drain into larger branches and ultimately into a “trunk” outside the liver. This trunk delivers bile to the intestine. If bile is not needed in the intestine, the bile is stored in the gall bladder.



What is Biliary Tract 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.



There are two main biliary tract cancers—gallbladder cancer and cholangiocarcinoma (bile duct cancer).

Cholangiocarcinomas are broken into smaller groups depending on where in the bile duct the cancer occurs:

1. in the liver (intrahepatic)
2. at the junction of the right and left ducts (perihilar, also known as Klatskin's tumor)
3. near the intestine (distal)

Risk Factors

A risk factor is anything that increases a person's chance of developing cancer.

Risk factors for biliary tract cancers include:

- gender (female for gallbladder cancer, male for cholangiocarcinoma)
- history of bile duct infections (more common in East Asia and Africa)
- race (Hispanics, Native Americans, North Indians, Central Europeans)
- gallstones and bile duct stones; gallbladder polyps
- older age
- conditions that can cause cirrhosis such as alcohol use and hepatitis infection
- primary sclerosing cholangitis
- cysts in the bile duct or abnormalities in the bile duct anatomy
- obesity and diabetes mellitus (high levels of glucose/sugar in the blood)

Over 10,000 new cases of biliary tract cancers are diagnosed in the U.S. each year. Some people with several risk factors never develop cancer, while others who have no known risk factors do.

Staging Cancer

If your doctor suspects you have biliary tract 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.

	Stage I	Stage II	Stage III	Stage IV
Gallbladder Cancer	A small cancer within the muscle layer of the gallbladder wall. It has not spread outside the gallbladder.	Cancer that has grown beyond the muscle layer of the gallbladder but has not spread outside the gallbladder.	Cancer that has grown beyond the gallbladder to EITHER 1. invade the liver or another surrounding organ OR 2. invade lymph nodes around the bile duct.	Cancer that 1. invades the major blood vessels of the liver OR 2. invades multiple surrounding organs OR 3. has spread to distant lymph nodes or organs.
Intrahepatic Cholangio-carcinoma (Bile duct cancer that starts within the liver)	A single cancer that has not invaded blood vessels.	Either a single cancer with blood vessel invasion OR multiple tumors with or without blood vessel invasion.	Cancer that has grown through the liver capsule and/ or directly invades surrounding organs.	Cancer that has invaded lymph nodes, the common duct, OR has spread to distant organs.
Perihilar Cholangio-carcinoma (Bile duct cancer that starts at the junction of the right and left bile ducts)	Cancer is confined to the bile duct.	The cancer invades beyond the bile duct wall and may invade the liver.	Cancer invades the blood supply to one side of the liver or the surrounding lymph nodes.	Cancer 1. invades the blood supply to both sides of the liver 2. invades the bile ducts to both sides of the liver so that surgery is not possible OR 3. has spread to distant organs.
Distal Cholangio-carcinoma (Bile duct cancer that starts near the intestine)	Cancer is confined to, or invades beyond, the bile duct wall but does not invade any surrounding organs.	Cancer invades surrounding organs or lymph nodes.	The cancer involves the major arteries that supply the intestines with blood.	Cancer has spread to distant lymph nodes or organs.

Surgical options are usually available only for early stage cancers - Stages I and II. It is used selectively for Stage III cancer, usually after chemotherapy. Sometimes, patients are treated with chemotherapy after surgery to prevent disease recurrence. Patients who are not able to undergo surgery or who have Stage IV disease are treated with combinations of chemotherapy and radiation. These therapies are aimed at preventing disease spread and, in some cases, can shrink tumors. Importantly, clinical trials are available for patients at **any** stage of disease.

Grade

While stage refers to the size of the tumor and whether it has spread, tumor grade refers to how abnormal the cancer cells look under a microscope – how different they look from normal cells. If the tumor cells don't look that different from normal cells, the tumor is called well-differentiated, and they tend to grow and spread at a slower rate. Undifferentiated tumors, where the cancer cells look very different from normal cells, tends to be more aggressive – more likely to grow and spread.

Tests to Diagnose and Stage Biliary Tract Cancers

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

- **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, liver function, chemistry, and blood count tests involve taking a small blood sample from you and measuring how much of certain substances are in your blood. High levels of certain substances may indicate a problem with your liver.
- **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 gallbladder and bile duct 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. Biliary tract 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.
- **PET/CT scan:** Combines images from a nuclear PET scan (Positron Emission Tomography) and a CT scan. Results are more accurate than either test alone.
- **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.
- **Endoscopic retrograde cholangio/pancreatogram / endoscopic ultrasound (ERCP/EUS):** While you are under general anesthesia, a gastroenterologist passes a scope through your mouth, esophagus, stomach, and small intestine to your bile duct. Brushings of the bile duct, biopsies, and (if needed) a stent.
- **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 Biliary Tract 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).
 - **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.
 - **Nurse Practitioners (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 Assistants (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 tumor
- 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 (chemotherapy or radiation given directly to the liver)
- microwave ablation (using microwave energy to burn tumors)
- clinical trials

Surgery

You may have a resection or an ablation.

Resection: The surgeon removes tumors from your bile duct and/or liver. 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. If necessary, the surgeon may need to create a new connection between your intestine and the remaining bile duct.

Ablation: This surgical or radiologic procedure uses microwave energy to burn the tumor without removing the liver. While not as effective as resection, ablation is a good option for patients who cannot undergo resection. For ablation to be possible, tumors must be within the liver and away from major blood vessels.

Drug Therapies

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

Chemotherapy

Chemotherapy has been shown to improve survival for patients with biliary tract cancers that is not surgically treatable. The most common drugs given are gemcitabine and cisplatin. Sometimes, chemotherapy and radiation are given together before a planned surgery to shrink tumors, or after surgery to prevent cancer recurrence.

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.

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: Radiation is delivered from a machine outside the body aimed directly at tumors within the liver or bile duct.

Internal radiation therapy: Radiation is delivered through a temporary catheter placed in the artery supplying one side of the liver. This treatment is called selective internal radiation therapy, or SIRT.

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.

Liver Transplant

A liver transplant is only effective for a certain type of biliary tract cancer (perihilar cholangiocarcinoma). 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.

Treating Jaundice

In many biliary cancers, the bile duct can get blocked and cause jaundice (yellow skin and eyes, dark urine, light stools). Without treatment, jaundice can lead to life-threatening infections and liver failure. Several procedures can be performed to unblock bile ducts. These include stents (most often placed via [endoscopy*](#)) and cholangiocatheters (tubes placed from outside the body, through the liver, and into the common duct). Both often need to be changed every 4-6 weeks to prevent blockage.

*Endoscopy lets your doctor look inside your body with an endoscope – a long, flexible tube with a tiny camera at the end. Endoscopes are often inserted through natural opening such as the mouth.

Overview of Current Treatment Options

Treatment	When it Can be Used
Resection (surgery)	Used most often for stage I or II cancers. May be used for stage III disease
Liver Transplant	Used only for select cases of perihilar cholangiocarcinoma
Ablation (surgery or radiology)	Used when patients cannot undergo surgery for early stage cancers
Chemotherapy	Used for stage IV and some stage III cancers. It is given intravenously (IV) and treats the entire body. May be given before or after surgery and in combination with radiation
Radiation (external beam or internal)	Given for multiple tumors and later stage cancer. Usually given only when there is no cancer beyond the liver, surrounding lymph nodes, or bile duct

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?

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 (first floor hospital, in cafeteria).
- 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. Join the Roswell Park online community to connect and share with folks who understand what you are going through. All you need is an email address.
community.roswellpark.org

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.

Assessment & Treatment Center

Roswell Park's Assessment and Treatment Center (ATC) can help if you have urgent, but not life-threatening symptoms. The ATC is open 24 /7 but does not accept walk-ins. You must be referred by your doctor or the doctor on call. If you are having urgent symptoms, call the GI Center or Roswell Park's main number **716-845-2300**.

The Resource Center for Patients and Families

Stop in our Resource Center, located on the first floor of the main hospital, inside the Sunflower Café. You will find a warm, welcoming staff, free cancer information and support, computers with WiFi and printers, a lending library (laptops, DVDs), and more. The Center also offers a complimentary wig, hat, and scarf boutique for cancer patients who have treatment-related hair loss, and a Cancer Coach program to provide support. Phone: **716-845-8659**.

Supportive and Palliative Care Department

Provides symptom control, pain management, and supportive care at any time after diagnosis, including patients with advanced disease who are continuing treatment. Services include:

Supportive and Palliative Care: **716-845-8214**
(or ask your doctor for a referral)

Psychology Department: **716-845-3700**

Spiritual Care (interfaith): **716-845-8051**

Cancer Pain Management: Ask your doctor or call **716-845-4595** for a referral.

Medical Cannabis (Marijuana) Program: **716-845-1619**

Social Work

Social workers work with patients and families on the challenges a cancer diagnosis can bring. Services: counseling, transportation, lodging, foreign language assistance, intimacy concerns, hospice information, disability concerns, and referrals for financial and legal assistance.

Hours: Monday – Friday, 9 a.m. - 5 p.m.

Phone: **716-845-8022**. Services are free and confidential.

Nutrition

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**.

Rehabilitation Services

Rehabilitation Services provide physical, occupational, and lymphedema therapy specifically designed for cancer patients and survivors before, during, and after cancer treatment. Talk to your health care provider for a referral or call **716-845-3271** to make an appointment.

Case Management

Staffed by registered nurses who help coordinate home care services after discharge from the hospital and review inpatient stays and specialty medications. Phone: **716-845-5735**.

Other Resources

Roswell Park General Information

1-800-ROSWELL (716-767-9355)

**Roswell Park
Cancer Coach Program**
716-845-8659

Roswell Park's Online Community

cancerconnect.com/roswellpark

The Cholangiocarcinoma Foundation

801-999-0455

cholangiocarcinoma.org

American Liver Foundation

1-800-GO-LIVER (1-800-465-4837)

liverfoundation.org

CancerCare

1-800-813-HOPE (1-800-813-4673)

cancercares.org

National Cancer Institute

1-800-4-CANCER

cancer.gov

American Cancer Society

Buffalo Resources: 716-689-6982

Toll-free: 1-800-227-2345

cancer.org

Hospice & Palliative Care Buffalo

716-686-8000

hospicebuffalo.com



GI CENTER
716-845-4005



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