A Patient's Guide to

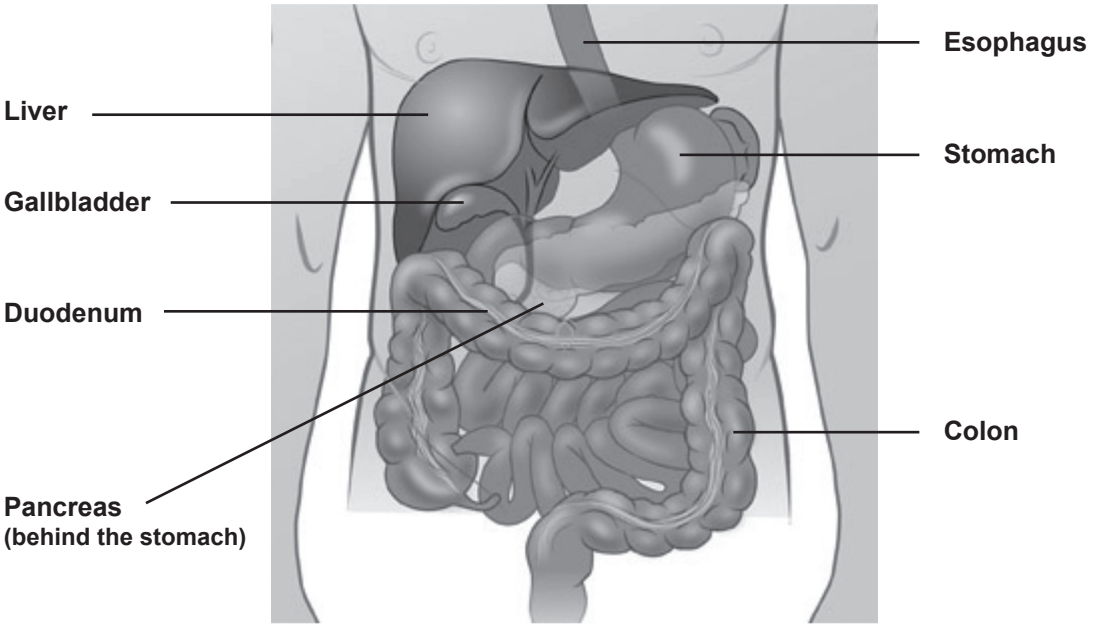
Pancreatic Cancer

COMPREHENSIVE CANCER CENTER

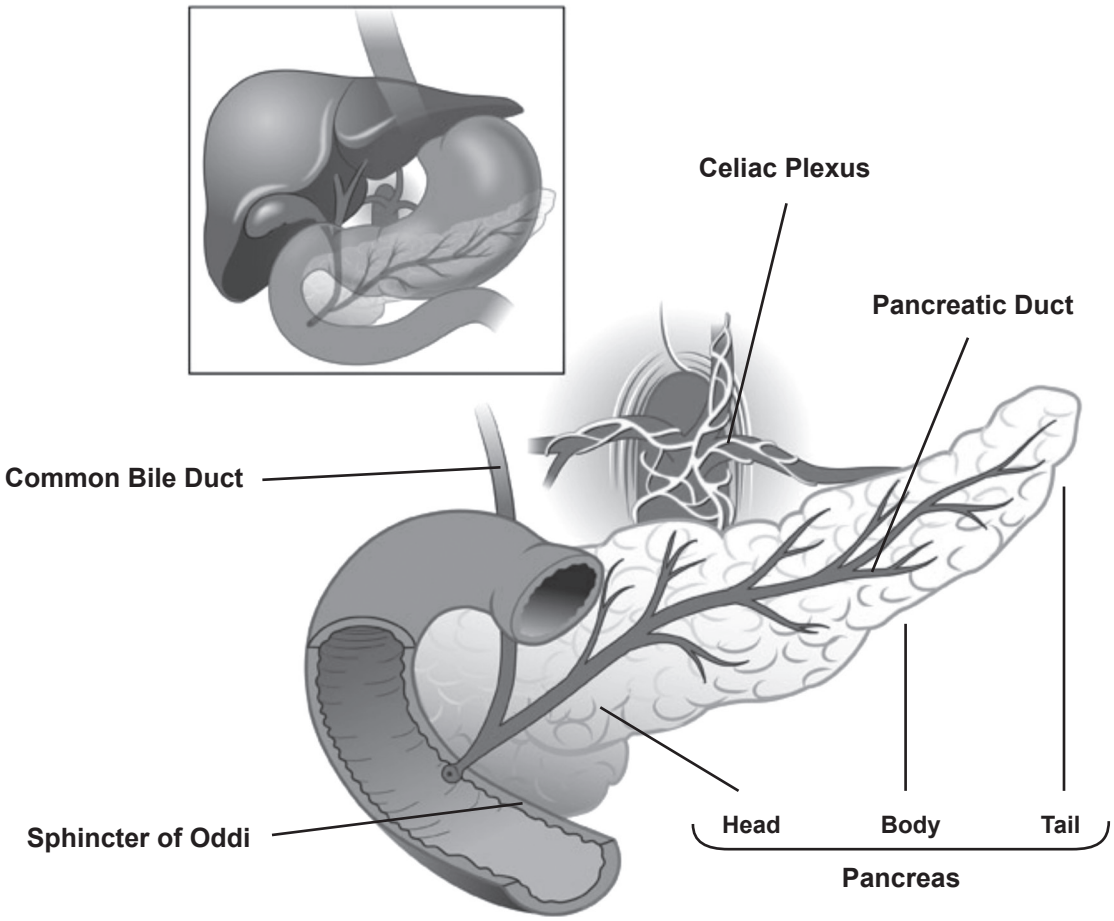
UNIVERSITY OF MICHIGAN
HEALTH SYSTEM

Staff of the Comprehensive Cancer Center's Multidisciplinary Pancreatic Cancer Program provided information for this handbook
GI Oncology Program, Patient Education Program, Gastrointestinal Surgery Department, Medical Oncology, Radiation Oncology and Surgical Oncology

Digestive System Anatomy



Anatomy of the Pancreas



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Introduction

The medical team at the University of Michigan Pancreatic Cancer Clinic at the Comprehensive Cancer Center created this booklet to help explain pancreatic cancer and the treatment options available to you. Your medical team is available to help answer questions about this material and to help answer any questions you may have. Do not hesitate to contact us as you make your treatment decisions. Resource phone numbers are listed in the back of this booklet.

All of this information is available at the Patient Education Resource Center located on level B1 of the Cancer Center Building.

The information in this booklet will be reviewed and discussed throughout your treatment.

Please bring this booklet with you to all appointments.

You will find blank pages at the back of the book to use for questions, appointments or other notes.

Pancreatic Cancer

Where is the pancreas located?

The pancreas is pear-shaped and approximately 6-8 inches long. It has a wider end called the head, the middle part called the body and a tapered end called the tail. *Refer to Figure 1.* The head of the pancreas is on the right side of your body. It lies close to the liver and the section of the small bowel called the 'duodenum'. The tail is close to the stomach on the left side of the abdomen. The pancreatic duct is a channel that runs through the pancreas and empties digestive juices into the small bowel. The common bile duct is another channel that drains bile from the gallbladder and runs through the head of the pancreas connecting with the pancreatic duct to form the Ampulla of Vater.

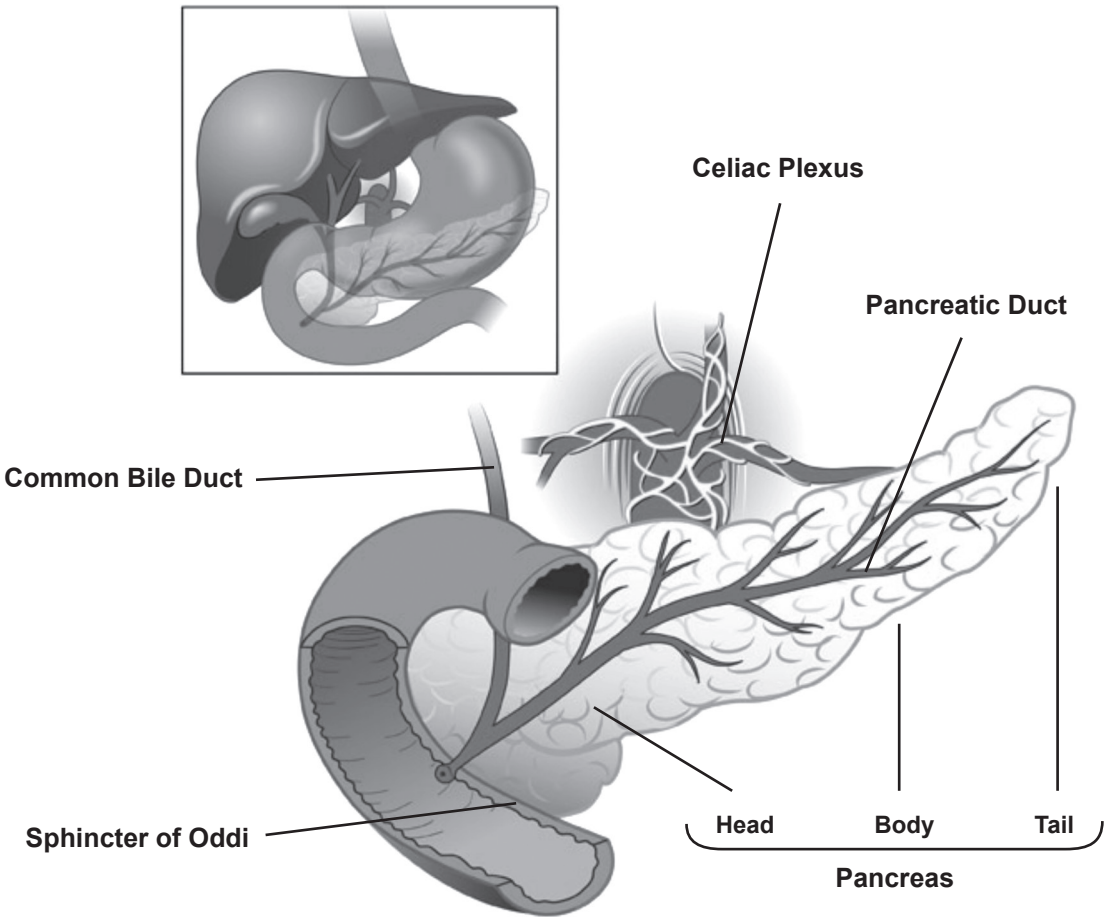

Figure1. Anatomy of the Pancreas

What does the pancreas do?

The pancreas has 2 main functions in the body:

- to make digestive juices (called enzymes) that flow through the pancreatic ducts and help break down fats and sugars in the digestive system, and
- to secrete hormones, like insulin, that affect how the body uses and stores nutrients.

The part of the pancreas that produces the digestive juices is called the exocrine pancreas and the other part that produce hormones is called the endocrine pancreas.

What is cancer and how does it affect the pancreas?

Normal cells grow, divide, and die in a controlled fashion that is regulated in the body. Cancer is a disease where cells divide and grow in an abnormal, poorly controlled manner where the balance of cell growth and death is disturbed. Medical research has led to an increase understanding of these abnormalities and continues to be a focus in the understanding of how to treat cancer.

Cells that continue to grow and divide unchecked become a malignant mass or tumor that can affect how an organ works. The original site of the abnormal cell growth is called the cancer's "primary site". In pancreatic cancer, the primary site is the pancreas. Even when the pancreatic cancer is found in areas outside the pancreas, such as the liver, the disease is still called pancreatic cancer.

Abnormal or unchecked cells can also grow to invade nearby organs and structures. Cancer cells spread and invade organs by traveling to other structures in the body by way of the lymphatic system and the blood stream. This spreading is called metastasis.

How common is pancreatic cancer and who is at risk?

The American Cancer Society estimates that 32,180 men and women will be diagnosed with pancreatic cancer in 2005. It is the fourth leading cause of cancer death in the United States. It most commonly affects patients in the 60-80 year age range, although older and younger patients can be affected. Pancreatic cancer may be related to exposure to cancer-causing agents called carcinogens.

Some factors that increase the risk of pancreatic cancer are:

- Cigarette smoking
- A diet high in fat and low in fiber
- Diabetes mellitus
- Chronic pancreatitis
- Family history (see below)

There is no reliable way to prevent pancreatic cancer, however, general cancer prevention guidelines include eating a high-fiber, low-fat diet, exercising, and avoiding smoking.

Is pancreatic cancer hereditary?

Information about genetic counseling at the University of Michigan can be found at www.mcancer.org or at the Patient Education Resource Center (PERC) on level B1 of the Cancer Center.

Research is being done to better understand possible hereditary factors in pancreatic cancer. There does seem to be a hereditary component in 10-15% of patients with pancreatic cancer. Genetic syndromes such as hereditary pancreatitis, hereditary nonpolyposis colorectal cancer, familial atypical multiple mole melanoma syndrome, and Peutz-Jeghers syndrome are currently being studied for their specific gene changes.

Families with medical histories of known hereditary cancer syndromes that include pancreatic cancer should consider genetic counseling and testing in a research setting. Patients who have a family history of colon cancer, pancreatic cancer, and melanoma may be at an increased risk for pancreatic cancer.

What are the symptoms of pancreatic cancer?

Symptoms do vary and are related to the extent of disease and the location of the tumor in the pancreas. The head of the pancreas is located close to the common bile duct and duodenum (small bowel) so tumors located in the head of the pancreas may grow and block these structures. *Refer to Figure 2.*

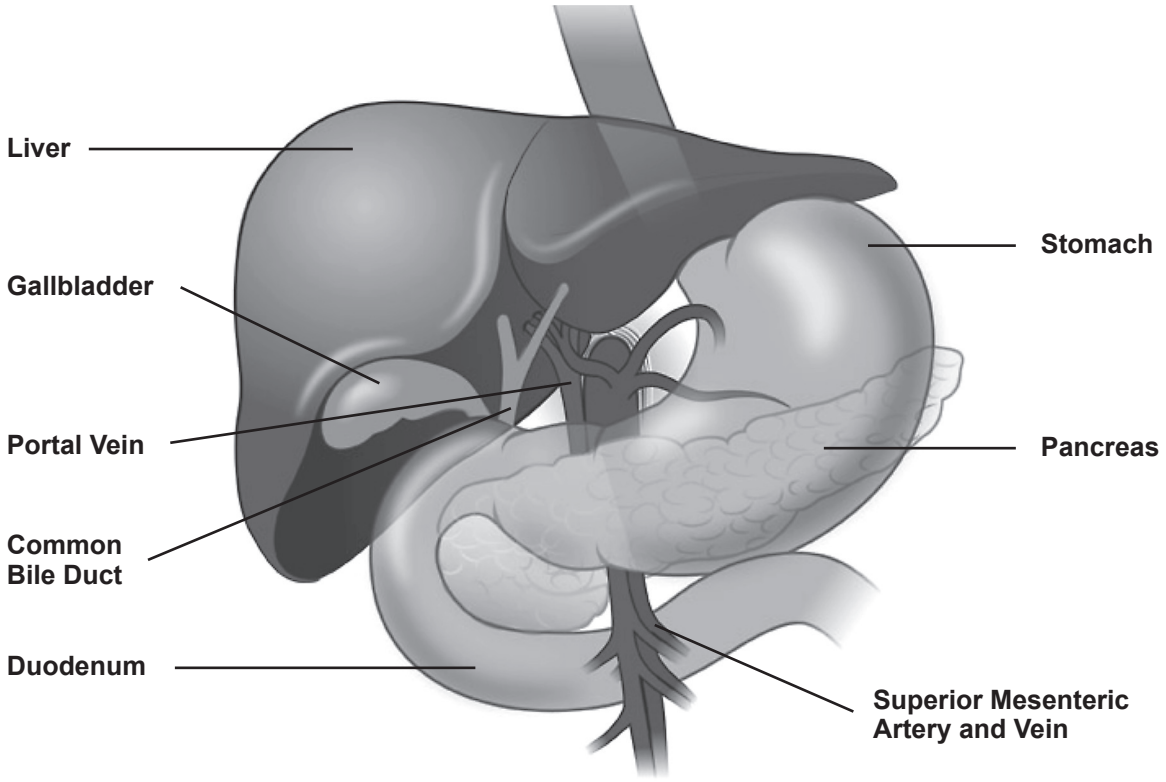

Figure 2. The pancreas and surrounding organs

Jaundice

Bile duct blockage can lead to jaundice in 70-85% of patients with tumors in the head of the pancreas. Symptoms of jaundice include:

- yellowing of the skin,
- yellowing of the whites of the eyes,
- light-colored (clay colored) bowel movements,
- dark-colored urine and
- itching

Nausea, Vomiting, Weight Loss

Stomach emptying can be delayed when the duodenum is compressed. This causes a feeling of fullness and contributes to symptoms of nausea and vomiting. These symptoms are initially present in 35-45% of patients with pancreatic cancer. Patients sometimes have a loss of appetite and nausea that leads to weight loss. In advanced disease, up to 5% of patients have tumors that cause complete blockage of the duodenum (small bowel). In this case, surgery may be done to bypass the blockage and improve digestion.

Fatigue

In more advanced disease, patients can have a feeling of being tired and fatigued.

There are many causes of fatigue in patients with cancer,

Abdominal Pain

75-90% of patients with pancreatic cancer have abdominal pain. This may be described as cramping or gas-like pain. Pain may also spread, or radiate, to the back and shoulders.

Blood Clots

There is an increased risk for blood clots in patients with pancreatic cancer. A blood clot can be a first symptom of pancreatic cancer. The cancer itself causes changes in the blood that increases the risk for blood clots. Some clots have no symptoms, but swelling, pain and redness can be present in the area of a clot.

Diabetes

The onset of diabetes mellitus (called simply, diabetes) or difficulty controlling blood sugar levels is also associated with pancreatic cancer. Diabetes may be diagnosed before or after the diagnosis of pancreatic cancer. Diabetes occurs when the body does not produce enough of the hormone, insulin, or is unable to use insulin properly. Insulin helps your body regulate the blood sugar level, so without insulin, blood sugar levels are often high.

Pancreatic Insufficiency

The pancreas secretes digestive enzymes, or juices into the small intestines. These juices help digest food in the intestines. Patients with pancreatic cancer may not have adequate amounts of these juices in the intestines. If this happens, food isn't digested normally. This is called pancreatic insufficiency.

Symptoms of pancreatic insufficiency include diarrhea and cramping often after eating. This happens because food passes through the digestive tract not fully digested. As the indigestible food passes through, it pulls water into the intestines that causes diarrhea and cramping. *Refer to page 38* for a discussion on management of pancreatic insufficiency with enzymes.

How is pancreatic cancer diagnosed?

Patients with symptoms suspicious for pancreatic cancer will undergo tests to determine the cause of these symptoms. Diagnosing pancreatic cancer can be a challenge. It is often difficult to get an adequate biopsy for the pathologist to look at under the microscope. It is frustrating for the patient and the doctor who want to move ahead quickly in making a diagnosis and beginning treatment. Below are some of the tests and procedures used to diagnose pancreatic cancer.

Ultrasound of the abdomen

An ultrasound can identify a tumor or mass in the pancreas or the bile duct system that may be causing a blockage and jaundice.

Further information about these tests and procedures can be found @ www.umich.edu/pteducation or visit the Patient Education Resource Center on level B1 of the Cancer Center.

Endoscopic Ultrasonography (EUS)

The EUS test is done with a lighted tube that is inserted through the mouth and placed into the stomach. Ultrasound images of the pancreas are obtained through the stomach wall. It is highly sensitive for diagnosing pancreatic cancer. EUS is particularly useful for detecting small (<2 cm) pancreatic tumors which may not be well visualized by CT. It can also identify tumors that may involve important blood vessels. The procedure can provide details about the arteries and veins next to the pancreas. A biopsy with a small or 'fine' needle aspiration (FNA) of the tumor may also be performed during an EUS to diagnosis pancreatic cancer. Intravenous sedation is used for this procedure.

ERCP (endoscopic retrograde cholangiopancreatography)

An ERCP is done with a lighted tube called an endoscope to look at the bile ducts. It can also be used to place a stent or tube to open a blocked bile duct for drainage. Intravenous sedation is most commonly used for this procedure.

The patient is not awake during the test. This procedure helps determine what is causing a blockage. Some causes of these blockages include ampullary tumors, cholangiocarcinoma (bile duct cancer), inflammation or cancer of the pancreas. Bile duct juice and tissue samples may be obtained and sent to a pathologist to evaluate for cancer cells. *Refer to Figure 3.*

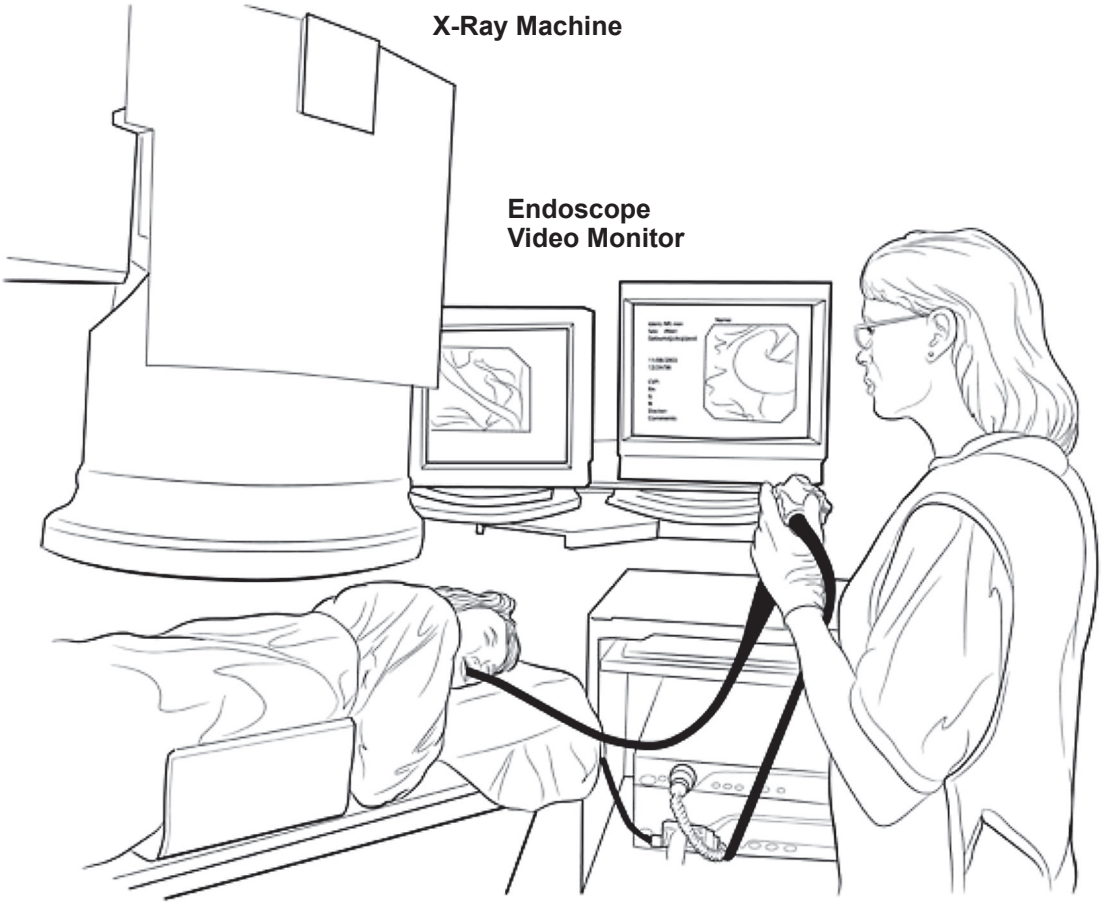

Figure 3. Patient undergoing endoscopic procedure

Computed Tomography (CT)

The CT scan can show small tumors as well as important blood vessels that the tumor might be growing into or around. A CT scan can also look at surrounding organs for spread (metastasis) of the cancer into lymph nodes, liver and other areas. The doctor may suggest a 'pancreatic mass' CT to be done at the UM for your first clinic visit to better assess the tumor for the size, location and involvement of surrounding vessels and organs. This is a special CT scan

done at the University of Michigan that examines the pancreas very closely. A special dye is used for the CT, to give additional information to the radiologist; therefore a temporary IV (intravenous catheter) will be placed prior to the scan.

The CT will be reviewed by the radiologist and the consulting doctor in 1-2 days.

Interventional Radiology

In some cases the radiology department can perform needle biopsies using the CT or ultrasound technique to locate the mass (tumor) and obtain a tissue sample through the abdomen for a diagnosis. At the UM Interventional Radiology department we have specialists who may be consulted to do one of these procedures.

What are the types of cancer found in the pancreas?

There are many different kinds of pancreatic tumors; however, pancreas cancer is mainly (95%) ductal adenocarcinoma. This type of pancreatic cancer arises from the lining of the pancreatic duct which is the exocrine part of the pancreas that produces the digestive juices.

Tumors may arise from the endocrine part of the pancreas in approximately 5% of the cases. This is sometimes referred as Islet (insulin producing) cell or neuroendocrine cancer. Even rarer tumors are sometimes found, such as sarcomas and lymphomas.

For more information on islet cell or neuroendocrine cancer, visit the Patient Education Resource Center (PERC) on level B1 of the Cancer Center or call them at (734) 647-8626. Information is available online through the National Cancer Institute at www.cancer.gov.

This booklet will focus on treatment for ductal adenocarcinoma of the pancreas.

Treatment of Pancreatic Cancer

What are the treatment options?

Pancreatic cancer can be classified (or staged) into three main groups;

- **operable cancer,**
- **locally advanced cancer,** and
- **metastatic cancer**

These classification groups help to determine the most effective way to treat the cancer. If it's determined that the cancer can be successfully removed, then surgery is considered. For patients with localized, but not operable, cancer, two treatment strategies are used:

1. a combination of chemotherapy and radiation or
2. chemotherapy alone

For patients with cancer that has spread, chemotherapy can be offered as treatment.

Operable cancer means a tumor is able to be surgically removed. (also called resectable)

✦ ✦ ✦

Locally advanced cancer means the tumor is found only in the pancreas with no evidence of spread to other organs. (tumors at this stage are unresectable)

✦ ✦ ✦

Metastatic disease means that the cancer has spread to other parts of the body for example, the liver. (tumors at this stage are unresectable)

Doctors and nurses discussing treatment options stress the importance of treating the disease while at the same time making those treatments as tolerable as possible. The goal of treatment is to stop the growth of the cancer, to shrink it, if possible, and to help the patient live a quality life for as long as possible.

How does a patient decide on treatment?

Pancreatic cancer is very hard to control with our current treatment options. When patients are first diagnosed they are overwhelmed. Shock and stress can make it difficult to think of everything you might want to know. It is always helpful to have family or friends accompany the patient for discussions about treatment.

The Multidisciplinary Pancreatic Cancer Clinic has surgeons, medical oncologists and radiation oncologists to review and discuss your individual case. Treatment generally starts within a few weeks of the initial evaluation. There is time to discuss options and to learn more about pancreatic cancer, treatment approaches, and the clinical trials that are available at the University of Michigan Comprehensive Cancer Center.

What factors affect prognosis or chance of recovery and treatment options?

The prognosis (chance of recovery) and treatment options for pancreatic cancer depend on many factors. Some of these are:

- The stage of the cancer (the size of the tumor and whether the cancer has spread outside the pancreas to nearby tissues or lymph nodes or to other places in the body).
- Whether or not the tumor can be removed by surgery, or is "operable" or "resectable".
- Whether the cancer has just been diagnosed or has recurred (come back).
- Your general health

Pancreatic cancer can be controlled for a lifetime, or cured, only if it is found before it is spread and it can be removed in its entirety by surgery. If the cancer has spread, or is inoperable, your doctors will discuss treatments that can improve your quality of life by controlling the symptoms and complications of the disease.

Surgery

When is surgery a treatment for pancreatic cancer?

When patients are diagnosed with pancreatic cancer, approximately 20% of the tumors are found to be operable or resectable. The location of the pancreas adds to the technical difficulties of a surgical operation.

Ideally, surgery would remove the tumor with a wide band of surrounding normal tissue. However, important veins and arteries are located near the pancreas and it may not be possible to do surgery.

Diagnostic tests give information about the size, location and involvement of other surrounding tissues and vessels. These tests help the surgeon determine whether a cancer is operable or resectable. In addition, a surgeon will evaluate the patient's overall health to determine if they can tolerate the surgical procedure. Each case is individual. In some cases, chemotherapy and radiation therapy will be recommended to potentially reduce the size of the tumor and improve the outcome of surgery.

If the tumor is found to be in the head of the pancreas and is operable, the surgical procedure performed is a pancreaticoduodenectomy, also called a Whipple procedure. This surgery involves removing the head of the pancreas, the gallbladder, part of the bile duct, and part of the stomach. Surgery includes re-connecting the remainder of the bile duct, pancreas and stomach to bowel so that these structures can drain properly. *Refer to Figure 4.*

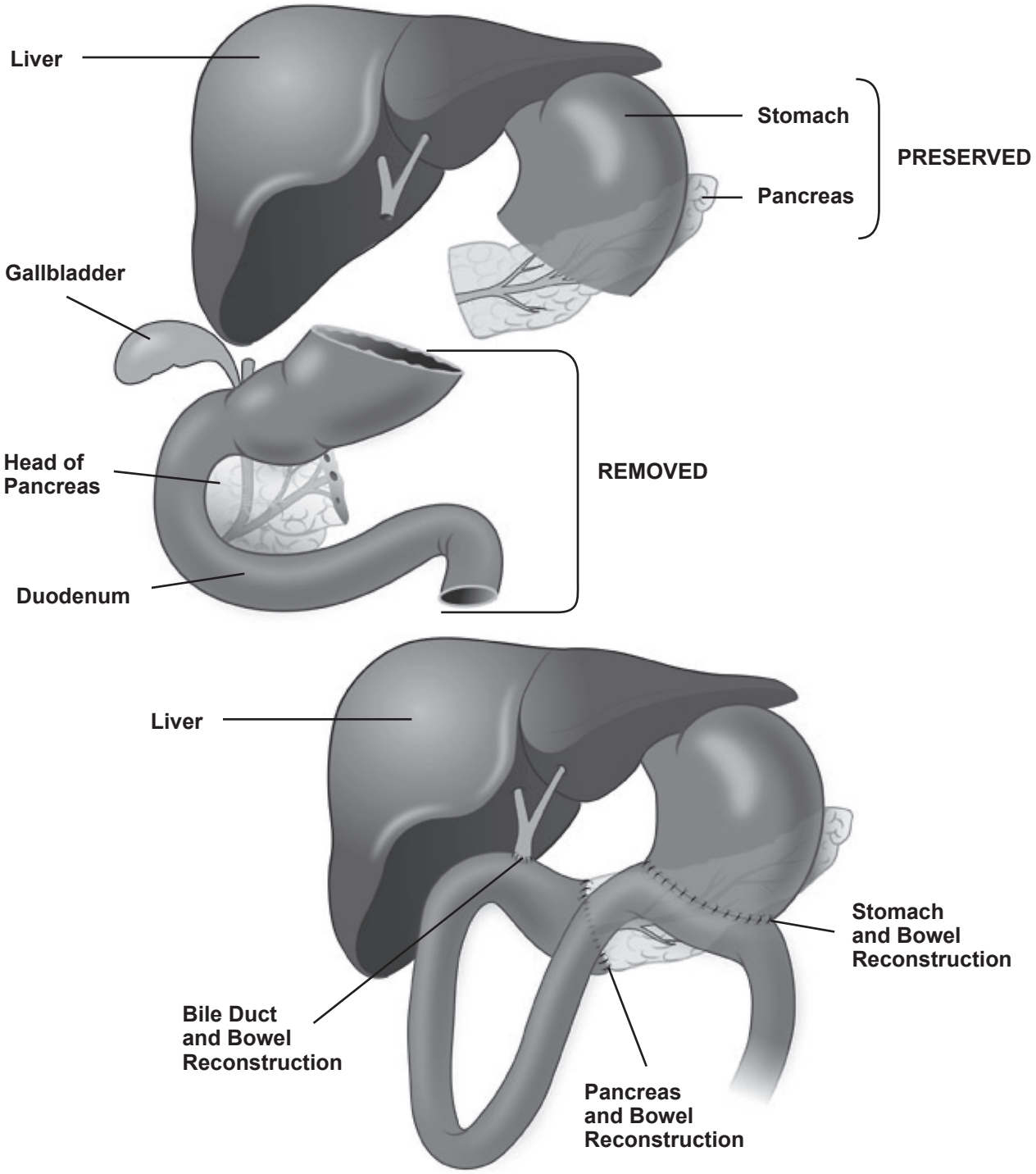

Figure 4. Whipple surgical procedure

Tumors that are in the body or tail of the pancreas, which are less common, can be removed by removing the distal part of the pancreas and the spleen. This is called a distal pancreatectomy. *Refer to Figure 5.*

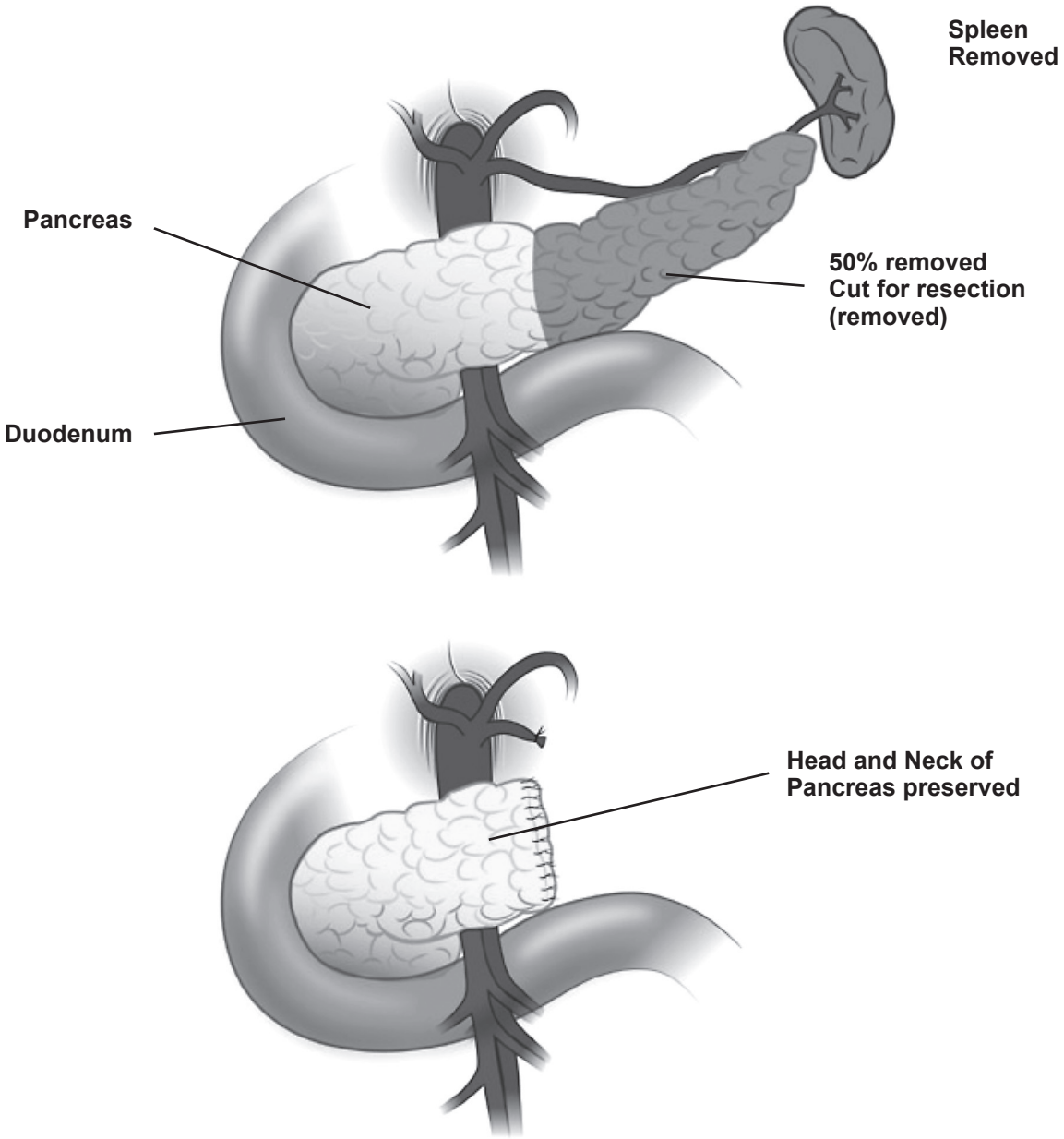

Figure 5. Distal pancreatectomy surgical procedure

What other procedures are done to treat patients with pancreatic cancer?

At the time of diagnosis, 80% of patients are not candidates for potentially curative resection. Other procedures may be necessary to relieve the symptoms caused by the cancer. These symptoms include bile duct obstruction, gastric outlet obstruction and abdominal pain. *Refer to Figure 6.*

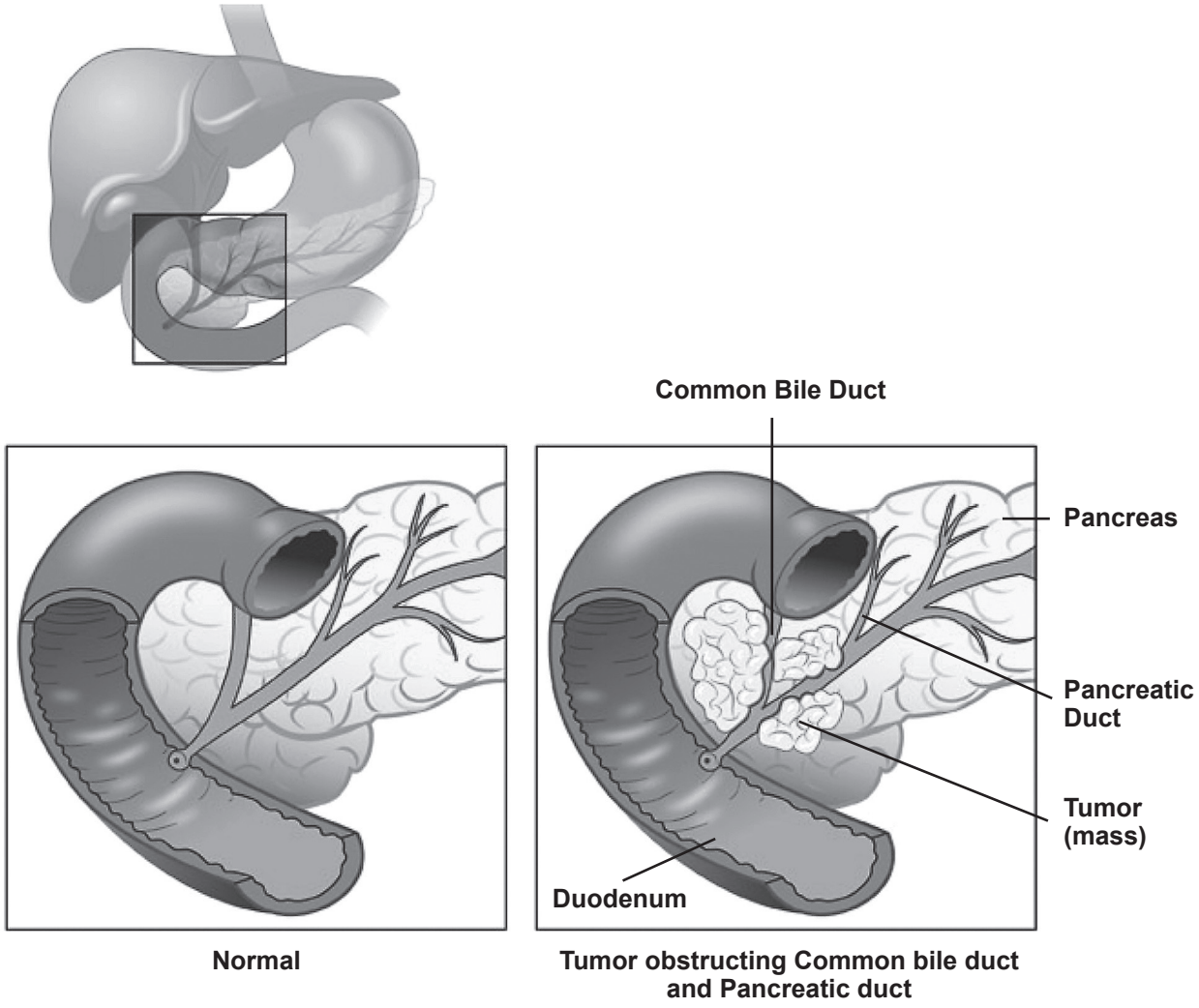

Figure 6. Pancreatic head mass (tumor) illustrating an obstruction

Bile Duct Obstruction

Patients who develop bile duct obstruction due to the tumor are candidates for biliary stent placement, either done with a scope through the mouth (endoscopically) or through the abdomen wall or skin (percutaneously). The endoscopic procedure is called an 'ERCP' and is illustrated and described in the *Tests and Procedures section on page 8* of this handbook. The stent placement is illustrated in *Figure 7.*

Endoscopic Placement:

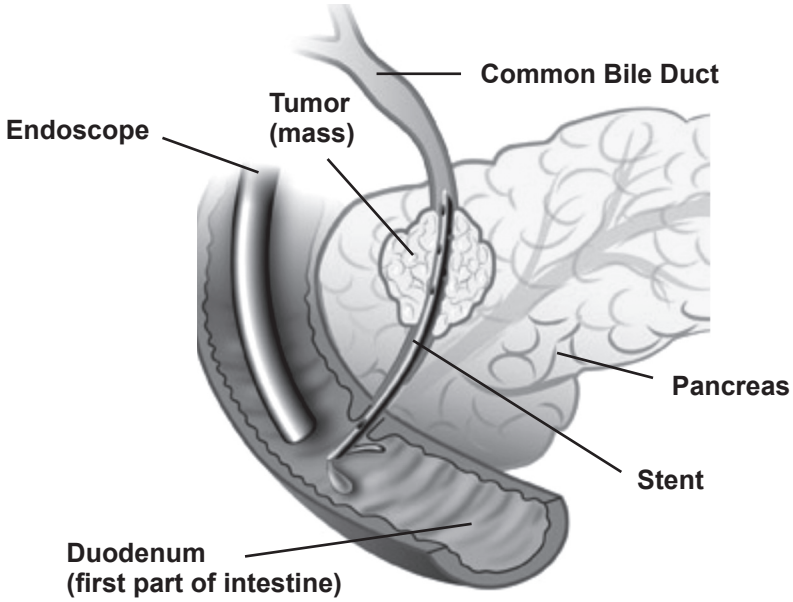

Figure 7. Stent placed endoscopically to relieve bile duct obstruction

Percutaneous Placement:

When a patient is jaundiced due to a bile duct obstruction it may not be possible to place a stent endoscopically. A 'PTC' (percutaneous transhepatic cholangiogram) procedure may be done to place a tube directly into the liver bile ducts through the skin on the right side of the abdomen. This tube will drain the bile into a bag ***outside*** the body. Local anesthesia is most commonly

used for this procedure. Most patients will stay overnight in the hospital after the procedure. This allows time to make sure the tube is working correctly and to instruct you on the care of the drainage tube. *Refer to Figure 8.*

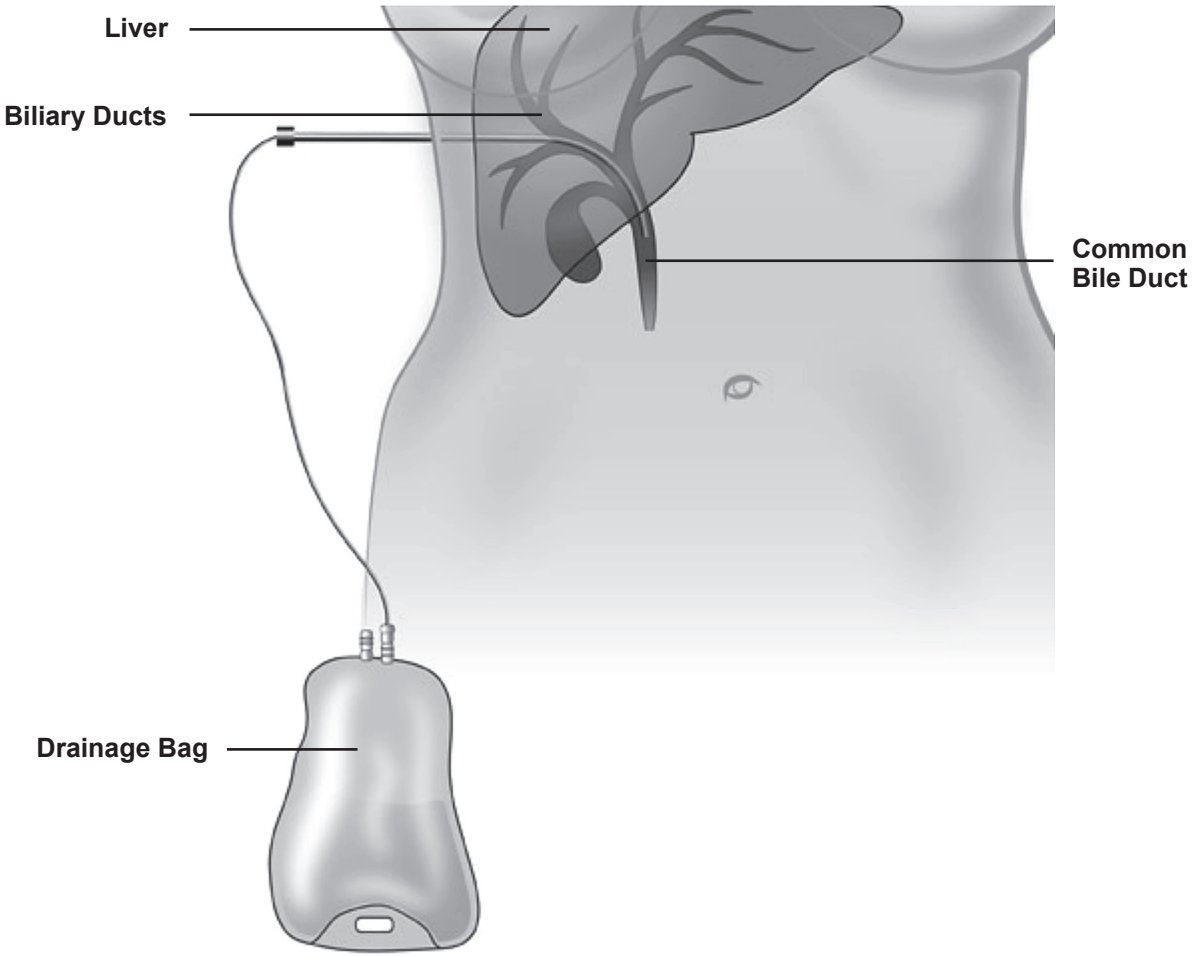

Figure 8. Biliary drainage tube placement

(Percutaneous transhepatic cholangiogram)

Over time, the liver bile duct should be relieved of pressure with this external drainage. Once that happens, it may be possible to perform a second procedure that places a stent ***inside*** the body.

Gastric Outlet Obstruction

Patients who develop gastric outlet obstruction, which appears as severe nausea and vomiting, may undergo either a surgical bypass or placement of a duodenal stent. The stent is placed endoscopically.

Radiation Therapy

What is radiation therapy?

For more information about radiation therapy: http://www.med.umich.edu/radonc/patientinfo/patient.htm or visit the Patient Education Resource Center on Level B1 of the Cancer Center

Radiation therapy (also called radiotherapy, x-ray therapy, or irradiation) is the use of a beam of energy (called ionizing radiation) to kill cancer cells and shrink tumors. Radiation therapy injures or destroys cells in the area being treated (the "target tissue") by damaging their genetic material (DNA), making it impossible for these cells to continue to grow and divide. Although radiation damages both cancer cells and normal cells, most normal cells can recover from the effects of radiation and function properly. The goal of radiation therapy is to damage as many cancer cells as possible, while limiting harm to nearby healthy tissue.

When is radiation therapy given to treat pancreatic cancer?

Radiation therapy is used in three ways:

- to decrease the risk of local recurrence after surgery;
- to reduce the size of the tumor before surgery (preoperative) and
- as a primary treatment for patients who have a tumor that is found not to be operable.

Local recurrence means that cancer cells have come back in the same area of the body where the tumor started and this can happen when tumor cells were left behind or were not killed.

When radiation is used it is often in combination with chemotherapy which enhances the effectiveness of the radiation. Radiation and chemotherapy has been found to benefit patients with locally advanced disease.

What happens at my first Radiation Oncology Appointment?

Your Radiation Therapy treatment will need to be planned before it can begin. Your initial visit will include meeting with the radiation oncologist who plans your treatment in a process called simulation. You will not receive treatment on this first visit, it is for planning only.

During the visit, you will be asked to lie very still on an examining table while the radiation therapist uses a special x-ray machine to define your treatment port or field. This is the exact place on your body where the radiation will be aimed. Simulation involves a CT scans, and possibly other imaging studies to plan how to direct the radiation. You will receive instructions to prepare for the CT scan prior to your appointment. The preparation for a CT scan includes fasting 6 hours prior to your scan; therefore, if you are diabetic your doctor may need to make adjustments in your diabetes medication. You will be given a liquid drink called 'contrast' before your scan. You will also receive an intravenous form of contrast just before your scan. Both the liquid and IV contrast improve the images that the CT scan takes.

The simulation appointment may take from 1-2 hours. Plan to be in the Radiation Oncology Department for several hours that day.

Chemotherapy

What is chemotherapy?

Chemotherapy is the treatment of cancer with drugs that can destroy cancer cells. These drugs often are called “anticancer” drugs.

For more information about chemotherapy: www.mcancer.org **or visit the Patient Education Resource Center on Level B1 of the Cancer Center**

How Does Chemotherapy Work?

Normal cells grow and die in a controlled way. When cancer occurs, the abnormal tumor cells keep dividing and forming more cells without control. Anticancer drugs destroy cancer cells by stopping them from growing or multiplying. Healthy cells can also be harmed, especially those that divide quickly. Harm to healthy cells is what causes side effects. These cells usually repair themselves after chemotherapy.

Because some drugs work better together than alone, two or more drugs are often given at the same time. This is called combination chemotherapy.

Other types of drugs may be used to treat your cancer. These may include certain drugs that can block or increase the effect of your body’s response to the cancer.

When is chemotherapy given to treat pancreatic cancer?

Chemotherapy is the treatment of choice for cancer that is found to be locally advanced or metastatic (spread to other organs). These drugs can have an effect on the cancer by stopping the growth of cancer cells or their ability to multiply.

The goals of chemotherapy treatment are to control the cancer, keep it from spreading by slowing the cancer’s growth and improve or reduce the symptoms of the disease.

Locally Advanced Disease

For patients with locally advanced disease, drugs are given to increase the effectiveness of radiation. These are called radiosensitizers. They are considered chemotherapy and are administered in the chemotherapy infusion area. Examples of these drugs are 5-fluorouracil (5-FU®), capecitabine (Xeloda®), and gemcitabine (Gemzar®).

Metastatic Disease

If the cancer has spread outside the pancreas, a standard therapy plan is to use gemcitabine (Gemzar) alone or in combination with other drugs. Gemcitabine has been shown to decrease symptoms and improve overall quality of life.

Remember, chemotherapy treatment is planned by the oncologist who considers the patient's medical condition and other factors when deciding on the type of chemotherapy. Other chemotherapy agents and combinations may be recommended.

Clinical Trials

Your doctor may suggest that you consider participating in a clinical trial (a research study or protocol) for the treatment of pancreatic cancer.

Clinical trials are used to test and develop new treatments. The goal of these trials is to find ways to improve therapy and / or decrease side effects. While a trial or study is active or in-progress we will not know whether any potential improvement has been achieved. The trial must be closed and the data analyzed before the treatment is made widely available to patients.

For more information about clinical trials: www.mcancer.org **or visit the Patient Education Resource Center on Level B1 of the Cancer Center**

There may be some additional risks associated with research. Your doctor will discuss in detail with you both the potential risks and benefits and obtain your written permission before you can be started on a research protocol.

Oversight committees at the University of Michigan Medical Center conduct an extensive review of all clinical trials. These committees include an "institution review board" or IRB composed of other cancer doctors, doctors in other specialties and lay people. The IRB reviews all protocols before they are available to patients and again at different times during the research to ensure that the protocol remains appropriate and safe for patients.

All patients who are on a protocol receive the best supportive care possible, and their reactions to the treatment are watched very closely. If the treatment does not seem to be helping, a doctor can stop the treatment and take a patient out of a study. Also, the patient may choose to leave the study at any time. If a patient leaves a study for any reason, standard care and treatment will be initiated.

Clinical trials are voluntary. Your pancreatic cancer will be treated whether you decide to join a protocol or not. Talk to your doctor about any questions you have regarding clinical trials at the University of Michigan Comprehensive Cancer Center.

What are some examples of clinical trials?

For more information about biologic therapies: www.cancer.gov **or visit the Patient Education Resource Center on Level B1 of the Cancer Center**

Biologic therapies are drugs that may boost the bodies' immune system to work against the cancer or interfere with tumor growth and progression. Some of these drugs are given in combination with standard chemotherapy and are being investigated in clinical trials.

How do I find out about pancreatic cancer research?

You can search online to find available clinical trials. The Pancreatic Cancer trials are found at https://www.umms.med.umich.edu/engage/disp_pub_condition.do

If you have cancer, you may notice every ache, pain, or sign of illness. Even little aches may make you worry. The information in this section is designed to help you become an informed partner in your care, but it is only a guide. Self-help can never take the place of professional health care.

Ask your medical team any questions you may have. Also don't hesitate to tell them about any side effects you may have. They want and need to know.

Not all patients will experience the symptoms or side effects listed in this section. We include them to help you understand what may be happening to you. We know these are obstacles to your health and quality of life. Our multidisciplinary team is here to work with you in reducing or eliminating these problems.

When to call the doctor?

There are times when symptoms can be managed by you at home, and other times when you should notify your medical team. Never hesitate to call the clinic if you are unsure or have new symptoms. The following are reasons to notify your doctor:

- Shaking chills or fever (a temperature of 101˚ F or 38.3˚ C)

  Notify your doctor immediately if you develop a temperature, do not delay.
- Unusual cough, sore throat, lung congestion or shortness of breath
- Burning discomfort when you urinate
- Redness, pain or sores in your mouth
- Nausea, vomiting or inability to eat or drink for more than 24 hours.
- Diarrhea (loose, watery stools) for more than 24 hours.
- Constipation (no bowel movement in 2-3 days)
- Bleeding or unusual bruising
- Pain not controlled by your current medications
- Any new or unusual symptom that concerns you

What can I do to maintain my weight and increase my appetite?

Why does this happen?

Weight loss can be a common problem for patients with pancreatic cancer. You may see your appetite decrease or feel bloated or 'gassy' after eating. It may be hard to eat normally because foods taste different to you. You may have times when you feel nauseated, or have constipation or diarrhea. These are some common reasons that you may not feel hungry and lose weight.

Cancer can also cause changes in your body that affect your metabolism and will contribute to weight loss. Many patients do not make enough of the digestive juices needed to digest food properly; this can cause diarrhea and additional weight loss.

For all of these reasons, weight loss is common in patients with pancreatic cancer.

What can be done?

The overall goal during treatment is to keep you at a stable weight. We will monitor your weight closely throughout your treatment.

Talk to your medical team about your symptoms

There are medications available to reduce or treat any pain, nausea, constipation or digestion problems you may be experiencing. Your doctor can order these for you.

Also, nutrition specialists are available at the cancer center who can offer suggestions and guidance, and will prepare a dietary plan during your treatment. The nutrition clinic is open Monday through Friday from 8am to 3pm.

Appointments can be made in advance at your clinic checkout area or you can call (734) 936-6000

There are some steps you can take to improve your diet and prevent weight loss. These include:

- Eat five to six small meals or snacks throughout the day.
- Choose foods that are high in protein and calories
- Try new foods regularly as taste can change from day to day
- Limit fluids at meals and drink liquids in-between to avoid fullness at meals
- Increase protein and calories by using supplements such as Carnation Instant Breakfast®. There are several flavors to choose from and you can add ice cream, whole milk, yogurt and fruit to increase calories.
- Take anti-nausea medications as prescribed by your doctor during your chemotherapy treatments.
- Appetite stimulating medications such as megestrol acetate (Megace®)) or dronabinol (Marinol®) may be recommended by your doctor.

There are many nutrition resources available to patients and families at the Cancer Center. The Patient Education Resource Center (PERC) has many recipe books and other information resources for patients with cancer. They also have a nutrition information guide available that lists websites, books, pamphlets and other resources for cancer patients seeking nutrition information.

The most important thing to remember is that weight loss is common and we will work with you to help prevent and treat this problem.

What can be done for itching and yellowing of skin (jaundice)?

Why does this happen?

Jaundice (yellowing of the skin) occurs when bilirubin builds up in the bloodstream. Bilirubin is made in the liver and moves from the liver through the gallbladder and bile duct to be dumped into the small intestine. Jaundice is a sign that the bile duct is partially or completely blocked, possibly by a pancreatic mass. When a pancreatic mass causes a blockage, bilirubin can't get through and has no where to go, so it backs up in the bloodstream. This causes a yellowing of the skin, the whites of the eyes and a darkening of the urine. Pancreatic cancers that start in the head of the pancreas are more often associated with jaundice. *Refer to Figure 6 on page 16.*

What can be done?

Jaundice can be treated by relieving the blockage with a bile duct stent. There are ways to make you more comfortable if jaundice continues.

Some suggestions include:

- Good skin care using mild soaps to bathe,
- Avoid using very hot water or anything that might dry your skin,
- Apply lotions or creams to prevent skin dryness,
- Keep room temperatures cooler and hydrated. This may help to decrease itching.

Lastly, there are medications that can be suggested for itching. Talk to your doctor about these if you have tried other treatments.

What can be done to treat my pain?

Why does this happen?

Patients who are diagnosed with pancreatic cancer commonly have pain. Pain is described differently by each patient, but many describe it as a cramping, aching, and radiating (spreading) to back or shoulders. The most common areas of pain experienced by patients with pancreatic cancer are the upper abdominal and back areas. There are many causes of pain including the cancer itself, which may cause pressure on other organs, nerves and vessels.

What can be done?

Pain can be treated, but oftentimes there are barriers that prevent proper treatment. Some of these barriers are a lack of understanding in how to take the pain medications, fear of addiction and a concern that pain may be uncontrollable later if medicines are used at the time of initial pain. These are all issues that should be addressed with your medical team. Do not let these barriers prevent you from keeping any pain you may have under control.

Good pain control can lead to increased physical activity and well-being in patients with pancreatic cancer. Patients who have chronic pain may need to take medications regularly to obtain the best control of pain. An understanding of how to take these medications will help you get better control of your pain.

There are many different medications used to treat pain. Narcotics are the most common. Other types of medications used to treat pain include antidepressants, anticonvulsants (anti seizure medications), anti-inflammatory and steroid medications.

Narcotic medications come in several forms: tablets, liquids, skin patches and intravenously via a pump. These medicines are available as a sustained release or long acting preparation, and as an immediate release pain medication. The long acting and immediate release pain medications are often used together.

Sustained release or long acting pain medications

These should be taken on a **regular, scheduled time,** usually morning and evening, whether you have pain or not. They are taken on a schedule and work best when that schedule is not changed.

Long Acting Pain Medications (sustained release) work best when taken on a regular schedule that does not change.

Examples of these types of medications include;

- Fentanyl (Duragesic® patch)
- Morphine (Oramorph®, MSContin®)
- Oxycodone (Oxycontin®)

Immediate release medications "Breakthrough pain medications"

The immediate release medications should be taken when you are having pain while taking a long acting pain medication. This is called "breakthrough pain" as it occurs while you are taking regularly scheduled medication, but may need some extra medication for control and to prevent it from becoming severe. These medications work within 15-20 minutes and are usually taken on an 'as needed' basis because pain can vary from day to day. These medications can be taken at any time, even if it is the same time as the sustained release or long-acting pain medications.

Examples of breakthrough pain medications;

- Oxycodone
- Hydrocodone (Vicodin®)
- Hydromorphone (Dilaudid®)
- Morphine immediate release(MSIR)
- Morphine oral solution (Roxanol®)
- Fentanyl lozenge (Actiq®)

Suggestions for patients on sustained release/long-acting pain medications.

- Continue the sustained release medication on a regular basis whether you are having pain or not at that time.
- Do not change this schedule without talking to your doctor.
- Use your 'breakthrough' pain medication as needed. Do not wait until pain becomes severe or it will become difficult to get good control.
- Keep a record of the breakthrough medications taken over a 24 hour period. This information is helpful when you call you doctor about poor pain control.

Rule of thumb:

If breakthrough pain medication is needed 4-6 times a day regularly
OR
if pain keeps you up consistently at night
THEN
Notify your doctor who may consider increasing your sustained release pain medication.

Celiac Plexus Nerve Block

If medications taken by mouth or patch are not adequate to control pain then a nerve block may be considered.

Pain sensations from your abdomen pass through the bundle of nerves called a plexus. A celiac plexus block is the injection of a local anesthetic into your back in the area of a nerve bundle (called a plexus) that goes to the organs in your abdomen (see Figure 1 on page 1). Doctors who specialize in pain anesthesia can inject a drug that will damage the nerve plexus. The drug stops the pain

sensation from reaching the nerves for a longer period of time. This is called a 'block'. Blocking the nerve should help decrease the feeling of pain. This procedure is available to patients who are seen in the interventional pain clinic and can be further discussed, if needed.

Other Ways to Reduce Pain

In addition to medications, a number of other treatment strategies can be employed to relieve pain. Although on their own, these tools might not be enough to eliminate moderate to severe pain, they are often helpful when used in combination with medication. Some of these strategies, commonly referred to as complementary therapies include:

- Relaxation, guided imagery,
- Hypnosis,
- Biofeedback,
- Creative therapies such as music and art,
- Prayer, meditation,
- Massage,
- Acupressure and acupuncture,
- Application of heat or cold, and
- Therapeutic exercise.

Information about these programs can be found in the Patient Support Services Handbook in the back pocket of this handbook, or at the Patient Education Resource Center on Level B1 of the Cancer Center.

Many pain medications cause constipation.

If you are taking pain medications on a regular basis, you will need to review the section on "Preventing Constipation" on page 33.

My glucose is high and I have diabetes.

Why does this happen?

Normally, the pancreas secretes the amount of insulin needed for your body to maintain a normal glucose level. When you have pancreatic cancer or if you have had part of your pancreas removed, you may not secrete enough insulin or your body may become resistant to insulin. In these cases, the blood level of glucose increases in the blood and doesn't get into the body's cells where it is needed for energy. This will lead to symptoms of diabetes that include:

- frequent urination,
- thirst, fatigue,
- blurred vision and
- weight loss.

What can be done?

You may need to take medication to reduce your blood glucose level. Medications can be tablets or insulin injected under the skin on a daily basis. Tell your doctor or nurse if you are experiencing any of the symptoms of diabetes.

What can be done to prevent constipation?

Why does this happen?

Constipation is common during cancer treatment. Constipation is a decrease in the number of bowel movements combined with hard stool, excessive straining, bloating, increased gas, and/ or abdominal cramping.

Pancreatic cancer patients are at risk for constipation because they are often treated with pain medications, receive chemotherapy and antinausea medications, have decreased their physical activity and have had a change in their eating and drinking habits…. all of these can cause constipation. Other causes of constipation include dehydration and a lack of fiber in your diet.

What can be done?

There are a number of preventative things to do. These include:

- Increasing the fiber in your diet with foods high in fiber such as fresh or raw fruits and vegetables, whole grains, prunes, nuts and dates.
- Increase fluids in your diet (drink at least 2 quarts of fluid daily).
- Avoid cheese products
- Get regular exercise every day if possible…keep up your activity as much as you are able.
- Go to the bathroom whenever you have an urge to go.

For patients taking pain medications that are narcotics or opiods, we recommend a combination of stool softener and laxative on a regular basis. Here are some suggestions:

- Take Senokot-S®, two to six tablets daily in divided doses to keep regular bowel movements every day. This can be decreased or increased according to results and tolerance. Generic versions of Senokot-S® can be substituted. Ask your pharmacist for information about generic versions. They are often cheaper.
- If no bowel movement in any 24 hour period (1 day), take two tablespoons of Milk of Magnesia® (MOM) at bedtime with a full glass of water.
- If no bowel movement in any 48 hour period (2 days), take three Senokot-S® tablets twice a day (total of 6 tablets per day) plus two tablespoons of MOM at night before bedtime.
- If no bowel movement in any 72 hour period (3 days), add one of the following:

  Magnesium Citrate 8 oz (1/2 bottle) now then repeat in 6 hours. If no bowel movement, then Dulcolax® tablets, two or three tablets.

My doctor recommended pancreatic enzymes for my frequent loose stools and abdominal cramping.

What do they do?

The pancreas secretes digestive juices into the small intestines. These juices help break down and absorb food in the intestines. Patients with pancreatic cancer or who have had part of the pancreas removed may not have adequate amounts of these juices in the intestines. If this happens, food isn't digested normally. This is called pancreatic insufficiency.

Symptoms of pancreatic insufficiency include diarrhea, gas, burping and cramping. This happens because food passes through the digestive tract not fully digested. As it passes through, it pulls water into the intestines that causes diarrhea and cramping.

> It is important to take enzyme tablets with any food that needs to be digested.
>
> This means even a glass of milk or a can of Ensure® will need the enzyme tablets to be broken down and absorbed.
>
> Remember to take the enzyme tablets with any food, not just "meals".

Pancreatic enzymes are a tablet form of pancreatic juice. They work just like the juices, so when they are taken with food, they help digestion and lessen the abdominal discomfort and diarrhea.

Generally people take 1-2 enzyme tablets as they start eating. If they eat a larger meal, they will take additional tablets 10-15 minutes into the meal. For smaller meals or snacks, 1-2 tablets alone may be enough.

Talk with your doctor if enzymes do not control the problem.

My leg is swollen and it feels warm to touch.

Why does this happen?

Patients with pancreatic cancer are at a greater risk for developing blood clot than the average person. Blood clots most commonly occur in the legs. You may develop swelling or pain, but some patients have no symptoms at all. Signs of a blood clot include:

- Swelling (usually of one leg, sometimes both)
- Pain or tenderness in an area
- Redness

What can be done?

Patients who have had blood clots are treated with medications that stabilize the blood clots and lessen the chances of the blood clots traveling to other organs. Some patients may have a filter placed to prevent a blood clot traveling into the lungs, which can be a very serious condition. If you notice swelling in one leg you should call your clinic. An ultrasound of the area will be done to determine if there is a blocked blood vessel caused by a blood clot.

Sometimes patients have swelling of both legs and this can be due to a decrease in protein in the blood that causes fluid to leak out into the tissue. In addition, sometimes the lymph vessel and veins are compressed by the tumor and these blocked vessels can cause swelling of the legs.

Suggestions for this include:

- Wearing loose fitting socks, shoes and pants.
- Tightening of your leg muscles regularly during the day
- Walking for short distances.
- Avoid long periods of standing.
- When sitting, keep legs uncrossed and if possible raise your legs higher than your chest

How do I cope with my feelings?

If you have been diagnosed with pancreatic cancer, it is normal for you and your family to experience a wide range of emotions. Important issues in the life of any person with cancer may include the following:

- Fear of death.
- Interruption of life plans.
- Changes in body image and self-esteem.
- Changes in social role and lifestyle.
- Money and legal concerns.

Everyone who is diagnosed with cancer will react to these issues in different ways. Many patients experience feelings of anxiety, depression, sadness, stress, and have difficulty sleeping or eating. It is important to know when and where to seek help for these feelings. These symptoms and fears usually lessen as a person adjusts to the diagnosis.

There are many misconceptions about cancer and how people cope with it, such as the following:

- All people with cancer are depressed.
- Depression in a person with cancer is normal.
- Treatment does not help the depression.
- Everyone with cancer faces suffering and a painful death.

A person who cannot adjust to the diagnosis after a long period of time, and who loses interest in usual activities, may be depressed. Mild symptoms of depression can be distressing and may be helped with counseling. Even patients without obvious symptoms of depression may benefit from counseling; however, when symptoms are intense and long-lasting, or when they keep coming back, more intensive treatment is important. These are often signs of what is called “major depression”.

Major depression is not simply sadness or a blue mood. Major depression affects about 25% of patients and has common symptoms that can be diagnosed and treated. Symptoms of depression that are noticed when a patient is diagnosed with cancer may be a sign that the patient had a depression problem before the diagnosis of cancer. Anyone experiencing these symptoms, or who has a history of depression should talk to their healthcare team. It is important to remember that this can be treated. The symptoms of major depression include the following:

- Having a depressed mood for most of the day and on most days.
- Loss of pleasure and interest in most activities.
- Changes in eating and sleeping habits.
- Nervousness or sluggishness.
- Tiredness.
- Feelings of worthlessness or inappropriate guilt.
- Poor concentration.
- Constant thoughts of death or suicide.

Depression can affect caregivers too

Just as patients need to be evaluated for depression throughout their treatment, so do family caregivers. Caregivers have been found to experience a good deal more anxiety and depression than people who are not caring for cancer patients.

If the family of a patient diagnosed with cancer is able to express feelings openly and solve problems effectively, both the patient and family members have less depression. Good communication within the family reduces anxiety.

Seeking help

The Multidisciplinary Pancreatic Medical Team believes that helping patients cope with their cancer diagnosis is an essential part of providing care. Our social worker is an essential member of the team who provides evaluation, counseling, and referral to additional resources such as support groups, the PsychOncology clinic and group therapy. The social worker for the pancreatic clinic can be reached at (877) 907-0859.

Remember, our team is here to help address any emotional needs you or your family may have. Do not hesitate to contact us.

Resources

There are many resources available to patients and families at the University of Michigan Comprehensive Cancer Center. We have included a comprehensive handbook of these programs in the back pocket of this book. These programs are available to any patient receiving care at the University of Michigan.

These programs are also available on our cancer center website: www.mcancer.org, or you can visit the Patient Education Resource Center on level B1 of the Cancer Center for a complete list of all events and resources available to assist you during your cancer treatment.

Resources you will find in the Patient Support Handbook include:

- Information Resources:
  - The Patient Education Resource Center (PERC)
  - The Patient & Family Teaching Center (Skills Lab)
  - The Cancer Center website
- Assistance with Practical Matters:
  - Discounted lodging, parking,
  - Assistance with transportation, meals and other expenses
  - Financial counseling
- Resources to Help You Cope:
  - Social Work
  - Support groups and peer counseling
  - PsychOncology Clinic
- Resources to Enhance Treatment:
  - Nutrition
  - Complementary Therapies
  - Pain Services
  - Wig Bank Program
- Cancer Center Resources:
  - Maps, important phone numbers and websites

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Appointments

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☐ Other _____

Date_____ Time _____ Place_____

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Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Important Phone Numbers

(all numbers are 734 area code unless noted)

Doctors:

Dr. Michael Mulholland 936-5781

Dr. Diane Simeone 615-1600

Dr. Kevin Nguyen 936-7944

Dr. Rebecca Minter 936-7644

Dr. Christopher Sonnenday 936-5816

Dr. Edward Kim 936-8902

Dr. Mark Zalupski 936-8902

Nurses:

Surgery Nurses: 936-5781

(for questions about surgery, preparing surgery, postoperative concerns)

Pancreatic Clinic Nurse Coordinator

Jan Hampton 615-8839

(for questions during the diagnosis, while making treatment decisions and for follow-up issues)

To Reach a Doctor For Medical Problems Monday-Friday after 5pm, Weekends & Holidays:

Call the UM Page Operator @ 936-6267 and ask them to page:

General surgery residents for Drs. Simeone, Mulholland, Nguyen and Minter

Hepatopancreatobiliary (HPB) for Drs. Simeone, Mulholland, Nguyen and Minter

Transplant surgery resident for Dr. Sonneday

Oncology resident for Drs. Zalupski and Kim

Appointments

Multidisciplinary Pancreatic Clinic 647-8902

Nuclear Medicine Department 936-5090

Radiation Oncology Department 936-4320

Endoscopy Appointments. 615-5123

877-334-2943 Toll Free

Cancer Center Infusion Appointments 647-8908

Patient/Family Learning Center (Skills Lab) 877-907-0859

Resources

Cancer Center Nutrition Clinic 877-907-0859

Patient Education Resource Center 647-8626

Patient Support Services 877-907-0859

Social Work 877-907-0859

PsychOncology Clinic Appointments 877-907-0859

Operating Rooms

Main OR Family Waiting Room. 936-4388

Cancer Center B2 Procedure Room 615-4657

This document is not intended to take the place of the care and attention of your personal physician or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education.

Questions about individual health concerns or specific treatment options should be discussed with your physician.

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