A Patient's Guide to

Pancreatic Cysts

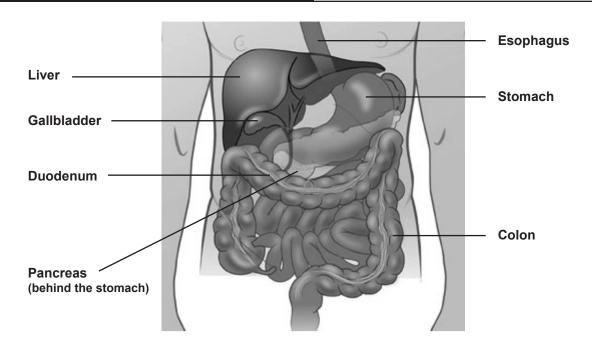


Staff of the Comprehensive Cancer Center's Multidisciplinary Pancreatic
Cancer Program provided information for this handbook
GI Oncology Program, Patient Education Program, Hepatopancreatobillary Surgery,
Medical Oncology, Radiation Oncology Programs

Note: We will refer to this booklet during many of your visits.

Please bring it with you to all appointments.

Digestive System Anatomy



Pancreas and the Surrounding Organs

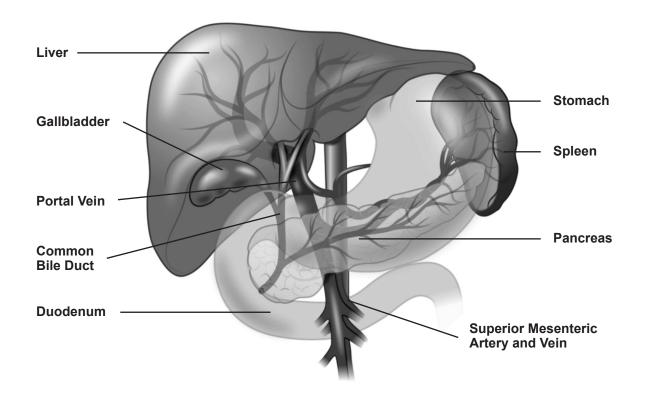


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Introduction

The medical team at the University of Michigan Multi-disciplinary Pancreas Clinic at the Comprehensive Cancer Center created this booklet to provide information on pancreatic cysts 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.

Overview of Pancreatic Cysts

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.

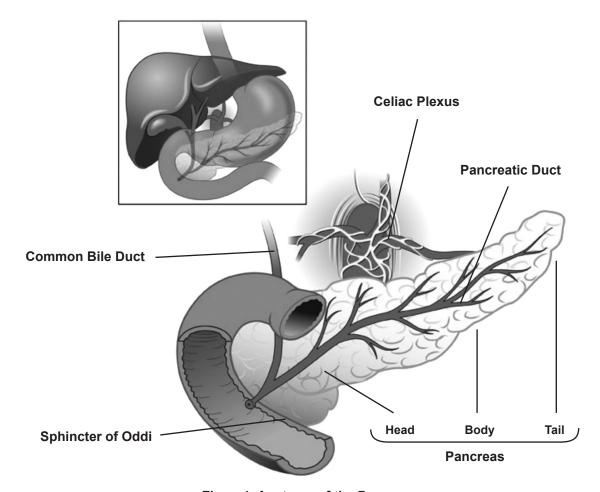


Figure 1. Anatomy of the Pancreas

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 produces hormones is called the endocrine pancreas.

What are pancreatic cysts?

Pancreatic cysts are abnormal, sac-like pockets of fluid within your pancreas. Though it may be alarming to learn you have a pancreatic cyst, the good news is that most pancreatic cysts aren't cancerous and many don't even cause symptoms.

In fact most pancreatic cysts aren't technically cysts at all. One type of cyst is called a pseudocyst. These pockets of fluids aren't lined with the type of cells found in true cysts. They can arise from inflammation in the pancreas called "pancreatitis". Pseudocysts are never cancerous. The identification of pancreas cysts is increasing and is often found on CT or MRI scans done for other reasons. The causes of other types of pancreatic cysts, the diagnosis and the appropriate management is still being understood.

Pancreas cysts can be associated with underlying disorders such as von Hippel-Lindau disease and are seen in about 10% of patients with polycystic kidney disease.

What are the symptoms of a pancreatic cyst?

Very often patients with a pancreatic cyst have no symptoms at all. In those that do, symptoms vary and are related to the extent of disease and the location of the cyst in the pancreas. Below are symptoms that may occur:

Jaundice

The head of the pancreas is located close to the common bile duct and duodenum (small bowel) so cysts located in the head of the pancreas may grow and block these structures, which can lead to jaundice (yellow color of the skin and/or eyes) or blood abnormalities.

Nausea and Vomiting

Stomach emptying is delayed when the duodenum is compressed. This causes a feeling of fullness and may lead to nausea and vomiting. Patients sometimes have a loss of appetite and nausea that leads to weight loss.

Abdominal Pain

Pancreatic cysts can be associated with persistent upper abdominal pain which may also radiate to the back and shoulders. Abdominal pain can be related to pancreatitis which is inflammation of the pancreas. This can occur suddenly and last for days or years.

How are pancreatic cysts diagnosed?

Most often pancreatic cysts are found when a scan is done for another reason such as to evaluate for kidney stones. However, patients with symptoms such as abdominal pain, weight loss, or nausea and vomiting will undergo tests to determine the cause of these symptoms. Diagnosing a pancreatic cyst can be a challenge and other conditions such as pancreatic cancer should be ruled out. Your doctor may want to take a sample of the cyst fluid to determine whether it has potential to be malignant or not. If your cysts is, or can become cancerous,

treatment usually involves surgical removal. It is often difficult to get an adequate biopsy that allows the pathologist to decide with complete certainty if it is cancer or a benign cyst. It is *frustrating* for the patient and the doctor who want to move ahead quickly in making a diagnosis and begin treatment; however, it is important to approach the work-up of these pancreas cysts in a thoughtful manner with an experienced multi-disciplinary team. Below are some of the tests and procedures used to diagnose pancreatic cysts. These tests can provide valuable information to you and your physician to determine the risk of the cyst becoming malignant or cancerous. Many of these tests allow the care team to see the cyst in great detail. This includes the size of the cyst, location of the cyst, findings for solid components associated with the cyst and other features that could help in a diagnosis and treatment planning.

Trans Abdominal Ultrasound:

An ultrasound can sometimes identify a cyst in the pancreas or bile duct. These abnormalities can then lead to CT or MRIs. Visualization of the pancreas is hindered by underlying bowel gas.

Endoscopic Ultrasonography (EUS)

An EUS is performed with a lighted tube that is inserted through the mouth and placed into the stomach and small intestine. Ultrasound images of the pancreas are obtained through the stomach or internal wall. It is highly sensitive for detecting pancreas abnormalities. EUS is particularly useful for detecting small (<2 cm) pancreatic tumors, including cysts, that may not be well visualized by a CT scan. It can also identify tumors that may involve important blood vessels, (arteries and veins next to the pancreas). An aspirate with a small or 'fine' needle (FNA) of the cyst may also be performed during an EUS to examine the cells for cytology to help diagnosis the abnormality. Pancreatic cyst fluid can be sampled and sent for analysis to the laboratory. This procedure is performed with intravenous sedation.

ERCP (endoscopic retrograde cholangiopancreatography)

An ERCP is done with a lighted tube called an endoscope to look at the bile and/or pancreas ducts. This procedure helps determine what is causing a blockage. It can also be used to place a stent or tube to open a blocked bile duct for drainage. General anesthesia is most commonly used for this procedure. The patient is not awake during the test. *Refer to Figure 2.*

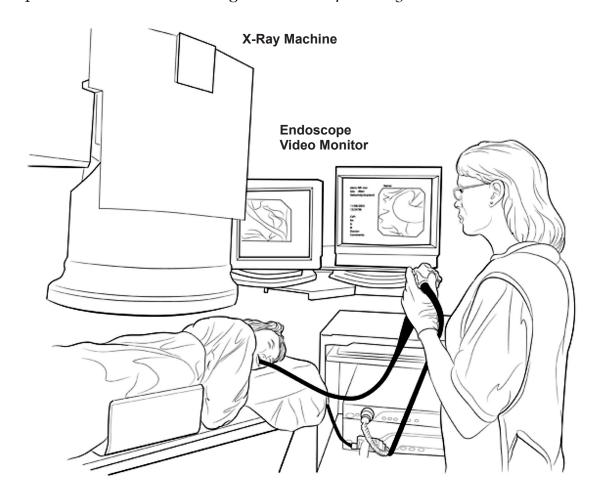


Figure 2. Patient undergoing endoscopic procedure

Magnetic Resonance Cholangiopancreatography (MRCP)

MRCP is a special type of MRI. It uses computer software that specifically images pancreatic and bile ducts, which are often the site of tumors. Fluid naturally present in the ducts serves as a contrast substance. MRCP produces images similar to an ERCP and is an excellent tool for visualizing blockages in the ducts and pancreatic cysts.

MRCP provides a similar picture as ERCP, but without the risks of an invasive ERCP procedure. MRCP may be used in place of ERCP for diagnostic purposes. If therapeutic interventions, such as stent placement to alleviate jaundice, are required, ERCP rather than MRCP will be used. In addition, MRI/MRCP cannot be used to biopsy or sample lesions in the way done using EUS or ERCP.

Computed Tomography (CT)

The CT scan can show small cysts or tumors as well as important blood vessels that the cyst might be growing into or around. The doctor may suggest a 'pancreatic protocol' CT to be done at the UM for your first clinic visit to better assess the cyst 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 in great detail. 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.

What are the types of pancreatic cysts?

There are 5 types of cysts:

Pseudocysts

- · Most common type
- · Recent history of pancreatitis and elevated blood amylase level
- Recommended treatment is observation for patients without symptoms
- · Cannot become malignant

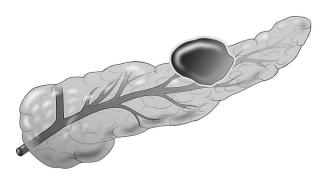


Figure 3. Pseudocyst

Serous Cystadenomas

- · Twice as likely to be found in women
- · Suspected when there are multiple small cysts called microcysts
- · Does not become malignant
- · Symptoms can include abdominal pain and fullness

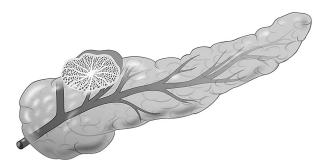


Figure 4. Serous Cystadenomas

Mucinous Cystic Neoplasm

- · Have potential to become malignant
- · Mostly in women with an average age of 40-50 years
- · Most present with vague epigastric symptoms
- · Most commonly located in the tail of the pancreas
- · Surgery is recommended

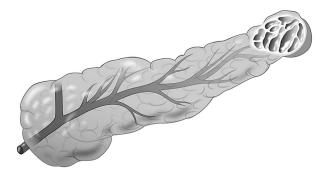


Figure 5. Mucinous Cystic Neoplasm

Intraductal Papillary Mucinous Neoplasm

- $\cdot\,$ Can cause symptoms or be asymptomatic
- · Pancreatitis can be found at the same time
- · More often in men than in women
- \cdot In the main duct operate if medically fit
- In the branch ducts observe or operate if large or associated with symptoms or other concerning features

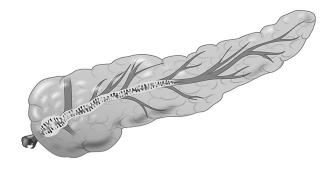


Figure 6. Intraductal Papillary Mucinous Neoplasm

Solid Pseudopapillary Neoplasm

- · Most uncommon pancreatic cyst
- · Mostly in young women median age 27
- · Most common symptom is abdominal pain
- · Surgery recommended

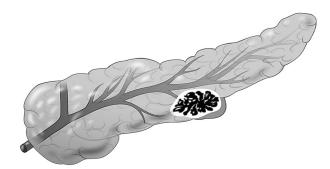


Figure 7. Solid Pseudopapillary Neoplasm

Treatment of Pancreatic Cysts

What are the treatment options?

Your physician will discuss your individual circumstances and discuss treatment options depending on:

- · Cyst size and type of cyst
- · Ability to operate and location of cyst
- · Presence of symptoms such as pain or weight loss or jaundice
- Surgical risks
- Malignant potential
- · Other medical conditions you may have

Depending on the type of cyst and your symptoms you have your doctor may recommend one of several treatments:

- 1. Surgery to remove cyst
- 2. Further testing often with imaging
- 3. Monitoring the cyst with imaging and/or clinical follow up
- 4. No further evaluation or treatment

How does a patient decide on treatment?

Even a large pseudocyst can be left alone as long as it is not causing you symptoms. If it is causing you symptoms your doctor may elect to analyze the cyst with a needle or surgically treat it. This surgery can also be done endoscopically in some cases.

Serous cystadenomas almost never evolve into cancer, so they also may be left alone, unless they are causing symptoms or getting larger over time. Your doctor may want to follow its size by repeat imaging tests.

For the other three types of cysts: Solid Pseudopapillary neoplasms, Mucinous Cystic Neoplams, Intraductal Papillary Mucinous Neoplasm (IPMN), or if your doctor is unable to tell for sure what kind of cyst you have...surgery may be recommended.

Surgery

When is surgery recommended for pancreas cysts?

The location of the pancreas adds to the technical difficulties of a surgical operation. Important veins and arteries are located near the pancreas and may interfere with the surgeons ability to remove the portion of the pancreas containing the cyst. The extent of the abnormality will also determine how much of the pancreas will need to be removed surgically.

Diagnostic tests give information about the size, location and involvement of other surrounding tissues and vessels. These tests help the surgeon determine whether the cyst is operable or resectable. In addition, a surgeon will evaluate the patient's overall health to determine if he or she can tolerate the surgical procedure.

When considering undergoing pancreatic surgery, it is important to identify a high volume pancreatic center and an experienced pancreatic surgeon. The pancreas surgeons at the University of Michigan perform over 100 pancreatectomies annually, with a peri-operative mortality rate of < 1%.

Whipple Procedure

If the cyst 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, part of the small intestine and sometimes 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 8*.

Although the Whipple procedure can successfully remove the cyst from your body, there are some serious complications that are possible that should be

carefully considered when deciding to go ahead with the surgery. Some patients are unable to properly absorb fat so you may have to avoid large meals or fatty foods or otherwise modify your diet after you have a Whipple procedure. You can ask to speak to a dietician for help managing symptoms.

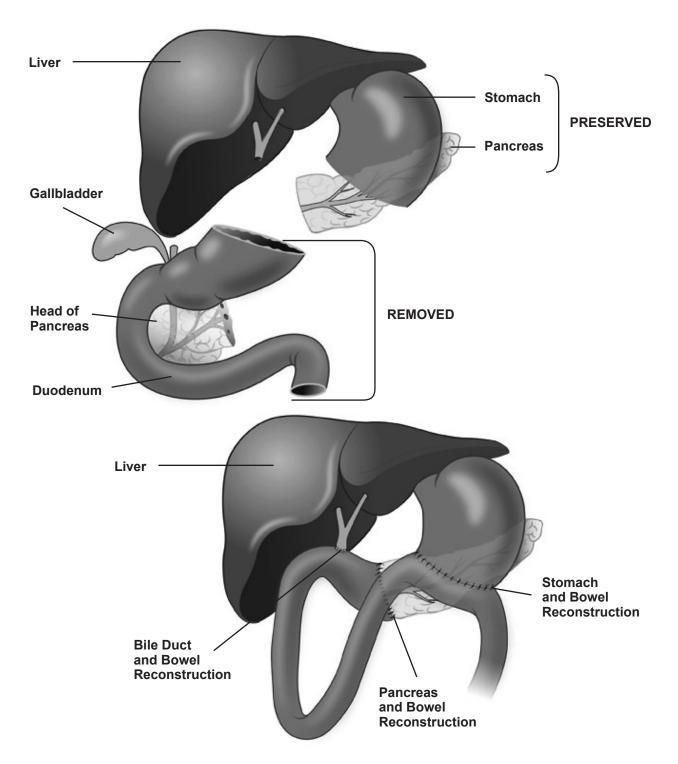


Figure 8. Whipple surgical procedure

Distal pancreatectomy

Cysts that are in the body or tail of the pancreas can be removed by removing the distal part of the pancreas and the spleen. This is called a distal pancreatectomy.

In some cases surgery can be performed using minimally invasive techniques through small incisions in the abdomen (laparoscopy or robotic surgery).

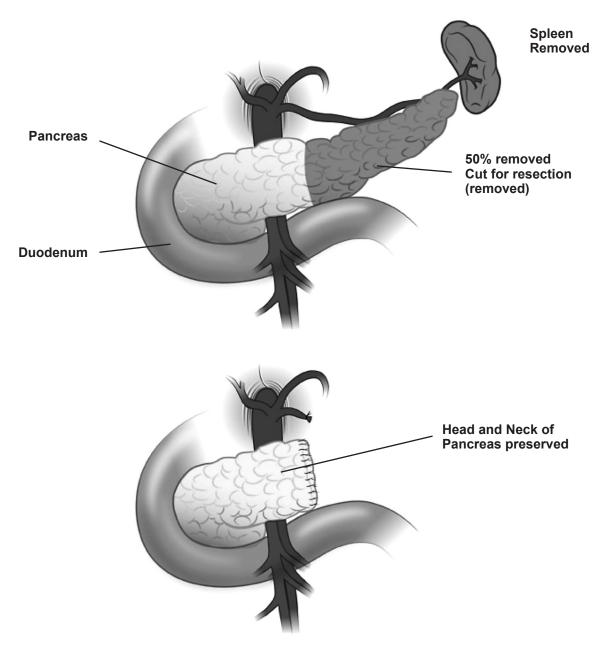


Figure 9. Distal pancreatectomy surgical procedure

After surgery will I need to take insulin?

There is a potential that you may become diabetic depending on the amount of pancreas removed and the health of the remaining pancreas. If a total pancreatectomy (complete removal of the pancreas) is recommended then a consultation with an endocrinologist will be arranged pre-operatively so that you will understand what to expect with respect to lifestyle changes and management following removal of the entire pancreas.

Surveillance

What is surveillance?

Our present ability to distinguish between benign (non- cancerous) cysts and those that have potential to grow into cancer is limited. Studies are being conducted to guide physicians and patients on how to follow a pancreas cyst by using radiographic imaging, typically MRI and/or endoscopic ultrasound.

For cysts that are not considered high risk for becoming cancer the pancreas surgeon and medical gastroenterologist will work closely together to follow pancreas cysts over time. EUS and MRI should be done every 6 months for the first year, then annually for surveillance. In some cases the interval will be yearly and in other cases it may be more often. Patients will be instructed to contact their physician with any change in symptoms that might suggest earlier imaging is indicated.

EUS or MRI every 6 months for first year. Surveillance for rest of life based on above findings.

After Pancreatic Cyst Surgery

Life after the Whipple Procedure

Recovering from Surgery

Post-operative restrictions will include lifting restrictions of no greater than 5 pounds for 6 weeks and no driving while taking narcotic pain medication. You may have a drain in place when discharged, and you will be taught how to care for it prior to discharge. Expect 6-12 weeks for recovery from Surgery.

Dietary Changes after a Whipple Procedure

Your diet begins with a liquid diet and advances to solid foods. After a Whipple, you may not be able to adequately digest and absorb fats and avoidance of fatty foods may be recommended after surgery. Small frequent meals (5-6 meals daily) are easier to digest with spacing of 2 to 3 hours apart.

You should understand that each person has individual dietary needs. Your goal is to maintain weight, have regular bowel movements and restore adequate nutrition. You will be given an individualized plan by a dietitian or your doctor and will have the opportunity to meet with a dietitian after surgery.

In the long term, you may need to continue to avoid or limit fatty foods and may require pancreatic enzymes daily. Refer to section pancreatic enzymes right below.

What are pancreatic enzymes and why do I need to take them?

Pancreatic enzymes are chemicals secreted by the pancreas which help break down the fats, proteins and carbohydrates in the food you eat. When part of the pancreas is removed what is left of the pancreas can often not produce enough of these enzymes to break down food. If this occurs, in order to resume normal fat absorption it is necessary to take pancreatic enzymes.

The symptoms of insufficient pancreatic enzymes include:

- · Indigestion
- · Cramping after meals
- · Large amounts of gas
- · Foul smelling gas or stools
- · Floating or greasy/fatty stools
- · Frequent or loose stools
- · Weight loss

Your doctor can prescribe enzyme supplements to help with this. The type and dosage of pancreatic enzymes must be individualized for each person. Talk to your doctor about what the best plan is for you. Your doctor may also recommend an acid-reducing medication such as Prevacid, Nexium, or Zantac (add generic names) to improve the effectiveness of your pancreatic enzyme supplement.

Special considerations for patients having a distal pancreatectomy (including a splenectomy)

Patients who have no spleen have to pay more attention to infections and preventive care for the rest of their life, though the risk of severe overwhelming infection in adults following splenectomy is < 1%. Talk to your doctor about how to protect yourself from infections. Always alert your doctors, dentist, and other health care workers that you have no spleen. We also recommend the following:

- 1. Repeat your Pneumovax, Hib, and Meningococcal vaccines every five years.
- 2. Call your doctor at the FIRST sign of infections such as fever, chills, cough, abdominal pain, or severe sore throat.
- 3. Contact your physician or go to an Emergency room immediately if you have a temperature of 102 degrees Fahrenheit or higher, as though it is rare, a person without a spleen can develop sepsis quickly.
- 4. Carry a medical alert card, and if traveling out of the country contact your doctor before you leave to obtain a prescription for antibiotics. It is recommended that you fill the prescription and carry the antibiotics with you for international travel, and take them if you develop a fever of 101 degrees Fahrenheit or higher.

Resources

There are many resources available to patients and families at the University of Michigan Health System. We have included a Map and Guide to the University of Michigan in the back pocket of this book. Patient resources are described in detail on the University of Michigan website: www.mhealthy.org.

Resources you may find helpful include:

- The Cancer Center Patient Education Resource Center (PERC)
- The Health Education Resource Center (HERC)
- · The UMHS website
- To assist with Practical Matters at the Guest Assistance Program (GAP)

Discounted lodging, parking

Assistance with transportation, meals, and other expenses

Financial counseling

Social Work

· Resources to Enhance Treatment:

Nutrition Services

Pain Services

Physical Therapy

· General Health Resources

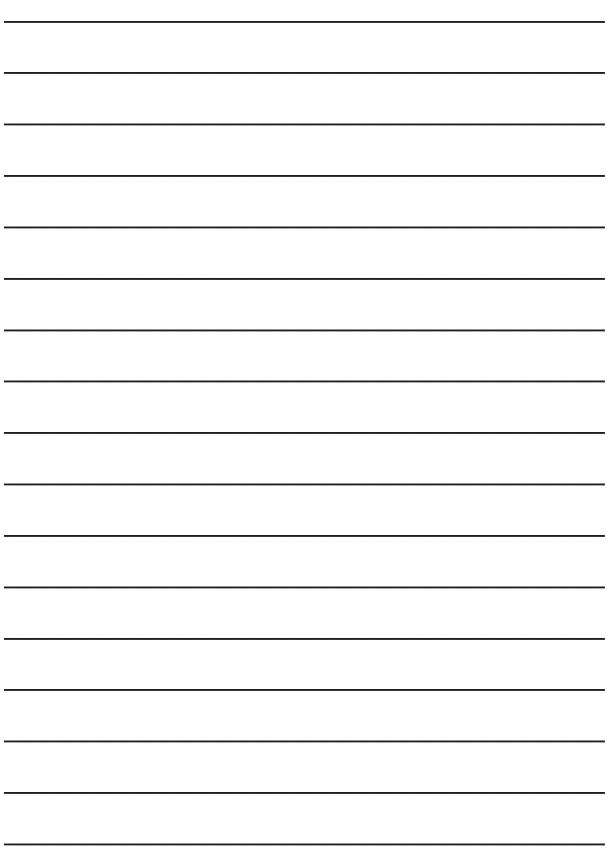
Maps, Important phone numbers and websites

Chapels and Pastoral Care

Cafeteria and Coffee shops

ATM and Cashier's Office

NOTES



RESOURCES

NOTES

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Appointments

Date	_ Time	Place
		Place
Date	_ Time	Place
	_ Time	Place

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			<u> </u>		1	ļ

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

RESOURCE

Important Phone Numbers

(all numbers are 734 area code unless noted)

Surgical Doctors:

Dr. Diane Simeone	615-1600			
Dr. Rebecca Minter	936-7944			
Dr. Kevin Nguyen	936-7944			
Dr. Michael Mulholland	936-5781			
Nurses and Physician Assistants:				
University of Michigan Pancreas Destination Program Physician Assistant				
Colleen Debeauclair				
Pancreatic Clinic Nurse Coordinator				
Jan Hampton	615-8839			
(for questions during the diagnosis, while making treatment decisions and for follow-up issues)				
Pancreatic Biliary Nursing Office				
Contact for the following doctors				
Dr. Richard Kwon	Dr. Cyrus Piraka			
Dr. Michelle Anderson	Dr. Erik Wamsteker			
Dr. James Scheiman	Dr. Joseph Elmunzer			

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:

· The Hepatopancreatobiliary (HPB) resident on call, if you are a patient of Drs. Simeone, Minter, Nguyen, or Mulholland

Appointments

To Schedule an Appointment888-229-7408
Resources
Nutrition Services 936-5197
Cancer Patient Education Resource Center 647-8626
Health Education Resource Center
Support and Coping
Social Work and Guest Assistance Program800-888-9825

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.

Authors: D. Simeone, MD and R. Minter, MD Reviewers: J. Hampton, RN and K. Hammelef, RN

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