

THE LUSTGARTEN FOUNDATION FOR
PANCREATIC CANCER RESEARCH

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The Lustgarten Foundation for Pancreatic Cancer Research
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UNDERSTANDING PANCREATIC CANCER

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A Guide for Patients and Caregivers

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This handbook is not intended to provide medical advice and is not a substitute for consulting with qualified healthcare professionals who are familiar with your individual medical needs. This handbook should not take the place of any discussion with your physician, but should be used to help guide you in these discussions. All matters about your health should be under professional medical supervision.

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THE LUSTGARTEN FOUNDATION FOR PANCREATIC CANCER RESEARCH

Established in 1998 and named for Cablevision Systems Corporation Executive Marc Lustgarten, The Lustgarten Foundation for Pancreatic Cancer Research is dedicated to advancing the science related to the diagnosis, treatment, cure, and prevention of pancreatic cancer. The Lustgarten Foundation concentrates on stimulating the scientific and medical communities to conduct the research necessary to find a cure for the disease.

Advancing the Scientific Dialogue

The Lustgarten Foundation co-sponsors international scientific symposia that attract leading experts from various fields of basic and clinical oncology. In addition to these meetings, the Foundation supports and joins various activities of the National Cancer Institute and other leading research institutions and organizations.

Research Funding Opportunities

The Lustgarten Foundation supports promising pancreatic cancer research at the basic and clinical levels through a *Request For Proposals*, representing one-year, investigator-initiated awards, and a *Request For Applications*, representing multi-year, targeted research awards. Additional funding opportunities may become available as the state-of-the-science advances and new areas of pancreatic cancer investigation are identified.

Patient Education Services

The Lustgarten Foundation recognizes that patients with pancreatic cancer and their caregivers require and deserve access to the most up-to-date, accurate information in order to help them make *informed decisions*. Toward this end, the Foundation creates and disseminates free materials designed to respond quickly and effectively to patient concerns.*

* Bulk copies of The Lustgarten Foundation's patient education materials are available by request.

The following are some of the educational services provided by The Lustgarten Foundation:

- *Understanding Pancreatic Cancer: A Guide for Patients and Caregivers* handbook
- *Ask An Expert* series featuring topics of interest to pancreatic cancer patients
- Comprehensive website offering access to information and support resources at www.lustgarten.org
- The Lustgarten Foundation Clinical Trials Matching Service available at www.lustgarten.org

Public Awareness Activities

The Lustgarten Foundation maintains a national public awareness campaign that includes several public service announcements (PSAs) featuring the Honorary Chairman of the Foundation's Corporate Advisory Board, former President Jimmy Carter, as well as distinguished actor and Lustgarten Foundation Board Member, Matthew Modine. More than 30 million Americans have already seen the PSAs. The Foundation also airs a special 30-minute PSA to increase awareness of pancreatic cancer and the work of The Lustgarten Foundation.

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After earning a medical degree from the University of Chicago-Pritzker School of Medicine, Dr. Abbruzzese completed a residency in internal medicine at The Johns Hopkins Hospital in Baltimore, Maryland, and a fellowship in infectious diseases and medical oncology at Johns Hopkins and Dana-Farber Cancer Institute/Harvard Medical School.

Dr. Abbruzzese serves on the Scientific Advisory Board of The Lustgarten Foundation for Pancreatic Cancer Research and is an active member of the National Cancer Institute, American Association for Cancer Research, American Society of Clinical Oncology, and National Comprehensive Cancer Network. He is also a member of the American Association for the Advancement of Science, American Pancreatic Association, and European Society of Medical Oncology. He has lectured at numerous national and international conferences, has edited and written textbooks and book chapters, and has authored more than 250 articles.

Dr. Abbruzzese is one of the world's foremost leaders in the clinical study and treatment of pancreatic cancer. His major clinical and laboratory interests are in pancreatic cancer, new drug development and evaluation, and unknown primary tumors.

Ralph H. Hruban, MD, is Professor of Pathology and Oncology at The Johns Hopkins University School of Medicine in Baltimore, Maryland. He also is the Director of the Sol Goldman Pancreatic Cancer Research Center at Johns Hopkins.

After receiving an undergraduate degree from the University of Chicago and a medical degree from The Johns Hopkins University, Dr. Hruban continued his residency training in anatomic pathology at Johns Hopkins. He then completed a fellowship in surgical pathology at Memorial Sloan-Kettering Cancer Center in New York and returned to join the faculty at Johns Hopkins.

Dr. Hruban is recognized by the Institute for Scientific Information (now Thomson Scientific) as a Highly Cited Researcher and by *Essential Science Indicators*SM as the most highly cited pancreatic cancer scientist, which are designations given to the most highly influential scientists. He is a member of the Scientific Advisory Board of the Pancreatic Cancer Action Network (PanCAN), Joseph C. Monstra Foundation for Pancreatic Research, and Michael Rolfé Pancreatic Cancer Foundation, and is Director of Science for The Lustgarten Foundation for Pancreatic Cancer Research. Dr. Hruban has written more than 400 articles, 80 book chapters and reviews, and three books.

The goals of Dr. Hruban's research are to understand the following: the noninvasive precursor lesions from which invasive pancreatic cancers develop (PanINs), why pancreatic cancer aggregates in some families, and the pathologic ramifications of

genetic alterations in the pancreas. Dr. Hruban has applied molecular genetics to the study of noninvasive precursor lesions in the pancreas. A better understanding of these lesions may provide an avenue for the early detection of pancreatic cancer.

Charles J. Yeo, MD, is Samuel D. Gross Professor and Chair of Surgery at Thomas Jefferson University, Jefferson Medical College, in Philadelphia, Pennsylvania. He is board-certified in surgery and is a Fellow of the American College of Surgeons.

After graduating from Princeton University *summa cum laude* with a degree in biochemistry, Dr. Yeo earned a medical degree from The Johns Hopkins University School of Medicine in Baltimore. After completing an internship and a residency in general surgery at The Johns Hopkins Hospital, he pursued a research fellowship at the State University of New York Downstate Medical Center in Brooklyn. Dr. Yeo joined the faculty of The Johns Hopkins University as an instructor and as Assistant Chief of Service in the Department of Surgery in 1985, rose to the rank of Professor in 1996, and became a professor in the Department of Oncology in 1997.

Dr. Yeo serves on the editorial boards of *Langenbeck's Archives of Surgery* and *Surgery*; is an associate editor of *Advances in Surgery*, the *Journal of Gastrointestinal Surgery*, and *Current Problems in Cancer*; is Editor-in-Chief of the two-volume encyclopedic *Shackelford's Surgery of the Alimentary Tract, 6th Edition*, published in 2007; and has authored more than 325 peer-reviewed articles, numerous abstracts, and more than 75 book chapters.

Dr. Yeo has personally performed more than 750 Whipple procedures, and has treated more than 1,000 patients with pancreatic cancer and related cancers. His primary interests and research have been in the fields of hepatopancreaticobiliary surgery, the evaluation of patients with pancreatic cancer and related cancers, and the management of patients with unusual pancreatic neoplasms.

Elizabeth R. Campbell, RN, OCN, CCRC, is currently Clinical Program Manager of the Translational Research Division at the Translational Genomics Research Institute's (TGen) Pancreatic Cancer Research Program, and Project Manager at TGen Clinical Research Services (TCRS) at Scottsdale Healthcare in Phoenix, Arizona. She is a certified oncology nurse and certified clinical research coordinator. In these roles, Ms. Campbell assists with navigating patient care by serving as a Patient Care Coordinator at the Scottsdale Clinical Research Institute and by providing expertise to her colleagues in the areas of patient care activities and genomics-based clinical trials for cancer. Ms. Campbell has worked with physician colleagues as a Clinical Research Nurse Coordinator in the early development of more than 25 Phase I and Phase II trials studying agents now being used to treat many types of cancer such as capecitabine, paclitaxel, docetaxel, gemcitabine, and irinotecan.

Ms. Campbell is an active member of the Oncology Nursing Society, and has held several elected positions, including Director-at-Large; Co-chair, Membership Committee; a member of the Board of Directors; and President-Elect in the local chapter.

ABOUT THIS GUIDE

The board and staff of The Lustgarten Foundation for Pancreatic Cancer Research understand that many unique challenges are associated with a diagnosis of pancreatic cancer. Patients, and their families and friends, deserve access to the most accurate, up-to-date information about this disease in order to help them make *informed decisions* about their care.

Over the last 10 years, research into pancreatic cancer has increased significantly. Today more educational materials are also available for patients and caregivers, and the Internet is providing unprecedented access to information for patients with all types of cancers.

This handbook, *Understanding Pancreatic Cancer: A Guide for Patients and Caregivers*, is a summary of the growing amount of information available. *Understanding Pancreatic Cancer* is based on the premise that being knowledgeable about the challenges that a pancreatic cancer diagnosis poses will better equip patients to make informed decisions about all aspects of treatment and care. This handbook provides accurate information about many aspects of pancreatic cancer, including symptoms, diagnosis, staging, treatment, clinical trials, supportive care, and research. A Glossary is provided for ease of use. Terms in boldface type in the text are listed in the Glossary. An Appendix is included that contains a list of resources and a list of centers designated by the National Cancer Institute as the best cancer facilities.

If you or a loved one has been diagnosed with pancreatic cancer, we encourage you to seek support from family and friends, and to ask for help when you need it. Your treatment team – physicians, nurses, social workers, counselors and clergy, nutritionists, and other healthcare specialists – are excellent sources of information and support, and can help to address your questions and concerns. You can use this handbook to find the appropriate resources. We sincerely hope that this guide will help make a difference in your treatment and care.

For additional information, please contact:
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- Dr. Ralph H. Hruban, Professor of Pathology and Oncology at The Johns Hopkins University School of Medicine in Baltimore, Maryland
- Dr. Charles J. Yeo, Samuel D. Gross Professor and Chair of Surgery at Thomas Jefferson University, Jefferson Medical College, in Philadelphia, Pennsylvania
- Elizabeth R. Campbell, RN, OCN, CCRC, Clinical Program Manager at the Translational Genomics Research Institute's Pancreatic Cancer Research Program in Phoenix, Arizona

SECTION 1 • PANCREATIC CANCER

THE PANCREAS

The **pancreas** is an organ of the digestive system located deep in the upper part of the **abdomen**, behind the stomach and in front of the spine (**Figure 1-1**). It is only about 2 inches wide and 6 to 8 inches long and sits horizontally across the abdomen (**Figure 1-2**). The pancreas is composed of three parts.

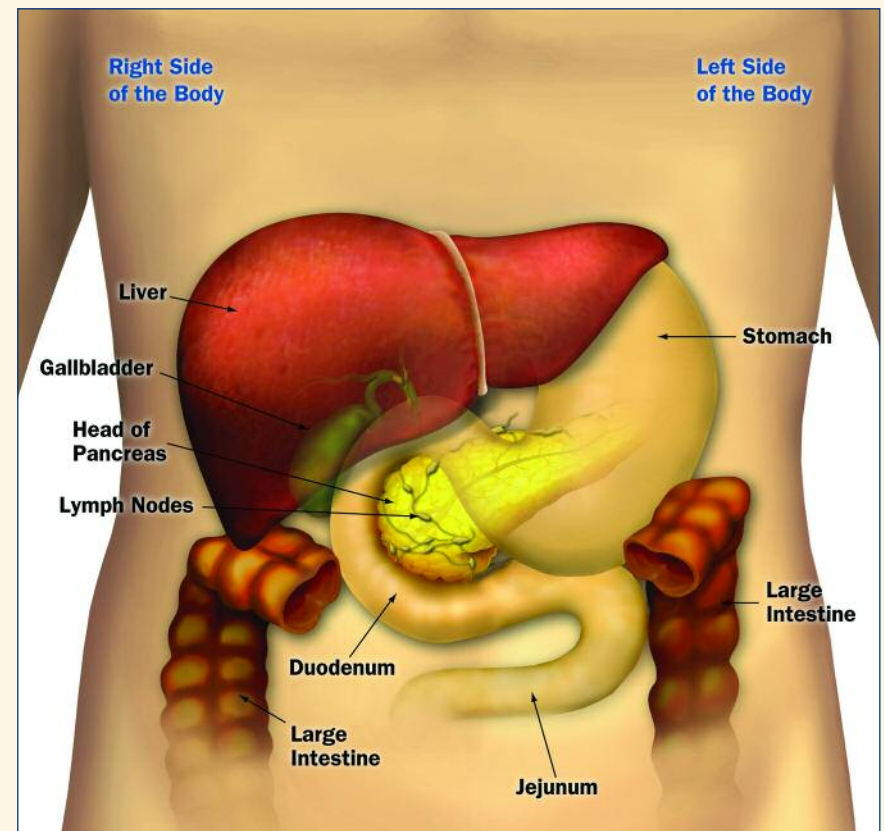


Figure 1-1. The pancreas is an organ of the digestive system located deep in the upper abdomen, behind the stomach.

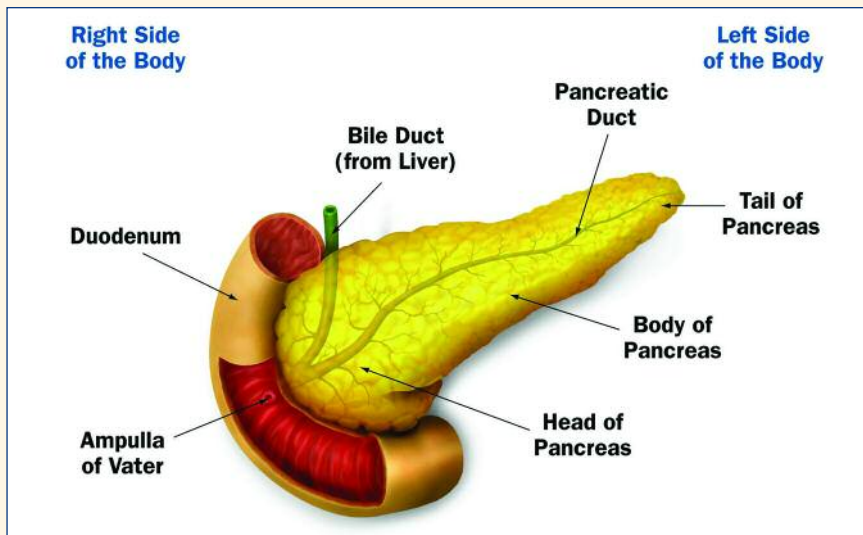


Figure 1-2. The pancreas is about 2 inches wide and 6 to 8 inches long. The head is the large, rounded end on the right side of the abdomen. The body is the middle section. The tail is the thin end located on the left side of the abdomen.

The large, rounded end is called the *head*. It is located on the right side of the abdomen and near the beginning of the small intestine, which is called the **duodenum**. The middle section, called the *body*, is tucked behind the stomach. The thin end of the pancreas, called the *tail*, is located on the left side of the abdomen next to the **spleen**.¹⁻³

Two separate types of glandular tissue make up the bulk of the pancreas, exocrine and endocrine tissue. The exocrine tissue comprises 95 percent of the pancreas and acts as an **exocrine gland**. The endocrine tissue makes up the remaining 5 percent of the pancreas and acts as an **endocrine gland**.³

Exocrine glandular tissue produces **pancreatic enzymes** to aid in the digestion of food. These **enzymes** are made in cells (called **acinar cells**) in the exocrine tissue. The pancreatic enzymes flow down a tube called the **pancreatic duct**, which is the main **duct** of the pancreas. This duct runs along the entire length of the pancreas and merges with the **bile duct**. From the pancreatic duct, the enzymes enter the duodenum. **Bile** from the liver flows down the bile duct and also empties into the duodenum. All of these fluids help the body digest food.³

The endocrine glandular tissue of the pancreas produces hormones and releases them into the bloodstream. The hormones are made in collections of cells called the **Islets of Langerhans**, which are found in small clusters throughout the pancreas. **Insulin** is an important hormone made in these cells and helps control blood sugar levels.³

CANCER OF THE PANCREAS

The word **cancer** is used to describe any one of a group of diseases in which the cells are abnormal, grow out of control, and can spread. These abnormal cells are different from normal cells in both appearance and function. Pancreatic cancer occurs when abnormal cells grow out of control in the tissue of the pancreas and form a tumor.^{1,2}

Because the pancreas lies deep in the abdomen, a doctor performing an examination on a patient would not be able to feel a pancreatic tumor. Pancreatic cancer has no early warning signs, and there are no effective screening tests. As a result, pancreatic cancer rarely is discovered early. Many times the diagnosis is not made until the cancer has spread to other areas of the body.³

In the United States, cancer of the pancreas is the fourth leading cause of cancer deaths in both men and women.⁴ In 2007, about 37,000 patients will be diagnosed with pancreatic cancer.⁵ Almost all patients with pancreatic cancer are older than 55 years (90 percent), and more than 70 percent are older than 65 years.³ Unfortunately, pancreatic cancer can also occur in younger people, especially those who have a family history of the disease. Today, better diagnostic tests and newer treatments are beginning to change these statistics and provide a more optimistic future for patients diagnosed with pancreatic cancer.

TYPES OF PANCREATIC CANCER

The most common types of pancreatic cancers are exocrine tumors called ductal **adenocarcinomas**, which are thought to form in the pancreatic ducts. About two thirds of all pancreatic cancers form in the head of the pancreas. The other third form in the body and tail.³ These tumors are **malignant**, meaning they can invade nearby tissues and organs. Cancerous cells can also spread through the blood and **lymphatic system** to other parts of the body. When this occurs, it is called **metastatic cancer** and it may be life-threatening.

Tumors can also form in the endocrine cells of the pancreas. These types of rare tumors are called islet cell tumors or pancreatic endocrine neoplasms, and most often they are **benign**. Those that are malignant are called islet cell cancers or malignant pancreatic endocrine neoplasms. Other rare forms of pancreatic cancer are listed in **Box 1-1**. It is important to distinguish between exocrine and endocrine tumors because each has different signs and symptoms, are diagnosed using different tests, have different treatments, and have different prognoses.³ This handbook does not focus on endocrine tumors or other rare tumors of the pancreas and related organs. However, most National Cancer Institute–Designated Comprehensive Cancer Centers have experts who can help patients who have these rare pancreatic tumors. (See the Appendix for a list of these Centers.)

BOX 1-1

RARE FORMS OF PANCREATIC CANCER⁶

Endocrine tumors

- Gastrinomas
- Glucagonomas
- Insulinomas
- Somatostatinomas
- VIPomas

Cystic tumors

- Mucinous cystic neoplasms
- Serous cystic neoplasms
- Solid pseudopapillary tumors
- Cystic islet cell tumors
- Intraductal papillary mucinous neoplasms (IPMNs)

Acinar cell cancer

Variants of ductal adenocarcinoma, such as

- Adenosquamous carcinoma
- Colloid carcinoma
- Hepatoid carcinoma
- Medullary carcinoma
- Signet ring cell carcinoma
- Undifferentiated carcinoma

Pancreatic lymphoma

Metastases to the pancreas from a cancer arising in another organ

Until recently, little was known about cancer of the pancreas. Because of new discoveries in all types of cancer, more research is being focused on pancreatic cancer. Scientists are beginning to understand the genetic basis of this disease. (See Section 2 on Causes.) This knowledge may help in understanding its causes and in determining who is most at risk. Eventually, new and better ways to treat pancreatic cancer will be discovered.

PRECURSORS TO PANCREATIC CANCER

Intraductal papillary mucinous neoplasms (IPMNs) have been recognized as a special type of abnormal tumors in the pancreas. These tumors are called “mucinous” because they produce large amounts of mucus, which clogs and enlarges the pancreatic duct. IPMNs are very different from most pancreatic tumors. They may be present for a long time without spreading, and patients with some types of IPMNs have a good chance of a cure with surgery. Because IPMNs also have very distinct features, researchers believe that studying them and their genetic makeup may lead to new ways of diagnosing more typical forms of pancreatic cancer.⁷

Pancreatic intraepithelial neoplasia (PanIN) are lesions too small to see with the naked eye. Like IPMNs, PanIN lesions can also progress to invasive pancreatic cancer over time.

SECTION 2 • CAUSES

GENES AND PANCREATIC CANCER

All the cells in the body contain DNA (deoxyribonucleic acid). DNA is the molecule in the cell nucleus that carries the instructions for making living organisms.¹ When cells grow and divide, they also copy DNA. Sometimes mistakes, called **mutations**, occur during this copying process.

Mutations in DNA occur frequently, especially when cells divide. Cells have an exceptional ability to repair these changes in DNA. However, the DNA repair mechanisms also can fail. When they do, these mistakes in DNA can be passed along to future copies of the altered cell. More abnormal cells then can be produced. When these abnormal cells continue to grow unchecked, cancer may develop.²

The DNA mutations that cause pancreatic cancer may be either inherited from a parent or acquired.³ **Inherited mutations** are carried in the DNA of a person's reproductive cells and can be passed on to that person's children.² *Not everyone who has an inherited mutation will develop pancreatic cancer.*

Acquired mutations are ones that develop during a person's lifetime, either as random mutations in DNA or in response to injuries from harmful environmental factors such as exposure to radiation or chemicals.^{2,4} Scientists believe that most cancers result from complex processes that occur both among many different **genes** and between genes and outside factors.² Some of these outside factors are called risk factors. *Not everyone who has an acquired mutation will develop pancreatic cancer.*

RISK FACTORS

There is a long list of risk factors for pancreatic cancer (**Box 2-1**). **Risk factors** are characteristics, habits, or environmental exposures that have been shown to increase the odds of developing a disease.

You can decrease some of your risk by maintaining a healthy body weight, eating a healthy diet that is high in fruits and vegetables and low in

BOX 2-1

RISK FACTORS FOR PANCREATIC CANCER³⁻⁵

- Smoking
- Diet
- Obesity
- Age
- Race
- Family history
- Medical factors
 - Chronic pancreatitis
 - Diabetes
 - History of stomach surgery (partial gastrectomy)
- Environmental exposure to certain chemicals

Not everyone with one or even more than one of these risk factors will develop pancreatic cancer.

processed meats, and not smoking. Some risk factors that you cannot influence are your age and family history. *Not everyone who has one or more of these risk factors will develop pancreatic cancer.*

Risk Factors You Can Influence

Smoking. Smoking is a direct risk factor because people who smoke have two to three times the chance of getting pancreatic cancer compared with people who do not smoke.⁴

Diet. A diet high in cholesterol, fried foods, and processed meats, such as bacon and sausage, may increase the risk of pancreatic cancer. A diet high in fruits and vegetables may reduce the risk of pancreatic cancer.^{3,4}

Obesity. People who are significantly overweight are 20 times more likely to develop pancreatic cancer compared with those who are not overweight.⁴

Other Risk Factors

Age. As people age, their risk of pancreatic cancer increases. Pancreatic cancer mostly affects people 55 years of age and older.⁴

Race. In the United States, pancreatic cancer is more common in African Americans than in whites. The reasons are not clear. Differences in dietary

habits, the rates of obesity and diabetes, and the frequency of cigarette smoking exist between these groups. Genetic or other unknown factors may also explain the higher incidence in African Americans.⁵

Medical Factors. The incidence of pancreatic cancer is higher in people who have any of the following medical conditions^{3,4}:

- **Chronic pancreatitis** (inflammation that causes irreversible damage)
- Long-standing **diabetes mellitus** (high blood sugar)
- History of stomach surgery (partial gastrectomy)

Environmental Factors. Occupational exposure to some chemicals, such as pesticides, dyes, or chemicals related to gasoline, may increase the risk for pancreatic cancer.⁴

Presence of Risk Factors

When a person has any one or even more than one of these risk factors, it does not mean that the person is certain to develop pancreatic cancer. In contrast, some people who do not have risk factors will still get pancreatic cancer. Researchers do not know the reasons for these differences but are working to understand how lifestyle and environmental risks interact with individual genetic makeup to influence the chances of developing pancreatic cancer.^{4,6}

FAMILY HISTORY AND PANCREATIC CANCER

Pancreatic cancer may be inherited because it tends to run in families.⁴ This means that relatives of patients with pancreatic cancer may have an increased risk of developing the disease. One recent study done in Iceland

FAMILIAL PANCREATIC CANCER

Relatives of patients with pancreatic cancer have an increased risk of developing it. Inherited mutations in known cancer-causing genes have been shown to be the cause of familial pancreatic cancer in some families.⁷ *Not everyone who has one of these mutations will develop pancreatic cancer.*

found that people who had one **first-degree relative** (parent, sibling, or child) with pancreatic cancer had two to three times the risk of developing pancreatic cancer compared with people with no family history.⁸ ***Not everyone with a family history of pancreatic cancer will develop the disease.***

From 5 to 10 percent of pancreatic cancers result from hereditary factors.² Researchers believe that studying specific cancer genes may provide a better understanding of the causes of pancreatic cancer. In turn, a better understanding of the causes may lead to more effective screening methods.^{9,10} Researchers in the United States have set up national pancreatic cancer registries to study the hereditary factors that influence pancreatic cancer. (See the Appendix for more information and a list of registries.)

HEREDITARY SYNDROMES

The hereditary syndromes listed below may be associated with the development of pancreatic cancer.¹¹

Familial Breast Cancer Syndrome. People who have the breast cancer 2 gene (*BRCA2*) mutation have an increased risk of several cancers, among them pancreatic adenocarcinoma.¹² The *BRCA2* gene is particularly common in the Ashkenazi Jewish population.

Familial Atypical Multiple Mole Melanoma (FAMMM) Syndrome. People with FAMMM syndrome have many different-sized skin moles that are asymmetrical and raised.¹¹

Peutz-Jeghers Syndrome (PJS). In people with PJS, the risks of gastrointestinal tumors such as esophageal, small bowel, colorectal, and pancreatic cancer are increased.¹³ Polyps in the small intestine and dark spots on the mouth and fingers characterize the disease.¹⁴

Hereditary Pancreatitis. Hereditary pancreatitis is a rare disease in which patients develop recurrent episodes of severe chronic pancreatitis at an early age.³ This is not the same as chronic pancreatitis.

Hereditary Nonpolyposis Colon Cancer (HNPCC; Lynch Syndrome). People with HNPCC have a higher than normal chance of developing colon, pancreatic, uterine, stomach, or ovarian cancer.³

Multiple Endocrine Neoplasia Type 1 Syndrome (MEN1; Wermer's Syndrome). MEN1 is a rare, inherited disorder that affects the endocrine glands and can cause tumors in the pancreas and other organs, which usually are not cancerous.¹¹

ASHKENAZI JEWS: ARE THEY AT RISK FOR PANCREATIC CANCER?

Pancreatic cancer is more common in people of Ashkenazi Jewish ancestry. Researchers believe there is a genetic basis for this increased risk. A defect in the **BRCA2** gene, which is found in about one percent of Ashkenazi Jews, is responsible for a 10-fold increased risk of developing pancreatic cancer. A defect in the **BRCA1** gene, which is found in 1.5 percent of Ashkenazi Jews, is responsible for a twofold increased risk.¹⁵ Doctors can test for the presence of these genetic mutations. *Not everyone who has one of these inherited genetic mutations will develop cancer.*

SECTION 3 • SIGNS AND SYMPTOMS

A SILENT DISEASE

Pancreatic cancer can be called a silent disease because many times no **signs** or **symptoms** are noticed until the cancer is in an advanced stage. Even when there are early signs and symptoms, they may be vague and easily attributed to another disease. The signs and symptoms also may be confusing to patients and healthcare providers because they vary, depending on where the tumor is located in the pancreas (the head, body, or tail).¹ It is important to see your doctor if you have any of the signs or symptoms of pancreatic cancer (**Box 3-1**).

BOX 3-1

SIGNS AND SYMPTOMS TO TAKE SERIOUSLY¹⁻⁶

- Jaundice, with or without
 - Itching
 - Dark urine
 - Light stool
- General symptoms
 - Back pain
 - Fatigue or weakness
- Other illnesses
 - Pancreatitis
 - Diabetes
- Digestive problems
 - Unexplained weight loss
 - Loss of appetite
 - Malnutrition
 - Nausea or vomiting
 - Abdominal pain

JAUNDICE AND ITS SIGNS AND SYMPTOMS

Jaundice is a yellowing of the skin and the whites of the eyes. Signs and symptoms that may occur with jaundice are itching, dark urine, and clay-colored stool. The itching may be severe.^{2,3}

Jaundice occurs when bilirubin stains the skin. **Bilirubin** is a dark-green substance made in the liver.³ Starting in the liver, bilirubin travels down the bile duct and into the small intestine. When the bile duct is blocked by a tumor or when a tumor is located in the head of the pancreas near the bile duct, the bile is prevented from reaching the intestines. The bile then accumulates in tissues, blood, and the skin, leading to jaundice.³

There are other, more common causes of jaundice, such as **hepatitis** (inflammation of the liver) or obstruction of the bile duct by a gallstone.³

GENERAL SYMPTOMS

Back Pain

This common sign of advanced pancreatic cancer occurs when the tumor presses on organs and nerves around the pancreas. The pain may be constant or intermittent and can be worse after eating or when lying down. Many conditions other than pancreatic cancer can cause back pain.^{2,3}

Fatigue or Weakness

People with pancreatic cancer may feel very tired.³

OTHER ILLNESSES

Pancreatitis

An inflammation of the pancreas called **pancreatitis** can be a sign of pancreatic cancer when it is chronic or when it appears for the first time and is not related to either drinking alcohol or gallstones.^{4,5}

Diabetes

Developing diabetes mellitus (sugar diabetes), especially after the age of 50, can be a sign of pancreatic cancer.⁶

DIGESTIVE PROBLEMS OR PAIN

Unexplained Weight Loss, Loss of Appetite, or Malnutrition

People with pancreatic cancer may lose weight, may have little or no appetite, or may suffer from malnutrition.^{2,3} When pancreatic enzymes cannot be released into the intestine, digesting food, especially high-fat foods, may be difficult. Over time, significant weight loss and malnutrition may result.²

Nausea or Vomiting

If the tumor blocks the upper part of the small intestine (the duodenum), nausea and vomiting may result.²

Abdominal Pain

Just as in back pain, abdominal pain is a common sign of advanced pancreatic cancer. It occurs when the tumor presses on organs and nerves around the pancreas.^{2,3}

WHEN TO SEE A DOCTOR

Many other illnesses can cause these signs and symptoms, but it is important to take them seriously and see your doctor. If you have a first-degree relative with pancreatic cancer, tell your doctor and consider joining a pancreatic registry. (*See the Appendix.*)

IMPORTANT INDICATOR FOR PANCREATIC CANCER: CLUES IN THE BLOOD⁷

In a study of more than 2,000 people with diabetes over 50 years of age, researchers at the Mayo Clinic in Rochester, Minnesota, found an association between newly developed sugar diabetes and pancreatic cancer. Within 3 years of diagnosis, people with diabetes had a risk of pancreatic cancer that was eight times that of same-age, average persons. It is thought that new-onset diabetes may be an indicator that would allow for earlier detection and treatment of pancreatic cancer. It is too early to tell if this indicator can be used to screen people over the age of 50 for pancreatic cancer.

SECTION 4 • DIAGNOSIS

INITIAL EXAMINATION

Several steps are involved in making a diagnosis of pancreatic cancer. The first thing your doctor will do is ask questions about your medical history, family history, possible risk factors, and symptoms (**Box 4-1**). Answering these questions honestly and completely will help both you and your doctor during the diagnostic process.

BOX 4-1

MEDICAL HISTORY QUESTIONS ¹

- Where do you have the pain?
- How long have you had the pain?
- How bad is the pain, for example, on a scale from 1 to 10?
- Are you able to do anything to make the pain happen?
- Are you able to do anything to make the pain go away?
- Have you lost weight without trying?
- What other symptoms do you have?
- If you have jaundice: When did you notice the jaundice?
- If you have dark urine or light stools: How long have you had this?
- Has anyone in your family ever had cancer?
- Has anyone in your family ever had pancreatic cancer?

You will also have a physical examination. Your doctor will check your abdomen for tenderness, fluid buildup, enlargement of your **gallbladder** or liver (that may result from blockage of the bile duct), and masses. Your lymph nodes will be checked for tenderness and swelling. Any sign of jaundice will be noted. Your doctor also may order blood or urine tests, testing of stool samples, or imaging tests.

IMAGING TESTS

The most important tests used to detect pancreatic cancer are **imaging tests**. These tests use a variety of methods to see inside the body. Imaging

tests can be simple X-rays or more complex scanning methods that use computers to reconstruct the structures in the body. Some typical imaging tests are described in this section, and their uses are listed in **Table 4-1**.

Keep in mind that results from many of the imaging tests outlined in this section are complementary to each other. Your doctor will decide which tests would be best, given your particular situation.

Table 4-1. Imaging Tests and Their Uses ¹⁻⁹

Imaging Test	Use(s)
Computed tomography (CT) scan	Can help determine if the tumor is localized or has spread
CT scan with contrast dye	Can detect abnormal masses Can detect blockages of the pancreatic and bile ducts
Dual-phase helical CT scan	Can detect 98% of pancreatic cancers Can detect distant metastases
Multidetector row CT (MDCT) scan	Has improved image resolution Can rapidly scan large volumes
Ultrasonography	Can determine if pancreatic tissue is normal or abnormal Can help detect blockages of the pancreatic and bile ducts
Endoscopic ultrasonography (EUS)	Highly reliable Can determine local extent of disease Can detect lesions in the head, body, and tail of the pancreas Tissue samples can be taken at the same time
Laparoscopic ultrasonography (LUS)	Can determine if the tumor has spread to the peritoneum Can detect liver metastases
Magnetic resonance imaging (MRI)	Can detect masses Can detect blockages
Positron emission tomography (PET) scan	Can show the difference between healthy and abnormal tissue in the entire body
Endoscopic retrograde cholangiopancreatography (ERCP)	Can detect obstructions in the pancreatic and bile ducts Usually reserved for people who require stent placement for symptom management
Magnetic resonance cholangiopancreatography (MRCP)	Can detect obstructions in the pancreatic and bile ducts

Computed Tomography (CT) Scan

Many people either are familiar with or have had a **computed tomography (CT) scan**, which is also called a CAT scan. The CT machine is very large and shaped like a donut. During a CT scan, you will lie on a table that will move into the machine. The scanner will take detailed, cross-sectional, X-ray images from many different angles. The computer combines these images into a series of views of the area in question for diagnostic purposes. (Figure 4-1).¹

A CT scan may be done at a special center or in a hospital but does not require an overnight stay. This test is not painful, and no sedation is needed.

A dye, called a **contrast agent**, can be injected into a vein to produce better CT images of body structures. Typically, a contrast agent is also given by mouth to provide better images of the stomach and small intestines.

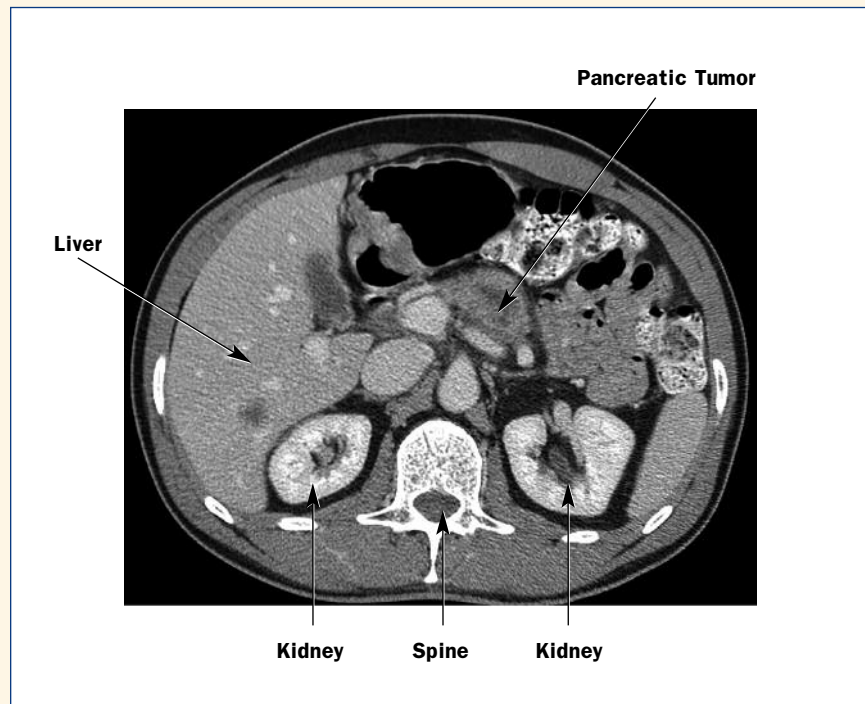


Figure 4-1. Computed tomography scan of the abdomen showing a pancreatic tumor.

In many centers, modifications of basic CT scanners are used to image the pancreas more accurately. Two of these modified scanners are a dual-phase helical CT scan and a multi-detector row helical CT scan. A **dual-phase helical** (also called spiral) CT scan is a sensitive imaging test used to evaluate patients suspected of having pancreatic cancer. Dual-phase helical CT scanning produces detailed, three-dimensional images of the pancreas. It is estimated that this type of CT scan can diagnose about 98% of all pancreatic cancers and distant metastases.⁶

A helical CT scanner with multiple detector rows, called a **multi-detector row helical CT (MDCT) scan**, is one of the latest technological advances in CT scanners. MDCT has advantages over other CT methods, including improved image resolution and the ability to rapidly scan large volumes, thus allowing for imaging of the entire pancreas in a single breath-hold by the patient.⁷

Ultrasonography

Ultrasonography is another imaging test that is commonly used, and thus, many people are familiar with it. Ultrasonography is also called a sonogram, an ultrasonogram, or an ultrasound scan. During this test, sound waves are bounced off internal organs to produce echoes. The computer creates patterns from these echoes. Because echoes from normal and abnormal tissue produce different patterns, pancreatic cancer can be detected.¹

During a sonogram, an ultrasound probe will be placed on your abdomen and moved methodically. Images of the echo patterns will be displayed on a computer screen.¹ Ultrasound examination is noninvasive, painless, and can be performed in an outpatient setting. Its major limitation is that gas in the gastrointestinal tract can interfere with the sound waves, and therefore, it is not considered a very sensitive test to detect pancreatic cancer.

There are two other types of sonograms, **endoscopic ultrasonography (EUS)** and **laparoscopic ultrasonography (LUS)**. Each is a minimally invasive procedure. EUS is performed using an **endoscope**, which is a long, thin instrument with a light at the end used to look deep inside the body. During EUS, you will receive numbing medication for your throat and medication for sedation. The endoscope is passed down the **esophagus**, through the stomach, and into the duodenum. The machine that makes the sound waves is then turned on, and images are created by visualizing the pancreas through the stomach or the duodenum.^{1,8}

Advantages of EUS are that the ultrasound probe can be placed immediately adjacent to the pancreas, producing detailed images, and tissue samples can be obtained through the same instrument.

The LUS procedure is not used as often as EUS but may be employed to evaluate whether the cancer has spread to the **peritoneum**, which is the membrane that lines the abdominal cavity and covers most of the abdominal organs. During an LUS procedure, typically, general anesthesia is given. A small incision will be made in the abdomen, and the doctor will use a **laparoscope** (a small telescope-like instrument connected to a video monitor) to view the pancreas. This procedure can be done in the hospital or on an outpatient basis.⁸

Magnetic Resonance Imaging (MRI)

Magnetic resonance imaging is another imaging method that is in common use today, and many people are familiar with it. When having an MRI, you lie on a table that is moved into a narrow tube. Today, open MRIs are commonly available to avoid the uncomfortable feeling of being in an enclosed space, although images from open MRIs may not be optimal. The procedure is noninvasive and painless.¹

MRI uses radio waves and powerful magnets, instead of X-rays as in a CT scan, to view internal structures and organs. The energy from the radio waves is absorbed by the body and then released. A computer translates the patterns formed by this energy release into detailed images of areas inside the body. MRI produces cross-sectional slices like a CT scanner, but also produces slices that are parallel to the length of the body.¹

An MRI scan is performed at a special imaging center or at a hospital. If you have any metal in your body, you should check with your doctor prior to undergoing an MRI scan. Some types of metal implants, such as prosthetic hips, knees, pacemakers, and heart valves, may cause problems when exposed to high magnetic forces such as those used in MRI.

Positron Emission Tomography (PET Scan)

Positron emission tomography, or **PET scan**, is an imaging test that shows not only anatomy but also biological function. During a PET scan, a small amount of **radioactive glucose** (sugar) is injected into a vein. Then a special camera detects the radioactivity that is preferentially taken up by malignant

tissue, and a computer creates detailed images. Because cancer cells often absorb much more glucose than normal cells do, the images created by a PET scan can be used to find cancer cells in the pancreas and in other areas of the body.¹ Recently developed machines combine CT imaging with PET scanning to more accurately identify cancer.

Endoscopic Retrograde Cholangiopancreatography (ERCP)

Endoscopic retrograde cholangiopancreatography, or **ERCP**, is an invasive procedure that is used in conjunction with a dye to view the bile and pancreatic ducts for obstructions. During an ERCP, you will receive an anesthetic to numb the throat and medication for sedation. A thin tube is passed down the throat, through the stomach, and into the small intestine. From there, the gastroenterologist who is performing the procedure will identify the pancreatic duct so that the dye can be injected into it. Then X-rays are taken. This is an outpatient procedure but also may be performed in the hospital.⁹

ERCP has advantages over magnetic resonance cholangiopancreatography (see below). ERCP is especially helpful in patients with jaundice because a **stent** can be inserted and left in place to keep ducts open, often relieving the jaundice and its associated symptoms. Tissue samples also can be taken during the procedure.⁹ Less invasive tests are being used more often in place of ERCP.¹⁰

Magnetic Resonance Cholangiopancreatography (MRCP)

Magnetic resonance cholangiopancreatography (MRCP) is a type of MRI and is an alternative to ERCP. It is safer and faster than ERCP, because it is noninvasive and no dye is used. MRCP is used to view the pancreatic and bile ducts, which are difficult to see with CT or MRI. No sedation or preparation on the part of the patient is needed, except for fasting.^{3,4} Typically, MRCP is combined with MRI.

BIOPSY

Because the only definitive way to diagnose cancer is to directly visualize cancer cells under a microscope, a biopsy may be performed when pancreatic cancer is suspected. A **biopsy** is the process of removing tissue samples, which are then examined under a microscope to check for cancer cells.⁹ A biopsy can be performed in an outpatient setting or in the hospital.

Biopsy specimens can be obtained in different ways. It is generally not necessary to have a biopsy performed prior to surgery.

Fine-Needle Aspiration (FNA) Biopsy

In a **fine-needle aspiration (FNA) biopsy**, imaging by CT or EUS is used together with a long, thin needle to obtain tissue specimens. The CT or EUS imaging method allows the doctor to view the position of the needle to ensure that the needle is in the tumor. EUS also can be used to place the needle directly through the wall of the duodenum or stomach and into the tumor for collection of tissue specimens. General anesthesia is not required, but local anesthesia may be provided.¹

Brush Biopsy

A **brush biopsy** procedure is used with ERCP. A small brush is inserted through an endoscope into the bile and pancreatic ducts. Cells are scraped off the insides of the ducts with the brush.¹

Laparoscopy

Laparoscopy is a minimally invasive procedure, during which you will receive general anesthesia. A laparoscope is inserted through a small incision in the abdomen. The doctor can view the tumor and remove tissue samples for examination.¹

BLOOD TESTS

Blood tests are frequently performed for diagnostic purposes. No single blood test can be used to make a diagnosis of pancreatic cancer. When a person has pancreatic cancer, however, elevated levels of bilirubin or liver enzymes may be present.⁶

Different tumor markers in the blood are used to detect and monitor many types of cancer. **Tumor markers** are substances, usually complex proteins, produced by tumor cells. **Proteins** form the basis of body structures such as cells, tissues, and organs. Enzymes and some hormones are composed of protein. Some tumor markers can indicate specific types of cancer; others are found in several types of cancer. Many of the well-known tumor markers, such as PSA for screening prostate cancer, are also found in people who do not have cancer.¹¹

Two commercially available tumor marker tests are of use in patients with pancreatic cancer, **cancer antigen 19-9 (CA 19-9)** and **carcinoembryonic antigen (CEA)**.¹ These markers are not accurate enough to be used to screen healthy people for or to make a diagnosis of pancreatic cancer. However, CA 19-9 and CEA are frequently used to track the progress of treatment in patients with pancreatic cancer. CA 19-9 is a protein found on the surface of certain types of cells and is shed by tumor cells, making it useful in following the course of cancer. The presence of the protein CEA may indicate cancer because elevations in CEA levels are not usually found in people who are healthy. CEA is not as useful as is CA 19-9 in pancreatic cancer testing.¹¹

TEST RESULTS

If you have blood and urine testing, your doctor will receive written reports from the laboratory. If the results show high levels of bilirubin, it may be an indication of pancreatic cancer. However, many other medical situations can cause an elevation in bilirubin. Additional testing will almost always be needed to establish a diagnosis of pancreatic cancer. Liver function tests will also be performed on blood samples to determine if a tumor is affecting the liver.

Results of imaging tests such as CT and MRI scans will be conveyed to your doctor by a **radiologist**, a physician who is trained to interpret many different types of imaging techniques. The radiologist will consult with your doctor and provide a written report of the results.

If you have a biopsy procedure performed, your doctor will receive a written report from the **pathologist**, a physician trained to examine cells under a microscope in the laboratory for cancer and other diseases. Your doctor may also speak with the pathologist to obtain a better understanding of your disease. The results of the biopsy will help your doctor make treatment recommendations, and can help you make treatment decisions.

SECTION 5 • STAGING

MEASURING CANCER

Staging cancer is a standardized way to classify a tumor based on its size, whether it has spread, and where it has spread. In other words, staging measures the extent of the disease.¹ Your doctor will order diagnostic tests to determine the stage of your disease. Knowing the stage of your cancer will help your doctor determine which treatment options are right for you. The stage of your cancer is the most important factor in making good treatment choices.

Most cancers are staged using the TNM system of classification, which was developed by the American Joint Committee on Cancer (AJCC).²

TNM CLASSIFICATION SYSTEM

The **TNM system** uses three factors to evaluate cancer: tumor, node, and metastasis^{1,3}:

- T stands for *tumor* and describes the size and location of the primary tumor, if and how far it has spread within the pancreas, and if it has spread to nearby structures.
- N stands for *node* and describes evidence of metastases in lymph nodes close to the pancreas, that is, whether or not the tumor has spread to the regional lymph nodes.
- M stands for *metastasis* and describes evidence of distant metastases, that is, whether or not the cancer has spread to distant parts of the body.

Tumor Evaluation (T)

Based on information from diagnostic tests, the “T” is given a number to describe the size and location of the tumor^{1,4}:

TX: The primary tumor cannot be evaluated

T0: No evidence of cancer is found in the pancreas

Tis: This classification is used when there is a condition called carcinoma (cancer) *in situ*, or Tis, meaning that the tumor remains in a pre-invasive state and is within the pancreas

T1: The tumor is in the pancreas only, and it is 2 centimeters (cm) or smaller in size [2 cm = .80 inches]

T2: The tumor is in the pancreas only, and it is larger than 2 cm

T3: The tumor has spread to surrounding tissue near the pancreas but not to the major blood vessels

T4: The tumor extends beyond the pancreas into the major blood vessels near the pancreas; T4 tumors cannot be removed completely by surgery

Node Evaluation (N)

Lymph nodes are small, bean-shaped structures found in the neck, underarm, groin, chest, abdomen, and pelvis – and throughout the body. They store white blood cells, called **lymphocytes**, which the body uses to fight infection and disease. **Lymphatic fluid** circulates through lymph vessels, just as blood circulates through blood vessels. Eventually, the lymphatic fluid empties into blood vessels in the upper chest.⁵

Lymph node enlargement detected either by CT or MRI scan may indicate that cancer has spread to that lymph node. (*See Section 4 on Diagnosis.*) A biopsy also can be performed on lymph nodes to check for cancerous cells. The node staging method is as follows^{1,4}:

NX: The regional lymph nodes cannot be evaluated

N0: The cancer was not found in the regional lymph nodes

N1: The cancer has spread to the regional lymph nodes

Metastasis Evaluation (M)

Pancreatic cancer may spread locally to the lymph nodes and major blood vessels near the pancreas or to distant lymph nodes or organs such as the liver or lungs.⁶ In staging, this spread is documented as follows^{1,4}:

MX: Distant spread of the disease (metastasis) cannot be evaluated

M0: The disease has not spread to distant lymph nodes or to distant organs

M1: The disease has spread to distant lymph nodes or to distant organs

STAGING SYSTEM

Combining T, N, and M defines the stage of cancer. Each patient's condition is evaluated for T, N, and M, and the descriptions are combined to form a stage (*Figures 5-1 to 5-4*).^{1,4,7}

Stage 0: Refers to cancer *in situ*, or the cancer has not invaded outside the ducts in which it originated (Tis, N0, M0)

Stage IA: The tumor in the pancreas is 2 cm or smaller and has not spread to lymph nodes or other parts of the body (T1, N0, M0)

Stage IB: The tumor in the pancreas is larger than 2 cm and has not spread to lymph nodes or other parts of the body (T2, N0, M0)

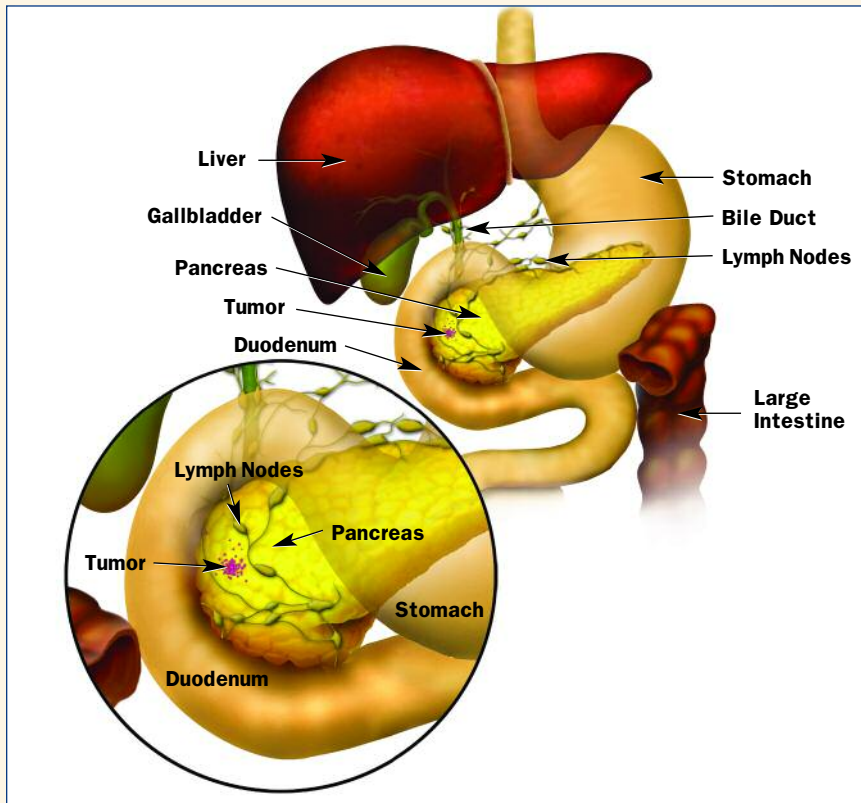


Figure 5-1. In Stage I pancreatic cancer, the cancer is confined to the pancreas.

Stage IIA: The tumor extends beyond the pancreas but has not spread to nearby lymph nodes, major blood vessels, or other parts of the body (T3, N0, M0)

Stage IIB: The tumor is any size and is either limited to or extends beyond the pancreas and has spread to lymph nodes but not to major blood vessels or other parts of the body (T1, T2, T3; N1; M0)

Stage III: The tumor has spread to nearby blood vessels, may or may not have spread to nearby lymph nodes, but the cancer has not spread to other parts of the body (T4, any N, M0)

Stage IV: The cancer has spread to other parts of the body (any T, any N, M1)

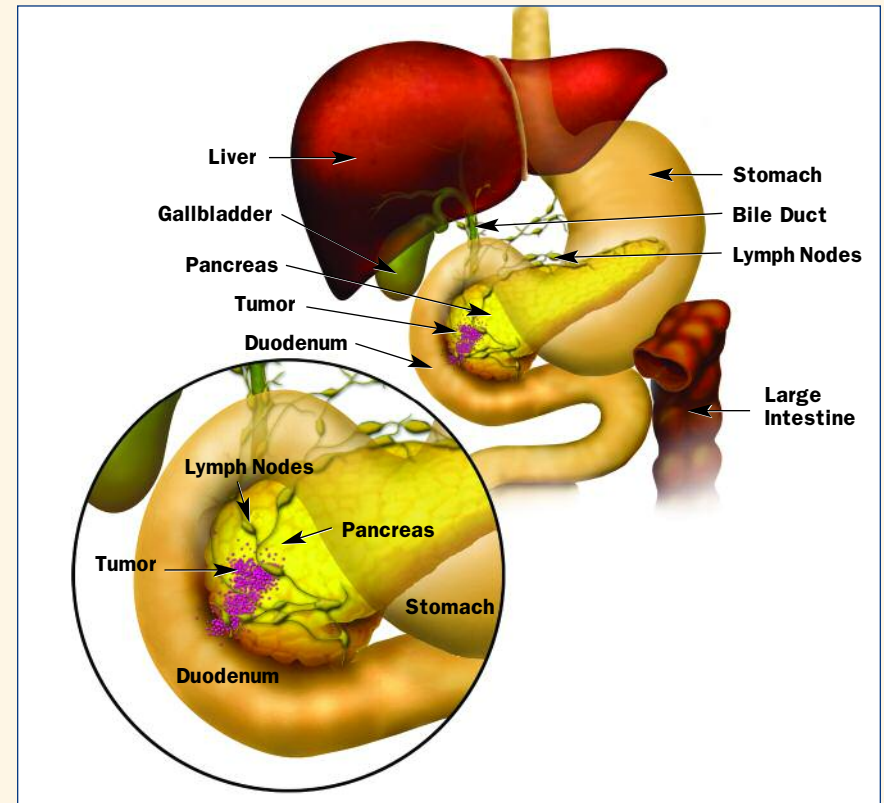


Figure 5-2. In Stage IIA pancreatic cancer, the cancer has spread beyond the pancreas, but not to lymph nodes, major blood vessels, or other parts of the body.

CLINICAL CLASSIFICATION

A simpler, more descriptive staging system for pancreatic cancer is often used by doctors. This system divides cancers into groups based on whether or not the tumor can be removed surgically.¹

Resectable Cancer

This type of pancreatic cancer can be surgically removed. These tumors may lie within the pancreas or extend beyond it, but there is no involvement of the critical arteries or veins in the area. There is no evidence of any spread to areas outside of the tissue removed during a typical surgery for pancreatic cancer.⁷ (See Section 7 on Treatment.)

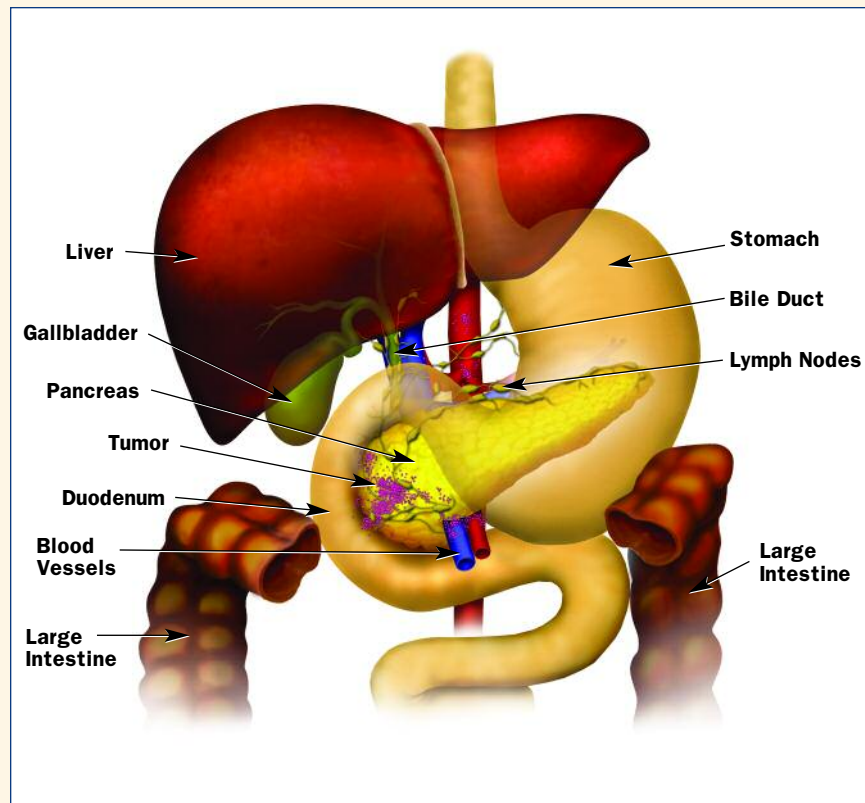


Figure 5-3. In Stage III pancreatic cancer, the cancer has spread to major blood vessels and possibly to lymph nodes, but not to other parts of the body.

Locally Advanced Cancer

The cancer is confined to the area around the pancreas but cannot be surgically removed because the tumor may be intertwined with major blood vessels and may have invaded surrounding organs. No evidence of spread to other areas of the body can be found.⁷

Metastatic Cancer

The tumor has spread beyond the area of the pancreas and involves other organs, such as the liver or lungs, or other areas of the abdomen. Unfortunately, almost half of all patients are diagnosed at this stage.⁷

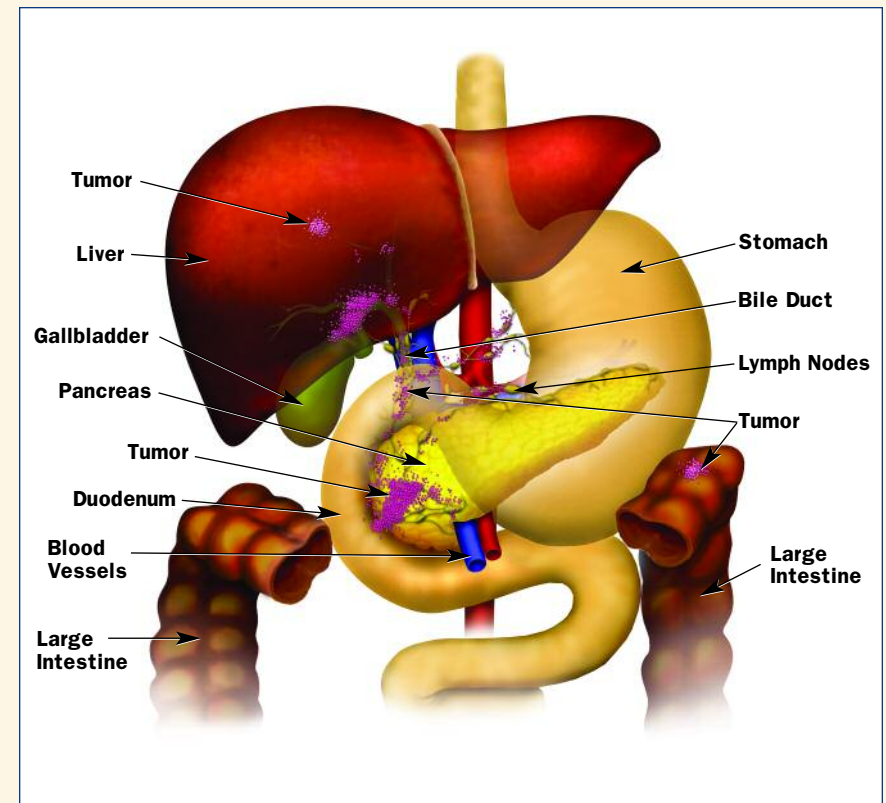


Figure 5-4. In Stage IV pancreatic cancer, the cancer has spread to distant organs (liver, lung) and possibly to organs and tissues near the pancreas or to lymph nodes.

Table 5-1 provides a simplified version of the information given in this section. Remember that it is important to know the stage of your cancer to help make good treatment choices.

Table 5-1. Staging for Tumors of the Pancreas ^{1,4,6,7}

Stage	Classifications for Tumor, Nodes, Metastases	Description	Resectable	Locally Advanced	Metastatic
0	Tis, N0, M0	Cancer is confined to cells in the pancreas; also called carcinoma <i>in situ</i>	√		
IA	T1, N0, M0	Cancer is only in the pancreas and is 2 cm or smaller	√		
IB	T2, N0, M0	Cancer is only in the pancreas and is larger than 2 cm	√		
IIA	T3, N0, M0	Cancer has spread beyond the pancreas but has not spread to nearby lymph nodes, major blood vessels, or other parts of the body	√ Sometimes	√ Sometimes	
IIB	T1, T2, or T3; N1; M0	Cancer either is limited to or extends beyond the pancreas, with spread to the lymph nodes but not to major blood vessels or other parts of the body	√ Sometimes	√ Sometimes	
III	T4, any N, M0	Cancer has spread to major blood vessels and possibly to the lymph nodes, but not to other parts of the body	√ Sometimes	√	
IV	Any T, any N, M1	Cancer has spread to other parts of the body			√

SECTION 6 • MAKING DECISIONS

MAKING DECISIONS ABOUT TREATMENT

The ultimate result of the process of cancer diagnosis and staging is a recommendation of a treatment plan. You will need to decide whether you will accept that recommendation and, ultimately, where you will be treated and by whom. Some basic questions to ask yourself before beginning treatment are listed in **Box 6-1**.

BOX 6-1

QUESTIONS BEFORE MAKING A TREATMENT DECISION

- Do I need any more information before I begin treatment?
- Do I have confidence in the diagnosis?
- Do I have confidence in my doctors?
- Do I have confidence in the facility?
- Do I understand what will happen before, during, and after treatment?
- How far from home am I willing to travel to be treated?
- Do I want what is the “standard of care,” or am I interested in participating in a clinical trial?

FACING TREATMENT CHALLENGES

The best treatment results are obtained if surgery can be included as part of the treatment when pancreatic cancer is found at an early stage, before it has spread. Despite the great increase in research into pancreatic cancer, however, early detection is uncommon. When diagnosed, people usually are older than 55, and most often are older than 65, and **co-existing conditions** may limit treatment options. Disease-related side effects may make patients very ill, again limiting treatment options. Even so, treatment aimed at controlling symptoms and preventing additional harm may increase patients’ quality of life.^{1,2}

GETTING A SECOND OPINION

Keep in mind that the diagnosis and staging of cancer is a complicated process and that cancer is different in every person. “Every person with

cancer – even two people with cancer at precisely the same stage – differs from every other.”³ It may feel much safer and simpler to take the advice of the doctor who diagnosed your cancer, but getting a second opinion by an expert in your type of cancer may be a wiser choice.

A SECOND OPINION FOR ALL PATIENTS WITH CANCER

The National Cancer Institute (NCI) recommends that *all patients with cancer* get a second opinion for two reasons: (1) to confirm the diagnosis and (2) to review the proposed course of treatment.⁴

You may want to obtain a second opinion for peace of mind. You may want to confirm that your diagnosis is correct and that you will be receiving the most up-to-date treatment. You may want a second opinion because your doctor is not experienced in your type of cancer. You may have read about a treatment your doctor does not know about, and may wish to pursue such a treatment.

If you decide to get a second opinion, it may be best to go to an expert who is *not* affiliated with your doctor and to a hospital that is *not* affiliated with your hospital. This is so that you can obtain an unbiased review of your individual case.

NCI-DESIGNATED CANCER CENTERS

For information about NCI-Designated Cancer Centers, call the NCI at 1-800-4-CANCER or go to: <http://cancercenters.cancer.gov>

CHOOSING A TREATMENT CENTER

Today, more than 60 cancer centers across the United States are designated by the NCI as Comprehensive Cancer Centers or Cancer Centers. A list of these centers with contact information is provided in the *Appendix*. You can get a second opinion or be treated at one of these centers. Most have patient information services that will help you.

There are many advantages to receiving treatment at a large cancer center. A center that treats a high number of patients with cancer will have more experience in every aspect of your care: diagnosis, staging, surgery, and managing side effects and complications. More experience usually means more expertise, which can improve the results of your treatment. For example, at an NCI-designated Comprehensive Cancer Center you may be able to have a type of surgery for pancreatic cancer that a small hospital may not be able to offer. (See *Section 7 on Treatment*.) Or another hospital may offer the procedure, but not many are performed there. You want a facility that treats many patients with pancreatic cancer.

A list of questions to ask when you are looking for a treatment center is given in **Box 6-2**. A list of components of quality of care is given in **Box 6-3**.

Many Americans live a manageable distance from a major cancer center. At one Comprehensive Cancer Center as many as half of patients are seen for only a single visit. Doctors at top cancer centers often can plan patients' treatments then refer them to doctors closer to home who will carry out those treatments.⁴

BOX 6-2

SOME QUESTIONS TO ASK WHEN LOOKING FOR A TREATMENT CENTER^{4,5}

- Has the facility been rated by state, consumer, or other groups for its quality of care?
- How does the facility check on and work to improve its quality of care?
- Has the facility been approved by a nationally recognized accrediting body, such as the American College of Surgeons (ACS) and/or the Joint Commission on Accreditation of Healthcare Organizations (JCAHO)?
- Does the facility explain patients' rights and responsibilities? Are copies of this information available to patients?
- Does the treatment facility offer support services to help with day-to-day obstacles such as providing assistance to obtain medical equipment and supplies, arranging transportation for treatment, or handling the emotional, psychological, or financial issues that go along with having cancer?

BOX 6-3

SOME QUALITY-OF-CARE COMPONENTS OF A CANCER TREATMENT CENTER^{4,5}

- Experience in diagnosing and treating pancreatic cancer, for example, a specialized center within a cancer facility that is dedicated to the evaluation and treatment of patients with pancreatic cancer
- Experience in managing the symptoms and side effects of pancreatic cancer
- On-site, advanced techniques and technology, such as a state-of-the-art dual-phase helical CT scanner
- An on-site laboratory
- Access to investigational treatments for pancreatic cancer, such as in clinical trials
- Services for pain management and **palliative care**

Multidisciplinary Clinics Dedicated to Pancreatic Cancer

More and more today, cancer centers are opening multidisciplinary clinics specifically dedicated to pancreatic cancer. The goal is to provide the highest quality of care. Patients who have suspected or known pancreatic cancer may receive a comprehensive evaluation that incorporates all of the resources available at these clinics for the diagnosis and treatment of pancreatic cancer. Because highly experienced pancreatic cancer clinicians and specialists are available at these clinics, the most advanced treatments are offered. These clinics also provide patients with the infrastructure, coordinated services, and team approach needed to carefully walk them through all phases of treatment.⁶

CHOOSING A TREATMENT TEAM

One doctor will be in charge of your care, but an entire team may be involved in creating and implementing your treatment plan. The team approach is a way to benefit from the expertise and experience of many people. It is called **multidisciplinary care**.³

Treatment teams for patients with pancreatic cancer may include doctors such as surgeons, medical oncologists, radiation oncologists, pathologists, endocrinologists, gastroenterologists, genetic counselors, and experts in pain management. Oncology nurses, physician's assistants, and oncology social workers also may be part of your team.

Medical oncologists are medical doctors who prescribe anticancer medications. **Radiation oncologists** specialize in treating cancer with radiation. **Endocrinologists** specialize in disorders of glands of the endocrine system. **Gastroenterologists** specialize in disorders of the digestive system.³ It is important to seek specialists who have experience in pancreatic cancer and work together to plan your treatment.

Physician's assistants are trained in an accredited program and certified by an appropriate board to perform certain duties of a physician, under the supervision of a licensed physician. Some of the duties include history-taking, physical examination, treatment, and certain minor surgical procedures. Physician's assistants and **oncology nurses** have special training in managing the treatment and care of patients with cancer. Among their duties are giving chemotherapy drugs, helping manage side effects, and providing patient education.⁷

Oncology social workers are professionally trained to counsel patients who have cancer and help provide practical assistance. These professionals can help find support groups, locate community services, and help with financial assistance.⁷

Patient Advocacy

Patient advocacy has changed with treatment advances and a greater appreciation of the daily needs of patients with cancer and their families. From diagnosis to recovery, the best cancer care requires far more expertise than any single healthcare provider can give. The person with cancer is best served by a multidisciplinary team, led by a professional team leader. All team members have the same goal: to offer services that provide the highest quality of life and extend survival.³

SECTION 7 • TREATMENT

SURGERY

Surgery to remove the tumor as a component of the treatment is the only way to cure pancreatic cancer. Surgery is performed when the surgeon believes all of the cancer can be removed. This generally applies to patients who are in the early stages of pancreatic cancer. Other types of surgical procedures may be performed in patients who are in later stages of pancreatic cancer to relieve symptoms such as pain and obstructions of the bile or pancreatic ducts or of the intestines.¹

Pancreatic surgery has improved significantly over the past two decades. Nonetheless, surgery to remove a pancreatic tumor is complex for the surgeon to perform and difficult for a patient to undergo. Recovery after surgery usually is very slow; it may take several weeks, and complications are not uncommon (**Box 7-1**). Patients need to frankly discuss the risks and benefits of this type of surgery with their doctors before making a decision.² In addition, patients need to find a surgeon and a facility with a great deal of experience in performing this procedure.³ It cannot be emphasized enough that, in patients with pancreatic cancer, operative complications are significantly fewer at high-volume surgical centers compared with low-volume centers.

BOX 7-1

SOME COMPLICATIONS OF SURGERY²

- Problems digesting different foods
- Insufficient pancreatic enzymes or hormones
- Leaking from the various connections made by the surgeon
- Infection
- Bleeding

HOW TO REDUCE YOUR SURGICAL RISKS

If you are a candidate for surgery, find a surgeon and a hospital with a great deal of experience to reduce your risks and increase your chances of a successful outcome. According to a study in the 2002 issue of *The New England Journal of Medicine*, the mortality rate for Whipple procedures for pancreatic cancer performed at low-volume centers was four times higher than at high-volume centers.³

In addition – and it cannot be emphasized enough for patients with pancreatic cancer – operative complications are significantly fewer at high-volume surgical centers than at low-volume centers.

Procedures to Remove the Tumor

Three major procedures are used to remove pancreatic tumors: a Whipple procedure (pancreaticoduodenectomy), a total pancreatectomy, and a distal pancreatectomy.

Pancreaticoduodenectomy. A **Whipple procedure**, or a **pancreaticoduodenectomy**, is the most common surgery performed to treat pancreatic cancer (*Figures 7-1A and 7-1B*). Two basic types of Whipple procedures exist. In one, the lower part of the stomach is removed. In the other more commonly used procedure, called a **pylorus-preserving Whipple procedure**, the entire stomach and first portion of the duodenum are spared. The surgeon removes the following:

- Most of the duodenum (the beginning of the small intestine)
- Head of the pancreas
- Part of the bile duct
- Gallbladder
- Lymph nodes in the area of the pancreas

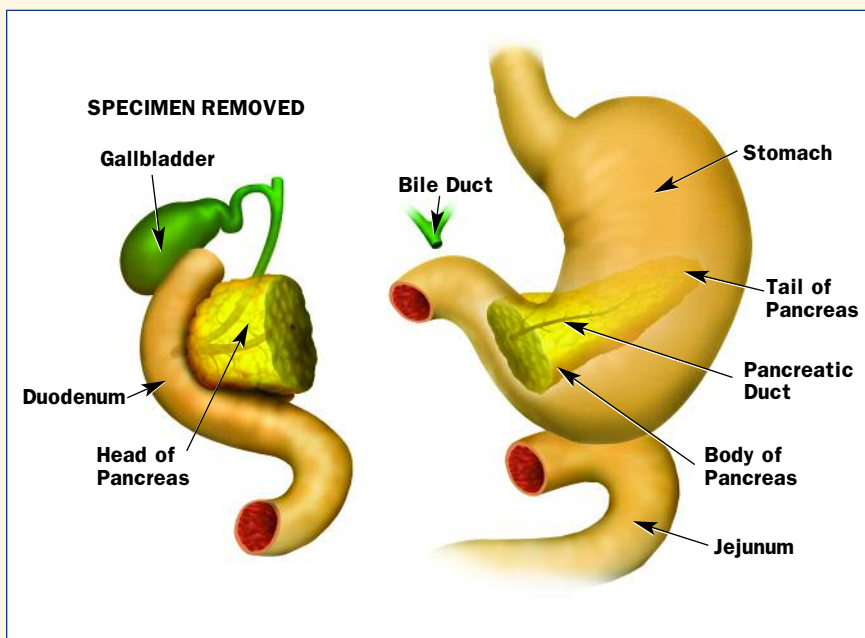


Figure 7-1A. Pylorus-preserving Whipple procedure. Most of the duodenum (beginning of the small intestine), the head of the pancreas, part of the bile duct, the gallbladder, and the lymph nodes near the pancreas are removed.

After these organs are removed, the stomach (in a standard Whipple procedure) or the remaining part of the duodenum (in a pylorus-preserving Whipple procedure), pancreas, and remaining part of the bile duct are joined to the small intestine. This allows bile and pancreatic enzymes to enter the digestive system normally and mix with ingested food.²

Total Pancreatectomy. A **total pancreatectomy** is a seldom used procedure that removes the entire pancreas and spleen. When the entire pancreas is removed the endocrine cells in it are also removed, leaving the patient with no islet cells. Because islet cells make insulin, which controls blood sugar levels in the body, removal of the entire pancreas will result in diabetes. The patient will then be dependent on insulin injections.²

Distal Pancreatectomy. In a **distal pancreatectomy**, the tail and body of the pancreas are removed, usually along with the entire spleen. Sometimes part of the body of the pancreas can be preserved.²

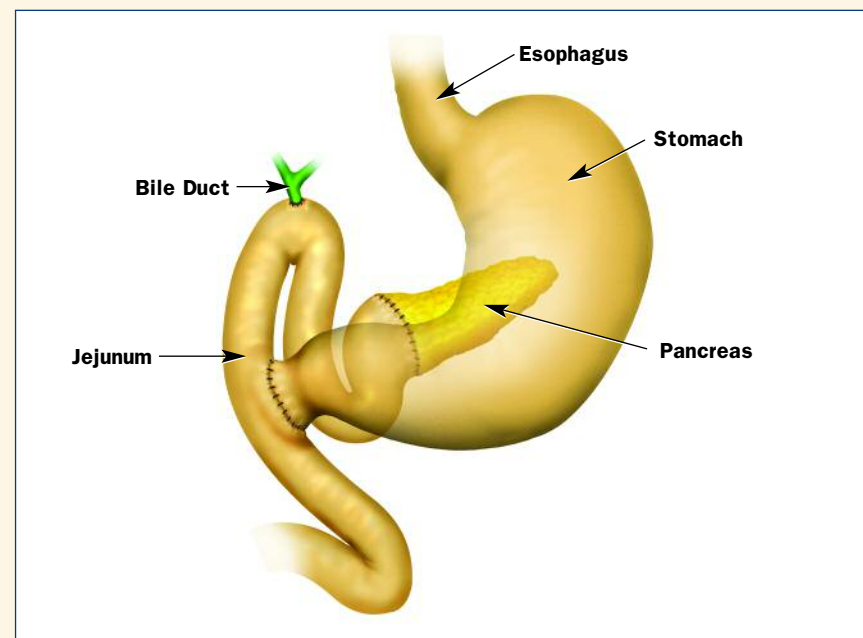


Figure 7-1B. After a pylorus-preserving Whipple procedure. The pancreas and remaining parts of the duodenum and bile duct are joined to the small intestine (**jejunum**). This allows bile and pancreatic enzymes to enter the digestive system and mix with ingested food.

Palliative Surgery

Sometimes the cancer has spread, and surgical removal of the tumor is not an option. Other surgical procedures may be used to help relieve symptoms such as jaundice, nausea, vomiting, and pain in order to improve the patient's quality of life. Surgeons can bypass blockages of the pancreatic or bile ducts or gastrointestinal tract to relieve these symptoms. Surgeons can also cut nerves or perform **nerve blocks** to reduce pain.^{2,4} (See *Section 10 on Supportive Care.*)

RADIATION THERAPY

Radiation therapy, also called **radiotherapy**, uses high-energy X-rays to shrink tumors by killing cancer cells. **External beam radiation therapy** is the type used most often to treat pancreatic cancer. A beam of radiation from outside of the body is focused on the tumor, similar to what is done

during a diagnostic X-ray only at much higher doses of radiation. To improve the results of treatment and increase survival, radiation therapy may be used before *or* after surgery. Some of the common side effects of radiotherapy are shown in **Box 7-2**.¹

BOX 7-2

SIDE EFFECTS OF RADIATION THERAPY¹

- Skin changes
- Nausea
- Vomiting
- Diarrhea
- Fatigue
- Loss of appetite
- Weight loss
- Worsening of chemotherapy side effects

Sometimes radiation therapy is combined with chemotherapy, called **chemoradiation**. This combination is often used when the cancer has spread and cannot be removed surgically.

CHEMOTHERAPY

Chemotherapy is the use of drugs to kill cancer cells. It may be given orally or by injection, or may be delivered through a **catheter**. Chemotherapy is a **systemic treatment**, meaning that the drug enters the bloodstream and travels throughout the body to reach the tumor cells. Chemotherapy may be used alone or may be combined with either radiation therapy or surgery. To improve the results of treatment and increase survival, chemotherapy may be used before *or* after surgery. When chemotherapy is used before surgery, it is called **neoadjuvant therapy**; when it is used after surgery, it is called **adjuvant therapy**.

In the past, the most common chemotherapy drug given to patients with pancreatic cancer was **single-agent** fluorouracil, or 5-FU. Other drugs (cisplatin, oxaliplatin, and taxanes) are used both alone and in combination with 5-FU. The introduction of gemcitabine (Gemzar®) has changed the treatment of pancreatic cancer. Studies show that gemcitabine is better than 5-FU for treating metastatic cancer of the pancreas.¹

Targeted therapy is designed to kill only cancer cells and not normal, healthy tissue. (See Section 13 on *Research into Pancreatic Cancer*.) Targeted therapy is being used to treat pancreatic cancer. Erlotinib (Tarceva®) targets a protein in the cancer cell that stimulates growth.¹ Erlotinib is approved by the Food and Drug Administration (FDA) when used in combination with gemcitabine for the first-line treatment of patients with pancreatic cancer that is locally advanced, is inoperable, or has metastasized.⁵

The side effects of chemotherapy depend on which drugs are given, the dose, and the length of treatment. Generally, the chances of side effects occurring increase with higher doses and the use of a combination of chemotherapy drugs. Some common side effects of chemotherapy are listed in **Box 7-3**. Most side effects disappear once treatment is stopped.

BOX 7-3

SIDE EFFECTS OF CHEMOTHERAPY

Usually not serious

- Fatigue
- Hair loss
- Loss of appetite
- Mouth sores
- Nausea
- Vomiting

Potentially serious

- Bleeding or bruising
- Low blood cell counts
- Infection

OTHER OPTIONS

In addition to standard treatments approved by the FDA for pancreatic cancer, patients should be offered the opportunity to participate in clinical trials.⁶ Many studies are investigating the use of new medications and of new combinations of standard medicines in hopes of finding better ways to treat pancreatic cancer. (See Section 9 on *Clinical Trials*.)

SECTION 8 * COMPLEMENTARY AND ALTERNATIVE MEDICINE

USE OF COMPLEMENTARY AND ALTERNATIVE METHODS

Healthcare consumers in the United States are turning to complementary and alternative medicine in record numbers, and this trend is predicted to continue to grow. The use of over-the-counter herbal remedies and vitamins is also growing. As more people are living longer, chronic illnesses, including cancer, have become more common. Sometimes conventional medicine cannot cure chronic illnesses. As a result, many patients may turn to complementary and alternative medicine in search of cures.¹

Studies show that up to 60 percent of patients who have cancer use complementary or alternative methods.² Traditional medicine may seem cold and impersonal to some patients. Part of the problem is that doctors sometimes spend little time with patients because of pressures to provide cost-effective care.³ The use of complementary or alternative methods may make patients feel that they are taking an active part in their own treatment and care, and that they have more control over their disease.

DEFINITIONS OF TERMS

Some of the terms used in complementary and alternative medicine need to be defined³:

- **Complementary therapy:** A method *added to* conventional or traditional treatments. Complementary therapy may ease the side effects of standard treatments or provide physical or mental benefits to patients with cancer; examples are meditation to relieve stress and acupuncture to relieve pain.
- **Integrative therapy:** Combined use of proven treatments and complementary therapies. Integrative therapy is becoming available in cancer centers and hospitals across the United States.
- **Alternative therapy:** A treatment that has not been tested scientifically and is used *in place of* traditional treatments.

- **Unconventional therapy:** All types of complementary and alternative treatments that fall outside of proven therapies.
- **Proven therapies:** Traditional or standard treatments that have been tested and are approved by the Food and Drug Administration (FDA).
- **Questionable therapy:** Unproven or untested treatments.
- **Quackery:** Promotion of treatments claiming to prevent, diagnose, or cure cancers that are unproven or known to be false. These methods are often based on the use of anecdotal stories or patient testimonials about their effectiveness. Unfortunately for patients with pancreatic cancer, there has been much of this form of treatment touted, particularly on the Internet.

Table 8-1. *Some Reputable Sources of Information About Complementary and Alternative Medicine*

Organization	Web Site
American Cancer Society	www.cancer.org
National Cancer Institute	www.cancer.gov
National Center for Complementary and Alternative Medicine, National Institutes of Health	http://nccam.nih.gov
National Council Against Health Fraud	www.ncahf.org
QuackWatch	www.quackwatch.org

TYPES OF COMPLEMENTARY AND ALTERNATIVE METHODS

Complementary and alternative methods can be divided into several groups^{2,3}:

- Medical systems (eg, **homeopathic** and **naturopathic** medicine)
- Mind-body-spirit methods (eg, support groups, meditation, aromatherapy, biofeedback, yoga, and prayer), which focus on the connections between the mind, body, and spirit, and their power to heal
- Dietary (eg, the macrobiotic diet) and special nutritional programs or herbal mixtures (eg, foods, herbs, vitamins, and dietary supplements)
- Manipulative and body-based methods (eg, **chiropractic**, **osteopathic** manipulation, **acupuncture**, and massage), which are based on the idea that problems in one part of the body often affect other parts of the body

- Energy therapies (eg, **biofield therapy** and **bioelectromagnetic-based therapy**)
- Pharmacological and biological treatments, in which substances produced from chemicals or concentrated from plants and other living things (eg, laetrile and shark cartilage) are used

RISKS AND BENEFITS

Some complementary methods may improve a patient's well-being by relieving pain and reducing symptoms and side effects. These methods may help patients handle stress, anxiety, and depression. Some complementary methods that have been shown to be helpful to patients with cancer include²:

- Acupuncture for pain or for nausea and vomiting from chemotherapy
- Massage therapy for anxiety or pain
- Mind-body-spirit therapies such as hypnosis, relaxation training, imagery, and music therapy

ST. JOHN'S WORT AND DRUG INTERACTIONS⁴

One herbal remedy called St. John's Wort has been shown to interact with some drugs. The herb affects the way the body processes or breaks down drugs; in some cases, it may speed or slow the breakdown. Drugs that can be affected include indinavir and possibly other drugs used to control HIV infection; irinotecan and possibly other drugs used to treat cancer; cyclosporine, which prevents the body from rejecting transplanted organs; digoxin, which strengthens heart muscle contractions; warfarin and related blood-thinning drugs; birth control pills; and antidepressants.

However, complementary and alternative therapies have *risks*. Just because a product claims to be “natural” does not necessarily mean that it is safe.⁵ Most dietary supplements, vitamins, and herbs are not approved by the FDA because they have not been tested. These products may contain contaminants, or they may interact with prescription drugs.⁶ Some products can be very potent and may have unpredictable effects.² They also may be harmful (**Box 8-1**).⁵ In general, patients with pancreatic cancer who are considering the use of complementary therapy or alternative treatments should discuss these methods with their healthcare team.

BOX 8-1

ALERTS TO POTENTIALLY HARMFUL THERAPIES⁵

- It delays conventional treatment
- It has no proven **efficacy**
- It is administered by an unlicensed practitioner
- It is not FDA-approved

CONSIDERATIONS

Acknowledging the growing public interest in complementary and alternative methods, especially among patients living with cancer, the American Cancer Society³:

- Supports the rights of individuals with cancer to decide which treatment is best for them
- Encourages people to discuss all treatments they may be considering with their doctors and other healthcare providers
- Encourages people with cancer to consider using proven, effective methods
- Encourages people with cancer to consider enrolling in clinical trials
- Encourages healthcare professionals to ask patients about their use of these treatments
- Encourages healthcare professionals to listen and communicate with patients regarding these treatments

If you are considering using complementary or alternative therapies, the ACS has some tips for frank discussions with your doctor and other healthcare providers (**Box 8-2**).

BOX 8-2

TIPS FOR PATIENTS CONSIDERING COMPLEMENTARY OR ALTERNATIVE THERAPIES³

- Educate yourself about the proven treatment and about the complementary or alternative treatment you are considering
- Let your doctor know you are thinking about using complementary or alternative treatment
- Write down a list of questions and bring any literature you want to discuss to your office visit
- If you are considering stopping conventional treatment, discuss the implications with your doctor
- If you are taking dietary supplements or herbs, provide a list for your doctor and review the list with your doctor whenever you are given a new drug or any change is made in your medications
- Continue your conversations with your doctor, and let your doctor know of any decisions you have reached

SECTION 9 • CLINICAL TRIALS

BACKGROUND

Clinical trial is the scientific term for the study of a drug, a procedure, or a medical device. Clinical trials are performed to determine if the product being tested is safe and effective for use in people. Doctors and other healthcare professionals run clinical trials according to strict rules set by the Food and Drug Administration (FDA) to ensure that study participants are treated as safely as possible.¹ There are many different types of clinical trials, which are used to find better ways to prevent, screen for, diagnose, and treat diseases, and even to improve patients' quality of life.

Clinical trials are designed to answer many different questions about cancer treatments²:

- Does this treatment work?
- If so, how does it work?
- Does it work better than other treatments available?
- Are there side effects, and what are they?
- Which patients will benefit most from this treatment?

Clinical trials are often sponsored by governmental agencies.² For example, the National Cancer Institute sponsors about two thirds of clinical trials and is studying more than 250 anticancer agents. Other agencies that sponsor or conduct clinical trials related to cancer are the National Institutes of Health, Department of Defense, and Department of Veterans Affairs. Voluntary organizations, such as the American Cancer Society, also sponsor and support clinical trials. Drug companies often join with universities and cancer centers to conduct these trials.³

CLINICAL TRIAL PHASES

Before any new cancer treatment can be tested in humans, it is studied extensively in the laboratory. Generally, these studies are done in human cells in the test tube (*in vitro*) and animals (*in vivo*) to determine which drugs are most likely to affect the cancer. If the experimental results are promising, then the FDA may approve testing in humans.³

Most clinical trials are carried out in sequential steps called **phases** (**Table 9-1**). Each phase is designed to answer specific questions and builds on information from the previous phase. In **Phase 1** trials, researchers learn about the side effects of a new drug by gradually increasing the dosage and analyzing patients' responses. Based on the results, a larger study may be conducted to evaluate the potential effectiveness of the drug.³

Phase 2 trials determine if the treatment works.² Researchers try to learn if the new drug has the potential to be better than current treatments. Tumor size is measured and recorded to determine if the new drug shrinks the tumor, and blood samples are analyzed to look for side effects of the drug and the effect of the drug on cancer markers in the blood. If enough people have a response, Phase 3 testing will proceed.

The goal of **Phase 3** trials is to determine if the treatment is better than, as good as, or not as good as the accepted standard treatment.³ In general, participants in Phase 3 trials receive the study drug as a first treatment, that is, they have had no other treatment for their cancer. Phase 3 studies provide a more thorough understanding of the effectiveness, benefits, and side effects of the drug. Phase 3 studies also typically determine if the new therapy is better than the current standard of care.

CLINICAL TRIAL PARTICIPATION

Because there are few effective treatments for patients with tumors that cannot be removed surgically and for patients who have metastatic disease,

Table 9-1. Phases of Clinical Trials in Patients with Cancer³

Study Phase	No. of Patients	Patients' Cancer Characteristics	Primary Purposes
Phase 1	Usually less than 50	Usually with advanced cancer no longer responding to conventional treatments	Safety and dosage
Phase 2	Groups of 20 to 40	Usually have had standard therapy but the cancer has recurred	Safety and effectiveness
Phase 3	Hundreds	Usually have had no prior treatment for the cancer	Determine if study drug is as good as, better than, or not as good as standard treatment

clinical trials of pancreatic cancer treatments are important. They may investigate new combinations of currently available drugs or study new drugs that have worked in other cancers. Many clinical trials are underway for patients in all stages of pancreatic cancer.

Whether to take part in a clinical trial can be a difficult decision to make. Patients must weigh the risks and benefits of the treatment.² Moreover, patients need to get enough information about the trial to make a good decision. **Box 9-2** lists questions to ask to help you make that decision. Remember that participation in a clinical trial is always voluntary.

If you enroll in a clinical trial, you need to know that you have certain rights. You have the right to be told³:

- The purpose of the clinical trial
- All risks, side effects, and discomforts that might reasonably be expected
- Any benefits that can reasonably be expected

BOX 9-1

QUESTIONS TO ASK ABOUT CLINICAL TRIALS¹⁻⁴

- What is the study goal, that is, the purpose of the research?
- What are my other options?
- How much experience do the doctor and the institution have with this treatment?
- Has the treatment been used at other cancer centers?
- If so, are the results about its safety and efficacy available?
- Is the drug already being used in another country?
- What are the known potential risks and potential benefits of the treatment?
- What exactly does the treatment consist of, and how is it carried out?
- What are the major side effects seen so far? Minor side effects?
- Who looks out for me as a study participant?
- What happens if I do not respond to this treatment?
- What happens if I respond then stop responding?
- What part of the costs am I responsible for?
- Will I need to come to this institution to receive treatment in this clinical trial? If so, how long can I expect to be here for each treatment?

- What will happen during the study and whether any procedure, drug, or device is different from that used in standard medical treatment
- Your available options and how they may be better than or worse than being in the clinical trial
- Medical treatments available if complications occur during your participation

As a participant you also can do the following³:

- Ask any questions about the clinical trial before giving your consent to participate, and at any time during the clinical trial
- Have ample time, without being pressured, to decide whether to agree to participate
- Refuse to participate before entering the trial, and leave the trial at any time after it has begun

As a participant in a clinical trial, not only will you receive excellent care, but you will be protected in various ways. The FDA requires that you be given complete information about the study before you agree to take part, which is known as **informed consent**. You will be asked to read and sign an Informed Consent Form, and will be given a copy of the signed form. This form must be written in an understandable way for the patient. Signing the form shows that you have been given this information and that you understand it. However, when you sign the Informed Consent Form you are not signing a contract. You may leave the study at any time and for any reason. In addition, informed consent is an ongoing process. You have the right to be given all pertinent information and have your questions answered at any time during your participation in the clinical trial.¹

HIGH-QUALITY CARE IN CLINICAL TRIALS¹

As a participant, you will receive high-quality, individualized care. The research team will closely monitor your treatment response, your health, and any side effects you may have. Researchers also will follow strict scientific guidelines and ethical principles to protect participants.

You are protected in a clinical trial in three additional ways: by Institutional Review Boards (IRBs), Data Monitoring Committees, and FDA inspections. People from the local community, including doctors and clergy, serve on IRBs to review and monitor their facility's medical research that involves people. They ensure that there is the least possible risk to participants, and that the risks are reasonable in relation to the expected benefits.¹

Data Monitoring Committees are mainly used when one treatment is being compared with another. These committees are particularly important in testing treatments for serious or life-threatening diseases such as cancer. Experts review information from studies to make sure they are being done in the safest way. The Committee has the power to stop a study if the treatment is harmful, or to stop a study in order to provide the treatment to all participants when one treatment works better than another.¹

The FDA inspects records, clinics, and research sites involved in clinical trials. The FDA makes sure volunteers are being protected and that the studies are being done properly.

WILL I RECEIVE A PLACEBO?

Sometimes patients think that they may receive a **placebo** (a sugar pill) in a clinical trial. Most clinical trials for cancer do not use placebos. Patients usually get either the drug under study or a drug that is considered standard treatment. However, if you have any doubts, ask.

HOW TO FIND A CLINICAL TRIAL

Interested patients should ask members of their healthcare team about clinical trials. Many lists of ongoing clinical trials are available on the Internet. Unfortunately, there is no one place to search for all available clinical trials. Several groups have matching and referral services to help patients find appropriate clinical trials. (*See the Appendix for a list of organizations you can call or web sites you can search for clinical trials.*)

SECTION 10 • SUPPORTIVE CARE

CONTROLLING SIDE EFFECTS

Some of the most common side effects of pancreatic cancer are nausea, vomiting, and pain. Supportive care provided by the healthcare team can help ease and even eliminate these problems, thus increasing the patient's quality of life. **Supportive care** in patients with cancer is the use of medications to prevent or counteract the unwanted side effects of cancer or of cancer treatments.

PAIN

Causes of Pain

Pain is the body's way of indicating to the brain that something is wrong. Pain may be acute or chronic. **Acute pain** usually is short-lived, may be the result of an injury, and subsides when the injury heals. **Chronic pain** occurs over a long period of time and ranges from mild to severe.^{1,2}

Pain from cancer may be chronic and may be caused by the tumor when it presses on organs, nerves, or bone; blocks blood or lymph vessels; or blocks a hollow organ such as the intestines. Other causes are infection, constipation, indigestion, and immobility. Cancer treatments also may cause pain.^{1,2}

PATIENTS WHO HAVE CANCER DO NOT HAVE TO SUFFER WITH PAIN^{1,2}

As a patient with cancer, you do not have to suffer with pain. In the mid-1990s, the American College of Physicians said that "Most cancer pain can be eliminated, and all cancer pain can be controlled." If your pain relief is inadequate, tell your healthcare providers.

Ways of Controlling Pain

Patients who have cancer do not have to endure pain. They are entitled to and should receive aggressive pain management. In fact, management of

chronic pain in patients who have cancer is essential. Chronic pain may limit basic activities such as dressing, eating, and walking, and even may result in anxiety and depression. Chronic pain may disrupt sleep and curb the appetite, weakening the body's immune defenses, which fight infection and disease, and interfering with healing.^{1,2}

The goals of management of pain from pancreatic cancer are to³:

- Control pain
- Prevent or minimize side effects
- Enhance quality of life

MYTHS ABOUT PAIN^{1,2}

Myth: Pain in the early stages of cancer will always get worse.

Truth: Treatment intended to eliminate or reduce the size of tumors may relieve or eliminate pain.

Myth: There is nothing that can be done about pain caused by cancer.

Truth: There are very effective treatments available to control pain. Tell your doctor if you have pain, and seek appropriate treatment.

Myth: Patients who take strong pain medications will become addicted.

Truth: The risk of addiction to the strongest of painkillers, opioids, is low. Patients with cancer who take opioids to relieve pain usually can take a high dose, can take it often, and can remain on these medications for a long time if need be.

For patients who have pain, the healthcare provider should³:

- Understand the causes of the pain
- Perform a comprehensive pain assessment
- Select the most appropriate medications and nondrug interventions
- Evaluate the response to treatment for pain

Assessment of Pain

When assessing pain, your doctor will ask lots of questions^{2,3}:

- **Onset:**
 - When did the pain begin?
 - How often does it occur?
- **Location:** Where is the pain?
- **Quality:** What does it feel like?
- **Intensity:**
 - Numerical rating scale: 0 (no pain) to 10 (worst pain)
 - Verbal descriptor scale: mild, moderate, severe
- **Aggravating and relieving factors:**
 - What makes the pain better?
 - What makes the pain worse?
- **What are the effects of your pain on you?** For example, lack of sleep, fatigue, irritability, depression

You can help your doctor assess your pain by clearly communicating what your pain feels like and by keeping a pain log (**Box 10-1**).

BOX 10-1

ASSESSING YOUR PAIN^{2,3}

To clearly communicate what your pain feels like, you can use some of these descriptive words:

- Dull, sharp, achy, sore
- Radiating, spreading
- Penetrating, piercing
- Cold, numbing; hot, burning
- Exhausting, tiring
- Beating, pounding, throbbing, pulsing

You also can keep a pain log. Keep a record of the date, time, and severity of your pain from 0 (no pain) to 10 (worst pain).

Treatment for Pain

Pain Medications. Once the doctor knows the severity of the pain, a treatment can be chosen. Most doctors use a pain treatment approach developed by the World Health Organization (WHO) called the **WHO Three-Step Analgesic Ladder** (**Table 10-1**).⁴ An **analgesic** is a medication whose primary purpose is to relieve pain.

Table 10-1. The World Health Organization Three-Step Analgesic Ladder^{1,2,4}

STEP 1	STEP 2	STEP 3
Mild Pain Nonopioid pain reliever Alone With adjuvant drug	Moderate Pain Mild opioid painkiller With or without nonopioid drug With or without adjuvant drug	Severe Pain Strong opioid painkiller With or without nonopioid drug With or without adjuvant

Mild pain may be treated with acetaminophen (Tylenol®) or a **nonsteroidal anti-inflammatory drug (NSAID)** such as ibuprofen (Motrin®, Advil®) or naproxen (Naprosyn®, Anaprox®, Aleve®). Check with your doctor before taking aspirin, because it can thin the blood and thus may not be safe for use by patients who have cancer. For pain that is not relieved by NSAIDs, more potent drugs called **opioids** are used. These drugs are the very strongest pain relievers available³ and are some of the best medicines for controlling pain. Some mild opioids are codeine, hydrocodone, and oxycodone. Some strong opioids are morphine, fentanyl, and hydromorphone.² Sometimes combinations of these drugs are used.

Opioids have different side effects than NSAIDs (**Box 10-2**). Always discuss any side effects you may have with your doctor.

Pain medications may be given in various ways. Most are taken orally, that is, by mouth, with good results. Other ways of giving pain medications are **subcutaneously** (under the skin), through the skin using a **transdermal** patch, and rectally by the use of a suppository. Sometimes pain medications are given **intravenously**, that is, they are injected directly into a vein. Sometimes they are given **intrathecally**, that is, injected directly into the spinal canal.

BOX 10-2

POSSIBLE SIDE EFFECTS OF OPIOIDS⁵

- Constipation
- Sedation
- Nausea
- Vomiting
- Difficulty breathing
- Dry mouth
- Difficulty urinating
- Rash
- Muscle tightness
- Confusion
- Problems thinking
- Problems sleeping

Another method of delivering pain medication is **patient-controlled analgesia (PCA)**. In PCA, the patient controls the amount of pain medicine that is used by pressing a button on a computerized pump connected to a small tube in the body; patients cannot use more than the prescribed amount because the device is programmed for a maximum dosage.^{2,5} PCA is commonly used after pancreatic cancer surgery in the immediate postoperative period.

Adjuvant Drugs. Adjuvant drugs, which treat a variety of problems in addition to pain, are also commonly used to enhance the effectiveness of pain medications. Adjuvant drugs often have a greater effect than either nonopioid or opioid pain medications alone. Some provide pain relief by themselves. Typical adjuvant drugs include **corticosteroids**, **anticonvulsants**, tricyclic **antidepressants**, and antianxiety medications.^{2,5}

Other Pain Control Measures. Many nondrug therapies may be useful to help control cancer pain. Doctors may advise the use of heat therapy, cold therapy, or physical therapy. Massage, hypnosis, acupuncture, coping skills, and emotional support and counseling also may be effective. These techniques, and others, may be used in conjunction with pain medications.^{3,5}

For pain that does not respond to other measures, an **alcohol nerve block** may be performed. A local anesthetic is injected into the nerve root of the **celiac plexus** using ultrasound or computed tomography guidance. This procedure is performed by an anesthesia pain specialist in an outpatient setting. The effects may last for 3 to 4 months.³ Sometimes a skilled surgeon will perform a **neuroablation** in which part of the pain nerve fibers are cut or destroyed.² Radiation therapy can be used effectively to relieve pain by shrinking tumors.³ (See Section 7 on Treatment.)

NUTRITION

Patients with pancreatic cancer may have lost weight before the diagnosis. In addition, treatments may make patients not feel like eating. Good nutrition is essential to control weight loss, maintain strength, and promote healing. A diet high in calories and protein can help keep up weight.

High-calorie foods are⁶:

- Dairy products: whole milk, butter, cheese, yogurt, and ice cream
- Honey, jellies, and jams
- Granola and dried fruit

To these, add foods with protein⁶:

- Nuts, seeds, wheat germ, and peanut butter
- Meat and fish
- Nutritional drinks such as Ensure[®]

Some, but not all, studies have suggested that fish oil supplements can be particularly helpful in maintaining body weight.⁷

NAUSEA AND VOMITING

Nausea and vomiting are common side effects of treatments for pancreatic cancer and usually stop when treatment ends.⁶ Pancreatic cancer itself also may cause nausea and vomiting, which may occur in the early stages, later stages, or not at all.

Preventing nausea will help patients get the nutrition they need. Patients should eat foods that are easy to digest; avoid fatty foods; eat small portions and frequently; avoid smells that bring on nausea; eat warm, not hot, food; rest after eating to allow the food to digest; and wear loose-fitting clothing. If nausea persists, contact your doctor because anti-nausea medications can be prescribed.⁶

Vomiting can be controlled very effectively with the use of drugs called **antiemetics**.⁶ Talk to your doctor if you experience vomiting after eating. If vomiting is severe or lasts for more than a few days, contact your doctor.

CONSTIPATION

Constipation is a condition of the digestive system where a person experiences hard stools that are difficult to eliminate. Constipation may be painful and, in severe cases, may lead to a blockage of the bowel.

For some people, it may be normal to have a bowel movement daily; for others, it may be normal to have a bowel movement only three times each week. It is important to report any changes in bowel movements from your regular routine to a member of your healthcare team.

Different things can cause constipation. It is a common side effect of pain medications (usually opioids). These medications reduce the *motility* (movement) of the intestines, making it more difficult to move the bowels and resulting in hard, dry stools.² Your doctor may recommend that you begin taking a stool softener to help prevent constipation at the time that an opioid is prescribed. Other problems associated with cancer and cancer treatments can contribute to constipation, for example, reduced activity, poor appetite, and weakness.² If you have constipation, let your healthcare team know as soon as possible.

SECTION 11 • COPING

LEARNING ABOUT COPING

Coping refers to how people or family members come to terms with an illness, make decisions, solve problems, and adapt to life's changes, while still feeling good about themselves.¹ Some factors that apply to how well you are able to cope are your emotions, whether you have a sense of control, whether you have a positive outlook, and whether you have physical and emotional support.

It is common to have a full range of difficult and mixed emotions throughout an illness. Some emotions related to being diagnosed with or having cancer are shock, disbelief, fear, anxiety, guilt, sadness, loneliness, depression, grief, and anger. These feelings may come and go. It is important to remember that these are normal reactions. Your family members and friends may have similar feelings, and similar ups and downs.^{1,2}

Working through these emotions is essential to successful coping. Because you may not be prepared for the unique stresses imposed by cancer, you may need new ways of handling your emotions, thought processes, and behaviors. Talking with other people about your feelings, writing in a journal, and finding quiet time can help you cope.¹

Feeling that you have some control over what happens to you will make things easier. A large part of dealing with cancer is making decisions. Learning about pancreatic cancer will make you better equipped to make informed decisions, and will make you understand that you do have choices. It also is important to focus on things that you can change, not on those you cannot change.¹

It may be difficult to be hopeful and have a positive outlook when you are ill and worried. However, hoping for the best possible outcome often provides the motivation to follow medical advice and take care of yourself physically, mentally, and emotionally. Living in the present can help you focus on what is meaningful and enjoyable right now, rather than on what you do not have or what you may lose. Feeling hopeless, powerless, or that you have nothing to live for can be signs of depression.¹

Sometimes no matter how hard you try, you may have negative feelings that do not go away. They may be symptoms and signs of depression or anxiety. Being depressed is different from being sad. Depression takes over your whole life and causes emotional paralysis. Your family members and friends should be alert for these symptoms (**Box 11-1**).

Depression is common in patients with pancreatic cancer. Let your healthcare team know about your symptoms. Do not suffer needlessly, because effective medications and other methods to treat depression are available.²

BOX 11-1

DO YOU HAVE DEPRESSION?^{1,2}

Emotions

- Persistent sadness or a feeling of emptiness
- Loss of interest or pleasure in usual activities
- Feeling guilty, hopeless, or worthless
- Feeling overwhelmed
- Feeling angry or irritable
- Crying a lot
- Focusing only on worries and problems
- Inability to concentrate or to make decisions
- Thoughts of death or suicide

Physical problems

- Difficulty sleeping or sleeping too much
- Feeling tired all the time
- Headaches
- Weight loss or weight gain
- Upset stomach
- Diarrhea
- Dry mouth

Seeking the support, assistance, and companionship of others is a very important aspect of coping. Addressing legal and financial matters, and planning may also help you cope.¹

DEVELOPING A SUPPORT SYSTEM

As a patient, you can reach out to family and friends for emotional support to help you cope with your cancer. Sometimes, however, family members are too emotionally involved and may not want to – or be able to – hear what you have to say. It is difficult to deal with a diagnosis of cancer in a loved one. Joining a support group may make a positive difference for you.³ Finding new friends, especially others who have cancer, may help. They know

how you feel. You can express feelings to other patients with cancer that you may not be able to express to your family members. Other patients can validate your feelings. Support groups, individual counseling, and group counseling are available. Support groups can meet in person, by phone, or on the Internet. Not only does sharing with other people help you cope, but you can benefit from the experiences of all these other people. They have a wealth of information about many aspects of cancer. They can give you ideas about how to cope. You can trade advice. Some people like to join a group and just listen.^{2,3} Conversely, you may have an opportunity to help others cope with their disease.

Remember that members of your healthcare team are also part of your support system. Contact them to discuss anything related to your cancer and how you are dealing with it. They can aid you in finding what you need to help you cope.³

ADDRESSING FINANCIAL AND LEGAL MATTERS

When dealing with a life-threatening illness you may need to put your financial matters in order. With the help of a trusted individual, you can create an organized system for managing your financial resources.⁴ Financial aid may be available from government programs, disability benefits, voluntary organizations, and living benefits from life insurance policies. Having a financial plan may reduce some of the stress in your life and help you better cope.

You also may want to get your legal matters in order, because some of these are related to your healthcare needs. A number of documents may be involved. A lawyer is not always needed, but you may need a notary public.¹

Two documents that are involved with your healthcare, called **advance directives**, are a living will and a durable power of attorney.⁵ A **living will** lets people know what kind of medical care you want if you are ever unable to speak for yourself. A **durable power of attorney for healthcare** names a person to make medical decisions for you if you cannot. This person is chosen by you and is called a **healthcare proxy**. Note that each state has its own laws about advance directives. You may want to check with a social worker or lawyer about the laws in your state.²

Two documents that are not part of advance directives are a will and power of attorney. A **will** tells how a person wants his or her money and property

distributed. **Power of attorney** appoints a person to make financial decisions when you cannot.²

Because financial and legal matters can be very complex, you may need help. (*See the Appendix for more information on where to get this kind of help.*)

ADDRESSING END-OF-LIFE CARE

Patients and their families may want to make decisions to make end-of-life care as dignified and as physically and emotionally comfortable as possible. Patients may want to finish projects, have family and friends visit, speak with those closest to them, and have a spiritual advisor visit.

Being cared for at home may make you feel more secure and more comfortable. You may want to be near your family members, friends, and familiar surroundings. Healthcare providers can help you take advantage of the many services available to allow you to be at home: access to medical equipment, visiting nurses, physical therapists, help with daily hygiene and care, meal preparation, and delivery of medications.⁶

Home healthcare professionals may allow patients to receive even complex medical care in their homes. Services range from simple injections to complete care for seriously ill patients. Access is provided to a professional who can be contacted day or night to make an assessment and relay that information to your doctor. Your overall care is supervised by your doctor, who is provided with up-to-date information on your condition.⁴

Hospice

Hospice is a concept of care that emphasizes palliative treatments rather than curative ones, quality of life rather than quantity, and comfort measures. Hospice care may be provided in the home, at a hospice facility, or in a hospital. Patients who have a limited life expectancy and who are no longer undergoing treatment for cancer may receive hospice care.

Both the patient and family members are included in the hospice care plan. Based on their needs and wishes, practical, emotional, and spiritual support may be provided. The unique goals of the hospice team are to be sensitive and responsive to the special requirements of each individual and each family. The patient is under professional medical care, with a focus on symptom relief. Trained volunteers are available to support and offer respite to family members.⁷

SECTION 12 * CARING FOR A LOVED ONE

CAREGIVING

A **caregiver** is a person who provides help with daily activities, coordinates healthcare and other services, and provides emotional and other types of support for a patient with cancer. The main caregiver is usually, but not always, a spouse, a close family member, or a close friend. There are various kinds of caregivers, and each can provide a different type of care.¹ For example, a neighbor who visits a few times a week or takes the patient out to lunch or a movie is a caregiver.

Being the main caregiver for a loved one with cancer is challenging.¹ Main caregivers sometimes put their own needs and feelings aside while practicing patience and providing emotional support in the form of understanding and encouragement. As a main caregiver, you also may be taking on new roles, including helping with daily needs such as meals and personal care and taking over tasks that formerly were your loved one's responsibilities. Doing all of these things may consume all of your emotional and physical energy.²

COPING

Dealing with cancer can be an emotional roller coaster. Caregivers also may experience a range of various feelings, just as patients do: anger, guilt, grief, hopelessness, loneliness, and depression. As a caregiver, you also can use the information in Section 11 on coping with your feelings and developing a support system.¹

The caregiver also may have very different emotions from those of the patient. As a caregiver you may feel that you must be perfect – but no one is perfect. You may feel hurt when the person you are caring for takes anger out on you. Although the anger is not about you, it is difficult not to take it personally. You need to forgive yourself and your loved one, learn from the situation, continue to do the best that you can, and go on.¹

CARING FOR YOURSELF

As a caregiver, you probably have been putting your needs last, because they do not seem important right now. After dealing with everything else, you cannot find time for yourself. You may even feel guilty about getting enjoyment from anything at all. The combined pressures of all of these new responsibilities, of having to change your habits and routines, and of the worry about what is happening or what may happen can result in burnout (*Boxes 12-1 to 12-3*).¹

Here are some ways that you can recharge yourself mentally and emotionally so that you can be a better caregiver¹:

- Stay connected with your friends and community
- Give yourself an outlet for *your* feelings: talk with a friend, spend time alone
- Join a local support group; support groups are also available by phone and online

BOX 12-1

AVOIDING BURNOUT²

Here are some ways to avoid burnout:

- Do not make all activities revolve around the disease
- Seek support from others in the same situation
- Give yourself permission for quality time alone
- Provide time for yourself to grieve for losses that illness brings
- Maintain the patient's independence by not insisting on doing everything
- Become empowered by learning about pancreatic cancer

BOX 12-2

RECOGNIZING BURNOUT³

Here are some signs of burnout:

- Exhaustion
- Inability to sleep through the night, or difficulty getting up in the morning
- Loss of interest in friends who or activities that once brought you pleasure
- Feelings of guilt about not doing enough or not wanting to do more
- Being easily irritated by people who tell you to “take care of yourself”
- You are sure that nothing good is going to happen ever again

- Participate in an Internet chat room or discussion board such as the Pancreatic Cancer Chat Room (http://pathology.jhu.edu/Pancreas_chat)
- Talk with a counselor
- Find time for relaxation: take at least 15 minutes each day to do something you find relaxing
- Do something small for yourself each day: take a moment to think of something positive, to laugh, to be thankful
- Write in a journal

Here are some ways to take care of yourself physically¹:

- Make sure to keep up with your healthcare checkups
- Take any medicines that have been prescribed for you
- Eat healthy meals
- Get sufficient rest and exercise
- Avoid the use of alcohol in an attempt to cope with stress

BOX 12-3

DEALING WITH BURNOUT³

Here are some ways to deal with burnout:

- Recognize the importance of your own health and welfare
- Do not feel guilty for thinking of yourself
- Learn to delegate responsibilities
- Insist other family members provide their fair share; they may not know they are not doing so
- Ask friends and neighbors for any help they can provide; people often are happy to be asked
- Recognize that you have limits, and forgive yourself for not being perfect
- Practice stress reduction techniques, even something as simple as relaxing in a hot bath
- Distract yourself: have a good laugh, go out to dinner, relax and unwind
- Recognize and deal with depression

STAYING CONNECTED WITH YOUR LOVED ONE

Staying connected with a loved one in a normal, healthy way may be difficult. To help stay connected, try to view this person as before. Do something fun together, or celebrate a special occasion. Cherish your loved one's

presence in the here and now. Help your loved one create a special physical space for health and healing, and make it a special place for both of you. Touch and hug your loved one.²

Thinking of your relationship with your loved one as being a “team effort” may help you stay connected, reduce stress, and improve communication. It also may help your loved one feel more in control of some situations. For example, you can discuss some of the following topics²:

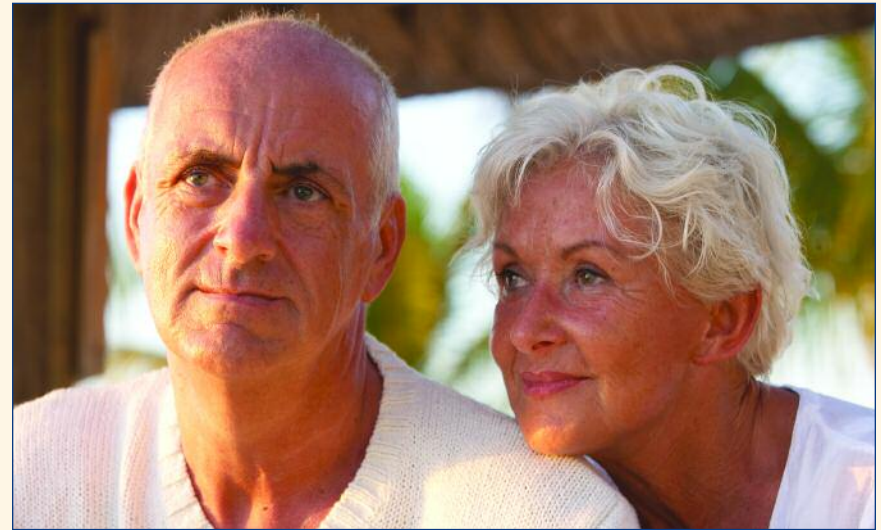
- In the past what other difficult times have we gone through together? How did we handle the problem?
- Which family and healthcare tasks do each of us prefer doing?
- Are there any tasks that we can share?
- What are the ways we can help each other?
- What activities can we do together to have fun and forget about cancer?

Talking about cancer with your loved one is an excellent way to stay connected, but it may be difficult. When talking about the disease use the same words that your loved one uses, such as “my disease” and not “pancreatic cancer.” Sometimes the best way to communicate with anyone is just to listen in a nonjudgmental way. However, there are ways of approaching a difficult topic that needs to be discussed²:

- Practice what you will say in advance
- Find a quiet time to talk
- First ask if it is OK to talk
- Explain why you want to talk
- Speak from your heart
- Allow time for your loved one to talk
- Do not feel the need to finalize everything after only one talk
- The most important thing you may be able to do is just *listen*

CAREGIVING AND THE HEALTHCARE TEAM

During the course of your loved one’s illness, you will interact with many members of the healthcare team. Make the best use of your time and their time by being prepared.²



For example²:

- Keep a file or notebook with all of the patient’s medical information, and bring it with you to all doctor appointments; it should include the following:
 - Current medications and dosages
 - Allergies
 - Test results and the dates they were performed
 - Past treatments and the dates they were given
 - The names, addresses, and phone numbers of the patient’s doctors
 - The names of the different members of your healthcare team and the roles they play
- Write down all questions you have before appointments
- Call the office ahead of time to make sure that the doctor has the results of any recent tests that have been performed
- Take notes during appointments so you can remember what was discussed
- Make sure that all of your questions are answered

SECTION 13 * RESEARCH INTO PANCREATIC CANCER

THE FOCUS IS ON PANCREATIC CANCER

Research into the causes, prevention, detection, and treatment of pancreatic cancer is ongoing in the United States, and worldwide.¹

In 2001, the National Cancer Institute (NCI) convened a committee of scientists, clinicians, and advocates to review research into pancreatic cancer and make recommendations regarding the most urgent needs and promising future directions.² The committee was named the Pancreatic Cancer Progress Review Group (PRG). As a result of the findings of the PRG, NCI funding for pancreatic cancer research projects in all identified areas increased. The areas identified were (1) health of the field and overarching issues; (2) tumor biology; (3) risk, prevention, screening, and diagnosis; (4) therapy; (5) health services research; and (6) scientific tool kit. Some of the 5-year funding results are shown in *Table 13-1*.

Table 13-1. Highlights of the National Cancer Institute Investment in Pancreatic Cancer Research²

	2000	2005	Increase
Total funding for pancreatic cancer	\$21.8 million	\$66.7 million	206%
Number of research projects	85	204	140%
Number of investigators with NCI-funded grants	34	82	141%
Number of scientific articles acknowledging NCI support	137	248	81%

Additional highlights of the meeting include funding to²:

- 3 Specialized Program of Research Excellence (SPORE) grants designed to create a flow of information from research to practice
- 129 active NCI-sponsored clinical trials relevant to pancreatic cancer

- 77 US institutions active in pancreatic cancer research
- 14 research projects that address three PRG priority areas: tumor biology; risk prevention, screening, and diagnosis; and therapy

RESEARCH INTO CAUSES

Pancreatic cancer results from changes in DNA that cause cells to become cancerous. Researchers have identified genes that may cause familial pancreatic cancer. These discoveries could lead to ways to predict which family members are at risk.³⁻⁶ For example, recent studies have found that people who have two first-degree relatives (parent, child, sibling) with pancreatic cancer have a greater risk of developing it.⁷ The higher the number of family members who have been diagnosed with pancreatic cancer, the more that risk increases. In 2007, Wang and colleagues developed and made available to genetic counselors a computer program that can be used to calculate a person's risk of developing pancreatic cancer based on family history.⁸

RESEARCH INTO DETECTION

Researchers are looking into tests to detect acquired genetic changes in pancreatic cancer. One of the most common DNA changes affects the **K-ras oncogene**, which alters the regulation of cell growth. Endoscopic ultrasonography, endoscopic retrograde cholangiopancreatography, and tests for K-ras changes are options currently being explored for people with a strong family history of pancreatic cancer.¹ (See *Section 4 on Diagnosis*.)

RESEARCH INTO TREATMENT

Research into various types of treatment are underway. Many clinical trials currently are being conducted to test new combinations of chemotherapy drugs. The best ways to combine chemotherapy with radiation therapy or other therapies are being studied.¹ New drugs that are effective in other cancers are being tested to see if they work in patients with pancreatic cancer.

One of the main areas of research into the treatment of pancreatic cancer is targeted therapies. (See *Section 7 on Treatment*.) Targeted therapies are drugs that block the growth of cancer cells by interfering with specific molecules. Instead of destroying all rapidly dividing cells, as traditional chemotherapy drugs do, targeted therapies kill only cancer cells. These treatments are being

developed and tested in clinical trials. The number of projects looking at targeted therapies has doubled in one year.² Some of the therapies being investigated include⁹:

- The *K-ras* oncogene by way of immunotherapy
- **Matrix metalloproteinases (MMPs)**
- **Epidermal growth factor receptors (EGFRs)**
- **Angiogenesis factors**

In **active immunotherapy**, which is a targeted therapy that works in the same way that vaccines work, the goal is for the immune system to recognize abnormal chemicals present in pancreatic cancer cells. For example, the *K-ras* protein is altered in more than 90 percent of pancreatic cancers. Researchers are testing ways to help the immune system attack cells that contain altered *K-ras* protein.

In **passive immunotherapy**, another targeted therapy, man-made antibodies to proteins are injected into patients. The goal is to have these antibodies seek out pancreatic cancer cells that contain abnormal *K-ras* protein or other abnormal proteins such as carcinoembryonic antigen, or CEA. The antibodies have radioactive atoms or toxins attached to destroy the abnormal protein.

Matrix metalloproteinase (MMP) inhibitors are a new class of drugs under study. Cancer cells make enzymes that dissolve the surrounding substance and allow cancer cells to spread. MMP inhibitors work by blocking these enzymes.

Epidermal growth factor receptors (EGFRs) are molecules on the surface of cancer cells that may stimulate the growth of many types of cancers, including pancreatic cancer. Researchers are studying different drugs that block these and other receptors.

Angiogenesis factors are blood vessel growth factors. To block the growth of new vessels that tumors depend on, and thereby starve the tumor of nourishment, anti-angiogenesis drugs have been developed. These drugs are being studied in clinical trials.

In 2007 results of another exciting avenue in pancreatic cancer research were reported. Researchers at the University of Michigan Comprehensive

Cancer Center identified cancer stem cells in pancreatic tumors. **Cancer stem cells** are believed to replicate to drive tumor growth. Current cancer treatments do not attack these cells. By identifying cancer stem cells, researchers may be able to develop drugs to target and kill them. This is a radically different approach compared with current treatments, which shrink tumors by killing as many cells as possible, including healthy cells. Stem cells also have been identified in breast, brain, central nervous system, and colon cancers, and in leukemia.¹⁰

This extensive research and these new developments offer hope for the thousands of people who will be diagnosed with pancreatic cancer.²

THE LUSTGARTEN FOUNDATION FOR PANCREATIC CANCER RESEARCH

The **Lustgarten Foundation for Pancreatic Cancer Research** is the nation's largest private supporter of pancreatic cancer research. Encouraged by the remarkable potential of genomics for the future of pancreatic cancer research and treatment, in 2007 The Lustgarten Foundation initiated a multi-million dollar project to sequence the genome of pancreatic cancers. It is anticipated that this endeavor will revolutionize the ways in which pancreatic cancer is diagnosed and treated for decades to come.

World-class investigator Bert Vogelstein, MD, and his team of collaborators at The Sidney Kimmel Comprehensive Cancer Center of The Johns Hopkins University Medical Institutions, including Kenneth W. Kinzler, PhD, Victor E. Velculescu, MD, and Scott E. Kern, MD, have been selected for the project. Dr. Vogelstein and his team have developed novel technologies that enable rapid analysis of the different genomes of cancers. The team completed the first sequencing of the breast and colorectal cancer genomes, identifying a treasure trove of genes whose involvement in those cancers was not previously known.

For more information about research and the latest in pancreatic cancer, visit <http://www.lustgarten.org>.

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GLOSSARY

Abdomen – The belly; the part of the body that contains all of the structures between the chest and pelvis.

Acinar cells – Special cells in the *pancreas* that produce digestive *enzymes*.

Acquired mutations – Genetic changes that develop during a person's lifetime, either as a random error made in *DNA* copying or as a result of harmful environmental factors.

Active immunotherapy – Activation of specialized immune cells to recognize and destroy abnormal chemicals in tumor cells.

Acupuncture – Practice of inserting needles through the skin into specific points on the body to reduce pain or induce anesthesia.

Acute pain – Sudden, short-lived pain that subsides when healing occurs.

Adenocarcinoma – Cancer that begins with cells that line certain internal organs and have gland-like properties.

Adjuvant drug – A drug that when added to another drug speeds or improves its effect.

Adjuvant therapy – A treatment given after surgery.

Advance directives – Documents involved in a patient's healthcare that allow others to know which types of care that patient wants and does not want, or to determine who will make medical decisions if the patient cannot do so.

Alcohol nerve block – Procedure in which a local anesthetic is injected into the nerve root of the *celiac plexus* using guidance by *ultrasonography* or *computed tomography* to produce numbness or reduce pain.

Alternative therapy – Treatments that have not been scientifically tested used in place of traditional therapies. (*See also Unconventional Therapy.*)

Ampulla of Vater – Enlargement of the *ducts* from the liver and *pancreas* at the point where they enter the small intestine; *bile* from the liver and secretions from the

pancreas come through the Ampulla of Vater to mix with food in the *duodenum* and aid digestion.

Analgesic – A drug that reduces pain: acetaminophen, ibuprofen, and aspirin are analgesics.

Angiogenesis – Formation of new blood vessels; some cancer treatments work by blocking angiogenesis, called anti-angiogenesis, with the goal of slowing or preventing tumor growth.

Anticonvulsants – Drugs used to prevent or treat seizures; they may also be used to enhance the effect of pain medications.

Antidepressants – Drugs used to treat depression; they may also be used to enhance the effect of pain medications.

Antiemetics – Drugs that help to prevent and control nausea and vomiting.

Benign – Not cancerous; benign tumors do not spread to tissues near them or to other parts of the body.

Bile – Fluid made by the liver and stored in the *gallbladder*; bile is excreted into the small intestine, where it helps digest fat.

Bile duct – A tube in the liver through which *bile* passes.

Bilirubin – Dark-green substance formed when red blood cells are broken down; bilirubin is part of the *bile*; the abnormal buildup of bilirubin because of an obstruction causes *jaundice*.

Bioelectromagnetic-based therapy – Involves the use of pulsed energy or magnetic fields to change the body's electromagnetic fields, and treat illness.

Biofield therapy – Various forms of energy work to assist in healing.

Biopsy – Process of removing tissue samples, which are then examined under a microscope to check for disease.

Biopsy specimen – Tissue removed from the body and examined under a microscope to determine whether disease is present.

BRCA1 gene – A *gene* that normally helps to suppress cell growth; a person who inherits an altered version of this gene has a higher risk of getting breast, ovarian, or prostate cancer, and possibly pancreatic cancer.

BRCA2 gene – A *gene* that normally helps to suppress cell growth; a person who inherits an altered version of this gene has a higher risk of getting breast, ovarian, prostate, or pancreatic cancer.

Brush biopsy – A procedure used with *endoscopic retrograde cholangiopancreatography (ERCP)*; a small brush is inserted through an *endoscope* and into the *bile duct* and *pancreatic duct* to scrape the inside of the ducts to collect cells for examination.

Cancer – Any of a group of diseases in which the cells are abnormal, grow out of control, and can spread.

Cancer antigen 19-9 (CA 19-9) – A *protein* on the surface of certain types of cells that is shed by tumor cells into the bloodstream; higher than normal amounts of CA 19-9 in the blood can sometimes be a sign of colorectal or pancreatic cancer.

Cancer stem cells – Subpopulation of cancer cells believed to be responsible for starting and maintaining the cancer.

Carcinoembryonic antigen (CEA) – A *protein* that may sometimes be found in the blood of people who have certain types of cancers, and not usually found in healthy persons.

Caregivers – Persons who provide help with daily activities, coordinate healthcare and other services, and provide emotional and other types of support for patients.

Catheter – A flexible tube used to deliver fluids into or withdraw fluids out of the body.

Celiac plexus – Complex network of nerves in the abdomen.

Chemoradiation – *Radiation therapy* used in combination with *chemotherapy*.

Chemotherapy – Use of drugs to kill cancer cells.

Chiropractic – A health profession concerned with the diagnosis, treatment, and prevention of mechanical disorders of the muscles and bones, and the effects of these disorders on the function of the nervous system and general health; it emphasizes manual treatments, including spinal manipulation.

Chronic pain – Pain that occurs over a long period of time that may range from mild to severe.

Chronic pancreatitis – Condition in which inflammation irreversibly damages the *pancreas*; or chronic damage with persistent pain or malabsorption.

Clinical trial – The study of a drug, procedure, or medical device to determine its safety and effectiveness in people; there are many types of clinical trials used to find better ways to prevent, screen for, diagnose, and treat disease, and to improve quality of life. (*See also Phases.*)

Co-existing condition – Occurring at the same time but independent of another condition or illness.

Contrast agent – A dye or other compound injected into the body to make specific tissues more visible during diagnostic imaging.

Complementary therapy – Treatment methods added to conventional or traditional therapy.

Computed tomography (CT) scan – Medical imaging test in which a scanner takes detailed, cross-sectional, X-ray images from many different angles that are combined by a computer.

Constipation – A condition of the digestive system where a person experiences hard stools that are difficult to eliminate; constipation may be painful and, in severe cases, may lead to a blockage of the bowel.

Coping – How people or family members come to terms with an illness, make decisions, solve problems, and adapt to life's changes, while still feeling good about themselves.

Corticosteroids – Drugs that reduce swelling and inflammation.

Diabetes mellitus – Disease in which the body does not properly control the amount of sugar in the blood, resulting in high levels; it occurs when the body does not produce enough *insulin* or does not use it properly.

Distal pancreatectomy – Surgical procedure in which the tail and body of the *pancreas* are removed, usually along with the entire *spleen*; sometimes part of the body of the pancreas can be preserved.

DNA – Deoxyribonucleic acid; DNA is the molecule in the cell nucleus that carries the instructions for making living organisms.

Dual-phase helical CT scan – Imaging test for evaluating patients suspected of having pancreatic cancer; this type of *computed tomography scan* can detect about 98% of pancreatic cancers.

Duct – A channel leading from an *exocrine gland* or organ.

Duodenum – The first part of the small intestine that connects to the stomach.

Durable power of attorney for healthcare – The legal designation of a person responsible to make medical decisions for a patient when that patient cannot do so.

Efficacy – Effectiveness; the power to produce a desired result.

Endocrine gland – A gland that secretes its hormone directly into the bloodstream that flows through it, rather than through an opening; endocrine tissue comprises 5 percent of the *pancreas*.

Endocrinologist – A physician who specializes in disorders of glands of the endocrine system.

Endoscope – Thin, tube-like instrument used to look at tissues inside the body; an endoscope has a light and a lens for viewing and may have a tool to remove tissue.

Endoscopic retrograde cholangiopancreatography (ERCP) – Minimally invasive procedure during which a thin, lighted tube

is passed down the throat, through the stomach and small intestine, and into the *bile duct* and *pancreatic duct* to view them for obstruction and to take X-rays.

Endoscopic ultrasonography (EUS) – Procedure in which an *endoscope* is inserted down the throat and into the stomach and *duodenum*; a probe at the end of the endoscope is used to bounce high-energy sound waves off internal organs to make images.

Enzymes – *Proteins* that speed up chemical reactions in the body and that the body produces naturally; enzymes help the body with functions such as digesting food.

Epidermal growth factor receptor (EGFR) – Molecule of a cell receptor that binds epidermal growth factor to aid in cell growth and proliferation.

Esophagus – The tube that connects the throat with the stomach; the esophagus lies between the *trachea* (windpipe) and the spine; it passes down the neck, pierces the diaphragm, and joins the upper end of the stomach.

Exocrine gland – A gland that secretes its fluid through a duct; exocrine tissue comprises 95 percent of the *pancreas*.

External beam radiation therapy – Treatment for cancer in which a beam of high-dose radiation is focused on the tumor from outside of the body.

Familial atypical multiple mole melanoma (FAMMM) syndrome – Genetic syndrome in which many different-sized, asymmetrical, raised moles are present; may be associated with *melanoma* or pancreatic cancer.

Familial breast cancer syndrome – People who have the breast cancer gene *BRCA2* mutation have an increased risk of several cancers, among them pancreatic cancer.

Fine-needle aspiration (FNA) biopsy – Technique in which a thin needle is inserted into a tumor; cells are removed and examined under a microscope.

First-degree relative – Parents, children, or siblings of an individual.

Gallbladder – Pear-shaped organ located under the liver in which *bile* is concentrated and stored.

Gastroenterologist – A physician who specializes in disorders of the digestive system.

Gene – The functional and physical unit of heredity passed from parent to child; most genes contain the information for making a specific *protein*; genes are composed of *DNA*.

Healthcare proxy – A person chosen by the patient to make medical decisions for that patient.

Hepatitis – Inflammation of the liver.

Hereditary nonpolyposis colon cancer (HNPCC; Lynch syndrome) – Syndrome in which there is a higher than normal chance of developing colon, pancreatic, uterine, stomach, or ovarian cancer.

Hereditary pancreatitis – Rare disease in which patients develop episodes of recurrent *pancreatitis* at an early age.

Homeopathic medicine – System of medicine based on the premise that “like cures like”; practitioners believe that a substance that produces a set of *symptoms* in a healthy person will, in small doses, cure those symptoms in a person with a disease.

Hospice – Concept of care that emphasizes *palliative care* rather than cures, quality of life over quantity, and comfort measures for patients provided at home, at a hospice facility, or in a hospital.

Ileum – Lowest part of the small intestine, located beyond the *duodenum* and *jejunum*, just before the *large intestine* (the colon).

Imaging tests – Methods used to produce pictures of internal body structures; for example, X-ray films, *ultrasonography*, *computed tomography (CT) scans*, and *magnetic resonance imaging (MRI)*.

Informed consent – Process in which a person is given important facts, such as the risks and benefits, about a medical procedure or treatment or a *clinical trial* before deciding whether to participate.

Inherited mutations – *DNA* mutations carried in a person’s reproductive cells and potentially passed on to that person’s children.

Insulin – A hormone made by islet cells of the *pancreas* that controls the amount of sugar in the blood by moving it into the cells, where it can be used for energy.

Integrative therapy – Combined use of a proven treatment and a *complementary therapy*.

Intraductal papillary mucinous neoplasm (IPMN) – A tumor of the *pancreas* that produces mucus that clogs and enlarges the pancreatic duct; IPMNs may progress to invasive pancreatic cancer if left untreated.

Intrathecal injection – Injection into the space surrounding the spinal cord.

Intravenous injection – Injection directly into a vein.

Islets of Langerhans – Collections of cells in the *pancreas* that produce *insulin* and glucagon, important regulators of sugar metabolism.

Jaundice – Condition in which the skin and the whites of the eyes become yellow, urine may become dark, and stool may become clay-colored; occurs when the liver is not working properly or a *bile duct* is blocked.

Jejunum – Portion of the small intestine that extends from the *duodenum* to the *ileum*.

K-ras oncogene – A *gene* capable of causing cancer when altered; drugs that block its activity may stop cancer growth.

Laparoscope – Small telescope-like instrument connected to a video monitor.

Laparoscopic ultrasonography – Procedure that uses a *laparoscope*, inserted through the abdominal wall, and is guided by *ultrasonography*.

Laparoscopy – Procedure during which a *laparoscope* is inserted through a small incision in the abdomen by which the internal organs can be viewed and tissue samples removed for examination.

Living will – One of several documents called *advance directives* that designate what

kind of medical care a patient wants, or does not want, in the event the patient cannot speak for himself or herself.

Lymph nodes – Small, bean-shaped structures in the neck, underarm, groin, chest, abdomen, pelvis, near the *pancreas*, and throughout the body; they store white blood cells.

Lymphatic fluid – Fluid that circulates through the lymph vessels and empties into blood vessels in the upper chest.

Lymphatic system – The body’s complex set of *lymph nodes*, lymph cells, and lymph vessels that fight infection and disease.

Lymphocyte – A type of white blood cell that helps fight infection and disease.

Magnetic resonance cholangiopancreatography (MRCP) – Imaging method that is safe and fast; a form of *magnetic resonance imaging (MRI)* used to view the *bile duct* and *pancreatic duct*.

Magnetic resonance imaging (MRI) – Imaging method that uses powerful magnets to view internal organs and structures; the energy from the magnets is absorbed by the body and released; a computer translates the energy patterns into detailed images of areas inside the body.

Malignant – Cancerous; malignant tumors can invade and destroy nearby tissues and spread to other parts of the body.

Matrix metalloproteinase (MMP) – Family of *enzymes* from the group called proteinases, which may be a good target for fighting cancer.

Medical oncologist – A physician who is trained to prescribe anticancer medications.

Melanoma – Serious form of skin cancer that begins in *melanocytes* (cells that make the pigment *melanin*).

Metastatic – Cancer that has spread to distant parts of the body from the original tumor site.

Multidisciplinary care – Team approach to the care of patients with cancer in which physicians in many different areas of

specialization join to provide their expertise and experience.

Multi-detector row helical CT (MDCT) scan – Helical CT scanner with multiple detector rows; advantages over other CT scanners include improved image resolution and rapid scanning of large volumes.

Multiple endocrine neoplasia type 1 syndrome (MEN1; Wermer’s syndrome) – A rare, inherited disorder that affects the *endocrine glands* and can cause tumors in the *pancreas* and other organs, which usually are not cancerous.

Mutations – Errors that occur in the process of cell replication and division; certain mutations may lead to cancer or other diseases. (See also *Inherited Mutations and Acquired Mutations*.)

Naturopathic medicine – Practitioners work with patients to provide nutritional and lifestyle counseling using dietary supplements, medicinal plants, and traditional Chinese medicine.

Neoadjuvant therapy – A treatment given before surgery.

Neoplasm – New growth; a tumor that may be *benign* or *malignant*.

Nerve block – Procedure in which a local anesthetic is injected around a nerve to produce numbness or pain reduction.

Neuroablation – Cutting or destroying part of pain fibers to help control pain.

Nonsteroidal anti-inflammatory drugs (NSAIDs) – Drugs that reduce inflammation and pain.

Oncology nurses – Nurses with specialized training in managing the treatment and care of patients with cancer; they may administer *chemotherapy* drugs, help in management of side effects, and provide patient education.

Oncology social workers – Social workers professionally trained to counsel patients with cancer and help provide practical assistance, for example, by helping patients find support groups and locate services.

Opioids – Strongest pain relievers available.

Osteopathic – Form of conventional medicine that emphasizes diseases arising in the musculoskeletal system.

Palliative care – Healthcare that specializes in the relief of suffering and improvement in quality of life.

Palliative surgery – Any noncurative surgical procedure that may be used in patients with pancreatic cancer to help relieve *symptoms* such as *jaundice*, nausea, vomiting, and pain to improve quality of life.

Pancreas – An organ of the digestive system located deep in the abdomen that produces *pancreatic enzymes* to aid in the digestion of food and hormones such as *insulin*.

Pancreatic duct – Main *duct* that runs along the entire length of the *pancreas* and merges with the *bile duct*.

Pancreatic enzymes – *Proteins* produced by the *pancreas* to aid in the digestion of food.

Pancreatic intraepithelial neoplasia (PanIN) – Lesions too small to see with the naked eye that can progress to invasive pancreatic cancer over time.

Pancreaticoduodenectomy – (See *Whipple procedure*.)

Pancreatitis – Inflammation of the *pancreas*.

Passive immunotherapy – Man-made antibodies to *proteins* used to seek out cancer cells that contain abnormal proteins; these antibodies have *radioactive* atoms or toxins attached to destroy the abnormal proteins.

Pathologist – A physician trained to examine cells under a microscope for the diagnosis of cancer and other diseases.

Patient-controlled analgesia (PCA) – Method of pain relief, commonly used after pancreatic surgery in the immediate post-operative period, in which the patient controls the amount of pain medication by pressing a button on a computerized pump connected to a small tube in the body; patients cannot use more than the prescribed amount because the device is programmed for a maximum dosage.

Peritoneum – Membrane that lines the abdominal cavity and covers most of the abdominal organs.

Peutz-Jeghers syndrome (PJS) – Genetic disorder in which polyps form in the intestine and dark spots appear on the mouth and fingers, and that increases the risk of developing many types of cancer, including pancreatic cancer.

Phases of clinical trials – Sequential steps of *clinical trials* designed to answer specific questions and build on information from the previous phase.

Phase 1 – Determines the side effects of a new drug by gradually increasing the dosage and analyzing patients' responses.

Phase 2 – Determines if the new drug has the potential to be better than current treatments. **Phase 3** – Determines if the treatment is better than, as good as, or not as good as the accepted standard treatment.

Physician's assistant – Trained professional who has completed an accredited program and is board-certified to perform certain duties of a physician, under the supervision of a licensed physician; some duties include history-taking, physical examination, and minor surgical procedures.

Placebo – A substance that has no active ingredient.

Positron emission tomography (PET scan) – Imaging test in which a small amount of *radioactive glucose* is injected into a vein, a camera detects the *radioactivity*, and a computer generates detailed images; because cancer cells absorb much more glucose than normal cells, images created by a PET scan can be used to find cancer cells in the *pancreas* and other parts of the body.

Power of attorney – Legal document that appoints a person to make financial decisions for the patient when the patient cannot.

Protein – A molecule made up of amino acids needed for the body to function properly; proteins are the basis of body structures such as the skin and hair, and of substances such as *enzymes*.

Proven therapy – A conventional, traditional, or standard treatment that has been tested and is approved by the Food and Drug Administration.

Pylorus-preserving Whipple procedure – Surgical procedure in patients with pancreatic cancer that removes most of the *duodenum*, the head of the *pancreas*, part of the *bile duct*, the *gallbladder*, and *lymph nodes* in the area of the *pancreas*; in this procedure, the stomach is spared.

Quackery – Promotion of treatments known to be false but that claim to prevent, diagnose, or cure cancer.

Questionable therapy – Unproven or untested treatments.

Radiation oncologist – A physician trained in treating cancer with high-dose X-rays.

Radiation therapy – Also called *radiotherapy*; treatment of cancer with irradiation.

Radioactive – Giving off radiation.

Radioactive glucose – Sugar injected into the body to make specific tissues more visible during a *PET scan*.

Radiologist – A physician trained to interpret many different imaging techniques.

Radiotherapy – Also called *radiation therapy*; treatment of cancer with irradiation.

Risk factors – Characteristics, habits, or environmental exposures shown to increase the odds of developing a disease.

Signs – Any objective evidence of a disease, that is, evidence perceptible to the examining physician. (See also *Symptoms*.)

Single-agent drug – A drug that is used as the only treatment.

Spleen – An organ located on the left side of the *abdomen* near the stomach that is part of the *lymphatic system*; it produces white blood cells, filters the blood, stores blood cells, and destroys old blood cells.

Staging cancer – A standardized way to classify a tumor based on its size, whether it has spread, and where it has spread; staging measures the extent of the disease.

Stent – Device placed in a body structure (such as the *pancreatic duct*) to keep it open.

Subcutaneous – Under the skin.

Supportive care – In patients with cancer, use of medications to prevent or counteract unwanted side effects of cancer or its treatment to increase quality of life.

Symptoms – Subjective sensations of the patient. (See also *Signs*.)

Systemic treatment – In cancer, a treatment in which a drug enters and travels throughout the body to reach tumor cells.

Targeted therapy – Treatment designed to kill only cancer cells and not healthy cells.

TNM system – A system used to evaluate cancer; T stands for tumor, N for node, and M for metastasis.

Total pancreatectomy – Procedure now seldom used to remove the entire *pancreas* and *spleen* in patients with pancreatic cancer.

Transdermal – Through the skin.

Tumor markers – Substances, usually *proteins*, produced by a cancer or by the body's response to the presence of cancer that can be detected in the blood.

Ultrasonography – Also called a *sonogram*, *ultrasonogram*, and *ultrasound scan*; imaging method that bounces sound waves off internal organs to produce echoes; a computer creates patterns from these echoes that can determine whether tissue is normal or abnormal.

Unconventional therapy – Term used to cover all types of complementary and alternative treatments that fall outside of proven therapies. (See also *Alternative Therapy*.)

Whipple procedure – Surgical procedure in patients with pancreatic cancer that removes part of the stomach, the *duodenum*, the head of the *pancreas*, part of the *bile duct*, the *gallbladder*, and *lymph nodes* in the area of the pancreas.

Will – Legal document that describes how a person wants his or her money and property divided after death.

APPENDIX

Information and Support Services

ORGANIZATIONS AND RESOURCES SPECIFIC TO PANCREATIC CANCER

The Lustgarten Foundation for Pancreatic Cancer Research

1111 Stewart Avenue, Bethpage, NY 11714
Phone: 516-803-2304

Toll-free Phone: 1-866-789-1000

Fax: 516-803-2303

www.lustgarten.org

The Lustgarten Foundation for Pancreatic Cancer Research is dedicated to advancing the science related to the diagnosis, treatment, prevention, and cure of pancreatic cancer.

The Foundation concentrates on stimulating the scientific and medical communities to conduct the research necessary to find a cure. The Foundation provides patient education services and support, a clinical trial matching service, and public awareness activities.

Hirshberg Foundation for Pancreatic Cancer Research

2990 S. Sepulveda Boulevard, Suite 300C
Los Angeles, CA 90064

Phone: 310-473-5121

Fax: 310-473-5107

www.pancreatic.org

Among its goals are to find a cure for pancreatic cancer, establish a premier Pancreatic Cancer Center for basic and clinical research for early detection and a cure, support patients with pancreatic cancer and their families, and create public awareness about pancreatic cancer.

The National Pancreas Foundation (NPF)

364 Boylston Street, 4th Floor

Boston, MA 02116

Phone: 617-578-0382

Toll-free Phone: 1-866-726-2737

www.pancreasfoundation.org

Supports research into pancreatic diseases and provides information and assistance to people with these illnesses.

Pancreatic Cancer Action Network (PanCAN)

2141 Rosecrans Avenue, Suite 7000

El Segundo, CA 90245

Phone: 310-725-0025

Toll-free Phone: 1-877-2-PANCAN

(1-877-272-6226)

Fax: 310-725-0029

Email: info@pancan.org

www.pancan.org

Works to focus national attention on the need to find a cure for pancreatic cancer and provides public and professional education to encourage more research, effective treatments, prevention programs, and early detection methods.

Pancreatic Cancer Alliance

www.pancreaticalliance.org

Supports the efforts of the medical and research communities as well as patients and their loved ones in the battle against pancreatic cancer.

Pancreatica.org

149 Bonifacio Place, Monterey, CA 93940

Toll-free Phone: 1-800-525-3777

www.pancreatica.org

One of its goals is to present impartial knowledge about pancreatic cancer where interested parties can sort through a large amount of information efficiently to find out about existing treatment options and help optimize personal treatment strategies.

Sol Goldman Pancreatic Cancer

Research Center

Johns Hopkins Medicine

<http://pathology.jhu.edu/pancreas>

Developed by The Johns Hopkins Medical Institutions, the Center provides a great deal of information about pancreatic cancer, including details about genetic testing and news on Hopkins research findings. This web site contains technical areas for healthcare providers, links to other pancreatic cancer sites, and many sections for patients, including a very active chat room.

www.Pancreas.org

A service of the University of Pittsburgh, www.Pancreas.org provides information on

diseases and resources related to the pancreas as well as names of physicians and scientists who specialize in pancreatic cancer.

GENERAL CANCER INFORMATION SERVICES

American Cancer Society (ACS) National Office

250 Williams Street

Atlanta, GA 30303

Toll-free Phone: 1-800-ACS-2345

(1-800-227-2345)

www.cancer.org

The ACS has many national and local programs to help people who have cancer with travel, lodging, and emotional support. The ACS offers a 24-hour support line for English- and Spanish-speaking patients.

CancerCare, Inc.

275 Seventh Avenue, Floor 22

New York, NY 10001

Toll-free Phone: 1-800-813-HOPE

(1-800-813-4673)

Email: info@cancercare.org

www.cancercare.org

A nonprofit organization that offers free education and support programs to help patients and their families understand and deal with their diagnosis, treatment, quality-of-life concerns, and other important issues. CancerCare offers Telephone Education Workshops, one-hour conference calls presented by experts from around the country, and free telephone support groups for both patients and caregivers.

National Cancer Institute (NCI)

Bethesda, MD 20892

Toll-free Phone: 1-800-4-CANCER

(1-800-422-6237)

www.cancer.gov

A division of the National Institutes of Health, the NCI has an enormous web site. It contains numerous statements, booklets, and books about cancer treatment and care; and a hotline number to help patients with various issues, such as physician referrals. To learn about the newest treatments available, call and ask for the PDQ® (Physicians Data

Query® www.cancer.gov/cancetopics/pdq) summary for pancreatic cancer. These free fact sheets explain the disease, state-of-the-art treatments, and ongoing clinical trials. Two versions are available: one for patients that uses simple language and contains no statistics; and one for healthcare professionals that is technical, thorough, and includes citations to the scientific literature.

The National Coalition for Cancer Survivorship (NCCS)

1010 Wayne Avenue, Suite 770

Silver Spring, MD 20910

Phone: 301-650-9127

Toll-free Phone: 877-NCCS-YES

(877-622-7937)

Fax: 301-565-9670

Email: info@canceradvocacy.org

www.canceradvocacy.org

Provides information on cancer support, employment, financial and legal issues, and advocacy.

OncoLink

Abramson Cancer Center of the University of Pennsylvania

3400 Spruce Street, 2 Donner

Philadelphia, PA 19104-4283

<http://oncolink.org>

Provides free, accurate, up-to-date, comprehensive information about specific types of cancers, treatments, symptom management, psychosocial support and personal experiences, responses to frequently asked questions, and news about research advances.

ONLINE SUPPORT GROUPS

Free email or chat rooms on the Internet that discuss topics specific to pancreatic cancer.

ACOR (Association of Cancer Online Resources)

www.acor.org

The Johns Hopkins Pancreas Cancer Discussion Page

Unmoderated Discussion Forum

www.pathology.jhu.edu/pancreas_chat

LiveHelp

LiveHelp provides live online assistance (from the National Cancer Institute).
<https://cissecure.nci.nih.gov/livehelp/welcome.asp>

Vital Options® International TeleSupport® Cancer Network

www.vitaloptions.org

A not-for-profit cancer communications, support, and advocacy organization whose mission is to facilitate a global cancer dialogue by using communications technology to reach every person touched by cancer.

The Group Room

Toll-free Phone: 1-800-GRP-ROOM
(1-800-477-7666)

www.vitaloptions.org

The nation's only call-in cancer talk-radio show. Listen over the radio or the web.

OTHER ONLINE RESOURCES

CancerGuide

www.cancerguide.org

Created by Steve Dunn to share his personal experience and clearly explain cancer types and staging, treatments, and pathology reports. The pros and cons of researching your own cancer are addressed.

CancerLinks

www.cancerlinks.org/pancreas.html

Provides information in several languages about pancreatic cancer, pain, and other topics.

CancerNet Database

<http://www.meb.unibonn.de/Cancernet/cancernet.html>

Sponsored by the National Cancer Institute, it provides information on cancer treatments, clinical trials, genetics, coping, support, resources, and more.

Medline Plus Health Information

www.nlm.nih.gov/medlineplus/pancreaticcancer.html

Provides a wealth of knowledge from the National Library of Medicine written at the patient level.

PubMed

www.ncbi.nlm.nih.gov/pubmed

Free search service of the National Library of Medicine that provides access to the clinical studies on MEDLINE and other related databases. In addition to brief abstracts from technical journals, PubMed offers frequently asked questions, news, and clinical alerts.

Quackwatch

www.quackwatch.org

A nonprofit organization dedicated to combating health-related frauds, myths, fads, and fallacies. Offers an entire Cancer Quackery section for patients.

TRAVEL AND HOUSING SERVICES

The Air Care Alliance

Toll-free Phone: 1-888-260-9707

Fax: 815-572-9192

Email: inquiries@aircareall.org

www.aircareall.org

A nationwide association of humanitarian flying organizations founded in 1990. Members have safely flown 24,000 patients to and from medical treatments.

Corporate Angel Network, Inc. (CAN®)

Westchester County Airport

One Loop Road

White Plains, NY 10604-1215

Phone: 914-328-1313

Toll-free Patient Line: 1-866-328-1313

Fax: 914-328-3938

Email: info@corpangelnetwork.org

www.corpangelnetwork.org

A nationwide, nonprofit program designed to give patients with cancer the use of available seats on corporate aircraft to get to and from recognized cancer treatment centers. There are no costs or financial need requirements, and patients may travel as often as needed.

National Association of Hospital

Hospitality Houses Incorporated

(NAHHH Inc.)

PO Box 18087, Asheville, NC 28814-0087

Phone: 828-253-1188

Toll-free Phone: 1-800-542-9730

Fax: 828-253-8082

www.nahhh.org

A nonprofit corporation that serves facilities that provide lodging and supportive services to patients and families when confronted with medical emergencies. Each facility ensures a homelike environment to persons who must travel to be with a patient or to receive necessary outpatient care.

National Patient Travel Center

4620 Haygood Road, Suite 1

Virginia Beach, VA 23455

Toll-free Phone: 1-800-296-1217

www.patienttravel.org

Provides information about all forms of charitable, long-distance medical air transport.

INSURANCE AND FINANCIAL ISSUES

Loyola Law School, Los Angeles

Cancer Legal Resource Center

919 Albany Street

Los Angeles, CA 90019-0015

Phone: 213-736-1455

Toll-free Assistance Hotline:

1-866-THE-CLRC

(1-866-843-2572)

Email: clrc@lls.edu

www.lls.edu/academics/candp/clrc.html

Provides free, confidential information and resources on cancer-related legal issues to patients, families, friends, employers, healthcare professionals, and others. The Center, a joint program of Loyola Law School and the Disability Rights Legal Center, provides training for support groups, caregivers, healthcare professionals, hospitals, cancer organizations, and others. Callers can also be matched with volunteer attorneys and other professionals for additional legal information.

National Association of Community

Health Centers, Inc.®

7200 Wisconsin Avenue, Suite 210

Bethesda, MD 20814

Phone: 301-347-0400

Fax: 301-347-0459

Email: contact@nachc.com

www.nachc.com

National Cancer Institute's Cancer Information Service™

Toll-free Phone: 1-800-4-CANCER

(1-800-422-6237)

<http://cis.nci.nih.gov>

National Hospice and Palliative Care Organization (NHPCO)

1700 Diagonal Road, Suite 625

Alexandria, VA 22314

Phone: 703-837-1500

Toll-free Phone: 1-800-658-8898

Fax: 703-837-1233

Email: nhpco_info@nhpco.org

www.nho.org

NeedyMeds

120 Western Avenue

Westchester, MA 01930

www.needymeds.com

Patient Advocate Foundation (PAF)

700 Thimble Shoals Boulevard, Suite 200

Newport News, VA 23606

Toll-free Phone: 1-800-532-5274

Fax: 757-873-8999

www.patientadvocate.org

A national, nonprofit organization that seeks to safeguard patients through effective mediation, ensuring access to care, maintenance of employment, and preservation of financial stability. Case managers assist patients in accessing legal resources, managed care consultants, and national financial resources regarding denial of insurance coverage, employment discrimination, public assistance programs, and related issues.

Pharmaceutical Research and Manufacturers of America (PhRMA)

950 F Street, NW, Washington, DC 20004

Phone: 202-835-3400

Fax: 202-835-3414

www.phrma.org

Government Agencies

Department of Veterans Affairs

Toll-free Phone for VA Benefits:

1-800-827-1000

Toll-free Phone for Healthcare Benefits:

1-877-222-8387

www.va.gov

Medicare
Toll-free Phone: 1-800-MEDICARE
(1-800-633-4227)
www.medicare.gov
Social Security Administration
Toll-free Phone: 1-800-772-1213
www.ssa.gov

CLINICAL TRIAL SEARCH SERVICES
Many clinical trials are currently being conducted on pancreatic cancer. In addition to therapies, clinical trials examine supportive measures to assist patients. Patients can search for a clinical trial that matches their needs by contacting the following organizations.

American Cancer Society
Toll-free Phone: 1-800-303-5691
www.cancer.org

CenterWatch Clinical Trials Listing Service™
Phone: 617-856-5900
www.centerwatch.com

Coalition of Cancer Cooperative Groups
Toll-free Phone: 1-877-520-4457
www.cancertrialshelp.org

eCancerTrials
A free, confidential cancer clinical trials matching and referral service provided by leading cancer information specialists at CancerConsultants.com.
www.ecancertrials.com

The Lustgarten Foundation Clinical Trials Matching and Referral Service (With EmergingMed)
Toll-free Phone: 1-800-535-1867
www.lustgarten.org

National Cancer Institute Clinical Trials
Toll-free Phone: 1-800-4-CANCER
(1-800-422-6237)
www.cancer.gov/clinicaltrials

National Institutes of Health
www.clinicaltrials.gov

Pancreatica
Toll-free Phone: 1-800-525-3777
www.pancreatica.org

Pharmaceutical Research and Manufacturers of America (PhRMA)
www.phrma.org

FAMILIAL REGISTRIES
Familial registries are powerful resources to gain a better understanding of pancreatic cancer. The following registries are set up to identify families in which multiple members have been diagnosed with pancreatic cancer. Researchers search for genes that may be the cause of pancreatic cancer. It is hoped that early detection methods and novel treatments will result from these efforts.

CAPS (Cancer of the Pancreas Screening Consortium)
Created by Dr. Marcia Canto and jointly supported by The Lustgarten Foundation and the National Cancer Institute (NCI), CAPS is a national, multicenter collaboration of medical centers with interest in pancreatic cancer, including centers receiving NCI-funded SPORE (Specialized Programs of Research Excellence) grants and cancer registries. The goal of CAPS is to allow screening to become more readily available by enabling patients to be identified using specific criteria.

The Johns Hopkins Medical Institutions
Principal Investigator: Mimi Canto, MD
Nurse Coordinator: Hilary Cosby, RN, CGRN
Phone: 410-502-2893
Email: hcosby1@jhmi.edu
<http://pathology.jhu.edu/pancreas>

PACGENE (Pancreatic Cancer Genetic Epidemiology) Consortium
A multidisciplinary consortium of cancer institutions working to identify susceptibility genes in high-risk familial pancreatic cancer pedigrees, and serve as a resource for genetic epidemiologic studies of pancreatic cancer. The Consortium is screening patients with pancreatic cancer and identifying those with a family history of the disease, and is recruiting

patients and relatives for genetic and epidemiologic studies.

PACGENE Consortium Sites
Dana-Farber Cancer Institute, MA
Phone: 617-632-4788
The Johns Hopkins School of Medicine, MD
Phone: 410-955-3502
Email: pancreas@jhmi.edu
Mayo Clinic, MN
Phone: 507-538-0364 (Collect calls accepted)

The University of Texas MD Anderson Cancer Center, TX
Phone: 713-745-2489
Toll-free Phone: 1-800-248-4856
University of Toronto Mt. Sinai Medical Center, Ontario, Canada
Phone: 416-586-5119

Wayne State University, MI
Barbara Ann Karmanos Cancer Institute
Phone: 313-833-0715, ext 2007

Additional Registries
Columbia University Medical Center Department of Surgery Familial Registry
To learn more about the Center's risk stratification program for you or a family member contact:
Dr. Harold Frucht
Phone: 212-305-1021
Memorial Sloan-Kettering Cancer Center Familial Pancreatic Cancer Registry
For more information or to see if you are eligible for this study, contact:
Dr. Robert C. Kurtz, Principal Investigator
Phone: 212-639-7620 or
Jennifer Simon, Research Assistant
Phone: 646-735-8194

University of Washington Division of Gastroenterology Familial Pancreatic Cancer & Surveillance
If you have a strong family history of pancreatic cancer and are interested in surveillance for this disease:
Phone: 206-685-2847
Email: pancanresearch@medicine.washington.edu

NATIONAL CANCER INSTITUTE–DESIGNATED CANCER CENTERS
The National Cancer Institute's Cancer Center Program coordinates broad-based interdisciplinary programs in cancer research. These cancer centers are dedicated to the advancement of cancer research. The NCI recognizes two types of centers: **Cancer Centers (*)** and **Comprehensive Cancer Centers (**)**. Each type of center has special characteristics and capabilities for organizing new programs of research that can take advantage of important new findings and address timely research questions. It is important to note, however, that the terms Comprehensive Cancer Center and Cancer Center do not denote a difference in the quality of care provided to patients.
<http://cancercenters.cancer.gov>

ALABAMA
****University of Alabama at Birmingham Comprehensive Cancer Center**
1824 Sixth Avenue South, Room 237
Birmingham, AL 35293-3300
Phone: 205-934-5077
Fax: 205-975-7428

ARIZONA
****Arizona Cancer Center**
University of Arizona
1515 North Campbell Avenue
PO Box 245024
Tucson, AZ 85724
Phone: 520-626-7685
Fax: 520-626-6898

CALIFORNIA
****City of Hope National Medical Center Beckman Research Institute**
1500 East Duarte Road
Duarte, CA 91010-3000
Phone: 626-256-HOPE
(626-256-4673)
Fax: 626-930-5394

***Salk Institute Cancer Center**
Salk Institute
10010 North Torrey Pines Road
La Jolla, CA 92037

Phone: 858-453-4100, ext 1386
Fax: 858-457-4765

***The Burnham Institute**
10901 North Torrey Pines Road
La Jolla, CA 92037
Phone: 858-646-3100
Fax: 858-713-6274

****Rebecca and John Moores UCSD
Cancer Center**
University of California, San Diego
3855 Health Sciences Drive, Room 2247
La Jolla, CA 92093-0658
Phone: 858-822-1222
Fax: 858-822-1207

****Jonsson Comprehensive Cancer Center**
University of California Los Angeles
Factor Building, Room 8-684
10833 Le Conte Avenue
Los Angeles, CA 90095-1781
Phone: 310-825-5268
Fax: 310-206-5553

****University of Southern California
Norris Comprehensive Cancer Center**
1441 Eastlake Avenue, NOR 8302L
Los Angeles, CA 90089-9181
Phone: 323-865-0816
Fax: 323-865-0102

****Chao Family Comprehensive
Cancer Center**
University of California at Irvine
101 The City Drive
Building 56, Rt. 81, Room 216L
Orange, CA 92868
Phone: 714-456-6310
Fax: 714-456-2240

***Stanford Cancer Center**
Stanford University
800 Welch Road, Room 284
Stanford, CA 94305-5796
Phone: 650-736-1808
Fax: 650-736-0607

***UC Davis Cancer Center**
University of California, Davis
4501 X Street, Suite 3003
Sacramento, CA 95817
Phone: 916-734-5800
Fax: 916-451-4464

****UCSF Comprehensive Cancer Center
and Cancer Research Institute**
University of California San Francisco
2340 Sutter Street, Box 0128
San Francisco, CA 94115-0128
Phone: 415-502-1710
Fax: 415-502-1712

COLORADO

****University of Colorado Cancer Center**
University of Colorado at Denver and
Health Sciences Center
PO Box 6508, Mail Stop F434
13001 E. 17th Place
Aurora, CO 80045
Phone: 303-724-3155
Fax: 303-724-3162

CONNECTICUT

****Yale Cancer Center**
Yale University School of Medicine
333 Cedar Street, Box 208028
New Haven, CT 06520-8028
Phone: 203-785-4371
Fax: 203-785-4116

DISTRICT OF COLUMBIA

****Lombardi Comprehensive Cancer Center
at Georgetown University**
3970 Reservoir Road, NW
Research Building, Suite E501
Washington, DC 20057
Phone: 202-687-2110
Fax: 202-687-6402

FLORIDA

****H. Lee Moffitt Cancer Center &
Research Institute**
University of South Florida
12902 Magnolia Drive, MCC-CEO
Tampa, FL 33612-9497
Phone: 813-615-4261
Fax: 813-615-4258

HAWAII

***Cancer Research Center of Hawaii**
University of Hawaii at Manoa
1236 Lauhala Street
Honolulu, HI 96813
Phone: 808-586-3013
Fax: 808-586-3052

ILLINOIS

***University of Chicago Cancer Research
Center**
5841 South Maryland Avenue, MC 2115
Chicago, IL 60637-1470
Phone: 773-702-6180
Fax: 773-702-9311

****Robert H. Lurie Comprehensive
Cancer Center**
Northwestern University
303 E. Superior Street, Suite 3-125
Chicago, IL 60611
Phone: 312-908-5250
Fax: 312-908-1372

INDIANA

***Indiana University Melvin and Bren
Simon Cancer Center**
Indiana Cancer Pavilion
535 Barnhill Drive, Room 455
Indianapolis, IN 46202-5289
Phone: 317-278-0070
Fax: 317-278-0074

***Purdue University Cancer Center**
Hansen Life Sciences Research Building
South University Street
West Lafayette, IN 47907-1524
Phone: 765-494-9129
Fax: 765-494-9193

IOWA

****Holden Comprehensive Cancer Center**
The University of Iowa
5970 "Z" JPP
200 Hawkins Drive
Iowa City, IA 52242
Phone: 319-353-8620
Fax: 319-353-8988

MAINE

***The Jackson Laboratory Cancer Center**
600 Main Street
Bar Harbor, ME 04609-0800
Phone: 207-288-6041
Fax: 207-288-6044

MARYLAND

****Sidney Kimmel Comprehensive
Cancer Center**

The Johns Hopkins University
401 North Broadway
The Weinberg Building, Suite 1100
Baltimore, MD 21231
Phone: 410-955-8822
Fax: 410-955-6787

MASSACHUSETTS

****Dana-Farber/Harvard Cancer Center**
Dana-Farber Cancer Institute
44 Binney Street, Room 1628
Boston, MA 02115
Phone: 617-632-2100
Toll-free Phone: 1-877-420-3951
Fax: 617-632-4452

***MIT Center for Cancer Research**
Massachusetts Institute of Technology
77 Massachusetts Avenue, Room E17-110
Cambridge, MA 02139-4307
Phone: 617-253-8511
Fax: 617-253-0262

MICHIGAN

****University of Michigan Comprehensive
Cancer Center**
University of Michigan
6302 Cancer Center
1500 East Medical Center Drive
Ann Arbor, MI 48109-0942
Phone: 734-936-1831
Fax: 734-615-3947

****The Barbara Ann Karmanos
Cancer Institute**
Wayne State University School of Medicine
4100 John R
Detroit, MI 48201
Phone: 1-800-KARMANOS
(1-800-527-6266)
Fax: 313-576-8630

MINNESOTA

****University of Minnesota Cancer Center**
MMC 806
420 Delaware Street, SE
Minneapolis, MN 55455
Phone: 612-624-8484
Toll-free Phone: 1-888-226-2376
Fax: 612-626-3069

****Mayo Clinic Cancer Center**
Mayo Clinic Rochester
200 First Street, SW
Rochester, MN 55905
Phone: 507-266-4997
Fax: 507-284-1544

MISSOURI

****Siteman Cancer Center**
Washington University School of Medicine
660 South Euclid Avenue
Campus Box 8109
St. Louis, MO 63110
Phone: 314-362-8020
Fax: 314-454-1898

NEBRASKA

***University of Nebraska Medical Center/Eppley Cancer Center**
600 South 42nd Street
Omaha, NE 68198-6805
Phone: 402-559-4238
Fax: 402-559-4652

NEW HAMPSHIRE

****Norris Cotton Cancer Center**
Dartmouth-Hitchcock Medical Center
One Medical Center Drive
Hinman Box 7920
Lebanon, NH 03756-0001
Phone: 603-653-9000
Fax: 603-653-9003

NEW JERSEY

****The Cancer Institute of New Jersey**
Robert Wood Johnson Medical School
195 Little Albany Street
New Brunswick, NJ 08903-2681
Phone: 732-235-8064
Fax: 732-235-8094

NEW MEXICO

***University of New Mexico Cancer Research and Treatment Center**
1 University of New Mexico
2325 Camino de Salud
MSC 08 4630
Albuquerque, NM 87131
Phone: 505-272-5622
Fax: 505-272-4039

NEW YORK

***Albert Einstein Cancer Research Center**
Albert Einstein College of Medicine
Chanin Building, Room 209
1300 Morris Park Avenue
Bronx, NY 10461
Phone: 718-430-2302
Fax: 718-430-8550

****Roswell Park Cancer Institute**
Elm and Carlton Streets
Buffalo, NY 14263-0001
Phone: 716-845-5772
Fax: 716-845-8261

***Cold Spring Harbor Laboratory**
PO Box 100
Cold Spring Harbor, NY 11724
Phone: 516-367-8383
Fax: 516-367-8879

***New York University Cancer Institute**
New York University Medical Center
550 First Avenue
New York, NY 10016
Phone: 212-263-6485
Fax: 212-263-8210

****Memorial Sloan-Kettering Cancer Center**
1275 York Avenue
New York, NY 10021
Phone: 212-639-2000
Toll-free Phone: 1-800-525-2225
Fax: 212-717-3299

****Herbert Irving Comprehensive Cancer Center**
College of Physicians & Surgeons
Columbia University
1130 St. Nicholas Avenue, Room 508
New York, NY 10032
Phone: 212-851-5273
Fax: 212-851-5236

NORTH CAROLINA

****UNC Lineberger Comprehensive Cancer Center**
University of North Carolina at Chapel Hill
102 Mason Farm Road, CB 7295
Chapel Hill, NC 27599-7295
Phone: 919-966-3036
Fax: 919-966-3015

****Duke Comprehensive Cancer Center**
Duke University Medical Center
Box 2714
Durham, NC 27710
Phone: 919-684-5613
Fax: 919-684-5653

****Wake Forest Comprehensive Cancer Center**
Wake Forest University
Medical Center Boulevard
Winston-Salem, NC 27157-1082
Phone: 336-716-7971
Fax: 336-716-0293

OHIO

****Case Comprehensive Cancer Center**
Case Western Reserve University
11100 Euclid Avenue, Wearn 151
Cleveland, OH 44106-5065
Phone: 216-844-8562
Fax: 216-844-4975

****Comprehensive Cancer Center**
The Ohio State University
A458 Staring Loving Hall
320 West 10th Avenue
Columbus, OH 43210
Phone: 614-293-7521
Fax: 614-293-7522

OREGON

***Oregon Health and Science University Cancer Institute**
3181 S.W. Sam Jackson Park Road
CR145
Portland, OR 97239-3098
Phone: 503-494-1617
Fax: 503-494-7086

PENNSYLVANIA

****Abramson Cancer Center**
University of Pennsylvania
16th Floor Penn Tower
3400 Spruce Street
Philadelphia, PA 19104-4283
Phone: 215-662-6065
Fax: 215-349-5325

***The Wistar Institute**
3601 Spruce Street
Philadelphia, PA 19104-4268
Phone: 215-898-3926
Fax: 215-573-2097

****Fox Chase Cancer Center**
333 Cottman Avenue
Philadelphia, PA 19111
Phone: 215-728-3636
Fax: 215-728-2571

***Kimmel Cancer Center**
Thomas Jefferson University
233 South 10th Street
BLSB, Room 1050
Philadelphia, PA 19107-5799
Phone: 215-503-4645
Fax: 215-923-3528

****University of Pittsburgh Cancer Institute**
UPMC Cancer Pavilion
5150 Centre Avenue, Suite 500
Pittsburgh, PA 15232
Phone: 412-623-3205
Fax: 412-623-3210

TENNESSEE

***St. Jude Children's Research Hospital**
332 North Lauderdale
Memphis, TN 38105-2794
Phone: 901-495-3982
Fax: 901-495-3966

****Vanderbilt-Ingram Cancer Center**
Vanderbilt University
691 Preston Research Building
Nashville, TN 37232-6838
Phone: 615-936-1782
Fax: 615-936-1790

TEXAS

***Dan L. Duncan Cancer Center**
Baylor College of Medicine
One Baylor Plaza
Mail Stop: BCM305
Houston, TX 77030
Phone: 713-798-1354
Fax: 713-798-2716

****MD Anderson Cancer Center**
The University of Texas
1515 Holcombe Boulevard, Box 91
Houston, TX 77030
Phone: 713-792-2121
Fax: 713-799-2210

*San Antonio Cancer Institute
University of Texas Health Science Center
2040 Babcock Road, Suite 201
San Antonio, TX 78229
Phone: 210-562-5286
Fax: 210-562-5292

UTAH

*Huntsman Cancer Institute
University of Utah
2000 Circle of Hope
Salt Lake City, UT 84112-5550
Phone: 801-581-4485
Fax: 801-581-2175

VERMONT

**Vermont Cancer Center
University of Vermont
89 Beaumont Avenue, Given E213
Burlington, VT 05405-0110
Phone: 802-656-4414
Fax: 802-656-8788

VIRGINIA

*University of Virginia Cancer Center
University of Virginia, Health Sciences
Center
MSB West Complex
Jefferson Park Avenue, Room 6171E
Charlottesville, VA 22908
Phone: 434-243-6784
Fax: 434-982-0918

*Massey Cancer Center
Virginia Commonwealth University
PO Box 980037
Richmond, VA 23298-0037
Phone: 804-828-0450
Fax: 804-828-8453

WASHINGTON

**Fred Hutchinson/University of
Washington Cancer Consortium
Fred Hutchinson Cancer Research Center
PO Box 19024, D1-060
Seattle, WA 98109-1024
Phone: 206-667-4305
Fax: 206-667-5268

WISCONSIN

**University of Wisconsin Paul P. Carbone
Comprehensive Cancer Center
600 Highland Avenue, Room K4/610
Madison, WI 53792-0001
Phone: 608-263-8610
Fax: 608-263-8613

QUESTIONS TO ASK YOUR DOCTOR AFTER DIAGNOSIS

Asking good questions will help you get the best care possible for pancreatic cancer. You have a right to have all questions answered to your satisfaction. Tear off this sheet, and bring it with you to your next doctor's appointment.

1. What type of pancreatic cancer do I have, and what is the stage?

2. Should I have any additional tests to more accurately stage my cancer?

3. What is the treatment that you recommend?

4. What are the potential benefits, risks, and side effects of that treatment?

5. Where will the treatment be given, and how often?

6. How will I know if the treatment is working?

7. Are clinical trials available for my type and stage of pancreatic cancer?

8. Do I have to make a decision right now, or can I take time to get a second opinion?

9. If surgery is recommended, is the center that will perform my surgery a high-volume one?

QUESTIONS TO ASK YOUR DOCTOR ABOUT SURGERY

The amount of expertise your surgeon has may add months or years to your life. In fact, an experienced surgeon may operate on pancreatic tumors that less experienced surgeons might declare inoperable.

Here are some questions for you to ask your surgeon. You have the right to have all questions answered to your satisfaction. Tear off this sheet, and bring it with you to your next doctor's appointment.

1. Why will I have this surgery?

2. What are the risks and benefits of this surgery?

3. How many pancreatic surgical procedures have you done, and how often do you do them?

4. How many pancreatic surgical procedures are done at this hospital, and how often?

5. How long will the surgery take?

6. How long will I be in the hospital?

7. What are all of the complications that can occur?

8. Do I have to make a decision right now, or can I take time to get a second opinion?

9. How much time do I have to think about other options, or to get a second opinion?
