

Navigating Pancreatic Cancer

A Guide for
Patients &
Caregivers

LUSTGARTEN
FOUNDATION®
PANCREATIC CANCER RESEARCH

Our Focused Mission

Our mission is to advance the scientific and medical research related to the diagnosis, treatment, cure and prevention of pancreatic cancer by:

Increasing funding and support of research into the biological mechanisms and clinical strategies related to diagnosis, treatment and prevention

Facilitating and enhancing the dialogue among members of the medical and scientific communities about basic and clinical research efforts

Heightening public awareness of pancreatic cancer diagnosis, treatment and prevention and providing informational support for patients, their families and friends.

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Published by Lustgarten Foundation.

Editorial support (updating content, assembling tables and figures, collating reviewer comments, copyediting, fact checking, and referencing) and graphic services were provided by AOIC, LLC, and were funded by Lustgarten Foundation.

Printed in the USA.

This guide 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 publication 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.

This guide is supported in part by an educational grant from Celgene and support from Ipsen Biopharmaceuticals. Neither had control over its content. Lustgarten Foundation does not release any personally identifiable information to any grant providers.



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Special Thanks

We would like to thank our talented team of medical advisors, without whose generous gifts of time and expertise this handbook would not be possible.



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Patricia Gambino, MSN, RN, received both her undergraduate and graduate degrees from the University of Pennsylvania School of Nursing. She has worked at Penn Medicine's Abramson Cancer Center for 20 years as a gastrointestinal nurse navigator, specializing in navigating pancreatic cancer patients during the trajectory of their care. Many times, Trish is the first point of contact once the diagnosis is confirmed. She is passionate about providing much hope and support during this extremely emotional time for patients and their families. Additionally, Trish has been asked to lecture to professional organizations, bringing awareness of treatment options for patients diagnosed with this disease. Trish has advocated on Capitol Hill for more funding for pancreatic cancer research and is constantly leading efforts in the community to raise money and awareness regarding pancreas cancer. She also served as a faculty speaker at the American Society of Clinical Oncology's (ASCO) Advantage Programs, dealing with pancreatic cancer, and is currently an active member of the Philadelphia chapter of the Oncology Nursing Society, having served on their board in various capacities. Additionally, Trish is a member of the Academy of Oncology Nurse & Patient Navigators.



Ralph H. Hruban, MD, is Professor of Pathology and Oncology, and Director of the Sol Goldman Pancreatic Cancer Research Center at the Johns Hopkins University School of Medicine in Baltimore, Maryland. Dr. Hruban attended the Johns Hopkins University School of Medicine and did a residency in Anatomic Pathology at Hopkins, followed by a

fellowship in Surgical Pathology at Memorial Sloan Kettering in New York. Dr. Hruban then returned to Johns Hopkins where he rose through the ranks. He is now the Baxley Professor and Director of the Department of Pathology, and the Director of the Sol Goldman Pancreatic Cancer Research Center. Dr. Hruban has devoted his academic career to the study of tumors of the pancreas. He has made significant contributions to our understanding of the genetic drivers of all types of pancreas tumors—ductal, acinar, cystic, and neuroendocrine—and he helped translate these genetic discoveries to patient care. His work on Pancreatic Intraepithelial Neoplasia (PanIN) and Intraductal Papillary Mucinous Neoplasms (IPMNs), the precursor lesions that give rise to invasive pancreas cancer, has led to new approaches to the early detection of pancreatic neoplasia. Dr. Hruban founded the National Familial Pancreas Tumor Registry (NFPT), and helped define the clustering of pancreatic cancer in families as well as discover new familial pancreatic cancer genes (*PALB2* and *ATM*). These discoveries now guide genetic counseling. Dr. Hruban has published over 750 scientific papers and authored or coauthored seven books, including the American Registry of Pathology's fascicle *Tumors of the Pancreas* and the World Health Organization's "blue book" on tumors of the digestive tract. In 2013 he was inducted into the German National Academy of Sciences Leopoldina. Selected awards include the Ramzi Cotran Award from the United States and Canadian Academy of Pathology; the Arthur Purdy Stout Prize from the Arthur Purdy Stout Society; the Fred Stewart Award; the Frank H. Netter Award for Special Contributions to Medical Education; the Ruth Leff Siegel Award for Excellence in Pancreatic Cancer Research; the Johns Hopkins University Distinguished Alumni Award; and five teaching awards from the School of Medicine, including the Educational Innovation Award. He received the Team Science Award from the American Association for Cancer Research in 2013 and in 2017. Dr. Hruban was appointed to the Board of Directors of the United States and Canadian Academy of Pathology in 2017.



Brian Wolpin, MD, MPH, is a Medical Oncologist and Translational Scientist at Dana-Farber Cancer Institute (DFCI) and Harvard Medical School. Dr. Wolpin is the Director of the Gastrointestinal Cancer Center and Director of the Hale Center for Pancreatic Cancer Research at DFCI and an Associate Professor of Medicine at Harvard Medical School. He is also the

Director of the Lustgarten Laboratory at DFCI. He obtained his MD from Harvard Medical School and completed a residency in internal medicine at Brigham and Women's Hospital. He completed fellowship training in medical oncology at DFCI and returned to Brigham and Women's Hospital to serve as Chief Medical Resident. Subsequently, he received an MPH from Harvard School of Public Health. His research program is focused on understanding the factors that promote initiation and progression of pancreatic ductal adenocarcinoma to identify new screening tests and therapeutic approaches. These studies involve evaluation of blood-based circulating markers, germline alterations, and somatic alterations in hundreds to thousands of subjects. He also serves as Chair of the NCI Pancreatic Cancer Detection Consortium Steering Committee, coprincipal Investigator for the Pancreatic Cancer Cohort Consortium, Vice-Chair of the NCI Pancreas Task Force, and codirector of the Pancreas and Biliary Tumor Center at Dana-Farber/Brigham and Women's Cancer Center. His research has been funded by the National Cancer Institute (NCI), Howard Hughes Medical Institute, Lustgarten Foundation, ASCO's Conquer Cancer Foundation, Pancreatic Cancer Action Network, Stand Up To Cancer, and US Department of Defense. Dr. Wolpin's clinical practice involves the care of patients with gastrointestinal cancers, with a focus on pancreatic cancer. He holds multiple leadership positions related to clinical expertise, including membership on the Alliance/CALGB Gastrointestinal Cancer Committee, NCCN Guidelines Committee for Pancreatic Adenocarcinoma, and NCI Pancreas Task Force.

About This Guide

Thank you for taking the time to read *Navigating Pancreatic Cancer: A Guide for Patients & Caregivers*, your resource and roadmap for navigating through pancreatic cancer. This guide focuses on pancreatic ductal adenocarcinoma (PDAC), the most common type of pancreatic cancer, which is thought to arise in the pancreatic ducts. Part 1 addresses your immediate needs—ranging from treatment to clinical trials to coping and support. Part 2 offers you background information about the disease and its causes, symptoms, and diagnosis.

We hope this guide will empower you to ask bold questions, seek out cutting-edge treatments, and face the unique challenges of pancreatic cancer head-on, armed with all of the knowledge you need to make informed decisions that are best for you.

At Lustgarten, we are making progress in our fight against pancreatic cancer. Our commitment to you has never been stronger, and we will continue to fund research until a cure is found.

Visit lustgarten.org for updates on our research and ways to get involved.

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PART 1: Navigating Pancreatic Cancer

This section addresses your immediate needs—ranging from treatment and clinical trials to coping and support—when you or a loved one is faced with a pancreatic cancer diagnosis.

Note: The terms in bold, and their definitions, can be found in the glossary at the end of this book.

1.1 – Checklist for Newly Diagnosed Patients

As overwhelming as a pancreatic **cancer** diagnosis can be, it is important to act quickly and put a treatment plan into place, as there are therapies available that you can benefit from. While it is important to identify an appropriate treatment team, treatment should ideally begin within one month after you receive your diagnosis. At Lustgarten Foundation, we are committed to helping you fight this disease and have developed the checklist below for immediate steps that you and your loved ones should take upon receiving this diagnosis.

1. **Understand your disease.** Thoroughly understand what stage of pancreatic cancer you have. **Staging cancer** is 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 and will impact treatment.
2. **Get genetic testing.** Ask about having your blood or saliva tested to identify possible genetic predispositions to cancer. This testing can have implications for family members and can guide your pancreatic cancer treatment program. According to the 2019 National Comprehensive Cancer Network guidelines, all patients with pancreatic cancer should undergo genetic or germline testing for inherited genetic **mutations**, regardless of family history. Under these new recommendations, this testing should be done by your physician and should be covered by insurance. There are also companies, such as Color Genomics (color.com) and Myriad Genetics (myriad.com), that can do the testing.
3. **Get tumor testing.** Inquire about having tumor testing, also known as somatic testing, if you are being treated at a major cancer center. Still in the early stages of being studied, having your tumor tested for genetic mutations can help identify, in some instances, additional therapy programs.

4. **Seek opinions from experts.** Get two opinions and make sure that one is from a large academic institution that specializes in treating pancreatic cancer.
5. **Know your healthcare team.** Treating pancreatic cancer requires an interdisciplinary approach that includes your oncologist and other specialists who will be involved in your care. Continue to see other doctors who are involved in your overall care, such as your internist.
6. **Contact your insurance company.** Thoroughly understand your health insurance policy. Know what services are covered and what your out-of-pocket obligation will be per calendar year. Request a case manager to help you optimize your benefits and to navigate the intricacies of your policy.
7. **Get organized.** Record your questions in a notebook and bring it with you to all doctors' appointments. Use it to keep track of test results and appointment dates. Write down the contact numbers of all your doctors in one place or save them in your cell phone. Additionally, know the number to call if you have a problem or concern after hours or on a weekend.
8. **Develop a support system.** Have someone accompany you to oncology appointments for support and clarification of the proposed plan of care.
9. **Delegate responsibilities.** Enlist the help of family members, friends, and neighbors who want to assist with errands or chores, meal preparation, and driving.
10. **Control what you can.** Closely monitor your nutrition, physical activity, and pain level and provide feedback to your healthcare team. Utilize **complementary therapy** such as Reiki therapy, yoga, meditation, **acupuncture**, and pet therapy.
11. **Initiate goals of care.** Incorporate the **palliative care** team to help you control your **symptoms** so that you can have a better quality of life. Proper symptom management will help you stay on your treatment plan. Palliative care doesn't mean you are giving up.
12. **Take care of your emotional health.** Maintain daily routines and continue to partake in activities you enjoy as much as possible. If needed, seek out supportive services such as counselors, social workers, and support groups.

1.2 – 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, including radiologic imaging studies and a **biopsy**, to determine the stage of your disease. In addition to identifying the stage of your disease, the biopsy, in some instances, can also be used for genetic profiling that could enable your medical team to identify particular genetic mutations in your tumor that indicate which treatment may be the best choice for you. Knowing the stage of your cancer will help your doctor determine which treatment options are right for you. Over half of patients with pancreatic cancer are diagnosed at Stage IV.² Patients diagnosed with Stage IV pancreatic cancer should not be discouraged, as there are treatment options available.

Most cancers are staged using the **TNM system** of classification, which was developed by the American Joint Committee on Cancer (AJCC).³ 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 that are close to the tumor, including the **duodenum, bile ducts**, or fat surrounding the pancreas.
- N stands for *node* and describes evidence of metastases in the **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.

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 (as summarized by the American Cancer Society based on the AJCC's overview).^{1,3,4}

Stage 0	The cancer is confined to the top layers of pancreatic duct cells and has not invaded deeper tissues. It has not spread outside of the pancreas. ¹ These tumors are sometimes referred to as carcinoma <i>in situ</i> (Tis). It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
Stage IA	The cancer is confined to the pancreas and is no bigger than 2 cm (0.8 inch) across (T1). It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
Stage IB	The cancer is confined to the pancreas and is larger than 2 cm (0.8 inch) but no more than 4 cm (1.6 inches) across (T2). It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
Stage IIA	The cancer is confined to the pancreas and is bigger than 4 cm (1.6 inches) across (T3). It has not spread to nearby lymph nodes (N0) or to distant sites (M0).
Stage IIB	<p>The cancer is confined to the pancreas and is no bigger than 2 cm (0.8 inch) across (T1) AND it has spread to no more than 3 nearby lymph nodes (N1). It has not spread to distant sites (M0).</p> <p>OR</p> <p>The cancer is confined to the pancreas and is larger than 2 cm (0.8 inch) but no more than 4 cm (1.6 inches) across (T2) AND it has spread to no more than 3 nearby lymph nodes (N1). It has not spread to distant sites (M0).</p> <p>OR</p> <p>The cancer is confined to the pancreas and is bigger than 4 cm (1.6 inches) across (T3) AND it has spread to no more than 3 nearby lymph nodes (N1). It has not spread to distant sites (M0).</p>

Stage III	<p>The cancer is confined to the pancreas and is no bigger than 2 cm (0.8 inch) across (T1) AND it has spread to 4 or more nearby lymph nodes (N2). It has not spread to distant sites (M0).</p> <p>OR</p> <p>The cancer is confined to the pancreas and is larger than 2 cm (0.8 inch) but no more than 4 cm (1.6 inches) across (T2) AND it has spread to 4 or more nearby lymph nodes (N2). It has not spread to distant sites (M0).</p> <p>OR</p> <p>The cancer is confined to the pancreas and is bigger than 4 cm (1.6 inches) across (T3) AND it has spread to 4 or more nearby lymph nodes (N2). It has not spread to distant sites (M0).</p> <p>OR</p> <p>The cancer is growing outside the pancreas and into nearby major blood vessels (T4). The cancer may or may not have spread to nearby lymph nodes (Any N). It has not spread to distant sites (M0).</p>
Stage IV	<p>The cancer has spread to distant sites such as the liver, peritoneum (the lining of the abdominal cavity), lungs, or bones (M1). It can be any size (Any T) and might or might not have spread to nearby lymph nodes (Any N).</p>

Adapted with permission of the American College of Surgeons, Chicago, Illinois. The original source for this information is the AJCC Cancer Staging Manual, Eighth Edition (2017) published by Springer International Publishing.³

Clinical Classification

Lustgarten Foundation recommends the National Comprehensive Cancer Network's (NCCN) guidelines for staging cancer.⁵ These guidelines focus on classifying pancreatic cancer and planning treatment based on the results of imaging and other tests done upon diagnosis. This system divides cancers into groups based on whether or not the tumor can be removed surgically.

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, and minimal involvement of 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.⁶ (See Section 1.4 – Surgery.) Only 15% to 20% of patients have resectable or borderline resectable tumors at diagnosis.⁷

Borderline Resectable Cancer

The cancer has not spread to other organs, but does approach nearby structures, such as a major artery or vein. There is concern that the cancer might not be able to be surgically removed with clear margins.

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 to confirm that the cancer has spread to other areas of the body can be found. Approximately 30% of patients with pancreatic cancer present with locally advanced disease.²

Note: Recent research funded by the Pancreatic Cancer Collective, an initiative of Lustgarten Foundation and Stand Up To Cancer, has demonstrated that some patients with locally advanced pancreatic cancer can undergo treatment to shrink their tumors so that they are then eligible for surgery. This type of treatment, which takes place prior to surgery, is called **neoadjuvant therapy.*

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**. Over half of all patients are diagnosed at this stage.^{6,7}

It is important to know the stage of your cancer to help make the appropriate treatment choices. Additionally, some patients with borderline resectable or locally advanced cancer respond to therapy and are “down staged” such that they can undergo surgery. It is extremely important to seek an experienced surgeon to see if surgery is possible.

Comparison of the Clinical Staging Systems for Tumors of the Pancreas at Time of Initial Staging^{1,3,6,8}

Stage	Resectable or Borderline Resectable	Locally Advanced	Metastatic
0	✓		
IA	✓		
IB	✓		
IIA	✓		
IIB	✓		
III	✓	✓	
IV			✓

1.3 – Making Treatment Decisions

Cancer diagnosis and **staging** are so important because they help physicians recommend the most appropriate treatment plan. You will need to decide whether you will accept that recommendation and, ultimately, where you will be treated and by whom. Below is a list of questions to ask yourself before beginning treatment.

QUESTIONS TO ASK YOURSELF BEFORE MAKING DECISIONS ABOUT TREATMENT

- Do I need any more information before I begin treatment?
- Do I have confidence in my diagnosis?
- Do I have confidence in my doctors?
- Is this facility considered a high-volume pancreatic cancer center?
- Have I checked that the treatment center offers **multidisciplinary care**?
- Do I have confidence in this facility?
- Do I feel comfortable at this 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 the “standard of care” (surgery, **chemotherapy**, and/or **radiation therapy**) or am I interested in participating in a **clinical trial**?
- Does this facility accept my insurance? If not, how much is the out-of-pocket cost?

Treatment Decisions

The best treatment results are obtained if surgery can be included as part of the treatment; however, surgery rarely has a role when treating Stage IV disease.

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 one another.⁹ 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 and at a different hospital may be a wise choice and may give you peace of mind.

The purpose of getting a second opinion is to confirm that your diagnosis is correct and that you will be receiving the most up-to-date treatment. You may also want a second opinion if your doctor is not experienced or does not specialize in treating patients with pancreatic cancer. You may also have read about a treatment your doctor does not know about and may wish to pursue such a treatment. Since a **pathologist's** review of a **biopsy** is the gold standard for establishing the diagnosis of pancreatic cancer, many patients also get a second opinion on their pathology and ask that their pathology slides are reviewed by an expert in **pancreas** pathology.

Choosing a Treatment Center

Choosing a treatment center is one of the most important decisions you will make during your pancreatic cancer journey.¹⁰ When selecting a treatment center, being seen as soon as possible should be a key factor in making your decision. Typically, getting an appointment within a few weeks of diagnosis is reasonable; longer than that is not. You should also consider whether the center has a dedicated interdisciplinary pancreatic cancer team with specific expertise in treating this disease.

The National Cancer Institute (NCI), a federal agency for cancer research and training, assigns NCI-Designated Cancer Center status to treatment centers in recognition of their scientific leadership and resources. The Comprehensive Cancer Center designation is reserved for those centers with the highest achievements in cancer research, clinical care, education, and community contributions. Studies show that being treated at NCI-Designated Comprehensive Cancer Centers leads to better survival and recovery rates due to the level of care, diverse oncology disciplines, subspecialty expertise, and multidisciplinary teams as well as access to clinical trials.

There are 70 NCI-Designated Cancer Centers located in 36 states and the District of Columbia in the United States, 67 of which are cancer centers or comprehensive cancer centers that treat adults. A list of these centers with contact information is provided in the Appendix of this guide and can also be found by calling 800-4-CANCER or at cancer.gov/research/nci-role/cancer-centers. You can get a second opinion or be treated at one of these centers, and most centers 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 pancreatic cancer will have more experience in every aspect of your care, which includes diagnosing, staging, performing surgery, and managing side effects and potential complications. More experience usually means more expertise, which can improve the results of your treatment. For example, at an NCI-Designated 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. Alternatively, another hospital may offer the procedure but with limited prior experience. Ultimately, you want to select a treatment center that you have confidence in that has significant experience in treating patients with pancreatic cancer.

Pancreas surgery is complicated, and several studies have shown that operative complication (morbidity) and death (mortality) rates are lower at hospitals that do a high volume of pancreatic surgeries. Many patients live a manageable distance from a major cancer center. Up to half of the patients who are seen at major cancer centers are seen for only one visit. Doctors from top cancer centers often plan patients' chemotherapy treatment regimens and then refer them to doctors closer to home who will carry out the treatment plan.¹¹

QUESTIONS TO ASK WHEN LOOKING FOR A TREATMENT CENTER^{10,11}

- How many patients with pancreatic cancer does the facility typically treat each year?
- How many pancreatic cancer surgeries does the facility typically perform each year?
- Does the treatment facility offer multidisciplinary care?
- Has the facility been rated by the state, consumer, or other groups for its quality of care?
- Has the facility been approved by a nationally recognized accrediting body, such as the American College of Surgeons and/or the Joint Commission on Accreditation of Healthcare Organizations?
- 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?

Multidisciplinary Clinics Dedicated to Pancreatic Cancer

Today, more cancer centers have multidisciplinary clinics specifically dedicated to pancreatic cancer, with the goal of providing the highest quality of care. Patients who have suspected or known pancreatic cancer, especially patients with borderline resectable pancreatic cancer, may benefit from a comprehensive evaluation that incorporates all of the resources available at these clinics for the diagnosis and treatment of their disease. 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.¹² Many of these centers also have the ability to arrange for a patient's blood or saliva to be tested to identify possible inherited genetic mutations that predispose the patient to cancer. These inherited cancer-predisposing mutations occur in about 10% of patients with pancreatic cancer and can be important for two reasons. First, they have implications for other family members who may inherit one of these mutations. Second, some can be used to guide therapy for the patient's cancer. In addition to this testing, major research centers often have the capability to test the

patient's tumor for acquired genetic mutations, which in some instances can help identify additional therapy programs.

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 and is referred to as **multidisciplinary care**.¹³

SOME QUALITY-OF-CARE COMPONENTS OF A CANCER TREATMENT CENTER^{10,11}

- Experience in diagnosing and treating pancreatic cancer (eg, 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 computed tomography (CT) scanner**
- An on-site laboratory to withdraw and analyze patients' blood
- Access to investigational treatments for pancreatic cancer, such as in clinical trials
- Services for pain management and **palliative care**
- Access to other specialists including psychiatrists, nutritionists, and social workers

Many different medical specialists may be involved in your care. It is important to seek specialists who have experience in pancreatic cancer and who will work together to plan and execute your treatment. These specialists may include¹³:

- **Surgeons:** Doctors with experience in pancreatic surgery and in managing potential complications of surgery.
- **Medical oncologists:** Doctors with specialized training in diagnosing and treating cancer and who prescribe anticancer medications. This specialist can act as a main healthcare provider and also coordinates treatment given by other specialists.
- **Radiation oncologists:** Doctors who specialize in treating cancer with radiation.
- **Gastroenterologists:** Doctors who specialize in disorders of the digestive system.
- **Endocrinologists:** Doctors who specialize in disorders of the glands of the endocrine system.

- **Pathologists:** Doctors who look at microscope slides prepared from tissues to establish a diagnosis.
- **Radiologists:** Doctors who perform and interpret imaging of your body.

Other healthcare personnel may also be involved in your care, including:

- **Advanced practice providers:** These are **nurse practitioners** and **physician assistants**. Both types of providers have had advanced education and special training in managing the treatment and care of patients with cancer. In some institutions, you may be seen periodically by an advanced practice provider.
- **Nurse navigators:** These are experienced nurses who expedite and coordinate patient care. They also educate and advocate on behalf of patients.
- **Oncology nurses:** Oncology nurses have special training in managing the treatment and care of patients with cancer. Among their duties are administering chemotherapy drugs, helping to manage side effects, and providing patient education.
- **Oncology social workers:** Oncology social workers are professionally trained to counsel patients who have cancer and to help provide practical assistance. These professionals can help find support groups, locate community services, and assist with finding financial assistance.
- **Dietitians and nutritionists:** These professionals can help develop food and nutrition plans to help maintain energy, weight, and muscle mass during treatment.¹⁴

In addition to the healthcare personnel who will assist with your care, you may want to consult other resources for information. Let's Win! Pancreatic Cancer Foundation (letswinpc.org), which is affiliated with Lustgarten Foundation, is an unprecedented platform that enables doctors, scientists, and patients to share fast-breaking information on potentially life-saving pancreatic cancer treatments and clinical trials. The goal is to provide actionable information all in one place.

1.4 – Surgery

Pancreatic cancer surgery has improved significantly over the past 2 decades. Nonetheless, surgery to remove a pancreatic tumor is complex for a surgeon to perform and difficult for a patient to undergo. You need to openly discuss and ask questions about the risks and benefits of this type of surgery with your doctors before making a decision.¹⁵ In addition, you need to find a surgeon and a facility with a great deal of experience in performing this procedure.^{16,17}

Surgery to remove the tumor as a component of the treatment plan is the most effective for achieving long-term survival. Surgery is performed when the surgeon believes all of the cancer can be removed safely or sometimes to relieve **symptoms** or prevent problems.¹⁵ Surgery generally applies to patients who are in the early stages of pancreatic cancer or those with locally advanced cancer or borderline resectable cancer who have a good response to neoadjuvant therapy.² Recent research suggests that many patients benefit from **neoadjuvant treatment**, which is treatment that is administered prior to surgery.⁵ 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 ducts** or **pancreatic ducts** or of the intestines.¹⁵

SOME COMPLICATIONS OF SURGERY¹⁸

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

Procedures to Remove the Tumor

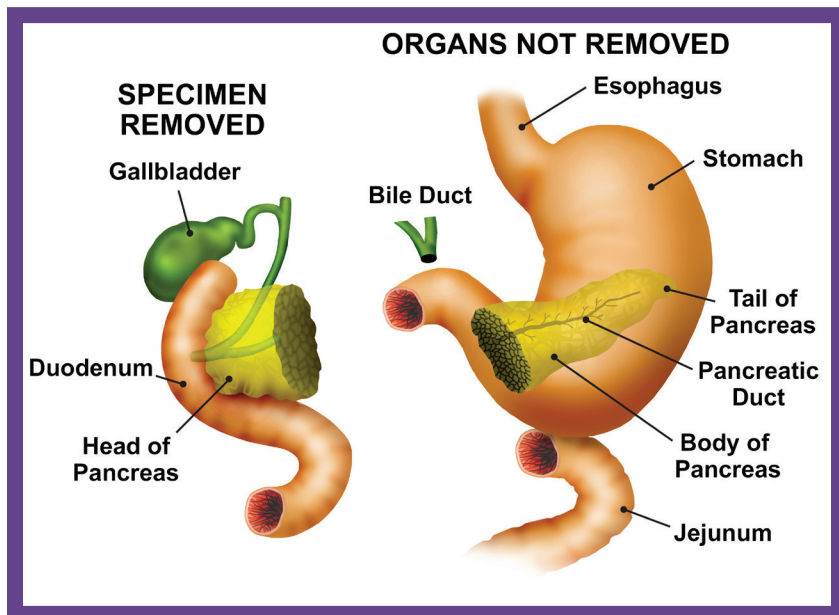
Major procedures used to remove pancreatic tumors are a **Whipple procedure (pancreaticoduodenectomy)**, a **total pancreatectomy**, and a **distal pancreatectomy**.¹⁸ Sometimes the procedure can be done using a laparoscopic approach, which is less invasive and can lead to a shorter hospital stay, less time needed to heal from the procedure, and an earlier return to your usual activity level.¹⁹

Whipple Procedure (pancreaticoduodenectomy): The most common surgery performed to remove tumors in the head of the **pancreas**.²⁰ Two basic types of Whipple procedures exist.²¹ 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** located in the area of the pancreas

Pylosus-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), remaining pancreas, and remaining part of the bile duct are joined to the small intestine.²¹ This allows **bile** and pancreatic enzymes to enter the digestive system normally and mix with ingested food. In some patients, **laparoscopy** can be used to perform the pancreaticoduodenectomy. During this procedure, the surgeon makes a few small cuts in the **abdomen** and inserts a video camera and surgical instruments to remove the tumor rather than using a longer incision, as would take place during open surgery.^{15,22}

Total Pancreatectomy: A seldom-used procedure that removes the entire pancreas, usually together with the **spleen**.¹⁵ When the entire pancreas is removed, the endocrine cells in it are also removed, leaving you with no pancreatic endocrine cells. Because these endocrine cells make **insulin**, which controls blood sugar levels in the body, removal of the entire pancreas will result in diabetes. You will then be dependent on insulin injections.

Distal Pancreatectomy: The tail and body of the pancreas are removed, usually, but not always, along with the entire spleen.¹⁵ Sometimes, part of the body of the pancreas can be preserved. This procedure can sometimes be done using laparoscopic or robotic techniques.^{15,22}

Palliative Surgery

When the cancer has spread and surgical removal of the tumor is not an option, other surgical procedures may be used.¹⁵ These surgeries help relieve symptoms such as **jaundice**, nausea, vomiting, and pain in order to improve your 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. (See Section 1.8 – Supportive Care.)

1.5 – Drug Treatments

If your medical team determines that you are not a candidate for surgery, other treatment options are available to you. In the past, chemotherapy was the only option; today, however, in addition to chemotherapy, **immunotherapy** and newer types of radiation are available. There are also many ongoing **clinical trials** involving immunotherapy and **targeted therapy**. In addition to these treatment options, in 10% of patients, treatment can be guided by the results of genetic sequencing of the patient's normal (inherited) **DNA**. Therefore, sequencing normal tissue (germline genetic testing) such as blood or saliva, is quickly becoming the standard of care.

Chemotherapy

Chemotherapy is the use of drugs to kill cancer cells. It may be given orally or by injection or delivered through a **catheter** in a vein. 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 combined with either radiation therapy or surgery.

Types of Chemotherapies Used for Pancreatic Cancer

The choice of which treatment to use depends on your health and the location and size of the tumor.²³ Additionally, certain characteristics of the tumor may make the tumor suitable for treatment with specific drugs. Therapy is usually given as a combination of drugs that has been tested and validated in clinical trials. Having your blood tested for **inherited mutations** such as mutations in the **BRCA2 gene** and, in some selected instances, having tissue from your tumor **biopsy** sequenced to determine if specific genetic mutations are present, may be beneficial. While it is more likely that this testing will be conducted at a research center, it is important to inquire about this type of testing wherever you choose to undergo treatment. Specific treatments that target some specific genetic mutations may be available, and could be an appropriate choice of treatment for you at some point during your care.⁵

At the time of diagnosis, most patients with pancreatic cancer have disease that is considered locally advanced or **metastatic**. In some cases, chemotherapy will be used to try to shrink the tumor in patients with locally advanced disease, which may make these patients eligible for surgery.

Physicians will tailor the chemotherapy regimen according to the initial health status of the patient and any side effects that appear. First-line chemotherapies for patients with nonresectable tumors commonly include the combination of gemcitabine (Gemzar) with nab-paclitaxel (Abraxane), or the combination of four chemotherapies in the FOLFIRINOX regimen (5-fluorouracil, leucovorin, irinotecan, and oxaliplatin). Additional strategies include fewer drugs, or the addition of cisplatin. Patients with metastatic pancreatic cancer whose disease progresses after receiving a gemcitabine-based treatment may be candidates to receive Onivyde (irinotecan liposome injection) in combination with fluorouracil (also known as 5-FU) and leucovorin. In 2015, Onivyde was approved by the US Food and Drug Administration (FDA) as the first and only second-line therapy for the treatment of pancreatic cancer.²⁴ In its active form, this treatment interrupts cell reproduction.

Side Effects

Most chemotherapy drugs damage some healthy cells in addition to tumor cells. Because cancer cells grow very quickly, they are more sensitive to these kinds of drugs and the cancer cells die. However, chemotherapy is not specific to cancer cells, and it can affect other kinds of cells such as red blood cells or white blood cells, leading to side effects. 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, but most side effects disappear once treatment is stopped. Some common side effects of chemotherapy are listed in the box on the next page.

COMMON SIDE EFFECTS OF CHEMOTHERAPY

- Fatigue
- Hair loss or thinning
- Loss of appetite
- Mouth sores
- Nausea
- Vomiting
- Diarrhea
- “Chemo brain,” which is the mental cloudiness that patients sometimes notice before, during, or after cancer treatment, affecting daily life
- Bleeding or bruising
- Low blood cell counts
- Infection
- Peripheral neuropathy, a condition that can cause numbness and tingling, typically in the hands and feet, and is a result of damage to peripheral nerves

Challenges of Chemotherapy

Tumors are often surrounded by a **stroma**.²⁵ The stroma is made up of normal cells called fibroblasts as well as immune cells and a sticky substance called the extracellular matrix. The stroma seems to protect the tumor from chemotherapy; however, on the positive side, it may also prevent the cancer from metastasizing. Research is ongoing to determine how to overcome the protection of cancer cells by the stroma, and drugs that target the stroma are in development. In addition to protection by a stroma, cancer cells can develop resistance to certain drugs over time, preventing the chemotherapy from killing them. Typically, if a patient stops responding to a particular therapy, he or she may move on to another treatment. Second- and third-line therapies are common in treating pancreatic cancer.

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.

Radiation is often given at the same time as chemotherapy (**chemoradiation therapy**) but may be given by itself before or after completing chemotherapy.^{2,23,26} Chemoradiation therapy is typically given over 5 to 6 weeks, for 5 consecutive days, and it takes approximately 15 to 30 minutes per treatment. Chemoradiation is very effective in controlling and/or improving a surgeon's ability to completely remove the pancreatic tumor.

Radiation can also be delivered through **stereotactic body radiation therapy** (SBRT). With SBRT radiologists can deliver multiple thin beams of high-dose radiation therapy or focused "arcs" of radiation in fewer sessions. SBRT has evolved so that 3 to 5 days of radiation may be as effective as or even more effective than a 5½-week chemoradiation regimen. Radiologists are continuing to explore the best approaches to treatment and are making substantial improvements in SBRT, including control of a patient's breathing motion, since pancreatic tumors move during breathing.

The CyberKnife System (Accuray Incorporated), which is the only fully robotic radiation delivery system, is a type of SBRT. The CyberKnife System's design, along with real-time imaging, ensure that the CyberKnife System can deliver a maximum dose of radiation directly to the tumor from varying angles with submillimeter precision in a noninvasive way that reduces how much the healthy tissue is exposed to radiation.

Radiation may also be helpful in alleviating pain caused by the tumor and in treating patients who are elderly or are not healthy enough for other therapies, including surgery.

Some of the common side effects of radiation therapy are shown on the next page.

COMMON SIDE EFFECTS OF RADIATION THERAPY²⁰

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

Patients should contact their physician if side effects are severe or unmanageable.

Targeted Therapy

Targeted therapy is a type of cancer treatment that targets the changes in cancer cells that help them grow, divide, and spread. Most targeted therapies are either small-molecule drugs or monoclonal antibodies.

Small-molecule drugs are small and can easily enter cells. These drugs have targets that are inside the cells. **Monoclonal antibodies** are large molecules that attach to specific targets on the outside of cancer cells. Monoclonal antibodies may have a direct effect on cancer cells, but they can also mark cancer cells so that a patient's immune system destroys the cancer cells. There are many targeted therapies and monoclonal antibodies currently being investigated in clinical trials to determine if they can benefit patients with pancreatic cancer.

Erlotinib (Tarceva) is the only targeted therapy approved for patients with pancreatic cancer. It blocks tumor cell growth by targeting a kinase (a kind of protein) called the epidermal growth factor receptor (EGFR) that is present on the surface of some cancer cells. It is used in combination with gemcitabine for patients with advanced-stage pancreatic cancer whose cancer has spread, grown, or cannot be surgically removed and who have not received previous chemotherapy.²⁷ Newer combination chemotherapies have proven more effective than erlotinib and this medication is no longer commonly used for patients with pancreatic cancer.

Immunotherapy

The immune system that protects a person against infection usually gets rid of mutated cells in the body. However, cancer cells are able to hide from the immune system, preventing the immune system from destroying them. **Immunotherapies** are types of biological therapy that use substances to stimulate the immune system to help the body fight cancer, infection, and other diseases. Currently, the only immunotherapy FDA-approved for pancreatic cancer is the immune checkpoint inhibitor pembrolizumab (Keytruda). This treatment has proven effective for patients whose tumors are mismatch repair deficient. This deficiency is found in approximately 1 in 50 patients with advanced pancreatic cancer.²⁸ The study leading to its approval was funded by Lustgarten Foundation.²⁹ In fact, in 2018, the American Society of Clinical Oncology updated their clinical practice guidelines to recommend routine testing for mismatch repair deficiency in patients with metastatic pancreatic cancer who are considered to be candidates for checkpoint inhibitor therapy. Pembrolizumab is recommended as a second-line treatment for patients whose tumors are mismatch repair deficient.

Immunotherapy has proven effective in cancers of other organs, and Lustgarten Foundation is funding research and clinical trials to bring additional forms of immunotherapy to patients.

1.6 – Clinical Trials

Background

A **clinical trial** is the scientific method by which the effectiveness of a drug, a procedure, or a medical device is determined.³⁰ Clinical trials are performed to determine if the product being tested is safe for public use and if it is more effective than the current standard of care treatment. Doctors and other healthcare professionals run clinical trials according to strict rules set by the US Food and Drug Administration (FDA) to ensure that study participants are treated as safely as possible. There are many different types of clinical trials, which are used to find better ways to prevent, screen, diagnose, and treat diseases, and even to improve patients' quality of life. Clinical trials may involve surgery, **chemotherapy**, radiation, or combinations of these, and patients with all stages of pancreatic cancer may be eligible for clinical trials.

Currently, less than 5% of patients with pancreatic cancer are enrolled in clinical trials.³¹ There are several reasons why patients do not participate in clinical trials, but most often patients may decline due to fear of side effects as well as concern about the loss of control over the treatment program, costs, and logistics involved with participating in a trial.³² However, because there are still limited treatments for patients with pancreatic cancer, clinical trials of new treatments can be considered at all steps of your care and should be discussed with your oncologist and all members of your cancer treatment team.

Clinical trials 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 with all stages of pancreatic cancer; in fact, some clinical trials are for patients who have not had prior treatment. Some of the ongoing clinical trials include combination therapies with gemcitabine, treatments targeting germline genetic changes, immunotherapeutic approaches, treatments to break down the **stroma** (the supportive tissue surrounding the tumor) and the use of targeted agents.³⁰ Some patients participating in a clinical trial may experience positive outcomes from an experimental therapy, and many are motivated to participate in a clinical trial to help others.

Additionally, some physicians may opt to allow for “compassionate use.” This refers to the treatment of a patient using a new, unapproved drug when no other treatments are currently available. Often this involves a drug that is already being used to treat other diseases.

Clinical trials can be sponsored by governmental agencies, private foundations, or by pharmaceutical companies that make new drugs. The National Cancer Institute's National Clinical Trials Network is currently conducting many pancreatic cancer clinical trials, with more being added all the time.³³ Lustgarten Foundation also sponsors and supports clinical trials. Drug companies often partner with universities and cancer centers to conduct these trials.

Clinical Trial Phases

Before any new cancer treatment can be tested in humans, it is studied extensively in the laboratory.³⁰ 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.

Clinical trials are designed to answer many different questions about cancer treatments such as:³⁰

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

Most clinical trials are carried out in sequential steps called **phases**.³⁰ Each phase is designed to answer specific questions and builds on information from the previous phase.

In **phase 1** trials, researchers learn about the safety and side effects of a new drug by gradually increasing the dosage and analyzing patients' responses.³⁰ Based on the results, a larger study may be conducted to evaluate the potential effectiveness of the drug.

Phase 2 trials determine if the treatment works.³⁰ 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. Many phase 2 studies are randomized trials where one set of patients receives the experimental drug and a second set receives a "control," which is the standard therapy. Often these trials are "blinded," which means that neither patients nor researchers know who is receiving which treatment. If enough people have a positive 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.³⁰ Often, patients are randomized to receive either the best available standard of care treatment or the best available care plus the study drug. In some cases, patients who are treated with the standard of care can be treated with the study drug if their cancer progresses. However, each study is designed differently, and it is important to clearly understand your treatment options from your oncologist before beginning the trial. Phase 3 studies provide a more thorough understanding of the effectiveness, benefits, and side effects of the drug. If researchers demonstrate that the drug is at least as safe and effective as others already on the market, the FDA will usually approve the drug.

Clinical Trial Participation

You should strongly consider participating in a clinical trial and weigh the risks and benefits of the treatment.³⁰ Moreover, be sure to obtain enough information about the clinical trial to make an informed decision. 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 to keep with your other medical records. This form must be written in a way that is easily understandable for you.

Signing the form for participation in a clinical trial shows that you have been given information about the trial and that you understand it. However, when you sign the Informed Consent Form, you are not signing a contract and you may leave the study at any time and for any reason, as participation in a clinical trial is always voluntary. 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.

If you enroll in a clinical trial, you need to know that you have certain rights.³⁰ You have the right to be told:

- the purpose of the clinical trial;
- all risks, side effects, and discomforts that might reasonably be expected;
- any benefits that can reasonably be expected;
- what will happen during the clinical trial 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; and
- medical treatments available if complications occur during your participation in the clinical trial.

As a participant, you may also do the following:³⁰

- 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 in the clinical trial
- Refuse to participate before entering the clinical trial, and leave the clinical trial at any time after it has begun

As a participant, you will receive high-quality, individualized care.³⁰ The research team will closely monitor your treatment response, your health, and any side effects that you may experience. Researchers will also follow strict scientific guidelines and ethical principles to protect all participants.

You are protected in a clinical trial in three additional ways:³⁰ 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.

Data Monitoring Committees are mainly used when one treatment is being compared with another. These committees are particularly important in testing treatments for serious diseases such as cancer.³⁴ 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 appears to be harmful, or to stop a study in order to provide the treatment to all participants when one treatment works better than another.

The FDA inspects records, clinics, and research sites involved in clinical trials. The FDA makes sure participants in the clinical trial 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, you should confirm this.

Finding 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. We suggest patients visit ClinicalTrials.gov, the clinical trials registry provided by the National Institutes of Health. Registration on ClinicalTrials.gov is required for all phase 2 and phase 3 trials, and most entities also register phase 1 trials on this site. Additionally, several groups have matching and referral services to help patients find appropriate clinical trials. The Lustgarten and Let's Win Clinical Trial Matching Service is a free matching and referral service easily accessed through lustgarten.org. (See the Appendix for a list of organizations you can call or websites you can search for clinical trials.)

Costs Associated With Participating in a Clinical Trial

Clinical trials are very expensive undertakings for the study sponsor. However, the cost to the patient varies depending on the trial, who is sponsoring the trial, what portion of the study-related expenses the sponsor will cover, and the patient's health insurance coverage. In many instances, there are no additional costs to participate in a clinical trial, and, at times, the institution running the clinical trial will cover patients' costs. The Affordable Care Act, as of June 2017, includes provisions that health insurance plans issued after January 1, 2014, cannot limit or deny coverage for those who want to participate in approved clinical trials. However, healthcare plans existing before June 2017 may not provide coverage for the basic medical procedures associated with a trial such as scans, lab tests, and hospitalization when required. Medicare also provides coverage for care associated with most clinical trials.

The National Cancer Institute (NCI) will pay for the study drug and all costs related to the study for patients taking part in an NCI trial that is conducted at their Bethesda, Maryland campus. Costs include those associated with travel, food, and lodging expenses. Financial assistance or discounted rates for lodging and meals are provided at some cancer centers, and they may also have special research units that will pay for study-related costs. Financial assistance for treatment-related expenses may be available through other organizations as well.

QUESTIONS TO ASK ABOUT CLINICAL TRIALS

- Is there a chance that I would be given a placebo and not a treatment?
- What is the study goal (eg, the purpose of the research)?
- What are my other treatment 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 being used to treat other cancers?
- 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?
- If this is a randomized trial, what are the treatment options?
- What are the major side effects seen so far? Minor side effects?
- What phase is this trial?
- Who looks out for me as a study participant?
- What happens if I do not respond to this treatment?
- What happens if I respond to the treatment but then stop responding?
- What are the costs?
- 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 happens when the clinical trial is over?

1.7 – Use of Complementary and Alternative Methods

As more people are living longer, chronic illnesses, including cancer, have become more common. Sometimes, patients may want to explore other methods besides conventional medicine to treat their disease. As a result, they may turn to complementary and alternative treatments, which are medical products and practices not considered standard medical approaches. **Complementary therapies** are added to conventional treatments because some believe that they may ease the side effects of standard treatment or provide physical or mental benefits to patients with cancer. Meditation to relieve stress and **acupuncture** to relieve pain are examples of complementary therapies. **Alternative therapies** are treatments that have not been tested scientifically and are used in place of traditional treatments. Some alternative therapies are unsafe and can cause harmful side effects.

Studies show that more than 65% of patients who have cancer use complementary or alternative methods.³⁵ 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.

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 include³⁵:

- Acupuncture for pain or for nausea and vomiting from **chemotherapy**
- Massage therapy for anxiety or pain
- Mind-body-spirit therapies such as yoga, hypnosis, relaxation training, imagery, and music therapy
- Medical marijuana. The US Food and Drug Administration (FDA) does not recognize marijuana as medicine, but many states have approved marijuana for medical use. Ask your healthcare team if medical marijuana is something you should consider, if it is available in your area, and what steps you would need to take to obtain a prescription.

Complementary and alternative therapies have risks.³⁶ Just because a product claims to be “natural” does not necessarily mean that it is safe. Most dietary supplements, vitamins, and herbs are not approved by the FDA because they have not been tested.³⁶ These products may contain contaminants, or they may interact negatively with prescription drugs. Some products can be very potent and may have unpredictable effects. Some alternative therapies may counteract the effects of chemotherapy or may be harmful in other ways.³⁶ If you are considering the use of complementary therapy or alternative treatments, always discuss these methods with your healthcare team before you begin using them.

TIPS FOR PATIENTS CONSIDERING COMPLEMENTARY OR ALTERNATIVE THERAPIES³⁶

- 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 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 if there is a change in your medications.
- Discuss any potential drug interactions for which you should monitor.
- Continue your conversations with your doctor, and let your doctor know of any decisions you have reached.

1.8 – Supportive Care

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. Supportive care directed at pain, diet, and depression are particularly important for patients with pancreatic cancer. Patients with clinical depression should consult a specialist for appropriate therapy. (See Section 1.9 – *Coping*.) Supportive care provided by the healthcare team can help ease and even eliminate these problems, thereby increasing patients' quality of life.

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** is usually 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.³⁶ The goals of pain management are to control pain and prevent or minimize side effects. 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.^{37,38}

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 result in anxiety and depression, disrupt sleep, and curb the appetite, weakening the body's immune defenses, which fight infection and disease, and interfere with healing.

If you have pain, this should be discussed with your healthcare provider, who should:

- understand the cause of the pain,
- perform a comprehensive pain assessment,
- select the most appropriate medications and non-drug interventions, and
- evaluate the response to provide treatment for pain.

Assessment of Pain

When assessing pain, your doctor will ask you a lot of questions:

Onset	<ul style="list-style-type: none">• When did the pain begin?• How often does it occur?
Location	<ul style="list-style-type: none">• Where is the pain?
Type	<ul style="list-style-type: none">• What does it feel like?
Intensity	<ul style="list-style-type: none">• Numerical rating scale: 0 (no pain) to 10 (worst pain)• Verbal descriptor scale: mild, moderate, severe
Aggravating and relieving factors	<ul style="list-style-type: none">• What makes the pain better?• What makes the pain worse?
Effects	<ul style="list-style-type: none">• What are the effects of your pain on you? For example, does your pain cause lack of sleep, fatigue, irritability, or depression?
Control	<ul style="list-style-type: none">• What have you tried or taken to control the pain you are experiencing?• Has it been successful?

You can help your doctor assess your pain by clearly communicating what your pain feels like and by keeping a pain log or journal.

Treatment for Pain

Pain Medications. Once your doctor knows the severity of the pain, treatment for the pain can be chosen. Most doctors use a pain treatment approach developed by the World Health Organization (WHO) called the WHO Three-Step Analgesic Ladder.³⁹ An analgesic is a medication whose primary purpose is to relieve pain.

ASSESSING YOUR PAIN

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 or journal. Keep a record of the date, time, location, and severity of your pain from 0 (no pain) to 10 (worst pain) to discuss with your doctor or healthcare team.

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).³⁹ Always check with your doctor first 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 extremely strong pain relievers and may be the best medicines for controlling pain. Some mild opioids are codeine, hydrocodone, and oxycodone, while strong opioids are morphine, fentanyl, and hydromorphone. Sometimes combinations of these drugs are used.

The WHO Three-Step Analgesic Ladder³⁹

Step 1	Step 2	Step 3
Mild Pain Nonopioid pain reliever <i>Alone</i> <i>With adjuvant drug</i>	Moderate Pain Mild opioid painkiller <i>With or without nonopioid drug</i> <i>With or without adjuvant drug</i>	Severe Pain Strong opioid painkiller <i>With or without nonopioid drug</i> <i>With or without adjuvant drug</i>

POSSIBLE SIDE EFFECTS OF OPIOIDS

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

Opioids have different side effects than NSAIDs. Always discuss any side effects that you have with your doctor.

Patients with cancer who use opioids to manage pain are at risk of physical dependence on these drugs. Physical dependence is often confused with substance abuse, but these two conditions are different. Unless you have a history of substance abuse, you are unlikely to become a substance abuser after taking opioids to relieve cancer pain.⁴⁰

Physical dependence means that a patient has withdrawal **symptoms** after suddenly reducing the dose of an opioid. Withdrawal symptoms include anxiety, chills, hot flushes, sweating, salivation, nausea and vomiting, and abdominal pain. In these cases, reducing the dose gradually until the drug can be discontinued is recommended.⁴⁰

Patients also have concerns about taking pain medications too soon and developing tolerance to the medications. However, this is rarely a concern, and it is more important that patients seek treatment for their pain so that it can be managed.

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

Another method of delivering pain medication is **patient-controlled analgesia (PCA)**. With 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. PCA is commonly used after pancreatic cancer surgery in the immediate postoperative period.

Adjuvant Drugs for Pain. **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.

Other Pain Control Measures. Many nondrug therapies may be useful to help control cancer pain. Doctors may suggest the use of heat therapy, cold therapy, or physical therapy. Massage, hypnosis, **acupuncture**, and emotional support groups and individual counseling may also be effective. These techniques, and others, may be used in conjunction with pain medications.

For pain that does not respond to other measures, a **nerve block** may be performed. A local anesthetic or an alcohol solution 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. Sometimes a skilled surgeon will perform a **neuroablation** in which part of the pain nerve fibers are cut or destroyed. Radiation therapy can also be used effectively to relieve pain by shrinking tumors. (See Section 1.5 – Drug Treatments.)

Nutrition and Exercise

Pancreatic cancer may cause you to lose weight before or after your diagnosis. In addition, treatments may cause you to lose your appetite. However, maintaining a healthy weight will help with treatment. In fact, good nutrition is essential to control weight loss, maintain strength, and promote healing. Consulting with a nutritionist or a dietitian may be helpful.^{2,23,26}

The following steps may help with nutrition management during pancreatic cancer treatment:

- Patients who feel bloated or are having difficulty eating larger meals should try eating five to six small meals throughout the day; eating smaller amounts is easier for the body to digest and absorb and can minimize nausea.⁴¹
- Because they can block the pancreatic duct and damage pancreatic tissue, pancreatic cancers can reduce the flow of digestive **enzymes** to the intestines. Replacement pancreatic enzymes, available by prescription, can be taken by mouth at meal time and can help with the digestion of food.
- Anti-reflux medications may reduce the sensation of food rising in the throat.

Besides addressing these key nutrition issues during pancreatic cancer treatment, the following are additional suggestions for nutrition management:

- Eat foods that contain healthy fat and avoid greasy, fried foods.
- Eat a balanced diet with fruits, vegetables, whole grains, and **proteins**.
- Avoid excess sugar, sweets, and carbohydrates.
- Drink plenty of fluids to prevent dehydration.
- Exercise regularly, even if it is just a short walk.
- For underweight patients: relax restrictions on low-cholesterol and low-fat foods.
- For patients with a relatively stable or healthy weight: maintain weight with a balanced diet.

A diet high in calories and protein can help you keep your weight up.⁴² Regular exercise coupled with a balanced diet that avoids carbohydrates can improve survival and give you strength for day-to-day activities.

High-calorie foods:

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

To these, add foods with protein:

- Nuts, seeds, wheat germ, and peanut butter
- Meat and fish
- Nutritional drinks such as Ensure or Boost

Pancreatic enzyme supplements can significantly help digestive symptoms in some patients with pancreatic cancer.^{2,23,25} These supplements contain enzymes that help in the digestion of fat, proteins, and carbohydrates. Supplemental enzymes are available both over-the-counter and as prescription forms. Consult your physician before taking over-the-counter enzymes.

To complement a balanced diet, emerging research demonstrates that preoperative exercise, or “prehabilitation,” can benefit patients who are receiving neoadjuvant treatment.⁴³ Preclinical data from researchers at MD Anderson Cancer Center demonstrate that the prehabilitation program for patients with pancreatic cancer at their facility could increase **chemotherapy** efficacy.

Ways Nutritional Health Can Be Compromised

Cachexia is a common condition in patients with later-stage pancreatic cancer. Cachexia causes muscle wasting, loss of appetite, and unintentional weight loss. Patients experiencing cachexia might benefit from appetite stimulants such as omega-3 fatty acids, alone or in combination with other nutritional supplements.

Nausea and vomiting. Nausea and vomiting are common side effects of treatments for pancreatic cancer and usually stop when treatment ends. Pancreatic cancer, itself, also may cause nausea and vomiting.

Preventing nausea will help you get the nutrition you need. You should eat foods that are easy to digest; avoid fatty foods; eat small portions; eat 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.

Vomiting can be controlled very effectively with the use of drugs called **antiemetics**. 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 in which 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, having a bowel movement daily is normal; for others, only one bowel movement three times each week is normal. It is important to report any changes in bowel movements that differ 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, resulting in hard, dry stools. 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 (eg, reduced activity, poor appetite, and weakness). If you have constipation, notify your healthcare team as soon as possible.

1.9 – Coping

Learning to Cope

It is very 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, uncertainty about your future, and anger. These feelings may come and go, and it is important to remember that these are normal reactions. Your family members and friends may also experience these feelings.

Coping refers to how people or family members come to terms with an illness, making decisions, solving problems, and adapting to life's changes, while still feeling good about themselves. 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.

Working through these emotions is essential to successful coping. Because you may not be prepared for the unique stresses caused 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.

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

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 focusing on what you do not have or what you may lose. Feeling hopeless, powerless, or like you have nothing to live for can be **signs** of depression and should be discussed with your healthcare team.

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 aware and take note of these symptoms.

Depression is common in patients with pancreatic cancer. Let your healthcare team know about your symptoms. Do not suffer needlessly. Seek out a mental health professional. Additionally, effective medications and other methods to treat depression are available.

DO YOU HAVE DEPRESSION?

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
- Frequent crying
- 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.

The impact of your diagnosis on your family and friends can have physical, emotional, or financial ramifications. The emotional impact on others may include disbelief, anger, fear, confusion, or denial. Friends and family may feel helpless and not know what to do or how to talk to you. Seeking support for family members and friends may be helpful.

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 diagnosis and treatment. Typically, family and friends will be eager to offer their help or support but may not know how to ask. You should ask for help (if needed) with daily activities such as running errands, helping with household tasks, assisting with child care, or just being there to listen.

Joining a support group (in-person or online) may make a positive difference for you. Finding new friends, especially others who have cancer, may help. They will understand how you feel and you can express your feelings to other patients with cancer in a way that you may not be able to express to your family or friends. Other patients can validate your feelings, so you don't feel isolated. 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 other patients who are going through the same thing. They have a wealth of information about many aspects of cancer. They can provide ideas about how to cope and you can share advice. Some people like to join a group and just listen. Conversely, you may have an opportunity to help others cope with their disease by expressing your emotions or your experiences. You will find that what you are experiencing is very normal, and you may find alternate ways to cope with your diagnosis or how you are feeling.

Remember that members of your healthcare team are also part of your support system. It is also important to contact your healthcare team to discuss anything related to your cancer and how you are dealing with it. They can assist you in finding what you need to help you cope, and they can provide suggestions about social workers, nutritionists, and other therapists.

Addressing Financial and Legal Matters

When dealing with a life-threatening illness, you will 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. Financial aid may be available from government programs, disability benefits, voluntary organizations, and living benefits from life insurance policies. Having a financial plan in place may reduce some of the stress in your life and help you better cope.

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

Two documents that are involved with your healthcare, called **advance directives**, are a **living will** and a durable power of attorney. A living will allows people to 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 are unable to do so. 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.

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. A power of attorney appoints a person to make financial decisions when you are unable to do so.

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

Navigating Finances

It is important to budget for healthcare costs and to ensure your financial security. This requires planning regardless of your income. Financial issues can also significantly add to the stress of a cancer diagnosis so it may be a good idea to delegate this task to a trusted family member or friend, or a certified financial planner who is knowledgeable about cancer issues. Insurance can cover many medical care costs, and there are various aid programs that can help you cover medication, travel, and/or housing costs. Federal and state programs may also be available for qualified cancer patients. However, it is important to note that the amount of homecare support paid by insurance is variable and not all insurance policies cover the same items. Most patients with pancreatic cancer will automatically medically qualify for Social Security disability benefits (ssa.gov/benefits/disability/).⁴⁴ For patients who participate in **clinical trials**, some costs may be covered by the trial sponsor. (See p 27 for additional information about clinical trial costs.)

There are also financial counselors available to help patients identify resources. Some sources of information are provided below:

- CancerCare Financial and Co-Pay Assistance: cancercares.org/financial_assistance
- National Comprehensive Cancer Network Patient and Payment Assistance: nccn.org/patients/about/resources/default.aspx
- Cancer Financial Assistance Coalition: cancerfac.org
- National Pancreatic Cancer Foundation: npcf.us/core-programs/financial-resources
- Medicare: medicare.gov
- Social Security Disability Benefits: ssa.gov/benefits/disability/
- American Cancer Society: cancer.org/treatment/finding-and-paying-for-treatment.html

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, spend time with family and friends, and have a spiritual advisor visit.

Being cared for at home may make patients feel more secure and more comfortable. They may want to be near family members, friends, and familiar surroundings. Healthcare providers can help coordinate the many services available to patients at home, including access to medical equipment, visiting nurses, and physical therapists; help with daily hygiene and care; assistance with meal preparation; and delivery of medications.

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 the doctor. Overall care is supervised by the doctor, who is provided with up-to-date information on a patient's condition.

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.

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

1.10 – 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 or partner, child, sibling, or close friend. There are various kinds of caregivers, and each can provide a different type of care. For example, a neighbor who visits a few times a week or takes the patient out to lunch or to a movie is considered a caregiver.

Being the main caregiver for a loved one with cancer is challenging. 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 a majority of your emotional and physical energy.

Coping

Dealing with cancer can be an emotional roller coaster. Caregivers also may experience a range of emotions, just as patients do, such as anger, guilt, grief, hopelessness, loneliness, and depression. The caregiver may also 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 his or her 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.

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 may not be able to 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.

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

- 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
- Join an online support community like *Pancreatic Cancer Connections*, which provides a safe space for patients and caregivers to share their experiences, get valuable coping resources, and support one another (inspire.com/groups/pancreatic-cancer-connections)
- Speak to 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
- Write in a journal

AVOIDING 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 the losses that your loved one's illness brings
- Maintain the patient's independence by not insisting on doing everything
- Become empowered by learning about pancreatic cancer

RECOGNIZING 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
- Feeling guilty about not doing enough or not wanting to do more
- Being easily irritated by people who tell you to "take care of yourself"
- Feeling hopeless

DEALING 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 of support
- Ask friends and neighbors for any help they can provide; people often are happy to be asked and to help
- 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
- Recognize and deal with depression

Here are some ways to take care of yourself physically:

- 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

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 he or she was before his or her diagnosis. 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.

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 topics:

- 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 at times. 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 discussed:

- Practice in advance what you will say
- Find a quiet time to talk
- First ask if it is okay 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 in one conversation
- The most important thing you may be able to do is just listen

Additional information on this topic is available in *The Four Things That Matter Most: A Book About Living* by palliative care specialist Ira Byock, MD.

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:

- 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 the tests 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 the patient's healthcare team and the roles they play
- Write down all questions you have before scheduled 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
- Program all phone numbers of your healthcare team, after hours numbers, and your local pharmacy in your cell phone so they are easily accessible in the event of an emergency or if you are not home where your medical documentation is kept



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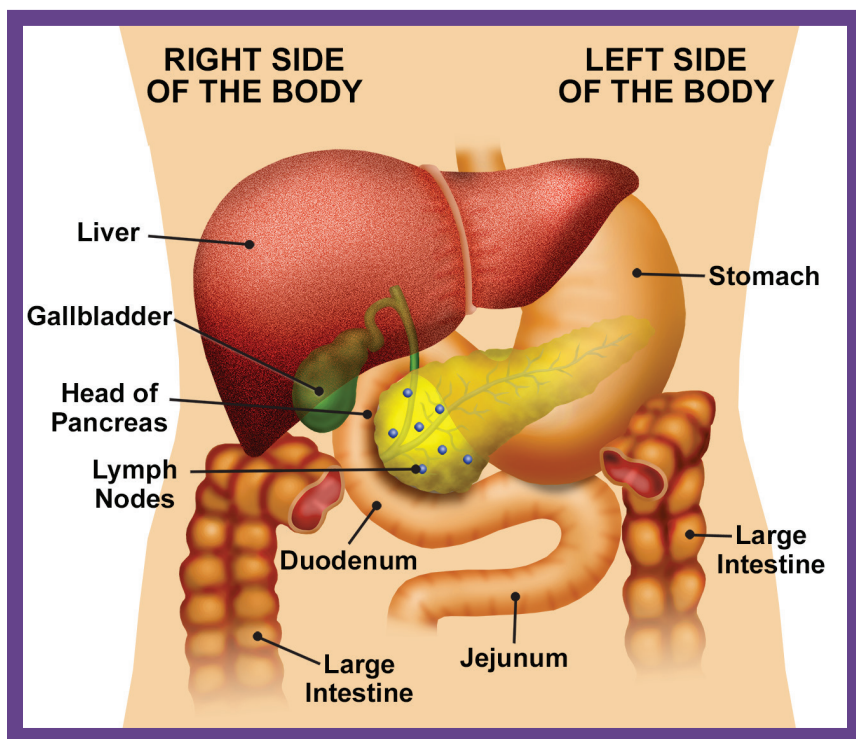
PART 2: Pancreatic Cancer Overview

2.1 – Background on Pancreatic Cancer and Pancreatic Cysts

The second part of this book provides background information about pancreatic cancer and its causes, **symptoms**, and diagnosis, as well as information about **pancreatic cysts**. This information is valuable not just for patients, but for family members and **caregivers** who want to more fully understand what their loved one is going through.

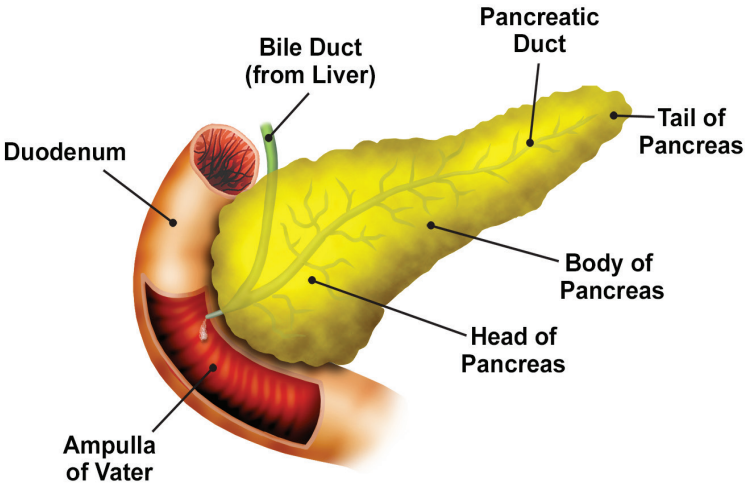
The Pancreas

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.¹



RIGHT SIDE
OF THE BODY

LEFT SIDE
OF THE BODY



The pancreas is about two inches wide and six to eight inches long.
The head is the large, rounded part of the gland 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 pancreas is only about two inches wide and six to eight inches long and sits horizontally across the abdomen.¹ It is composed of three contiguous parts:

- The large, rounded portion of the gland is called the *head*. It is located on the right side of the abdomen and abutting 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**.

The pancreas is a glandular tissue and it has two jobs to do in the body. Two separate cell types are in the pancreas: **exocrine** (produces and secretes digestive substances into a **duct**, which drains into the duodenum) and endocrine (produces and secretes hormonal substances into the blood).¹ The **exocrine tissue** comprises 95% of the pancreas, and the **endocrine tissue** makes up the remaining 5% of the pancreas.¹⁻⁴

Exocrine glandular tissue produces **pancreatic enzymes**.³ These enzymes travel down the **pancreatic duct** and into the duodenum where they aid in the digestion of food. The endocrine glandular tissue of the pancreas produces hormones and releases them into the bloodstream. Two of these hormones, **insulin** and glucagon, help control blood sugar levels.⁴

Cancer of the Pancreas

The word **cancer** is used to describe any one of a group of diseases in which abnormal cells 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.^{2,4}

Because the pancreas lies deep in the abdomen, a doctor performing a physical examination on a patient would not be able to feel a pancreatic tumor. Pancreatic cancer has no early warning **signs**, and there are currently no effective screening tests.^{1,5} As a result, pancreatic cancer is usually discovered late. Often, the diagnosis is not made until the cancer has spread to other areas of the body (stage IV). However, research focused on better diagnostic tests and newer treatments provides a more optimistic future for patients diagnosed with pancreatic cancer.⁵⁻⁷ In fact, a blood test and better scans, used for earlier detection, are in development.⁷

Before 2030, pancreatic cancer is expected to be the second-leading cause of cancer-related deaths in the United States, second only to lung cancer.^{1,8} In the United States, more than 56,000 people are diagnosed with pancreatic cancer each year.² Almost all patients with pancreatic cancer are older than 45 years;⁹ however, pancreatic cancer can also occur in younger people.

Types of Pancreatic Cancer

The most common type of pancreatic cancer resembles the cells of the ducts of the exocrine pancreas and is called **pancreatic ductal adenocarcinoma (PDAC)**. These tumors are designated “ductal” because they microscopically form structures that resemble the pancreatic ducts. About two-thirds of all pancreatic cancers arise in the head of the pancreas. The remainder arise in the body and tail.⁹ Ductal adenocarcinoma tumors are **malignant**, meaning they can invade nearby tissues and organs. Cancerous cells can also spread through the blood and **lymphatic systems** to other parts of the body. When this occurs, the cancer is called **metastatic cancer**.

Tumors can also resemble the endocrine cells of the pancreas. These types of rare tumors are called islet cell tumors, pancreatic endocrine neoplasms, or pancreatic neuroendocrine tumors. They are generally less aggressive and may be curable if detected early. It is important to distinguish between exocrine and endocrine tumors because each has different signs and **symptoms**, is diagnosed using different tests, has different treatments, and has different **prognoses** (likely course of the disease).³

Precursors to Pancreatic Cancer

An understanding of the lesions that give rise to pancreatic cancer is important because many of these precursor lesions can be identified and removed before they cause pancreatic cancer. Some of these precursors form cysts, which are collections of fluid within the pancreas.

Pancreatic Cysts

More than 2% of American adults have a **pancreatic cyst**.¹⁰ Improvements in **imaging tests** over the past decade have led to a significant increase in the number of patients found to have a cyst in their pancreas. Most of these cysts are harmless and can be safely watched and followed.¹¹

Intraductal papillary mucinous neoplasms (IPMNs) and mucinous cystic neoplasms (MCNs) have been recognized as special types of cysts in the pancreas because they are precursor lesions^{10,11} that can later progress to invasive cancers if left untreated. Both IPMNs and MCNs are called “mucinous” because they produce large amounts of mucus, which, in the case of IPMNs, may clog and enlarge the pancreatic duct. IPMNs and MCNs are very different from most pancreatic tumors because they may be present for a long time without spreading. Surgical removal is the treatment of choice for IPMN cysts that are at high risk for progressing to invasive pancreatic cancer.^{10,11} However, doctors have to balance the

risk of overtreating patients who have harmless cysts with the benefit of removing a precancerous lesion. Many small IPMN cysts can safely be followed with annual surveillance imaging, most commonly using **magnetic resonance imaging (MRI)** scans.

Because it can be hard to tell which IPMNs and MCNs are precancerous and which are harmless, researchers have been studying them and their genetic makeup for new ways to determine which are more likely to progress to pancreatic cancer.¹² Lustgarten-funded researchers at Johns Hopkins are actively developing new molecular tests to better classify pancreatic cysts and have identified a panel of molecular markers and clinical features that show promise for classifying pancreatic cysts and determining which cysts require surgery.¹³ This panel has the potential to lower the number of unnecessary surgeries by an overwhelming 91%. This more specific panel of markers is likely to provide physicians with additional information to help them determine whether surgery or surveillance of the cyst(s) is the most appropriate course of action for their patients, based on the type of mutation they see in a particular cyst.¹³ Avoiding unnecessary pancreatic surgery is important, and this research on cysts is one step forward.

2.2 – Causes

Genes and Pancreatic Cancer

All the cells in the body contain **DNA**. DNA is the molecule in the cell nucleus that carries the instructions (**genes**) for making living organisms.¹⁴ When cells grow and divide, they also copy their DNA.

Additional research conducted at Johns Hopkins found that random, unpredictable “mistakes” that occur when DNA is copied account for most cancer **mutations**, and that environmental factors, such as cigarette smoking, account for another 29%.¹⁵ 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 can also fail. When they do, these mistakes in DNA can be passed along to future copies of the altered cell. More abnormal cells can then be produced and when these abnormal cells continue to grow unchecked, cancer may develop.¹⁶

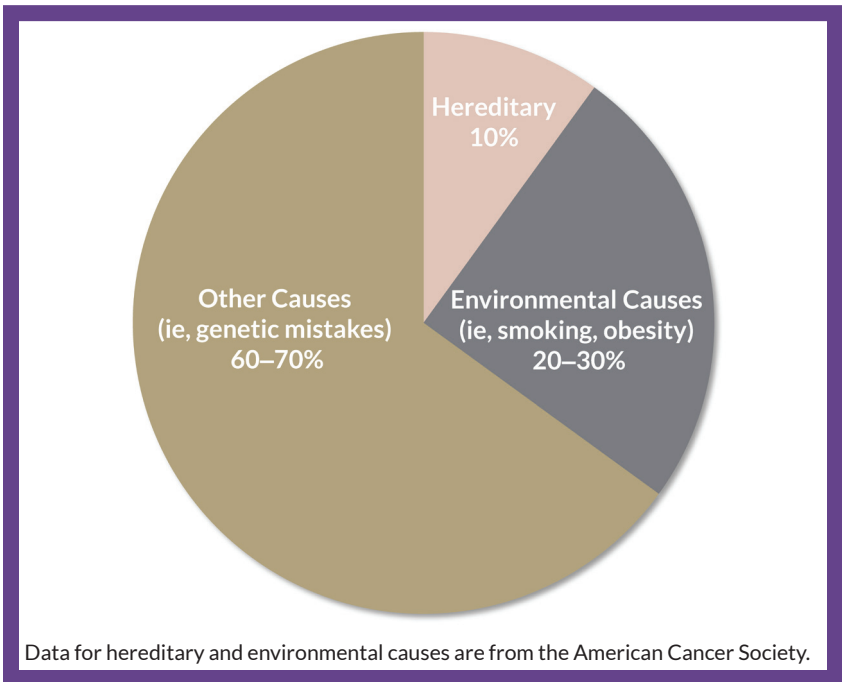
The DNA mutations that cause pancreatic cancer may be either inherited from a parent or acquired as we age.⁷ **Inherited mutations** are carried in the DNA of a person’s reproductive cells and can be passed on to that person’s children.¹⁶

Not everyone who has an inherited mutation will develop pancreatic cancer. It is important to note that pancreatic cancer is relatively rare, striking only 12 to 13 people per 100,000 each year in the United States, so even doubling a rare risk still means that the risk is very low.²

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 the carcinogens in tobacco smoke or cosmic rays.¹⁶ Scientists believe that most cancers result from complex DNA changes that involve many different genes.¹⁷ Some of these environmental factors are called **risk factors**. Certain risk factors increase the chances of a person developing cancer.¹⁶ ***Not everyone who has an acquired mutation will develop pancreatic cancer.***

Family History and Pancreatic Cancer

Pancreatic cancer may be inherited because it can run in families.⁷ This means that blood relatives of patients with pancreatic cancer may have an increased risk of developing the disease. The risk depends on the gene inherited. If the gene inherited isn't known, inherited risk can still be estimated based on the number of a person's **first-degree relatives** (ie, a sibling, parent, or child) who have been diagnosed with pancreatic cancer.¹⁸ One first-degree relative with pancreatic cancer confers a two-fold to four-fold risk, two first-degree relatives increase the risk by six-fold or seven-fold, and three first-degree relatives, which is highly unusual, results in a 32-fold risk. Having a family member who had a young age of onset of pancreatic cancer (younger than 50 years of age) confers an added risk of pancreatic cancer.¹⁴ **However, not everyone with a family history of pancreatic cancer will develop the disease.**



Inherited mutations in known cancer-causing genes such as **BRCA2**, **BRCA1**, **PALB2**, **p16/CDKN2A**, **ATM**, **STK11**, **PRSS1**, **SPINK1**, and in one of the DNA mismatch repair genes (ie, DNA is not properly repaired) have been shown to increase the risk of developing pancreatic cancer. These genes are therefore called familial pancreatic cancer genes.^{19,20} **However, not everyone who has one of these mutations will develop pancreatic cancer.**

It is estimated that 10% of pancreatic cancer is familial.¹⁹ Researchers believe that studying the specific cancer genes that cause pancreatic cancer to run in some families will help quantify the risk in families, form the foundation for screening for precursor lesions and early cancers, and may form the basis for new treatments of established cancers.¹⁹⁻²² Researchers around the world, therefore, have set up pancreatic cancer registries to study the hereditary factors that influence pancreatic cancer. The qualifications for joining a registry may vary from one registry to another and may include providing answers to a questionnaire and a blood or saliva sample.²³ Some registries enroll patients and family members who have at least one relative who has pancreatic cancer. Other registries require that enrollees have at least two relatives who have pancreatic cancer. Registry participants must be 18 years of age or older. (See the Appendix for more information and a list of registries.)

Screening for pancreatic cancer is also underway through the Cancer of the Pancreas Screening-5 (CAPS5) Study, funded by the National Institutes of Health and the American Association for Cancer Research. The CAPS5 study focuses on people who have a high risk for the disease due to a family history (at least two relatives) or genetic mutation and provides pancreatic cancer surveillance using a combination of endoscopic ultrasonography, MRIs, and **computed tomography (CT) scans**. The main research site of the CAPS5 study is Johns Hopkins Hospital (Baltimore, MD). The study is also being conducted at Case Comprehensive Cancer Center, Case Western Reserve University (Cleveland, OH); Columbia University Medical Center (New York, NY); Dana-Farber Cancer Institute (Boston, MA); University of Michigan (Ann Arbor, MI); University of Pennsylvania (Philadelphia, PA); University of Pittsburgh (Pittsburgh, PA); and Yale University (New Haven, CT). Information and eligibility criteria are available at clinicaltrials.gov/ct2/show/NCT02000089. There are other ongoing studies working to identify high-risk people through patients who have genetic mutations, including the GENERATE study (generatestudy.org).

Additionally, because some individuals with an inherited germline genetic mutation do not have a strong family history of cancer, the standard guidelines for treating patients with pancreatic cancer recommend that all patients with pancreatic cancer have germline genetic testing.²⁴ New research funded in part by the Pancreatic Cancer Collective, an initiative of Lustgarten Foundation and Stand Up To Cancer, and conducted by researchers at the Mayo Clinic and Johns Hopkins, suggests that these genetic testing recommendations miss genetic predispositions to cancer in as many as 90% of patients who have no family history of the disease.²⁵ This finding suggests that family

members of patients with an inherited mutation should have DNA testing to understand their risk for cancer, and that family history alone cannot predict who has the hereditary mutations that could cause the disease. In addition, certain germline genetic mutations, such as germline mutations in the *BRCA2* gene, make the pancreatic cancers that arise in these patients extremely responsive to specific therapies.²⁴ Germline testing therefore has implications for family members and for the patient.

Hereditary Syndromes

Hereditary syndromes are inherited genetic mutations in one or more genes that may predispose the affected individual to the development of certain cancers and may also cause the early age of onset of these cancers. The hereditary syndromes listed below have been associated with the development of pancreatic cancer.

Familial Breast Cancer Syndrome. People who have the breast cancer 2 (*BRCA2*) gene mutation have an increased risk of several cancers, among them pancreatic adenocarcinoma.²⁶ Inherited mutations in the *BRCA2* gene are particularly common in the Ashkenazi Jewish population.²⁶ It has recently been suggested that cancers that arise in patients with a *BRCA2* mutation may be particularly responsive to treatment with drugs called PARP inhibitors. Although the association is not as strong as it is with *BRCA2*, inherited mutations in other breast cancer genes, including *PALB2* and *BRCA1*, may also increase the risk of pancreatic cancer.²⁷ PARP inhibitors also work to treat pancreatic cancer that results from a *BRCA1* or *PALB2* mutation.

Familial Atypical Multiple Mole Melanoma (FAMMM) Syndrome. People with FAMMM syndrome, also called *p16/Leiden*, have many skin moles that are asymmetrical and raised.^{1,28} Most cases of FAMMM syndrome are caused by inherited mutations in the *p16/CDKN2A* gene.¹⁹ One study of people with a *p16/Leiden* gene mutation demonstrated a 17% risk of pancreatic cancer by the age of 75.²⁸ Patients with FAMMM syndrome also have an increased risk of developing **melanoma**, a type of skin cancer.

Peutz-Jeghers Syndrome (PJS). People with this rare syndrome have mutations in the *STK11/LKB1* gene. Polyps in the small intestine and dark spots on the mouth and fingers characterize the syndrome.²⁹ In people with PJS, the risks of gastrointestinal tumors such as esophageal, small bowel, colorectal, and pancreatic cancer are increased.³⁰ The risk of having pancreatic ductal adenocarcinoma over one's lifetime is 11% to 26%.³¹

Hereditary Pancreatitis. Hereditary pancreatitis is a rare disease in which patients develop episodes of severe recurrent **pancreatitis** at an early age.³² The main genes related to this disorder are *PRSS1*, *SPINK1*, and the cystic fibrosis gene, *CFTR*. About 30% to 40% of people with hereditary pancreatitis will develop pancreatic cancer by age 70, and the risk is especially high among patients with hereditary pancreatitis who also smoke cigarettes.³¹

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.³³ People with this disorder have inherited mutations in DNA mismatch repair genes.³¹ As of 2019, the drug pembrolizumab (Keytruda) has shown it may be very effective in the treatment of cancers that arise in patients with HNPCC who develop pancreatic cancer.³⁴

Partner and Localizer of BRCA2 (PALB2). As noted above, mutations in this gene, which is related to *BRCA2*, also increase the risk of breast and pancreatic cancers.³⁵

ATM. Inherited mutations in this gene increase the risk of pancreatic cancer.

Risk Factors

Risk factors are characteristics, habits, or environmental exposures that have been shown to increase the odds of developing a disease. Some can be controlled, while others cannot.

Risk Factors You Can Influence

Smoking. Smoking or being exposed to secondhand smoke is the leading preventable cause of pancreatic cancer. People who smoke have twice the chance of getting pancreatic cancer compared with people who do not smoke.³⁶ Importantly, the risk of cancer falls after smoking cessation. Smokers who quit demonstrate a decrease, over time, in their risk of developing pancreatic cancer, and after 20 years the risk in ex-smokers is the same as that of nonsmokers.³⁷

Obesity. People who are significantly overweight are more likely to develop pancreatic cancer compared with those who are not overweight, with those patients who are obese during their teens and twenties having the highest risk.³⁶

Exposure to Workplace Chemicals

Exposure to certain chemicals used in the dry cleaning and metal working industries may increase a person's risk of pancreatic cancer, but most of this risk is seen only with heavy, long-term exposures.³⁶

Other Risk Factors

Age. As people get older, their risk of pancreatic cancer increases. Pancreatic cancer mostly affects people 55 years of age or older.^{2,36}

Race. In the United States, pancreatic cancer is more common in African Americans than in Caucasians^{2,36} although 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.

Medical Factors. The incidence of pancreatic cancer is higher in people who have any of the following medical conditions^{9,36}:

- **Chronic pancreatitis** (inflammation that causes irreversible damage to the pancreas)
- Long-term **diabetes mellitus** (high blood sugar)
- *Helicobacter pylori* infection or ulcers

Adult-Onset Diabetes. Long-term diabetes is a risk factor for pancreatic cancer. New-onset diabetes in an older person can be the first manifestation of pancreatic cancer.³⁶ In fact, up to 80% of patients with pancreatic cancer are either prediabetic or are in a presymptomatic phase of diabetes.³⁸

Presence of Risk Factors

When a person has one or even more than one of these risk factors, it does not mean that the person will develop pancreatic cancer. Conversely, some people who do not have risk factors will still get pancreatic cancer. Researchers are working to understand how lifestyle and environmental risk factors interact with an individual's genetic makeup to influence pancreatic cancer development. Most importantly, the best way to reduce your risk of developing pancreatic cancer is to not smoke and to maintain a healthy body weight.³⁹

2.3 – Signs and Symptoms

A Silent Disease

Pancreatic cancer is often 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.

SIGNS AND SYMPTOMS TO TAKE SERIOUSLY⁴⁰⁻⁴³

- Jaundice, with or without
 - Itching
 - Dark urine
 - Light-colored stool
- General symptoms
 - Back pain
 - Fatigue or weakness
- Other illnesses
 - Pancreatitis
 - New-onset diabetes in an adult
- Digestive problems
 - Unexplained weight loss
 - Loss of appetite
 - Malnutrition
 - Nausea or vomiting
 - Abdominal pain
- Blood clots
 - Pain, swelling, redness, and warmth in the leg
 - Chest pain or trouble breathing

Jaundice

Jaundice is a yellowing of the skin and the whites of the eyes. Signs and symptoms that may occur with jaundice are itching (which may be severe), dark urine, and light or clay-colored stool.⁴⁰ Jaundice occurs when **bilirubin** stains the skin. Bilirubin is a dark yellow substance made in the liver that 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.

There are other, more common causes of jaundice, such as **hepatitis** (inflammation of the liver) or obstruction of the bile duct by a gallstone.⁴⁴

Itchy skin

Skin can start to itch or turn yellow when bilirubin builds up in the skin.⁴⁴

Back Pain

This common sign of advanced pancreatic cancer occurs when the tumor presses on organs and nerves around the pancreas.⁴⁰ The pain may be constant or intermittent and can be worse after eating or when lying down. Many conditions other than pancreatic cancer can also cause back pain, which makes this a challenging symptom.

Other Illnesses

Pancreatitis

An inflammation of the pancreas called pancreatitis can be a sign of pancreatic cancer when pancreatitis is chronic or when it appears for the first time and is not related to either drinking alcohol or gallstones.⁴⁰

Diabetes

Developing **diabetes mellitus** (high blood sugar), especially after the age of 50, can be a sign of pancreatic cancer.⁴⁰ Most patients with diabetes, however, will not develop pancreatic cancer. As noted earlier, long-term diabetes is also a risk factor for pancreatic cancer.

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.⁴⁰ 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, at which time a doctor should be consulted.

Nausea or Vomiting

If the tumor blocks the upper part of the small intestine (the duodenum), nausea and vomiting may result.⁴⁰

Abdominal Pain

Similar to back pain, abdominal pain is a common sign of advanced pancreatic cancer that occurs when the tumor presses on organs and nerves around the pancreas.⁴⁰ Many conditions other than pancreatic cancer can also cause abdominal pain, which makes this a challenging symptom.

Blood Clots

Pancreatic cancer can cause blood to clot more easily and can be the first sign of a tumor.⁴⁰ These clots occur in the veins and can block blood flow. They can occur in the legs (deep vein thrombosis), lung (pulmonary embolism), or organs such as the pancreas itself or liver (portal vein thrombosis).^{40-43,45}

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 as soon as possible. If you have a first-degree relative (parent, sibling, or child) with pancreatic cancer, tell your doctor and consider joining a pancreatic cancer registry. (*See the Appendix.*)

Cancer registries are used to collect accurate and complete data about people with cancer that can be used for cancer control and epidemiological research, public health program planning, and improvements in patient care.⁴⁶ Collecting this information also increases the chances of finding a cure, because these data help physicians and researchers learn more about the causes of cancer and how to detect cancer earlier.

Data from registries may point out environmental risk factors or high-risk behaviors, so that measures to prevent people from getting cancer can be identified.⁴⁶ Additionally, local, state, and national cancer agencies and cancer control programs may use registry data from defined areas to make important decisions about public health.

2.4 – Diagnosis

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**. Answering these questions honestly and completely will help both you and your doctor during the diagnostic process.

MEDICAL HISTORY QUESTIONS

- Do you have pain?
 - Where is the pain located?
 - How long have you had the pain?
 - How intense is the pain (ie, on a scale from 0 to 10)?
 - Is there something you can do that makes the pain go away?
 - Is there something you can do that causes the pain to come back?
- 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?

A doctor will perform a physical examination and 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, and any sign of jaundice will be noted. Your doctor also may order blood or urine tests, testing of stool samples, or **imaging tests**.

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.¹

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 or by other cells as the body's response to cancer. **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.

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)**.⁴⁷ 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 substance found on the surface of certain types of cells and is shed by tumor cells, making it useful in following the course of cancer.⁴⁷ 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 CA 19-9 in pancreatic cancer testing.⁴⁸

Lustgarten Foundation funded researchers at Johns Hopkins who designed a blood test called CancerSEEK that detects the presence of pancreatic cancer as part of a panel of eight common cancers (pancreas, ovary, liver, stomach, **esophagus**, colorectum, lung, and breast).⁴⁹ CancerSEEK detects genetic alterations and proteins from cancer cells. It can identify the presence of relatively early cancer, and can detect the organ of origin of the cancer. This test, still in the research phase, is an important breakthrough because these eight cancers account for more than 60% of US cancer deaths.⁴⁹ Additionally, there is no currently available screening test for five of these cancers, including pancreatic cancer. It is hoped that this test could be offered as part of routine medical checks. In 2018, the US Food and Drug Administration (FDA) granted expedited review of the pancreatic and ovarian cancer portions of CancerSEEK. This will accelerate the development process of this important blood test.

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 confirm a diagnosis of pancreatic cancer. Liver function tests will also be performed on blood samples to determine if a tumor is affecting the liver.

Imaging Tests

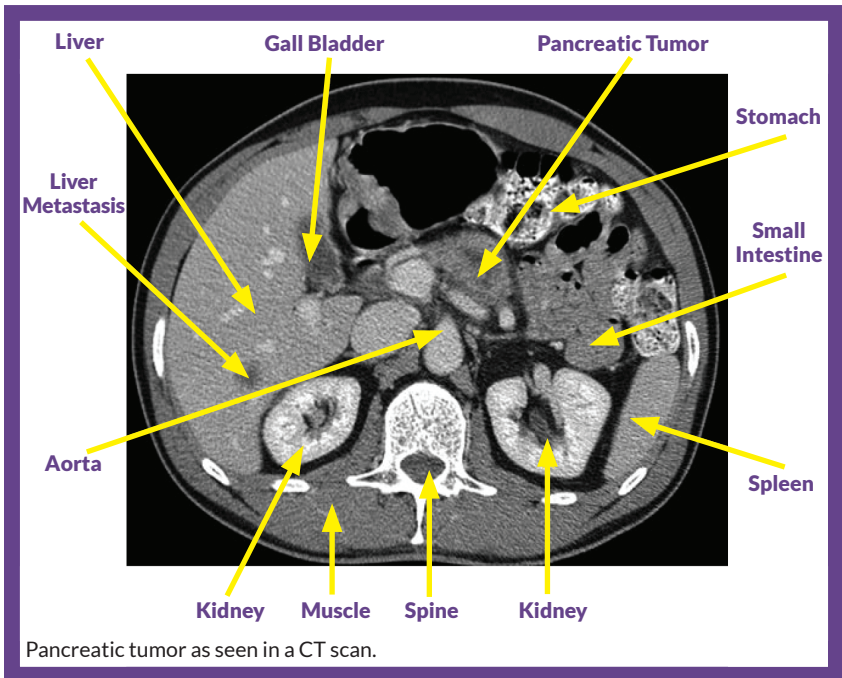
Imaging tests are important tests used to detect pancreatic cancer. These tests use a variety of methods to see inside the body. Some typical imaging tests are described in this section, and their uses are listed below. **Computed tomography (CT) scans** of the chest, abdomen, and pelvis are most commonly used in the diagnosis of pancreatic cancer. Your treating physician or surgeon can select the tests that are most useful in your care. Most patients need only one or a few imaging studies.

CT Scan

A **CT scan**, formerly called a computed axial tomography (CAT) scan, uses a large machine shaped like a doughnut to take detailed, cross-sectional X-ray images from many different angles while you lie on a table that moves into the machine. The computer combines these images into a series of views of the area in question for diagnostic purposes.

A CT scan may be done at a special center or in a hospital, but it 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.



In many centers, modifications of basic CT scanners are used to image the pancreas more accurately. A **multiphase CT scan** is a sensitive imaging test used to evaluate patients suspected of having pancreatic cancer. Multiphase CT scanning may produce detailed, 3-dimensional images of the pancreas.

A helical CT scanner with multiple detector rows, called a **multidetector row helical CT (MDCT)** scan, is one of the latest technological advances in CT scanners. The CT scans can be performed with special sequences to evaluate the pancreas.

Ultrasound

An **ultrasound**, also known as a sonogram, helps physicians look for tumors in areas of the body that do not show up well on X-rays. Physicians frequently use ultrasounds to guide a needle during a **biopsy**. They can usually be done quickly and don't require special preparation or exposure to radiation.

Endoscopic ultrasound (EUS) and **laparoscopic ultrasound (LUS)** are minimally invasive procedures. An endoscopy is a medical procedure in which a physician examines the inside of the body using a thin, tube-like instrument with a light and lens for viewing. During EUS, an **endoscope** is passed down the esophagus, through the stomach, and into the **duodenum**. A machine that makes the sound waves is then turned on, and images are created by visualizing the pancreas through the stomach or the duodenum. A laparoscopic ultrasound uses a **laparoscope**, inserted through a small incision in the abdominal wall, to view internal organs and remove tissue samples for examination.

Advantages of EUS are that the ultrasound probe can be placed immediately adjacent to the pancreas, producing detailed images.⁵⁰ It also allows for biopsies of the pancreas to be obtained to confirm the presence of cancer.

Magnetic Resonance Imaging (MRI)

MRI is a noninvasive, painless imaging method that is commonly used. 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 for imaging the pancreas.

MRI uses powerful magnets, instead of X-rays as in a CT scan, to view internal structures and organs.^{1,51} Since it does not involve radiation, MRI may be safer in patients who require repeated imaging over many years, such as patients with pancreatic cysts. The energy from the radio waves is absorbed by the body 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.

MRIs are 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, prosthetic 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

A **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.¹ Cancer cells take up sugar at higher rates than normal cells. A special camera detects the radioactivity that is taken up by **malignant** tissue, and a computer creates detailed images. 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 where cancer is located within the body.

Endoscopic Retrograde Cholangiopancreatography (ERCP)

ERCP is an invasive procedure that is used in conjunction with a dye to view the bile ducts and pancreatic ducts for obstructions.¹ 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 bile duct and pancreatic duct so that the dye can be injected into them. Then, X-rays are taken. This is an outpatient procedure but also may be performed in the hospital.

ERCP is especially helpful in patients with jaundice because a **stent** can be inserted into the bile duct and left in place to keep the bile duct open, often relieving the jaundice and its associated symptoms. Tissue samples also can be taken during the procedure.¹ ERCP can cause complications, and is usually used to help manage symptoms and not for diagnostic purposes.⁵¹

Biopsy

Because the only definitive way to diagnose cancer is to directly visualize cancer cells under a microscope, after having the necessary blood tests and scans, 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.⁵²

A biopsy can be performed in an outpatient setting or in the hospital. **Biopsy specimens** can be obtained in different ways, as listed below.

Fine-Needle Aspiration (FNA) Biopsy

In an FNA biopsy, imaging by CT scan or EUS is used together with a long, thin needle to obtain tissue specimens.⁵² The CT scan 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.

Brush Biopsy

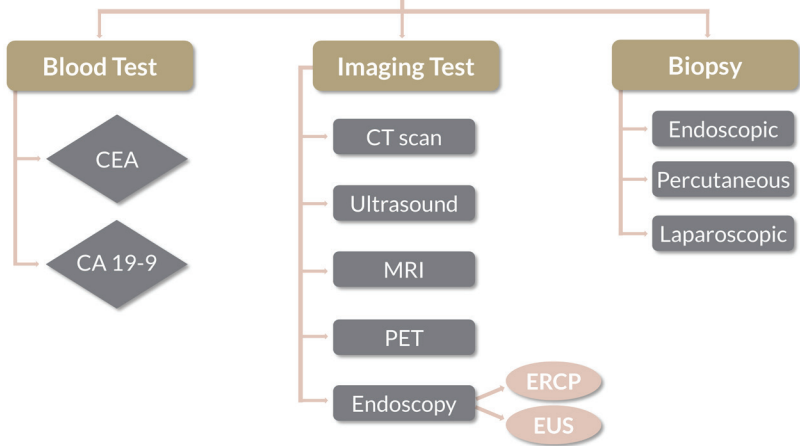
A **brush biopsy** procedure is used with ERCP. A small brush is inserted through an endoscope into the bile and pancreatic ducts.⁵² Cells are scraped off the insides of the ducts with the brush.

Laparoscopy

Laparoscopy is a minimally invasive surgical procedure. You will receive general anesthesia during the procedure. A laparoscope is inserted through a small incision in the abdomen.⁵² The doctor can then view the tumor and remove tissue samples for examination.

Methods for Diagnosing Pancreatic Cancer

(Your treating physician or surgeon will select the imaging tests that are most useful for your care)



CA, carbohydrate antigen; CEA, carcinoembryonic antigen; CT, computed tomography; ERCP, endoscopic retrograde cholangiopancreatography; EUS, endoscopic ultrasound; MRI, magnetic resonance imaging; PET, positron emission tomography.

2.5 – About Lustgarten Foundation

Since our inception, we have been committed to changing patient outcomes, so patients not only have more time, but more high-quality time and a better chance for long-term survival. To accomplish this goal, we have a focused and unique research strategy, which encompasses four key drivers:

Focus on patients: Advance research to deliver improved outcomes for patients.

Integrate science: Increase the impact of funding through the coordination of academic work with translational groups, industry, and clinicians.

Maximize leverage: Expand the impact of Foundation funds by matching investments of partners and industry.

Cultivate experts: Recruit the best experts in the world from a variety of disciplines and fields to work on pancreatic cancer.

Using these drivers as a guide, we have committed millions of dollars through our multiple grant programs. Our research focuses on earlier detection, personalized medicine, drug development, tumor biology and microenvironment, and immunotherapy.

For our earlier detection and early intervention program, we are working to significantly increase both the number of patients able to have surgery and improved outcomes for these patients and to develop innovative earlier diagnosis techniques. We are supporting research that advances personalized medicine by identifying existing therapies that can be used off-label and determining new combination treatments. We are applying our understanding of the biology behind pancreatic cancer to support clinical trials that will help to identify druggable targets, leading to the development of new therapies. Additionally, we fund dedicated pancreatic cancer research laboratories that are increasing collaborations between pancreatic cancer researchers and exploring new, promising avenues for understanding and treating this disease.

Research Milestones

Pancreatic cancer research is moving faster than ever before. There has never been a more hopeful time for patients and we know this trend will continue. At press time, the following were some recent research breakthroughs. We encourage you to visit lustgarten.org and letswinpc.org for the latest information.

Immunotherapy: Focusing on a Promising New Approach to Pancreatic Cancer Treatment

Immunotherapy, which involves using a person's own immune system to fight and destroy cancer cells, is considered by many leading researchers to represent the future of cancer treatment. In 2017, in an unprecedented, fast-tracked review, the US Food and Drug Administration (FDA) approved Keytruda (pembrolizumab) as the first immunotherapy treatment for patients with advanced pancreatic cancer whose tumors have a unique mutation called mismatch repair deficiency. This deficiency alters their capacity to repair DNA, which is a factor in cancer development. It is estimated that approximately 1 in 50 patients with advanced pancreatic cancer have tumors that are mismatch repair deficient, making them candidates for this type of therapy. Keytruda is the first cancer drug based on a genetic characteristic, rather than tumor site, to be approved by the FDA for use in patients with pancreatic cancer. The Foundation played a critical role in bringing this new treatment to patients by funding the research, encouraging patients to get tested, and funding patients' testing to determine if their tumors are mismatch repair deficient.

Earlier Detection: Finding Cancer Through a Single Blood Test

Lustgarten-funded researchers have designed a blood test called CancerSEEK that can detect the presence of pancreatic cancer as well as ovary, liver, stomach, esophagus, colorectal, lung, and breast cancers. The test has the capacity to not only identify the presence of relatively early cancer, but also to identify the organ of origin of these cancers.

The test results for pancreatic cancer were very promising. The sensitivity of the detection method was 72% and the specificity was greater than 99%. Sensitivity and specificity are terms used to evaluate a clinical test. **Sensitivity** is the ability of a test to correctly identify those with the disease (true positive), whereas test **specificity** is the ability of a test to correctly identify those without the disease (true negative). New blood tests for cancer must have very high specificity; otherwise, too many healthy individuals will receive positive test results, leading to unnecessary follow-up procedures and anxiety. This test is so critical because these eight cancers account for more than 60% of US cancer deaths, and pancreatic cancer and four other cancers in the panel have

no screening test available. This study lays the foundation for a single blood screening test for multiple cancers that could be offered as part of routine medical checks. In 2018, the FDA granted expedited review of the pancreatic and ovarian cancer portions of CancerSEEK, which is accelerating the development process of this important blood test.

Personalized Medicine: Tailoring Treatment Based on Specific Mutations

Researchers at Dana-Farber Cancer Institute are advancing personalized medicine by working to give each patient treatment that is tailored to his or her tumor. Now part of their protocol, Dana-Farber takes a two-pronged approach to implementing personalized medicine. The first approach focuses on genetic sequencing of both the tumor DNA and the inherited DNA, in order to have the sequencing data available in 6 to 8 weeks, the point at which follow-up CT scans show if the current treatment is working. The sequencing findings are then used to identify new treatment options for patients, which may include off-label use of medications that treat other cancers or clinical trial enrollment.

The second personalized medicine strategy being used at Dana-Farber involves growing organoids in the laboratory from fresh tissue biopsies, which provides an opportunity to go beyond DNA sequencing to identify new therapy approaches. Organoids for pancreatic cancer were first developed by the Foundation's Chief Scientist, Dr. David Tuveson, at the dedicated Lustgarten Foundation Pancreatic Cancer Research Laboratory at Cold Spring Harbor Laboratory. An organoid is a 3-dimensional cell culture system that reproduces a patient's tumor in a dish in order to test it repeatedly with different drugs, with the aim of identifying new potential treatments. Researchers have demonstrated that organoids can accurately predict how a patient with pancreatic cancer will respond to a variety of treatments. This translational technology offers the hope of personalized cancer treatments in the future.

Pancreatic Cancer Collective: Accelerating Pancreatic Cancer Research

The need to do more is at the root of the collaboration between Stand Up To Cancer (SU2C) and Lustgarten Foundation. Working together since 2012, this relationship has flourished with a combined investment of nearly \$100 million for the most promising research advances. In 2018, the Foundation and SU2C entered into a formal strategic partnership by establishing the Pancreatic Cancer Collective (pancreaticcancercollective.org). The goal of the Collective is to accelerate research for patients with pancreatic cancer who desperately need better treatments. The Collective is attracting new collaborators, improving the diagnosis of pancreatic cancer, using technology and data to develop new treatments for pancreatic cancer, and supporting the next generation of pancreatic cancer investigators.

Patient Support

Our research focuses on offering the best outcomes for patients and the latest, most up-to-date information on our website (lustgarten.org). In addition to our research initiatives, we strive to provide patients and their loved ones with valuable resources to help them navigate pancreatic cancer. Through our affiliation with Let's Win! Pancreatic Cancer (letswinpc.org), an interactive online community, patients and families can share information and experiences about innovative treatments. We also offer an online support community, Pancreatic Cancer Connections, accessible through inspire.com, and provide patients with the Lustgarten and Let's Win Pancreatic Cancer Clinical Trial Matching Service, a free matching and referral service accessible from our website. Our Interview with an Expert Q&A series features experts answering questions on topics related to pancreatic cancer.

For more information, visit lustgarten.org.

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.

1. What type of pancreatic cancer do I have, and what is the stage (resectable, borderline resectable, locally advanced, or metastatic)?
2. Should I have any additional tests to more accurately stage my cancer?
3. What is the treatment plan 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. Who will be part of my care team?

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

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

10. If I have borderline resectable or locally advanced pancreatic cancer, what will your institution do to try to make my cancer resectable?

11. Will my blood or saliva be tested to identify possible genetic predispositions to cancer?

12. Will a tumor biopsy be performed to check for genetic mutations in my tumor?

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 a less-experienced surgeon 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.

1. What is the goal of 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 resections with no residual disease do you perform each year?
5. How many pancreatic surgical procedures are done at this hospital, and how often?

6. What are the approximate out-of-pocket expenses for my treatment?
7. How long will the surgery take?
8. How long will I be in the hospital?
9. What are all of the complications that can occur?
10. How much time do I have to get a second opinion, think about other options, and make a decision?
11. Will I receive any treatment(s) before or after my surgery?
12. Can you estimate the amount of time I may need to recover from surgery?

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GLOSSARY

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

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 that damage *DNA*.

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

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

Adenocarcinoma – Cancer that has gland-like properties.

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

Adjuvant therapy – Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back.

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 is unable to do so.

Alternative therapy – Treatments that have not been scientifically tested and are used in place of traditional therapies.

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 (*tricyclic antidepressants*).

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

Bile – Green 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 from the liver through which *bile* passes.

Bilirubin – Dark yellow 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*.

Biopsy – Process of removing small tissue samples, which are then examined under a microscope by a pathologist 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 repair certain types of DNA damage; a person who inherits an altered mutant 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 repair certain types of DNA damage; a person who inherits an altered mutant 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 substance on the surface of cells, particularly cancerous cells, that is shed into the bloodstream; higher than normal amounts of CA 19-9 in the blood can sometimes be a sign of colorectal or pancreatic 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 therapy – *Radiation therapy* used in combination with *chemotherapy*.

Chemotherapy – Use of drugs to kill cancer cells.

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*.)

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 in which 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.

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 of blood sugar; 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 is unable to do so.

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

Endocrine tissue – Secretes its hormone directly into the bloodstream that flows through it, rather than through an opening; endocrine tissue comprises 5% 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 ultrasound (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* naturally produced by the body that speed up chemical reactions in the body; enzymes help the body with functions such as digesting food.

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, through the diaphragm, and joins the upper end of the stomach.

Exocrine tissue – Secretes its fluid through a duct; exocrine tissue comprises 95% 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 skin moles are present; it is associated with an increased risk of *melanoma* and of pancreatic cancer.

Familial breast cancer syndrome – People who have a breast cancer gene (*BRCA2*, *BRCA1*, or *PALB2*) mutation have an increased risk of several cancers, among them breast and 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 inherit a gene mutation (in genes such as *PRSS1* and *SPINK1*) that predisposes them to develop episodes of recurrent *pancreatitis* at an early age.

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 – The last part of the small intestine, located beyond the *duodenum* and *jejunum*. The ileum drains into 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)*.

Immunotherapy – A type of *biological therapy* that uses substances to stimulate the immune system to help the body fight cancer, infection, and other diseases.

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 promoting the movement of sugar into the cells, where it can be used for energy.

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

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

Intravenous injection – Injection directly into a vein.

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.

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

Laparoscopic ultrasound (LUS) – 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. Cancer cells can spread to lymph nodes.

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

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.

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

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

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

Monoclonal antibodies – A type of targeted therapy; large molecules that attach to specific targets on the outside of cancer cells and can also mark cancer cells for the immune system to destroy.

Multidisciplinary care – Team approach to the care of patients with cancer in which many different areas of specialization join to provide their expertise and experience.

Multidetector 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.

Multiphase CT scan – Sensitive CT imaging test; may produce detailed, 3-dimensional images.

Mutations – Errors in the DNA code 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*.)

Neoadjuvant treatment or **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 into the nerve root of the *celiac plexus* using guidance by *ultrasonography* or *computed tomography* to produce numbness or reduce pain.

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

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

Nurse practitioner – A registered nurse who has additional education and training in how to diagnose and treat disease. In cancer care, a nurse practitioner may manage the primary care of patients and their families, based on a practice agreement with a doctor.

Oncology nurses – Nurses with specialized training in managing the treatment and care of patients with cancer; they may administer *chemotherapy* drugs, help in the 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 (eg, by helping patients find support groups and locate services).

Opioids – Strongest pain relievers available.

Palliative care – Healthcare that specializes in the relief of suffering and improvement in quality of life. In some instances, palliative care has been shown to prolong 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 both *pancreatic enzymes* to aid in the digestion of food and hormones such as *insulin* to control blood sugar levels.

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

Pancreatic cyst – A pocket of fluid in the pancreas. Most cysts are not cancerous and can be safely watched and followed.

Pancreatic ductal adenocarcinoma (PDAC) – Pancreatic cancer whose tumors are designated “ductal” because they microscopically form structures that resemble the pancreatic ducts.

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

Pancreaticoduodenectomy – (*See Whipple procedure.*)

Pancreatitis – Inflammation of the *pancreas*.

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 postoperative 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 characterized by polyps of the intestine and dark spots in the mouth and on the 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. Typically 15 to 30 patients are enrolled in this phase of a study.

Phase 2 – Determines if the new drug has the potential to be better than current treatments. In randomized phase 2 studies, more than 100 patients can be enrolled.

Phase 3 – Determines if the treatment is better than, as good as, or not as good as the accepted standard treatment. There are often several hundred participants in this phase of a study.

Physician 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 is unable to do so.

Prognosis – The likely course of a disease.

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 treatment – A conventional, traditional, or standard treatment that has been tested and is approved by the US 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.

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. Cigarette smoking is the leading preventable risk factor for developing pancreatic cancer.

Sensitivity – The ability of a test to correctly identify those persons with the disease (true positive).

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

Small-molecule drug – A type of targeted therapy; small enough to enter cancer cells easily and reach its targets inside the cells.

Specificity – The ability of a test to correctly identify those persons without the disease (true negative).

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.

Stereotactic body radiation therapy – A type of external radiation therapy that uses special equipment to position a patient and precisely deliver radiation to tumors in the body (except the brain).

Stroma – Supportive tissue surrounding the pancreatic tumor.

Subcutaneous – Under the skin.

Supportive care – In patients with cancer, use of medications and integrative therapies 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, Ultrasound – Also called a *sonogram*, *ultrasonogram*, or *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.

Whipple procedure – Surgical procedure, usually for 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

Cancer Organizations and Associations

American Cancer Society (ACS)

250 Williams Street NW
Atlanta, GA 30303
Phone: 800-227-2345
www.cancer.org

ACS provides general information, resources, and statistics about all forms of cancer.

American College of Surgeons Commission on Cancer

633 N. Saint Clair Street
Chicago, IL 60611-3295
800-621-4111
www.facs.org

This organization can help navigate the surgery process and assist in finding a surgeon.

National Cancer Institute (NCI)

BG 9609 MSC 9760
9609 Medical Center Drive
Bethesda, MD 20892-9760
Phone: 800-422-6237
www.cancer.gov

NCI offers a wealth of information including a patient hotline and clinical trial finder.

National Coalition for Cancer Survivorship (NCCS)

8455 Colesville Road, Suite 930
Silver Spring, MD 20910
Phone: 877-622-7937
Email: info@canceradvocacy.org
www.canceradvocacy.org

This cancer advocacy group promotes policy change to ensure quality cancer care.

The American Association for Cancer Research

615 Chestnut Street, 17th Floor
Philadelphia, PA 19106-4404
Phone: 215-440-9300
Email: aacr@aacr.org
www.aacr.org

The mission of the American Association for Cancer Research is to prevent and cure cancer through research, education, communication, and collaboration.

Clinical Trial Search Services

Many clinical trials are currently being conducted on pancreatic cancer. While we encourage you to use our Lustgarten and Let's Win Clinical Trial Matching Service at app.emergingmed.com/lustgarten/home, other clinical trial finders include:

ClinicalTrials.gov

<https://clinicaltrials.gov/>

CenterWatch Clinical Trials Listing Service

Phone: 866-219-3440
www.centerwatch.com

eCancerTrials

www.ecancertrials.com

Clara Health

Phone: 888-973-7445
Email: hello@clarahealth.com
www.clarahealth.com

Government Agencies

US Department of Veterans Affairs

Phone for VA Benefits: 800-827-1000
Phone for Healthcare Benefits: 877-222-8387
www.va.gov

Medicare

Phone: 800-MEDICARE (800-633-4227)
www.medicare.gov

Social Security Administration

Phone: 800-772-1213
www.ssa.gov

Hospice and Palliative Care

American Academy of Hospice and Palliative Medicine

8735 West Higgins Road, Suite 300

Chicago, IL 60631

Email: info@aahpm.org

www.palliativedoctors.org

This is the professional association for hospice and palliative medicine.

Hospice Care of America

3815 N. Mulford Road, #4

Rockford, IL 61114

Phone: 815-316-2700

Email: info@hospicecareofamerica.com

www.hospicecareofamerica.com

Hospice Care of America provides medications, medical equipment, counseling, and innovative symptom management in addition to assistance with comfort, general support, personal care, encouragement, and relief for caregivers.

National Association for Home Care & Hospice

228 Seventh Street, SE

Washington, DC 20003

Phone: 202-547-7424

www.nahc.org

The National Association for Home Care & Hospice (NAHC) is the largest and most respected professional association representing the interests of chronically ill, disabled, and dying Americans of all ages and the caregivers who provide them with in-home health and hospice services. NAHC provides some consumer information including a service provider directory: www.agencylocator.nahc.org

National Hospice and Palliative Care Organization

1731 King Street

Alexandria, VA 22314

Phone: 703-837-1500

Fax: 703-837-1233

www.nhpco.org

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.

Insurance and Financial Issues

Loyola Law School, Los Angeles

Cancer Legal Resource Center
919 Albany Street
Los Angeles, CA 90015
Phone: 213-736-1000
Assistance Hotline: 866-THE-CLRC (866-843-2572)
www.lls.edu

Loyola Law School provides free, confidential information and resources on cancer-related legal issues to patients, families, friends, employers, healthcare professionals, and others. Callers can also be matched with volunteer attorneys and other professionals for additional legal information.

National Association of Community Health Centers, Inc.

7501 Wisconsin Avenue, Suite 1100W
Bethesda, MD 20814
Phone: 301-347-0400
www.nachc.org

Community Health Centers serve as the primary medical home for more than 27 million people in 10,400 rural and urban communities across America.

NeedyMeds

P.O. Box 219
Gloucester, MA 01931
Phone: 800-503-6897
www.needy meds.org

NeedyMeds is a national nonprofit organization that maintains a website of free information on programs that help people who can't afford medications and healthcare costs. NeedyMeds also publishes information about resources for specific diseases. All of their information is accessible online, at no charge and without registration.

Patient Advocate Foundation

421 Butler Farm Road
Hampton, VA 23666
Phone: 800-532-5274
www.patientadvocate.org

Patient Advocate Foundation (PAF) is a national nonprofit organization that provides professional case management services to Americans with chronic, life-threatening, and debilitating illnesses. PAF case managers serve as active liaisons between the patient and his/her insurer, employer, and/or creditors to resolve insurance, job retention, and/or debt crisis matters as they relate to diagnosis.

Patient Information

Cancer.Net

Cancer.Net offers information for people with cancer and their families and caregivers, from the American Society of Clinical Oncology (ASCO), the voice of the world's cancer physicians and oncology professionals.

Coping With Cancer Magazine

www.copingmag.com

This easy-to-read magazine deals with coping with cancer.

Let's Win! Pancreatic Cancer Foundation

www.letswinpc.org

Patients and caregivers share information about new, innovative pancreatic cancer treatments and learn about the latest research breakthroughs.

Medline Plus Health Information

www.medlineplus.gov

Medline Plus provides a wealth of information from the National Library of Medicine written specifically for patients.

Medscape

www.medscape.com

Email: info@letswinpc.org

Medscape is a website providing access to medical information for clinicians; the organization also provides continuing education for physicians and health professionals.

OncoLink

Abramson Cancer Center of the University of Pennsylvania
3400 Spruce Street, 2 Donner
Philadelphia, PA 19104-4283
www.oncolink.org

OncoLink offers information for patients and healthcare providers written by oncologists.

PubMed

www.ncbi.nlm.nih.gov/pubmed

PubMed 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.

The Cancer Letter

www.cancerletter.com

The Cancer Letter offers information on cancer research and drug development. An independent weekly newsletter, this publication is the leading source of information on the development of cancer therapies, cancer research funding and healthcare finance, legislation, and policy.

The Lancet

www.thelancet.com

This weekly medical publication covers a variety of topics, including oncology.

Support

CancerCare, Inc.

275 Seventh Avenue
New York, NY 10001
Phone: 800-813-4673
Email: info@cancercare.org
www.cancercare.org

Services include counseling and support groups over the phone, online and in-person, educational workshops, publications, and financial and co-payment assistance.

NCI's LiveHelp Service

https://livehelp.cancer.gov/app/chat/chat_launch

Information specialists can answer questions about cancer, clinical trials, and the process of quitting smoking. LiveHelp is confidential and does not provide medical advice.

Pancreatic Cancer Connections

www.inspire.com/groups/pancreatic-cancer-connections/

Pancreatic Cancer Connections, a partnership between the Lustgarten Foundation, Let's Win! Pancreatic Cancer Foundation, and Inspire, is an easy-to-use, online support community where patients and their loved ones can communicate about pancreatic cancer with others impacted by the disease.

Travel and Housing Services

The Air Care Alliance

2060 State Highway 595

Lindrith, NM 87029

Phone: 888-260-9707

Email: mail@aircarealliance.org

www.aircarealliance.org

The Air Care Alliance is a nationwide association of humanitarian flying organizations. Members have safely flown over 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

Email: info@corpangelnetwork.org

www.corpangelnetwork.org

Corporate Angel Network is the only charitable organization whose sole mission is to transport cancer patients to the hospital where they need to go to receive a specialized form of treatment.

Healthcare Hospitality Network

22640 Hazel Lane

Rapid City, SD 57702

Phone: 800-542-9730

www.hhnetwork.org

The Healthcare Hospitality Network, Inc. (HHN) is a nationwide professional association of more than 200 unique, nonprofit organizations that provide lodging and supportive services to patients and families when confronted with medical emergencies. Each facility ensures a homelike environment to people who must travel to be with a patient or to receive necessary outpatient care.

Patient AirLift Services (PALS)

7110 Republic Airport, 2nd Floor
Farmingdale, NY 11735
Phone: 888-818-1231
Email: info@palservices.org
www.palservices.org

Patient AirLift Services is a nonprofit organization that arranges free air transportation for individuals requiring medical diagnosis, treatment, or follow-up who cannot afford or are unable to fly commercially. PALS also arranges volunteer flights for family members of patients as compassionate missions, to ensure patients have support when they are away from home for long periods.

Patient Travel Referral Program

www.patienttravel.org

The Patient Travel Referral program, a program of Mercy Medical Angels, provides information about all forms of charitable, long-distance, medically related transportation and provides referrals to all appropriate sources of help available in the national charitable medical transportation network.

Webinars/Apps

CancerAid

www.canceraid.com

Designed by doctors, patients, and caregivers, CancerAid is the number one cancer app in the US, UK, and Australia.

Webinar by Johns Hopkins

http://cloud.lp.hopkinsmedicine.org/PancreaticWebinar?utm_medium=cpcsocial&utm_source=Facebook&utm_campaign=Surgery&utm_term=PancreaticWebinar&utm_content=PancreaticCancer

This 30-minute webinar provides information about surgery, chemotherapy, and immunotherapy.

Registries, Screening Centers, and National Cancer Institute Designated Cancer Centers

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.

Columbia University Medical Center Pancreatic Disease Cohort: A Registry and Biospecimen Bank to Better Understand Pancreatic Disease

Columbia University

161 Fort Washington Avenue

New York, NY 10032

Contact: Vilma Rosario

Phone: 212-305-6033

Email: vr2222@columbia.edu

<http://columbiasurgery.org/clinical-trials/predict-pancreatic-disease-cohort-registry-and-biospecimen-bank-better-understand>

The specific aims of this project are to create a registry, as well as a biospecimen (blood, urine, tissue, stool, or saliva samples) bank for individuals with pancreatic disease (eg, pancreatic adenocarcinoma, pancreatitis, intraductal papillary mucinous neoplasm [IPMN], mucinous cystic neoplasm [MCN]), and pancreatic intraepithelial neoplasia (PanIN) or have been determined to be at high-risk for pancreatic cancer. It is anticipated that the knowledge derived will ultimately lead to improvements in the diagnosis, prevention, detection, and treatment of pancreatic cancer.

**Creighton University
School of Medicine
Hereditary Cancer Center**

2500 California Plaza
Omaha, NE 68178
Phone: 402-280-2700
<http://medschool.creighton.edu/centers/hcc/>

The Hereditary Cancer Center (HCC) at Creighton University conducts comprehensive research projects dealing with cancer of all anatomic sites. Its primary objective is devoted to cancer prevention resulting from identification of hereditary cancer syndromes with particular attention given to surveillance and management programs melded to the natural history of these particular hereditary disorders. The HCC places emphasis on the hereditary breast ovarian cancer syndrome, the familial typical multiple mole melanoma syndrome in association with pancreatic cancer, and the hereditary nonpolyposis colorectal cancer syndromes, also referred to as the Lynch syndrome.

**Dana-Farber Cancer Institute
Pancreatic Cancer Genes Study (PAGES)**

Phone: 617-632-3354
www.dana-farber.org/legacy/uploadedFiles/Library/adult-care/treatment-and-support/centers-and-programs/cancer-genetics-and-prevention/pages.pdf.

The Pancreatic Cancer Genes Study (PAGES) is an ongoing study at Dana-Farber with the goal of advancing research into genes that make a person susceptible to pancreatic cancer.

**Indiana University School of Medicine
Indiana Familial Pancreatic Cancer Roster**

Department of Medical / Molecular Genetics
Indiana University School of Medicine
975 West Walnut Street, #130
Indianapolis, IN 46202
Phone: 317-944-3966
www.familialcancer.iupui.edu/page04.htm.

Information is collected from families with multiple family members with pancreatic cancer or from an individual with pancreatic cancer diagnosed at a young age.

**Johns Hopkins Medicine Pathology
The Sol Goldman Pancreatic Cancer Research Center
National Familial Pancreas Tumor Registry**

The Johns Hopkins Hospital
1550 Orleans Street, CRB II, Room 341
Baltimore, MD 21231
Phone: 410-955-3512
Email: pancreas@jhmi.edu
www.pathology.jhu.edu/pancreas/nfptr/

The National Familial Pancreas Tumor Registry (NFPTR) is a research registry that was established at The Johns Hopkins Hospital. Participation involves the completion of a questionnaire about your health history and that of your family members. A blood sample may be requested.

**Memorial Sloan Kettering Cancer Center
Pancreatic Tumor Registry**

Dr. Robert C. Kurtz
Principal Investigator
Phone: 212-639-7620
Research Assistant Phone: 646-888-8319
www.mskcc.org/cancer-care/types/pancreatic/clinical-trials/familial-pancreatic-tumor-registry

This registry is collecting and analyzing data from people with the disease and their family members. The researchers are using this information to find out more about the genetic, environmental, and lifestyle factors that increase a person's risk of developing pancreatic cancer.

**Oregon Health & Science University
Oregon Pancreatic Tissue Registry**

Brenden-Colson Center for Pancreatic Care
Oregon Health & Science University
2730 SW Moody Avenue, CL4RS
Portland, OR 97201-5042
Phone: 503-494-8988
Email: optr@ohsu.edu
www.ohsu.edu/xd/education/schools/school-of-medicine/departments/clinical-departments/surgery/research/dos-registries.cfm

The Oregon Pancreatic Tissue Registry collects information and tissue samples from people with a family history of pancreatic cancer, related syndromes, or chronic pancreatitis.

**Thomas Jefferson University Hospital
The Jefferson Pancreas Tumor Registry**

1015 Walnut Street

Curtis Building, Suite 620

Philadelphia, PA 19107

Phone: 215-955-5542

<https://hospitals.jefferson.edu/departments-and-services/pancreas-biliary-and-related-cancer-center/registry.html>

Participants are asked to complete a detailed questionnaire and may be asked to submit a blood sample and/or cheek swab.

**University of Nebraska Medical Center
Pancreatic Cancer Collaborative Registry
Fred & Pamela Buffett Cancer Center**

Michelle Desler, MS

986805 Nebraska Medical Center

Omaha, NE 68198-6805

Phone: 402-559-8885

Email: mdesler@unmc.edu

<http://pccr.unmc.edu/>

The Pancreatic Cancer Collaborative Registry (PCCR) collects personal background information, medical, and family details, as well as dietary and environmental exposure history and a biospecimen registry from pancreatic cancer patients and their family members. One of the major goals of the PCCR is to help researchers identify what specifically causes pancreatic cancer, and possibly identify those individuals/families that are at increased risk for pancreatic as well as other cancers. Researchers may also identify those individuals who might benefit from screening measures to detect precancerous changes at an earlier and potentially more treatable stage.

**University of Utah
Huntsman Cancer Institute
Hereditary Gastrointestinal Cancer Registry**

2000 Circle of Hope, Room 4529

Salt Lake City, UT 84112

Phone: 801-585-1936

Toll free: 877-422-6860

Email: registry.coordinator@hci.utah.edu

<https://healthcare.utah.edu/huntsmancancerinstitute/screening-prevention/hereditary-gastrointestinal-cancers-registry.php>

People with a personal or family history of hereditary gastrointestinal syndromes or cancers and their family members may be eligible.

Screening Centers and Programs

Baylor College of Medicine

The Elkins Pancreas Center

Dan L. Duncan Comprehensive Cancer Center

7200 Cambridge St, 7th Floor

Houston, TX 77030

Phone: 713-798-2262

Toll free: 877-PANC-CTR (877-726-2287)

www.bcm.edu/healthcare/care-centers/pancreas-center/for-patients/pancreatic-cancer/screening

Patients meet with a pancreas specialist who will assess risk factors of pancreatic cancer; perform tests including an MRI, an endoscopic ultrasound, and bloodwork; and provide genetic counseling.

Cancer of the Pancreas Screening-5 (CAPS5) Study

CAPS5 is for those considered at high risk for pancreatic cancer due to a family history or genetic mutation. Participants are offered genetic counseling and pancreatic screening. Screenings may include a combination of endoscopic ultrasonography, MRI, and CT scans. The CAPS5 study is taking place at Case Comprehensive Cancer Center, Case Western Reserve University; Columbia University Medical Center; Dana-Farber Cancer Institute; Johns Hopkins Hospital; University of Michigan; University of Pennsylvania; University of Pittsburgh; and Yale University.

Case Comprehensive Cancer Center

Nancy Furrey, RN
Phone: 216-844-7314
Email: nancyfurrey@uhhospitals.org

Columbia University Medical Center

Fay Kastrinos, MD
Phone: 212-305-9337
Email: fk18@cumc.columbia.edu

Dana-Farber Cancer Institute

Chinedu Ukaegbu, MBBS, MPH
Phone: 617-632-6355
Email: chinedu_ukaegbu@dfci.harvard.edu

Johns Hopkins Hospital

Hilary Cosby, RN, CGRN
Phone: 410-502-2893
Email: hcosby1@jhmi.edu

University of Michigan

Elena Stoffel, MD
Richard Kwon, MD
Phone: 888-229-7408
Email: estoffel@med.umich.edu;
rskwon@med.umich.edu

University of Pennsylvania

Maureen Marshall, RN

Phone: 215-349-8546

Email: demarshm@mail.med.upenn.edu

Diego Rodriguez

Phone: 215-349-8556

Email: diego.rodriguez@uphs.upenn.edu

<https://www.pennmedicine.org/departments-and-centers/department-of-medicine/divisions/gastroenterology/research/clinical-trials/familial-pancreatic-cancer>

University of Pittsburgh

Beth Dudley

Email: dudleyre@mail.magee.edu

Randall Brand, MD

Email: brandre@upmc.edu

Yale University

Barbara Clerkin, RN

Phone: 203-200-5083

Email: barbara.clerkin@ynhh.org

<https://www.yalecancercenter.org/patient/trials/available/747-2.trial>

Columbia University Medical Center

177 Fort Washington Avenue

New York, NY 10032

Phone: 212-305-2500

www.columbiasurgery.org/pancreas/our-screening-program

The effectiveness of screening for pancreatic cancer has revealed some encouraging results. Their screening program helps determine whether risk factors are present, while addressing the patient as a whole.

Dana-Farber Cancer Institute

Gastrointestinal Cancer Genetics and Prevention Program
MS 1068

450 Brookline Avenue

Boston, MA 02215-5450

Phone: 617-632-2178 new patients;

617-632-5022 established patients

www.dana-farber.org/cancer-genetics-and-prevention/gastrointestinal-cancer-genetics-and-prevention-program

The Dana-Farber Cancer Genetics and Prevention Program works with patients who believe they have a high risk for developing cancer to create a personalized program to lower that risk. Their goal is to help patients identify the steps they can take to lower the risk of developing a gastrointestinal cancer, which may include cancer screening, genetic testing, and clinical research.

Fox Chase Cancer Center

Risk Assessment Program

Main Campus

333 Cottman Avenue

Philadelphia, PA 19111-2497

Phone: 877-627-9684

www.foxchase.org/rap

The Risk Assessment Program at Fox Chase Cancer Center, run by the Department of Clinical Genetics, offers education, screening, and counseling to people with cancer and those who are at risk for getting many types of cancer, including gastrointestinal. Fox Chase offers Open Access Endoscopy services for referring doctors to expedite scheduling routine screening procedures.

Fred Hutchinson Cancer Research Center

1100 Fairview Avenue North

Seattle, WA 98109-1024

Phone: 206-667-5000

www.fredhutch.org/en/diseases/pancreatic-cancer.html

Fred Hutchinson Cancer Research Center runs the world's largest population-based study examining genetic and environmental risk factors that contribute to the development of pancreatic cancer.

The Froedtert & the Medical College of Wisconsin Clinical Cancer Center

Greater Midwest Pancreatic Cancer Screening Clinic

9200 W. Wisconsin Avenue

Milwaukee, WI 53226

Phone: 414-805-3666

www.froedtert.com/liver-pancreas-bile-duct-cancer/pancreatic-cancer/screening-program

This center offers a specialized service for people who may be at high risk of developing pancreatic cancer due to personal or familial health factors.

Indiana University Hospital

Pancreatic Cyst and Cancer Early Detection Center

550 University Boulevard

Indianapolis, IN 46202

Phone: 317-948-8358

www.pancyst.org

The mission of the center is to promote early detection and prevent pancreatic cancer through multidisciplinary screening clinics, registries, community outreach, education, and research discovery. The clinic coordinates the care, follow-up, and research involving more than 1,000 patients at increased risk for pancreatic cancer and maintains a registry to monitor all patients. The IU Pancreatic Cancer Signature Center is also advancing knowledge from bench to bedside to practice and work on novel approaches for early diagnosis.

Johns Hopkins University School of Medicine

Sol Goldman Pancreatic Cancer Research Center

401 North Broadway

Baltimore, MD 21287-5678

NFPTR: 410-955-3502

Cyst Program: 410-955-5800

Email: pancreas@jhmi.edu

www.pathology.jhu.edu/pc/BasicScreening.php?area=ba

Both the National Familial Pancreas Tumor Registry (NFPTR) and the Multidisciplinary Pancreatic Cyst Program are programs of the Sol Goldman Pancreatic Cancer Research Center.

The NFPTR is the first familial pancreas tumor registry in the country and is the longest standing and one of the largest familial pancreatic cancer registries in the world. There are more than 5,500 families enrolled in this registry, and the participants have been part of several different studies that have helped identify and quantify the risk of

pancreatic cancer in relatives. The NFPTTR works with a team of clinicians and scientists with backgrounds and training in areas such as epidemiology, pathology, gastroenterology, genetics, radiology, and oncology.

The Multidisciplinary Pancreatic Cyst Program evaluates patients with known or suspected pancreatic cysts. The program provides educational materials for patients and family members; same day diagnostic testing including specialized 3D pancreatic CT scans and MRIs read by expert pancreatic radiologists; access to endoscopic ultrasound (EUS); examination of pathological slides; and surgeons experienced in the resection of pancreatic cysts.

MD Anderson Cancer Center

1515 Holcombe Boulevard
Houston, TX 77030

Other locations: www.mdanderson.org/about-md-anderson/our-locations.html

Phone: 855-724-1365

www.mdanderson.org/cancermoonshots/cancer-types/pancreatic.html

The Pancreatic Cancer Moonshot™ initiative includes methods to identify pancreatic cancer earlier and provide a multidisciplinary clinic for individuals at high risk of pancreatic cancer.

Memorial Sloan Kettering Cancer Center

MSKCC Pancreatic Tumor Registry

Phone: 800-525-2225

www.mskcc.org/cancer-care/clinical-trials/02-102

Investigators at Memorial Sloan Kettering Cancer Center have developed a Pancreatic Tumor Registry that is focused both on patients with pancreatic cancer and on individuals with a strong family history of this disease.

**New York-Presbyterian Hospital/
Columbia University Medical Center**

Muzzi Mirza Pancreatic Cancer Prevention and Genetics Program
Pancreatic Cyst Surveillance Program
Herbert Irving Pavilion, 8th Floor
161 Fort Washington Avenue
New York, NY 10032
Phone: 212-305-9467
www.columbiasurgery.org/pancreas/muzzi-mirza-pancreatic-cancer-prevention-and-genetics-program

The Muzzi Mirza Pancreatic Cancer Prevention and Genetics Program focuses on screening, genetic testing, and research into pancreatic cancer. The program seeks to develop standards for those who should be screened; study the biology of the disease; develop strategies for early detection; and raise awareness of pancreatic cancer. The Pancreatic Cyst Surveillance Program is an extension of this program and monitors patients with known or suspected pancreatic cysts.

Northwestern University

Robert H. Lurie Comprehensive Cancer Center
Gastrointestinal Cancer Prevention Clinic
Galter Pavilion
675 North St. Clair Street, 17th Floor
Chicago, IL 60611
Phone: 312-695-5620
www.cancer.northwestern.edu/types-of-cancer/gastrointestinal/prevention-clinic.html

Northwestern University's Gastrointestinal Cancer Prevention Clinic focuses on the prevention, early detection, and diagnosis of gastrointestinal cancers, including pancreatic cancer. Services offered include genetic testing, screening, therapeutic endoscopy, imaging, gastrointestinal surgery, and psychological and nutrition counseling. The clinic also manages a High Risk Gastrointestinal Cancer Registry that gathers information about patients and their relatives who have had gastrointestinal cancers or are at risk of developing gastrointestinal cancer.

NYU Langone Perlmutter Cancer Center

Pancreatic Cancer Center

160 East 34th Street, 9th Floor

New York, NY 10016

Phone: 212-731-5655

www.nyulangone.org/conditions/pancreatic-cancer/screening

<https://find-pancancer-early.org>

The genetics program at the Pancreatic Cancer Center provides risk assessments and evaluations for people with an inherited genetic predisposition for pancreatic cancer, which can be more treatable when detected early. They order tests, review the results, and discuss any necessary additional screening tests. If genetic testing determines an increased risk of pancreatic cancer, doctors at Perlmutter Cancer Center may perform annual screening tests to detect developing tumors.

NYU Langone's Pancreatic Cancer Center also offers an online assessment tool (<https://find-pancancer-early.org>), designed for people who may be at risk for pancreatic cancer. Respondents answer some questions about their personal health and their family's health history, and based on the answers provided, it may be recommended that they speak to a healthcare provider for more information regarding their pancreatic cancer risk.

NYU Winthrop Hospital

Pancreatic Health Program

Pancreatic Cyst Surveillance Program

120 Mineola Boulevard, Suite 320

Mineola, NY 11501

Phone: 516-663-2436

Email: pancreasprogram@nyuwinthrop.org

www.winthrop.org/pancreas-health-program

www.pancreasny.com

Physicians in the Pancreatic Health Program screen high-risk individuals, with the goal of preventing the disease from becoming malignant. The NYU Winthrop Pancreatic Cyst Surveillance Program helps determine if patients' cysts are benign or if they require surgical removal to prevent malignancy.

Oregon Health & Science University

Knight Cancer Institute

Center for Early Detection and Research (CEDAR)

3181 S.W. Sam Jackson Park Road

Portland, OR 97239-3098

Phone: 503-494-1617

www.ohsu.edu/xd/health/services/cancer/research-training/research-programs/cedar/about-us/index.cfm

CEDAR is focused on the development of technologies to help support early detection, cancer evolution and development, and genetic predispositions to identify high-risk individuals. CEDAR is also focused on determining the underlying causes of cancer risk; preventing overdiagnosis; and developing precision therapies to either cure lethal cancers or turn them into chronic diseases.

University of California, Los Angeles

Agi Hirshberg Center for Pancreatic Diseases

10833 Le Conte Avenue, 72-215 CHS

Los Angeles, CA 90095-6904

Phone: 310-206-6889

www.uclahealth.org/pancreas

The Agi Hirshberg Center for Pancreatic Diseases combines experts from across disciplines who together review each patient's case and test results and map out a treatment plan.

University of California, San Francisco

Helen Diller Family Comprehensive Cancer Center

Pancreas Center

Ron Conway Family Gateway Medical Building

1825 4th Street, Fourth Floor

San Francisco, CA 94158

Phone: 415-353-7390

www.ucsfhealth.org/clinics/pancreas_center/

The UCSF Pancreas Center's mission is to advance the care of patients with pancreatic diseases through prevention, early detection, individual treatment, and research. The center conducts large population-based, case-control studies of pancreatic cancer. Its researchers in Epidemiology and Biostatistics lead laboratory and clinic-based studies of the molecular epidemiology of pancreatic cancer.

University of Chicago Medicine

Pancreatic Cancer Early Detection Clinic

5841 S. Maryland Avenue

Chicago, IL 60637

Phone: 855-702-8222

www.uchospitals.edu/specialties/cancer/pancreatic/screening.html

The Pancreatic Cancer Early Detection Clinic offers sophisticated screening and diagnostic tools for people who are at risk for developing pancreatic cancer through a collaborative team approach that includes experts in gastrointestinal interventional endoscopy, pancreatic surgery, radiology and pathology, and genetics, as well as nurses, laboratory technicians, and genetic counselors. As a team, these experts develop screening and treatment plans to fit each patient's specific needs and suggested screening procedures for relatives who may also be at risk.

University of Michigan Health System

Cancer Genetics Clinic

University of Michigan Comprehensive Cancer Center

Clinic is situated directly behind U-M Comprehensive Cancer Center

Med Inn Building, Floor 3, Reception B

1500 East Medical Center Drive

Ann Arbor, MI 48109-0944

Phone: 734-763-2532

Email: cancergenetics@med.umich.edu

www.mcancer.org/cancer-genetics/clinic

The Cancer Genetics Clinic evaluates people with a personal or family history of cancers that may have genetic links and provides advice on the best way to manage patients' healthcare. The University of Michigan Pancreatic Cancer Center is also using an interdisciplinary approach to advance earlier detection procedures. The team is utilizing genetic testing to determine risk, with the goal of increasing the early detection of risk to 100% accuracy.

University of Pennsylvania

Abramson Cancer Center
Gastrointestinal Cancer Risk Evaluation Program
3400 Civic Center Blvd.
South Pavilion, 4th Floor
Philadelphia, PA 19104
Phone: 215-349-8222

<https://www.pennmedicine.org/cancer/navigating-cancer-care/programs-and-centers/gastrointestinal-cancer-genetics-and-risk-evaluation-program/gi-cancer-genetics-and-risk-evaluation-team>

The Gastrointestinal Cancer Risk Evaluation Program (GI-CREP) evaluates people who are at an increased risk of developing gastrointestinal cancer. Patients undergo a comprehensive evaluation and genetic testing when appropriate. Following evaluation, the clinical team provides an expert assessment and coordinates a plan for managing a patient's risk of developing gastrointestinal cancer.

University of Pittsburgh Medical Center

Hereditary GI Tumor Program
Shadyside Medical Building
5200 Centre Avenue, Suite 409
Pittsburgh, PA 15232
Phone: 412-647-2811

<https://hillman.upmc.com/cancer-care/pancreatic/screenings>

Screenings are conducted on people who have major risk factors, including a family history of pancreatic cancer, so that early intervention can lead to more timely treatment.

University of Texas Southwestern Medical Center

Harold C. Simmons Comprehensive Cancer Center
Pancreatic Cancer Prevention Program
1801 Inwood Rd, 7th Floor
Suite 100
Phone: 214-645-8300 or 817-882-2700

www.utswmedicine.org/cancer/programs/pancreatic/prevention

The Pancreatic Cancer Prevention Program provides patients with care from a multidisciplinary team that develops a comprehensive plan for each patient in a single visit.

University of Virginia Health System

Emily Couric Clinical Cancer Center

High Risk Pancreatic Cancer Clinic

1240 Lee Street

Charlottesville, VA 22903

Phone: 434-243-5233

Email: highriskpancreas@virginia.edu

www.uvahealth.com/locations/profile/high-risk-pancreatic-cancer-clinic

UVA's High Risk Pancreatic Cancer Clinic screens and monitors patients who have an increased risk for pancreatic cancer. The center also has a pancreatic cyst clinic that provides testing to monitor cysts and determine if they are benign or if they could potentially cause cancer.

University of Washington Division of Gastroenterology

Familial Pancreatic Cancer & Surveillance

Maleng Building, 8th Floor

410 Ninth Avenue

Seattle, WA 98104

Phone: 877-520-5000

www.uwgi.org/pancreaticcancer/Pages/HereditaryFactors.aspx#risk

This center is for patients with a strong family history of pancreatic cancer who are interested in surveillance.

Vanderbilt-Ingram Cancer Center

Hereditary Cancer Clinic

The Village at Vanderbilt

1500 21st Avenue South, Suite 2500

Nashville, TN 37232

Phone: 615-343-7400

www.vanderbilthealth.com/cancer/51494

www.vicc.org/hcp

The Hereditary Cancer Clinic evaluates and provides counseling to patients with an increased risk of cancer due to hereditary factors. The clinic is part of Vanderbilt's Clinical and Translational Hereditary Cancer Program, which provides research, patient care, and education on hereditary cancer genetics.

Yale School of Medicine

Pancreas Disease Program

333 Cedar Street

New Haven, CT 06510

Phone: 203-200-5083

www.medicine.yale.edu/intmed/digestivediseases/pancreasprogram/diseases/screening.aspx

Consideration of screening is recommended for individuals with a significantly increased risk of developing pancreatic cancer beginning at age 50 or 10 years younger than the youngest relative with pancreatic cancer or at age 30 for individuals with Peutz-Jeghers syndrome.

National Cancer Institute Designated Cancer Centers

The National Cancer Institute (NCI) is a federal agency for cancer research and training. The NCI-Designated Cancer Centers are recognized for scientific leadership and resources. The Comprehensive Cancer Center designation is reserved for those centers with the highest achievements in cancer research, clinical care, education, and community contributions. Studies show that being treated at NCI-Designated Comprehensive Cancer Centers leads to better survival and recovery rates due to the level of care, diverse oncology disciplines, subspecialty expertise, and multidisciplinary teams as well as access to clinical trials.

The NCI recognizes three types of centers (Cancer Centers, Comprehensive Cancer Centers, and Basic Laboratory). Shown by state are centers that see patients (as noted):

***Cancer Centers**

****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.

A list of these centers can also be found at www.cancer.gov/research/nci-role/cancer-centers or by calling 800-422-6237 (800-4-CANCER).

ALABAMA

****University of Alabama at Birmingham Comprehensive Cancer Center**

Phone: 205-975-8222; 800-822-0933 (800-UAB-0933)

www.cancercenter.uab.edu

ARIZONA

****Arizona Cancer Center, University of Arizona**
Phone: 800-524-5928; 520-694-2873 (694-CURE)
www.uacc.arizona.edu

CALIFORNIA

****City of Hope National Medical Center**
Beckman Research Institute
Phone: 626-256-4673 (626-256-HOPE)
New Patient Services: 800-826-4673
www.cityofhope.org

***Salk Institute Cancer Center**
Salk Institute for Biological Studies
Phone: 858-453-4100
www.salk.edu/science/research-centers/salk-cancer-center/

***Sanford Burnham Prebys Medical Discovery Institute**
Phone: 858-646-3100
www.sbpdiscovery.org/medical-discovery/disease-focused-centers/nci-designated-cancer-center/overview

****UC San Diego Moores Cancer Center**
University of California, San Diego
Appointments: 858-822-6100
General Information: 866-773-2703
<https://health.ucsd.edu/specialties/cancer/Pages/default.aspx>

****Jonsson Comprehensive Cancer Center**
University of California, Los Angeles
Administrative Office: 310-825-5268
UCLA Cancer Hotline: 888-662-8252
www.cancer.ucla.edu/

****Norris Comprehensive Cancer Center**
University of Southern California
General Information: 323-865-3000
Phone: 800-872-2273 (800-USC-CARE)
<https://cancer.keckmedicine.org>

****Chao Family Comprehensive Cancer Center**
University of California, Irvine
Appointments: 714-456-8000
Physician Referral Service: 877-824-3627
www.cancer.uci.edu

*Stanford Cancer Institute
Stanford University
Referral Center: 650-498-6000
Phone: 877-668-7535
www.med.stanford.edu/cancer.html

**UC Davis Comprehensive Cancer Center
University of California, Davis
New Patient Referral Office: 916-703-5210
General Information: 916-734-5959
www.ucdmc.ucdavis.edu/cancer

**UCSF Helen Diller Family Comprehensive Cancer Center
University of California, San Francisco
Appointments & Physician Referral Service: 888-689-8273
International Inquiries: 415-353-8489
www.cancer.ucsf.edu

COLORADO

**University of Colorado Cancer Center
Adult Cancer Care: 720-848-0300
www.ucdenver.edu/academics/colleges/medicalschoo/cancercenter/Pages/CancerCenter.aspx

CONNECTICUT

**Yale Cancer Center
Yale University School of Medicine
Patient Care: 203-785-4191
Toll Free: 866-925-3226
www.yalecancercenter.org/index.aspx

DISTRICT OF COLUMBIA

**Georgetown Lombardi Comprehensive Cancer Center
Georgetown University
Appointments: 202-444-2223
Cancer Line: 202-444-4000
www.lombardi.georgetown.edu/

FLORIDA

**Moffitt Cancer Center
Phone: 813-745-4673 (813-745-HOPE)
New Patient/Physician Referral: 888-860-2778
www.moffitt.org

GEORGIA

*Winship Cancer Institute of Emory University
Phone: 404-778-1900
www.winshipcancer.emory.edu

HAWAII

*University of Hawaii Cancer Center
Phone: 808-586-3010
www.uhcancercenter.org

ILLINOIS

**University of Chicago Medicine
Phone: 855-702-8222
www.cancer.uchicago.edu

**Robert H. Lurie Comprehensive Cancer Center
Northwestern University
Phone: 312-695-0990
Appointments: 866-587-4322 (866-LURIE-CC)
www.cancer.northwestern.edu

INDIANA

*Indiana University Melvin and Bren Simon Cancer Center
Phone: 317-944-5000
Appointments & Referrals: 317-944-0920
www.cancer.iu.edu

IOWA

**Holden Comprehensive Cancer Center
University of Iowa
Appointments & Referrals: 319-384-8442
Cancer Information Service: 800-237-1225
<https://uihc.org/primary-and-specialty-care/holden-comprehensive-cancer-center>

KANSAS

*University of Kansas Cancer Center
Phone: 913-588-1227 or 844-323-1227
www.kucancercenter.org/

KENTUCKY

*Markey Cancer Center
University of Kentucky
Phone: 859-257-4500
Toll Free: 866-340-4488
<https://ukhealthcare.uky.edu/markey-cancer-center>

MARYLAND

******Sidney Kimmel Comprehensive Cancer Center

Johns Hopkins University

Phone: 410-955-5222

Appointments & Referrals: 410-955-8964

www.hopkinsmedicine.org/kimmel_cancer_center

******Marlene and Stewart Greenebaum Comprehensive Cancer Center

University of Maryland

Main and New Appointments: 410-328-7904

Toll Free: 800-888-8823

www.umms.org/umgcc

MASSACHUSETTS

******Dana-Farber/Harvard Cancer Center

Dana-Farber Cancer Institute

Phone: 617-632-3000

Spanish Speakers: 617-632-3673

www.dfhcc.harvard.edu/

*****David H. Koch Institute for Integrative Cancer Research

Massachusetts Institute of Technology

Phone: 617-253-6403

<https://ki.mit.edu/>

MICHIGAN

******University of Michigan Comprehensive Cancer Center

University of Michigan

Cancer Answer Line: 800-865-1125

www.mcancer.org

******The Barbara Ann Karmanos Cancer Institute

Wayne State University School of Medicine

Appointments: 800-527-6266 (800-KARMANOS)

www.karmanos.org/home

MINNESOTA

**Masonic Cancer Center

University of Minnesota Cancer Center
Cancer Information Line: 612-624-2620
Patient Appointments: 612-672-7422
www.cancer.umn.edu

**Mayo Clinic Cancer Center

Phone: 507-284-2511
www.mayoclinic.org/departments-centers/mayo-clinic-cancer-center

MISSOURI

**Alvin J. Siteman Cancer Center

Washington University School of Medicine and Barnes-Jewish Hospital
Phone: 314-747-7222
Toll Free: 800-600-3606
<https://siteman.wustl.edu>

NEBRASKA

*Fred & Pamela Buffett Cancer Center

Nebraska Medicine and the University of Nebraska Medical Center
Care Center: 402-559-6500
Medical Call Center - Physician & Service Referral: 402-559-5600
www.nebraskamed.com/cancer

NEW HAMPSHIRE

**Norris Cotton Cancer Center

Dartmouth-Hitchcock Medical Center
Administration: 603-653-9000
Cancer Help Line: 800-639-6918
www.cancer.dartmouth.edu/

NEW JERSEY

**Rutgers Cancer Institute of New Jersey

Rutgers Biomedical and Health Sciences
Phone: 732-235-2465
<http://rbhs.rutgers.edu/>

NEW MEXICO

****University of New Mexico Comprehensive Cancer Center**

Phone: 505-272-4946

In New Mexico: 800-432-6806

<http://cancer.unm.edu/>

NEW YORK

***Albert Einstein Cancer Center**

Albert Einstein College of Medicine

Phone: 718-862-8840

www.einstein.yu.edu/centers/cancer/

****Roswell Park Comprehensive Cancer Center**

Phone: 716-845-2300

www.roswellpark.org

***Laura and Isaac Perlmutter Cancer Center**

NYU Langone Cancer Center

Phone: 212-263-3276

www.cancer.med.nyu.edu/

****Memorial Sloan Kettering Cancer Center**

Phone: 212-639-2000

Patients: 212-639-4900

Toll Free: 888-675-7722

www.mskcc.org/

****Herbert Irving Comprehensive Cancer Center**

Columbia University

Phone: 212-305-2500

24-Hour Hotline: 877-697-9355

<http://cancer.columbia.edu/>

***Mount Sinai Cancer Center**

The Tisch Cancer Institute

Administration: 212-659-5600

Patient Information: 212-241-6756

<http://icahn.mssm.edu/research/tisch>

NORTH CAROLINA

**UNC Lineberger Comprehensive Cancer Center
University of North Carolina at Chapel Hill
Phone: 919-966-3036
Appointment Information: 866-869-1856
www.unclineberger.org

**Duke Cancer Institute
Duke University Medical Center
Consultation and Referral Service: 888-275-3853 (888-ASK-DUKE)
www.dukecancerinstitute.org

**Comprehensive Cancer Center of Wake Forest University
Phone: 336-716-7971
Appointments: 336-716-9253 (336-716-WAKE)
Toll Free: 888-716-9253 (888-716-WAKE)
www.wakehealth.edu/Comprehensive-Cancer-Center/

OHIO

**Case Comprehensive Cancer Center
Case Western Reserve University
Phone: 216-368-1122
<https://case.edu/cancer/>

**The James
Ohio State University Comprehensive Cancer Center
Toll Free: 800-293-5066
Patient Information Desk: 614-293-3300
www.cancer.osu.edu/

OKLAHOMA

*Stephenson Cancer Center
University of Oklahoma
Patient Care: 405-271-1112
Toll Free: 855-750-2273
<http://stephensoncancercenter.org/>

OREGON

*Knight Cancer Institute
Oregon Health & Science University
Cancer Institute: 503-494-1617
Health Care Services/OHSU Switchboard: 503-494-8311
Phone: 888-222-6478
<https://apps.ohsu.edu/health/knight-cancer/index.html>

PENNSYLVANIA

****Abramson Cancer Center**

University of Pennsylvania

Phone: 215-615-5858

<https://lp.pennmedicine.org/cancer/general>

***The Wistar Institute Cancer Center**

The Wistar Institute

Phone: 215-898-3700

<https://wistar.org/research-discoveries/wistar-institute-cancer-center>

****Fox Chase Cancer Center**

Temple Health

New Patient Appointments: 215-728-2570

Cancer Information Line: 888-369-2427

www.foxchase.org

***Sidney Kimmel Cancer Center**

Thomas Jefferson University

Phone: 215-503-5692

www.kimmeltcancercenter.org/cancer-center/patient-care.html

****UPMC Hillman Cancer Center**

University of Pittsburgh Medical Center

Phone: 412-623-3205

<http://upci.upmc.edu/index.cfm>

SOUTH CAROLINA

***Hollings Cancer Center**

Medical University of South Carolina

Phone: 843-792-0700

Health Connection Line: 800-424-6872 (800-424-MUSC)

<http://www.hollingscancercenter.org/index.html>

TENNESSEE

****Vanderbilt-Ingram Cancer Center**

Vanderbilt University

Phone: 615-936-8422

Toll Free: 877-936-8422

www.vicc.org

TEXAS

**Dan L. Duncan Comprehensive Cancer Center
Baylor College of Medicine
Phone: 713-798-1354
www.bcm.edu/centers/cancer-center

**The University of Texas MD Anderson Cancer Center
Phone: 713-792-6161
Toll Free: 877-632-6789
www.mdanderson.org

*Mays Cancer Center
University of Texas Health Science Center at San Antonio
Phone: 210-450-1000
Cancer Information Line: 800-340-2872
www.uthscsa.edu/patient-care/cancer-center/

**Harold C. Simmons Comprehensive Cancer Center
University of Texas Southwestern Medical Center
Phone: 214-645-4673 (214-645-HOPE)
Toll Free: 866-450-4673 (866-450-HOPE)
www.utsouthwestern.edu/simmons/

UTAH

*Huntsman Cancer Institute
University of Utah
Phone: 801-585-0303
Toll Free: 877-585-0303
<https://healthcare.utah.edu/huntsmancancerinstitute/>

VIRGINIA

*University of Virginia Cancer Center
University of Virginia, Health Sciences Center
Phone: 434-924-3627
Toll Free: 800-223-9173
<https://cancer.uvahealth.com/>

*Massey Cancer Center
Virginia Commonwealth University
Phone: 804-828-0450
New Patients: 804-828-5116
www.massey.vcu.edu

WASHINGTON

**Fred Hutchinson/University of Washington Cancer Consortium
Fred Hutchinson Cancer Research Center
New Patients/Intake: 206-288-1024
Phone: 206-288-7222
www.cancerconsortium.org/en.html

WISCONSIN

**Carbone Cancer Center
University of Wisconsin
Phone: 608-263-8600
Cancer Connect: 800-622-8922
www.uwhealth.org/uw-carbone-cancer-center/47424

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FOUNDATION®**
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415 Crossways Park Drive • Suite D
Woodbury, New York 11797
lustgarten.org
866-789-1000

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lustgarten.org
866-789-1000

The image features a background with three distinct color zones: a purple top section, a large light beige middle section, and a green bottom section. The text is positioned in the green section.

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