

THE
Educated Patient[®]

Advanced Pancreatic Neuroendocrine Tumor (PNET)

RESOURCE GUIDE



A collection of resources that provide information and support for patients with an advanced PNET and the oncology professionals who treat them.





At Novartis Oncology, we're always thinking about neuroendocrine tumors.

Novartis Oncology continues to demonstrate a commitment to addressing the unmet needs in neuroendocrine tumors.



What Is Advanced Pancreatic Neuroendocrine Tumor (PNET)?

The pancreas is an organ that is located behind the stomach and extends horizontally across the abdomen. The pancreas consists of 2 types of glands, the exocrine and endocrine glands.¹ Exocrine glands produce enzymes that are released into the small intestine to help the body digest food. Endocrine cells produce several types of hormones that control the actions of certain cells or organs in the body. Endocrine cells cluster together in small groups called islets throughout the pancreas.²

It is important to understand that the exocrine and endocrine cells form different types of tumors. The tumors have very different symptoms, and are diagnosed and treated in different ways. Exocrine tumors are more common and are most often referred to as pancreas cancer. Endocrine tumors are less common. When pancreatic endocrine cells begin to grow out of control and rapidly form abnormal cells, a pancreatic neuroendocrine tumor (NET) may form.¹

Pancreatic NETs make up less than 4% of all pancreatic cancers diagnosed.¹ When the cancer has progressed and the tumor cells spread to other organ sites, the pancreatic NET has reached the advanced stage of cancer.³ Cancer may spread to lymph nodes near the pancreas, or to the liver, lung, peritoneum, or bone.²

Advanced pancreatic NETs may be either functional or nonfunctional. Functional pancreatic NETs produce hormones such as gastrin, insulin, and glucagon, which are released into the blood and cause symptoms. There are several types of functional pancreatic NETs. The tumor type depends on the hormone being produced. Nonfunctional pancreatic NETs are more difficult to diagnose. Nonfunctional tumors produce substances that often do not cause symptoms until the tumor spreads and continues to grow.^{1,2}

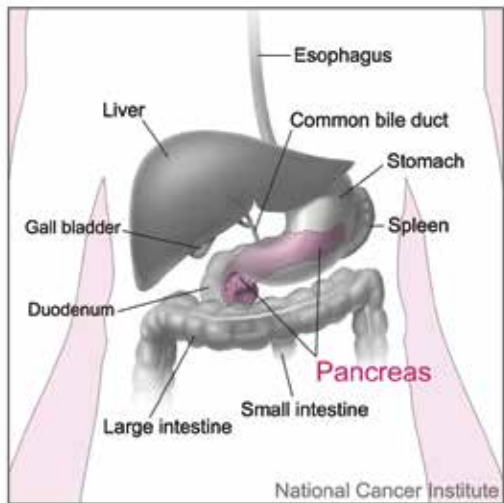


Illustration by Don Bliss / National Cancer Institute

Symptoms of Advanced Pancreatic NETs

Nonfunctional pancreatic NETs often do not show symptoms until they have spread outside the pancreas to other parts of the body. Symptoms will depend on where the cancer spreads to, although most pancreatic NETs spread to the liver. Some common symptoms of nonfunctional pancreatic NETs include diarrhea, indigestion, a lump in the abdomen, pain in the abdomen or back, and yellowing of the skin and whites of the eyes.^{1,2}

Symptoms of functional pancreatic NETs depend on the type of hormone being produced. Low or high blood sugar, diarrhea, cramps or pain in the abdomen, fast heartbeat, dehydration, and weight loss for unknown reasons are common universal symptoms of functional pancreatic NETs.²

Diagnosing Advanced Pancreatic NETs

There are various tests and procedures to help detect and diagnose advanced pancreatic NETs. Your healthcare professional may suggest certain testing and procedures based on your symptoms to help properly diagnose your condition.

Possible suggestions may include blood tests to determine the hormone levels in the pancreas. Elevated levels of a specific hormone will help diagnose the type of functional pancreatic NET.¹

Ultrasounds and imaging tests such as a computerized tomography (CT) scan, magnetic resonance imaging (MRI) test, or bone scan are procedures used to help determine the size and location of the tumor. Surgical procedures such as a laparotomy, an incision through the wall of the abdomen to study the abdomen, or a biopsy may also be necessary to remove cells or tissues to be studied.²

Treating Advanced Pancreatic NETs

Treatment options will be suggested to help manage your advanced pancreatic NET. It is important to discuss the different treatments with your healthcare professional to help improve your quality of life.

Commonly, systemic therapies and hepatic arterial occlusion are suggested, as these therapies use drugs to attack cancer cells and help manage the disease. Your healthcare professional may also suggest certain drugs to help you manage symptoms such as diarrhea, blood sugar, and stomach ulcers.²

Surgery may only be suggested to help relieve symptoms and prevent further complications. Some surgical options include ablative techniques such as radiofrequency ablation, the use of radio waves to heat and destroy tissues, or cryosurgery, which freezes tissue with liquid nitrogen or liquid carbon dioxide. Chemotherapy and radiation are not often helpful in treating advanced pancreatic NET.¹

Health, Diet, and Emotional Support

There are steps you can personally take to help manage and cope with your diagnosis and treatment. Adjusting to a lifestyle with cancer may include making changes to your diet and lifestyle, as well as openly communicating with loved ones and your healthcare professional.⁴ Remember to consult your physician before beginning anything new.

Exercise⁵

Most people with cancer experience a loss of energy. Fatigue may cause loss of function, muscle weakness, and reduced range of motion. For this reason, it is important to stay physically active. If beginning an exercise program, be sure to discuss your plans and the intensity of the intended workout with your physician.

Diet⁶

Proper nutrition is beneficial to managing your pancreatic NET symptoms and treatment. A proper diet should include a variety of foods that include nutrients such as protein, carbohydrates, fat, water, vitamins, and minerals.

To help manage common symptoms of diarrhea, avoid high-fiber foods such as nuts, whole grains, raw fruits and vegetables, and legumes. Instead, choose soluble fiber foods such as applesauce, bananas, and oatmeal. Avoid greasy, fried, spicy, or extremely sweet foods, and stay away from drinking carbonated beverages. Eating foods high in potassium will also help you manage diarrhea symptoms.

Emotional Support

Open communication with your loved ones, caregiver, and healthcare professional is important. Support in any form allows you to discuss your feelings and may help you develop coping skills.⁴ Some people find that by talking, they begin to solve problems and think about other issues as their family and friends ask questions. Friends, family, and caregivers can share their strength and concern with you, and help encourage you along the way.⁷

It is necessary to work closely with your caregiver and discuss how you feel physically and emotionally. Your caregiver will help you through your cancer treatments, and help manage your symptoms, side effects, and daily tasks.^{4,7} Caregivers should set a goal of openness by letting the patient know that they want to be included in his or her care. With the patient's consent, it is also important that the caregiver create an open relationship with the healthcare team.⁸

As a patient, discussing your diagnosis and speaking regularly with your healthcare professional is necessary. Treatment decisions are based on the type of disease, location of the cancer, amount of cancer, extent of spread, your overall health, and most importantly, your personal wishes.⁴

Other forms of support are also available to patients, their loved ones, and caregivers. Support groups for patients and family members are powerful, as they allow you to speak with others who have experienced, or are experiencing, similar situations.⁴ The resources in this guide provide forms of support through local meetings, toll-free hotlines, and online message boards, as well as Internet social networking.

Questions to Ask Your Physician^{1,9}

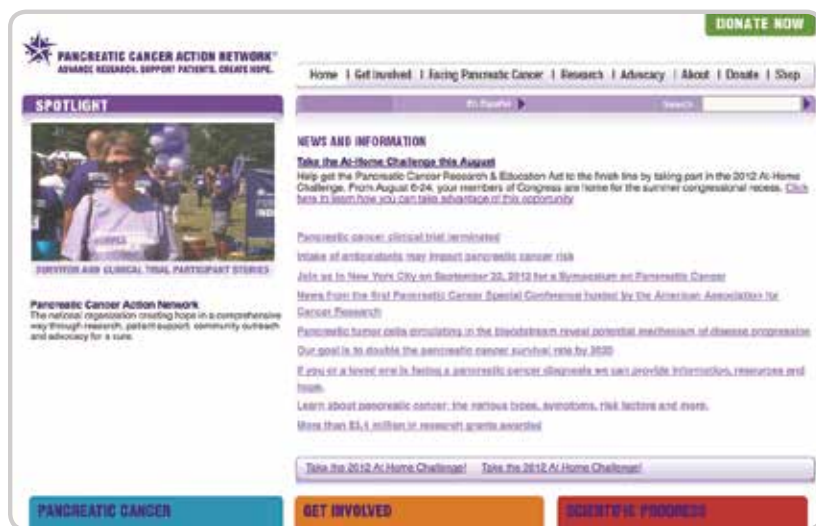
Below are common questions that may be helpful when you sit down to discuss your diagnosis of an advanced pancreatic NET. An initial diagnosis may be overwhelming. These questions can help you stay on track and will ensure that you gain a full understanding of your diagnosis and treatment options.

- What is my diagnosis?
- What is the stage of my cancer? What does this mean?
- What treatment choices do I have?
- What do you recommend and why?
- What risks or side effects are there to the treatments you suggest?
- How would treatment affect my daily activities?
- How is treatment likely to help in my case?
- I understand I have a rare disease. How often do you treat this?
- How experienced is the hospital in treating people with this cancer?
- Considering this is a rare disease, is there a reason for moving to a larger cancer treatment center?
- Should I think about taking part in a clinical trial?
- What can I expect in the near future?
- What should I do to be ready for treatment?
- Do I need to change or modify my diet?
- Do you have a dietitian or nutritionist that you recommend?
- Will I need to take pancreatic enzymes or vitamins? If so, how often?
- Will my ability to work, travel, or drive be affected?
- Will I need to spend time in the hospital?
- Will I have physical limitations?
- Are there any lifestyle changes I should make?
- What support programs are available for me and my family?
- Who can I speak with about my financial and/or insurance concerns?
- Who can help me navigate the medical system? Is there an oncology social worker or patient navigator available at this hospital?

It can also be helpful to bring another person along to your medical appointments. A friend or family member can be supportive, provide an extra set of ears, and ensure all questions are answered. Recording the meeting is another way to avoid missing important information. Ask the doctor for permission to record the meeting and then listen to the conversation at a later time, or bring a notepad and pen to write down any notes.

Pancreatic Cancer Action Network

www.pancan.org



The Pancreatic Cancer Action Network is a nationwide network of people dedicated to working together to advance research, support patients, and create hope for those affected by pancreatic cancer. The organization offers extensive reliable information to patients and caregivers to help them make informed decisions. In addition, the organization helps support individuals and communities across the country who work together to raise awareness and funding toward a cure for pancreatic cancer.

ADDRESS:

1500 Rosecrans Avenue
Suite 200
Manhattan Beach, CA 90266

CONTACT INFO:

Phone: 310-725-0025
1-877-272-6226
E-mail: info@pancan.org

Resource Checklist:

- ✓ Survivor stories
- ✓ Resources for scientists
- ✓ Clinical trials information
- ✓ Fundraising
- ✓ Support group directory
- ✓ Patient and Liaison Services (PALS) support program

Pancreatica Initiative Cancer Patients Alliance

www.pancreatica.org

Pancreatica
Confronting Pancreatic Cancer

our philosophy about pancreatic cancer
Pancreatic cancer is a complex disease. Taking an aggressive, rational stance against pancreatic cancer at the earliest possible time, supported by the best medical team, and treated in the most appropriate manner gives the best chance for pancreatic cancer survival. We believe in strong patient-physician bonds, scientifically-based pancreatic cancer treatment, and the comfort can come from knowing that everything that reasonably can be done - is being done. That the best approach to treating cancer of the pancreas has been and aimed with the best available information.

Home About Us Dashboard Medical Literature Events FAQs About Pancreatic Cancer Links Contact Us Search

MAIN TOOLS

- FREQUENTLY ASKED QUESTIONS**
1. What is the medical treatment of pancreatic cancer?
- PANCREATIC CANCER MEDICAL LITERATURE**
Clinical Guidelines of Conventional Survival Strategies for Pancreatic and Biliary Cancers
- PANCREATIC CANCER SELECT ABSTRACTS**
Neoadjuvant Chemotherapy, Twice-weekly Gemcitabine, and Gemcitabine-based Regimens
- NEUROENDOCRINE & GASTROINTESTINAL TUMOR**
Neuroendocrine Tumors of the Pancreas (PNET) and Islet Cell Tumors
- Our stories** get out to

The Cancer Patients Alliance Pancreatica website is a top-rated Internet resource containing unique educational resources for patients, their caregivers, physicians, and researchers. The foundation's mission is to promote education, awareness, and advocacy while providing the most current medical research results to help further pancreatic cancer research.

ADDRESS:
312 Fountain Avenue
Pacific Grove, CA 93950

CONTACT INFO:
Phone: 831-658-0600
E-mail: webmaster@pancreatica.org

Resource Checklist:

- ✓ Medical literature abstracts
- ✓ Toll-free counseling
- ✓ Free "Speak With a Survivor" service
- ✓ Clinical trials information
- ✓ Stories of inspiration

American Cancer Society

www.cancer.org/Cancer/PancreaticCancer/index

The screenshot shows the American Cancer Society website interface. At the top, it says "THE OFFICIAL SPONSOR OF BIRTHDAYS!". Navigation tabs include HOME, LEARN ABOUT CANCER, STAY HEALTHY, FIND SUPPORT & TREATMENT, EXPLORE RESEARCH, GET INVOLVED, and MY ACS. The main heading is "LEARN ABOUT CANCER" with a sub-heading "Find information and resources for a specific cancer topic:". The "Pancreatic Cancer" section is highlighted, with a sub-heading "Pancreatic Cancer" and a brief description: "If you (or a loved one) are worried about developing pancreatic cancer, have just been diagnosed, are going through treatment, or are trying to stay well after treatment, the Detailed Guide or the QuickFind feature can help you find the answers you need." Below this are three featured articles: "Circle Of Sharing", "Clinical Trials", and "Talking About Cancer". A "QUICK FINDER" sidebar is visible on the right, and a search bar is at the bottom right.

The American Cancer Society (ACS) is a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem. The society's international mission concentrates on capacity building in developing cancer societies and on collaboration with other cancer-related organizations throughout the world in carrying out shared strategic directions.

ADDRESS:

250 Williams Street NW
Atlanta, GA 30303

CONTACT INFO:

Phone: 1-800-227-2345
E-mail: Online

Resource Checklist:

- ✓ Clinical trials information
- ✓ Coping tips
- ✓ Caregiver information
- ✓ Circle Of Sharing community
- ✓ Extensive disease information
- ✓ Stories of hope
- ✓ Recent news

CancerCare

www.cancercare.org/diagnosis/pancreatic_cancer



CancerCare provides free professional support services to anyone affected by cancer, including patients, caregivers, children, loved ones, and the bereaved. The organization helps more than 100,000 people annually face the crisis of cancer, and the website has become a leading online resource for cancer information, with more than 1 million unique visitors last year.

ADDRESS:

275 Seventh Avenue
22nd Floor
New York, NY 10001

CONTACT INFO:

Phone: 212-712-8400
1-800-813-4673
E-mail: info@cancercare.org

Resource Checklist:

- ✓ Free counseling
- ✓ Limited financial assistance
- ✓ Free community programs
- ✓ Patient stories
- ✓ Podcasts
- ✓ Free publications
- ✓ Connect Education Workshops

National Cancer Institute

www.cancer.gov/cancertopics/pdq/treatment/isletcell/Patient/page1

National Cancer Institute
at the National Institutes of Health

English | Español
We Can Answer Your Questions
1-800-4-A-NCIS

NCI Home | Cancer Topics | Clinical Trials | Cancer Statistics | Research & Funding | News | About NCI

Pancreatic Neuroendocrine Tumors (Islet Cell Tumors) Treatment (PDQ)

Patient Version | Health Professional Version | En español
Last Modified: 02/09/2012

Pancreatic Neuroendocrine Tumors (Islet Cell Tumors) Treatment (PDQ)

- General Information About Pancreatic Neuroendocrine Tumors (Islet Cell Tumors)
- Stages of Pancreatic Neuroendocrine Tumors
- Recurrent Pancreatic Neuroendocrine Tumors
- Treatment Option Overview
- Treatment Options for Pancreatic Neuroendocrine Tumors
- To Learn More About Pancreatic Neuroendocrine Tumors (Islet Cell Tumors)
- Changes to This Summary (2008/09/12)
- Get More Information From NCI
- About PDQ

General Information About Pancreatic Neuroendocrine Tumors (Islet Cell Tumors)

Key Points for This Section

- Pancreatic neuroendocrine tumors form in hormone-making cells (islet cells) of the pancreas.
- Pancreatic NETs may or may not cause symptoms.
- There are different kinds of functional pancreatic NETs.
- Having certain symptoms can increase the risk of pancreatic NETs.
- Different types of pancreatic NETs have different signs and symptoms.
- Lab tests and imaging tests are used to detect (find) and diagnose pancreatic NETs.
- Other kinds of lab tests are used to check for the specific type of pancreatic NETs.
- Certain factors affect prognosis (chance of recovery) and treatment options.

Pancreatic neuroendocrine tumors form in hormone-making cells (islet cells) of the pancreas.

The pancreas is a gland about 6 inches long that is shaped like a thin pear lying on its side. The wider end of the pancreas is called the head, the middle section is called the body, and the narrow end is

The US National Cancer Institute's website provides accurate, up-to-date information about many types of cancer, information about clinical trials, resources for people dealing with cancer, and information for researchers and health professionals.

ADDRESS:

6116 Executive Boulevard
Suite 300
Bethesda, MD 20892

CONTACT INFO:

Phone: 1-800-422-6237
E-mail: Online

Resource Checklist:

- ✓ Live online chat
- ✓ Toll-free hotline
- ✓ Extensive disease information
- ✓ Clinical trials information
- ✓ Drug dictionary

Inspire

www.inspire.com



ADDRESS:
66 Witherspoon Street
Suite 402
Princeton, NJ 08540

CONTACT INFO:
Phone: 1-800-945-0381
E-mail: team@inspire.com

Inspire was created with the belief that patient contributions to medical progress have been historically underappreciated, and further believes that progress in medical research will result from involving patients as well as fully valuing their contributions. This privately held company partners with pancreatic NET organizations to provide online patient communities in a safe, privacy-protected environment.

MyLifeLine.org Cancer Foundation

www.mylifeline.org



ADDRESS:
55 Madison Street
Suite 750
Denver, CO 80206

CONTACT INFO:
Phone: 720-883-8715
E-mail: support@mylifeline.org

Proudly supporting more than 74,000 people, MyLifeLine.org encourages cancer patients and caregivers to create free, customized websites. Each personalized page helps build an online support community of family and friends to foster connection, inspiration, and healing.



Patient Assistance NOW Oncology 1-800-282-7630

Helping to make access to therapies easier

Support for patients and providers includes:

- Insurance verification
- Coding/billing questions
- Medicare education
- Assistance with denials/appeals
- Therapy-specific support programs for out-of-pocket costs
- Providing alternative coverage searches for federal or state assistance programs
- Referral to Independent Charitable Foundations for assistance with co-pay costs
- Patient assistance for low-income and uninsured patients
- Patients pre-qualified via phone screening for the Patient Assistance Program (PAP) will be sent a 30-day supply of their needed medication while completing the application

Disclaimer:

The Reimbursement Hotline and Novartis Pharmaceuticals Corporation do not guarantee success in obtaining reimbursement, nor do we submit appeals on behalf of providers or patients. Third-party payment for medical products and services is affected by numerous factors, not all of which can be anticipated or resolved by Reimbursement Hotline staff.





This Resource Guide was supported by Novartis Pharmaceuticals Corporation. The information is designed to be a summary of information and not an exhaustive list of available resources. Intellisphere Oncology Specialty Group was responsible for selecting the groups included in this supplement.