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# Pancreatic Neuroendocrine Tumors

## Early Detection, Diagnosis, and Staging

### Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- [Can Pancreatic Neuroendocrine Tumor Be Found Early?](#)
- [Signs and Symptoms of Pancreatic Neuroendocrine Tumor](#)
- [Tests for Pancreatic Neuroendocrine Tumor](#)

### Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- [Pancreatic Neuroendocrine Tumor Stages](#)
- [Survival Rates for Pancreatic Neuroendocrine Tumor](#)

### Questions to Ask About Pancreatic Cancer

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- [Questions to Ask About Pancreatic Neuroendocrine Tumor](#)

# Can Pancreatic Neuroendocrine Tumor Be Found Early?

Pancreatic neuroendocrine tumors (NETs) are hard to find early. The pancreas is deep inside the body, so small tumors can't be seen or felt by health care providers during routine physical exams. People usually have no [symptoms](#) until the cancer has already spread to other organs.

At this time, no major professional groups recommend routine screening for pancreatic NET in people who are at average risk. This is because no screening test has been shown to lower the risk of dying from this cancer. (*Screening* means testing for a disease in people who have no symptoms or history of the disease.)

## Genetic testing for people who might be at increased risk

Some people might be at increased risk of pancreatic NET because of a family history of the disease (or a family history of certain other cancers). Sometimes this increased risk is due to a specific [genetic syndrome](#)<sup>1</sup>.

Some of the [gene changes](#)<sup>2</sup> that increase pancreatic NET risk can be tested for. Knowing if you are at increased risk can help you and your doctor decide if you should have tests to look for pancreatic NET early, when it might be easier to treat. But determining whether you might be at increased risk is not simple. Talking to someone with experience in hereditary cancer syndromes such as a genetic counselor, geneticist, or an oncologist (doctor who treats people with cancer) is often helpful.

The American Cancer Society strongly recommends that anyone thinking about [genetic testing](#)<sup>3</sup> talk with a genetic counselor, nurse, or doctor qualified to interpret and explain the test results before they proceed with testing. Before deciding to be tested, it's important to understand what the tests can and can't tell you, and what any results might mean.

Genetic tests look for mutations in your genes that cause inherited conditions. The tests are used to look for these inherited conditions, not the cancer itself. Your risk may be increased if you have one of these conditions, but it doesn't mean that you have or definitely will get pancreatic NET.

## Testing for pancreatic neuroendocrine tumor in people at high risk

For people in families at high risk of pancreatic NET, such as MEN1 syndrome, tests for detecting cancer early may help. Although definitive screening guidelines for people with the MEN1 gene or their family members are not available, doctors have been able to find early, treatable pancreatic NETs in some members of high-risk families with these tests. Some [tests](#) that might be considered include:

- An endoscopic ultrasound of the pancreas every few years.
- A MRI of the pancreas every few years.
- Checking blood levels of certain hormones such as insulin, prolactin, gastrin, and calcium every few years. (Sometimes, changes in hormones can occur 10 years before the tumor is found by clinical symptoms.)
- An Octreoscan on a regular basis.

## Hyperlinks

1. [www.cancer.org/cancer/cancer-causes/genetics/family-cancer-syndromes.html](http://www.cancer.org/cancer/cancer-causes/genetics/family-cancer-syndromes.html)
2. [www.cancer.org/cancer/cancer-causes/genetics/genes-and-cancer.html](http://www.cancer.org/cancer/cancer-causes/genetics/genes-and-cancer.html)
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# Signs and Symptoms of Pancreatic Neuroendocrine Tumor

Having one or more of the symptoms below does not mean you have a pancreatic neuroendocrine tumor (NET). In fact, many of these symptoms are more likely to be caused by other conditions. Still, if you have any of these symptoms, it's important to have them checked by a doctor so that the cause can be found and treated, if needed.

Pancreatic NETs often release excess hormones into the bloodstream. Different types of tumors make different hormones, which can lead to different symptoms.

## Gastrinomas

These tumors make gastrin, a hormone that tells the stomach to make more acid. Too much gastrin causes a condition known as *Zollinger-Ellison syndrome*, in which the stomach makes too much acid. This leads to stomach ulcers, which can cause **pain, nausea, and loss of appetite**. Severe ulcers can bleed. Even if the bleeding is mild, it can lead to anemia (too few red blood cells), which can cause symptoms like **feeling tired** and **being short of breath**. If the bleeding is more severe, it can make **stool black and tarry**. Severe bleeding can itself be life-threatening.

If the stomach acid reaches the small intestine, it can damage the cells of the intestinal lining and break down digestive enzymes before they have a chance to digest food. This can cause **diarrhea** and **weight loss**.

## Glucagonomas

These tumors make glucagon, a hormone that increases glucose (sugar) levels in the blood. Most of the symptoms that can be caused by a glucagonoma are mild and are more often caused by something else.

Excess glucagon can raise blood sugar, sometimes leading to diabetes. This can cause symptoms such as **feeling thirsty and hungry**, and **having to urinate often**.

People with these tumors can also have problems with **diarrhea, weight loss, and malnutrition**. The nutrition problems can lead to symptoms like **irritation of the tongue and the corners of the mouth**.

The symptom that brings most people with glucagonomas to their doctor is a rash called

*necrolytic migratory erythema*. This is a **red rash with swelling and blisters that often travels from place to place on the skin.**

## Insulinomas

These tumors make insulin, which lowers blood glucose levels. Too much insulin leads to low blood sugar, which can cause symptoms like **weakness, confusion, sweating, and rapid heartbeat**. When blood sugar gets very low, it can lead to a person **passing out or even going into a coma and having seizures**.

## Somatostatinomas

These tumors make somatostatin, which helps regulate other hormones. Symptoms of this type of tumor can include **belly pain, nausea, poor appetite, weight loss, diarrhea, symptoms of diabetes (feeling thirsty and hungry, and having to urinate often), and jaundice (yellowing of the skin and eyes)**.

The early symptoms of a somatostatinoma tend to be mild and are more often caused by other things, so these tumors tend to be diagnosed at an advanced stage. Often, they are not found until they spread to the liver, when they cause problems like jaundice and pain.

## VIPomas

These tumors make a substance called *vasoactive intestinal peptide* (VIP). Too much VIP can lead to problems with **diarrhea**. This may be mild at first, but gets worse over time. By the time they are diagnosed, most people have severe, watery diarrhea.

Other symptoms can include **nausea, vomiting, muscle cramps, feeling weak or tired, and flushing (redness and warmth in the face or neck)**.

People with these tumors also tend to have low levels of acid in their stomachs, which can lead to **problems digesting food**.

## Carcinoid tumors

These tumors often make serotonin or its precursor, 5-HTP. Carcinoid tumors often don't cause symptoms until they spread outside the pancreas. When these tumors do spread, it is most often to the liver. There, the cancer cells can release hormones

directly into the blood. This can cause the carcinoid syndrome, with symptoms including **flushing (redness and warmth in the face or neck), diarrhea, wheezing, and a rapid heart rate.** These symptoms often occur in episodes, between which the person may feel fine.

Over a long time, the hormone-like substances released by these tumors can damage heart valves, causing **shortness of breath, weakness, and a heart murmur (an abnormal heart sound).**

## Non-functioning neuroendocrine tumors

These tumors don't make excess hormones, so they don't cause symptoms in early stages and often grow quite large before they are found. Most of these start to cause problems as they get larger or spread outside the pancreas. Symptoms can be like those from **exocrine pancreas cancers, including jaundice (yellowing of the eyes and skin), belly pain, and weight loss.** Sometimes, as a pancreatic NET grows, it can go from making too little of a hormone (nonfunctioning) to making too much of a specific hormone (functioning) which causes symptoms.

## Symptoms caused by the cancer spreading

When pancreatic NETs spread, most often they go to the liver. This can enlarge the liver, which can cause **pain and loss of appetite.** It can also affect liver function, sometimes leading to **jaundice (yellowing of the skin and eyes) and abnormal blood tests.**

These cancers can also spread to other organs and tissues. The symptoms depend on where the cancer is growing. For example, cancer spread to the lungs can cause **shortness of breath or a cough.** Spread to bones can cause **pain** in those areas.

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## Tests for Pancreatic Neuroendocrine Tumor

Certain [signs and symptoms](#) might suggest that a person could have a pancreatic neuroendocrine tumor (NET), but tests are needed to confirm the diagnosis.

### Medical history and physical exam

In taking your medical history, the doctor will ask you questions about your general health, lifestyle habits, symptoms, and risk factors. The doctor will also probably ask about symptoms related to excess hormone production such as diarrhea, abdominal (belly) pain, or rash.

Your doctor will also examine you to look for signs of pancreatic NET or other health problems. The exam will probably focus mostly on your belly. Pancreatic NETs can sometimes cause the liver or gallbladder to swell, which the doctor might be able to feel during the exam.

If the results of the exam are abnormal, your doctor will probably order tests, such as imaging, labs, or other procedures, to help find the problem. You might also be referred

to a gastroenterologist (a doctor who treats digestive system diseases) for further tests and treatment.

## Imaging tests

### Computed tomography (CT) scan

A [CT scan](#)<sup>1</sup> uses x-rays taken from different angles, which are combined by a computer to make detailed pictures of the organs. This test is most often used to look at the chest and/or belly (abdomen) to see the pancreas clearly and if the pancreatic NET has spread to nearby lymph nodes or other organs such as the liver. It can also be used to guide a biopsy needle into an area of concern.

### Magnetic resonance imaging (MRI)

Like CT scans, [MRI scans](#)<sup>2</sup> show detailed images of soft tissues in the body. But MRI scans use radio waves and strong magnets instead of x-rays. A dye called gadolinium may be injected into a vein before the scan to see details better. A MRI scan sometimes can see cancer spread to the liver better than a CT scan.

**MR cholangiopancreatography (MRCP)**, is a special type of MRI scan, which can be used to look at the pancreatic and bile ducts, and is described below in the section on cholangiopancreatography.

### Ultrasound

[Ultrasound](#)<sup>3</sup> tests use sound waves to create images of organs such as the pancreas.

**Abdominal ultrasound:** For this test, a wand-shaped probe is moved over the skin of the abdomen. It gives off sound waves and detects the echoes as they bounce off organs. If it's not clear what might be causing a person's abdominal symptoms, this might be the first test done because it is easy to do and it doesn't expose a person to radiation.

**Endoscopic ultrasound (EUS):** This test uses an endoscope with a small ultrasound probe on the end. The scope is then passed through your mouth or nose, down through the stomach, and into the first part of the small intestine. It is then pointed toward the pancreas, which is next to the small intestine. The probe on the tip of the endoscope can get very close to the pancreas, so this is a very good way to look at it. If a tumor is seen, a small, hollow needle can be passed down the endoscope to get biopsy samples



of it.

## **Cholangiopancreatography**

This is an imaging test that looks at the pancreatic ducts and bile ducts to see if they are blocked, narrowed, or dilated. These tests can help show if someone might have a pancreatic neuroendocrine tumor that is blocking a duct. They can also be used to help plan surgery. The test can be done in different ways, each of which has pros and cons.

**Endoscopic retrograde cholangiopancreatography (ERCP):** For this test, an endoscope (a thin, flexible tube with a tiny video camera on the end) is passed down the throat, through the esophagus and stomach, and into the first part of the small intestine. This is usually done while you are sedated (given medicine to make you sleepy).

The doctor can see through the endoscope to find the ampulla of Vater (where the common bile duct empties into the small intestine). The doctor guides a catheter (a very small tube) through the tip of the endoscope and into the common bile duct. A small amount of dye is then injected into the common bile duct, and x-rays are taken. This dye outlines the bile and pancreatic ducts. The x-rays can show narrowing or blockage in these ducts that might be due to pancreatic neuroendocrine tumor. The doctor doing this test can also put a small brush through the tube to remove cells for a biopsy (see below).

ERCP can also be used to place a stent (small tube) into a bile or pancreatic duct to keep it open if a nearby tumor is pressing on it.

**Magnetic resonance cholangiopancreatography (MRCP):** This is a non-invasive way to look at the pancreatic and bile ducts using the same type of machine used for standard MRI scans. Unlike ERCP, it does not require an injection of a dye. Because this test is non-invasive, doctors often use MRCP if the purpose is just to look at the pancreatic and bile ducts. But this test can't be used to get biopsy samples of tumors or to place stents in ducts.

**Percutaneous transhepatic cholangiography (PTC):** In this procedure, the doctor puts a thin, hollow needle through the skin of the belly and into a bile duct within the liver. A dye is then injected through the needle, and x-rays are taken as it passes through the bile and pancreatic ducts. As with ERCP, this approach can also be used to take fluid or tissue samples or to place a stent into a duct to help keep it open. Because it is more invasive (and might cause more pain), PTC is not usually used unless ERCP has already been tried or can't be done for some reason.

## Radionuclide scans

Scans using small amounts of radioactivity and special cameras can be helpful in looking for pancreatic NETs. They can help find tumors or look for areas of cancer spread if doctors aren't sure where it is in the body.

**Positron emission tomography (PET) scan:** For most types of cancer, [PET scans](#)<sup>4</sup> use a form of radioactive glucose (sugar) to find tumors. This type of PET scan is useful in finding poorly differentiated pancreatic neuroendocrine carcinomas (NECs), but a newer type of PET scan, called a Gallium-68 PET/CT Dotatate scan is being used for pancreatic NETs. It uses the radioactive agent gallium-68 dotatate which attaches to the somatostatin protein on neuroendocrine tumor cells. A special camera can detect the radioactivity. This Gallium-68 PET/CT scan is slowly becoming more widely available since it was approved by the FDA in 2016 and is able to find neuroendocrine tumors better than an OctreoScan (described below).

**Somatostatin receptor scintigraphy (SRS or OctreoScan):** This test can be very helpful in finding pancreatic NETs. It uses a drug called octreotide joined to radioactive *indium-111*. *Octreotide* is a hormone-like substance that attaches to pancreatic NET cells. A small amount of the octreotide-radioactive substance is injected into a vein and travels through the blood where it attaches to the tumor types of many types of pancreatic NET cells (although it is less helpful for insulinomas). A few hours after the injection, a special camera can be used to show where the radioactivity has collected in the body. More scans may be done over the next few days as well. Along with showing where tumors are, this test can also tell whether treatment with certain drugs such as octreotide and lanreotide is likely to be helpful.

## Blood and urine tests

Several types of blood and urine tests can be used to help diagnose pancreatic NET or to help determine treatment options if it is found.

Blood tests looking at the levels of certain pancreatic hormones can often help diagnose pancreatic NETs. Tests might be done to check blood levels of:

- Hormones made by different types of pancreatic NET cells, such as insulin, gastrin, glucagon, somatostatin, pancreatic polypeptide, and VIP (vasoactive intestinal peptide)
- Chromogranin A (CgA)
- Glucose and C-peptide (for insulinomas)

**Carcinoid tumors:** For carcinoids, a blood test may be done to look for serotonin, which is made by many of these tumors. The urine might also be tested for serotonin and for related chemicals such as 5-HIAA and 5-HTP.

Other common tests to look for carcinoids include blood tests for chromogranin A (CgA), neuron-specific enolase (NSE), substance P, and gastrin.

Depending on where the tumor might be located and the patient's symptoms, doctors might do other blood tests as well.

Some of these tests can also be used to show how well [treatment](#)<sup>5</sup> is working, since the levels of these substances tend to go down as tumors shrink.

## Biopsy

In many cases, the only way to know for sure if a person has some type of pancreatic NET is to remove cells from the tumor and look at them in the lab. This procedure is called a *biopsy*. Biopsies can be done in different ways.

**Percutaneous (through the skin) biopsy:** For this test, a doctor inserts a thin, hollow needle through the skin over the abdomen and into the pancreas to remove a small piece of a tumor. This is known as a *fine needle aspiration* (FNA). The doctor guides the needle into place using images from ultrasound or CT scans.

**Endoscopic biopsy:** Doctors can also biopsy a tumor during an endoscopy. The doctor passes an endoscope (a thin, flexible, tube with a small video camera on the end) into the throat, down the esophagus, and into the small intestine near the pancreas. At this point, the doctor can either use endoscopic ultrasound (EUS) to pass a needle into the tumor or endoscopic retrograde cholangiopancreatography (ERCP) to remove cells from the bile or pancreatic ducts. These tests are described in more detail above.

**Surgical biopsy:** In rare cases, an endoscopic biopsy or a CT-guided needle biopsy will not be able to get enough tissue to identify the type of tumor. In such cases, surgery may be needed to remove a tissue sample. Surgical biopsies are done much less often now than in the past since PNETs are mostly diagnosed using imaging (CT or MRI scans), somatostatin receptor-based imaging, EUS biopsy, and checking for excessive levels of hormones.

### Some people might not need a biopsy

Rarely, the doctor might not do a biopsy on someone who has a neuroendocrine tumor in the pancreas if imaging tests, blood tests, and somatostatin receptor-based imaging show the tumor is very likely to be cancer and if it looks like surgery can remove all of it. Instead, the doctor will proceed with surgery, at which time the tumor cells can be looked at in the lab to confirm the diagnosis. During surgery, if the doctor finds that the cancer has spread too far to be removed completely, only a sample of the cancer may be removed to confirm the diagnosis, and the rest of the planned operation may be stopped.

See [Testing Biopsy and Cytology Specimens for Cancer](#)<sup>6</sup> to learn more about different types of biopsies, how the biopsy samples are tested in the lab, and what the results will tell you.

## Hyperlinks

1. [www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html)
2. [www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html](http://www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html)
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## Pancreatic Neuroendocrine Tumor Stages

After someone is diagnosed with a pancreatic neuroendocrine tumor (NET), doctors will try to figure out if it has spread, and if so, how far. This process is called *staging*. The stage of a cancer describes how much cancer is in the body. It helps determine how serious the cancer is and how best to [treat](#)<sup>1</sup> it. Doctors also use a cancer's stage when talking about survival statistics.

The stages of pancreatic NET range from I (1) through IV (4). As a rule, the lower the stage, the less the cancer has spread. A higher number, such as stage IV, means cancer has spread more. Although each person's cancer experience is unique, cancers with similar stages tend to have a similar outlook and are often treated in much the same way.

### How is the stage determined?

The staging system most often used for pancreatic NETs is the American Joint Committee on Cancer (AJCC) **TNM** system, which is based on 3 key pieces of information:

- The size and extent of the main **tumor (T)**: How large is the tumor? Has it grown

into nearby structures or organs?

- The spread to nearby lymph **nodes (N)**: Has the cancer spread to nearby lymph nodes?
- The spread (**metastasis**) to distant sites (**M**): Has the cancer spread to distant organs? (The most common site of spread is the liver.)

Numbers or letters after T, N, and M provide more details about each of these factors. Higher numbers mean the cancer is more advanced. Once a person's T, N, and M categories have been determined, this information is combined in a process called *stage grouping* to assign an overall stage. For more information, see [Cancer Staging](#)<sup>2</sup>.

The system described below is the most recent version of the AJCC system, effective as of January 2018. It is used to stage well-differentiated pancreatic NETs, but not high-grade pancreatic NETs (known as *neuroendocrine carcinomas*) or other types of pancreatic cancer, which have [their own staging system](#)<sup>3</sup>.

Pancreatic NETs are typically given a **clinical stage** based on the results of a physical exam, biopsy, and imaging tests (as described in [Tests for Pancreatic Neuroendocrine Tumor](#)). If surgery is done, the **pathologic stage** (also called the *surgical stage*) is determined by examining tissue removed during the operation.

Staging for pancreatic NETs can be complex. If you have any questions about the stage of your cancer or what it means, please ask your doctor to explain it to you in a way you understand.

## Stages of pancreatic neuroendocrine tumors

AJCC Stage	Stage grouping	Stage description*
I	<b>T1 N0 M0</b>	The tumor is less than 2 centimeters (cm) across and is still just in the pancreas (T1). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
II	<b>T2 N0 M0</b>	The tumor is at least 2 cm across but no more than 4 cm across, and it is still just in the pancreas (T2). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
	<b>T3 N0 M0</b>	The tumor is more than 4 cm across and is still just in the

		pancreas, OR the tumor has grown into the duodenum (the first part of the small intestine) or the common bile duct (T3). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
III	<b>T4 N0 M0</b>	The tumor has grown into nearby organs (such as the stomach, spleen, colon, or adrenal gland) or it has grown into nearby large blood vessels (T4). The cancer has not spread to nearby lymph nodes (N0) or to distant parts of the body (M0).
	OR	
	<b>Any T N1 M0</b>	The tumor can be any size and might or might not have grown outside of the pancreas (any T). It has spread to nearby lymph nodes (N1), but not to distant parts of the body (M0).
IV	<b>Any T Any N M1</b>	The tumor can be any size and might or might not have grown outside of the pancreas (any T). It might or might not have spread to nearby lymph nodes (any N). The cancer has spread to distant parts of the body (M1).

\* The following additional categories are not listed in the table above:

- **TX:** The main tumor cannot be assessed due to lack of information.
- **T0:** There is no evidence of a main tumor.
- **NX:** Nearby lymph nodes cannot be assessed due to lack of information.

## Other prognostic factors

Although not formally part of the TNM system, other factors can also be important in determining a person's prognosis (outlook).

### Tumor grade

The grade describes how quickly the cancer is likely to grow and spread. For pancreatic NETs, an important part of grading is measuring how many of the cells are in the process of dividing into new cells. This is determined by:

- The **mitotic count**, which is the number of cells seen under a microscope that are in the process of splitting into two new cells (mitosis).
- The **Ki-67 index**, which is a measure of the portion of cells that are almost ready to

start splitting.

Based on these tests, NETs are divided into 2 main groups:

- **Well-differentiated tumors** (which include low-grade [G1] and intermediate-grade [G2] tumors) have 20 or fewer mitoses and a Ki-67 index of 20% or lower.
- **Poorly differentiated tumors** (high-grade [G3] tumors) have more than 20 mitoses or a Ki-67 index of more than 20%. These are also called **neuroendocrine carcinomas (NECs)**, and they often grow and spread quickly.

### Tumor functionality

The outlook for pancreatic NETs can be affected by whether the tumor is [functioning \(making hormones\) or non-functioning](#)<sup>4</sup>. For functioning tumors, the type of hormone can also be important. For example, insulinomas (NETs that make insulin) tend to have a lower risk of spreading than other types of NETs.

### Hyperlinks

1. [www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/treating/pnets-by-extent.html](http://www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/treating/pnets-by-extent.html)
2. [www.cancer.org/treatment/understanding-your-diagnosis/staging.html](http://www.cancer.org/treatment/understanding-your-diagnosis/staging.html)
3. [www.cancer.org/cancer/pancreatic-cancer/detection-diagnosis-staging/staging.html](http://www.cancer.org/cancer/pancreatic-cancer/detection-diagnosis-staging/staging.html)
4. [www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/about/what-is-pnet.html](http://www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/about/what-is-pnet.html)

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# Survival Rates for Pancreatic Neuroendocrine Tumor

Survival rates can give you an idea of what percentage of people with the same type and stage of cancer are still alive a certain amount of time (usually 5 years) after they were diagnosed. They can't tell you how long you will live, but they may help give you a better understanding of how likely it is that your treatment will be successful.

**Keep in mind that survival rates are estimates and are often based on previous outcomes of large numbers of people who had a specific cancer, but they can't predict what will happen in any particular person's case. These statistics can be confusing and may lead you to have more questions. Talk with your doctor about how these numbers may apply to you, as he or she is familiar with your situation.**

## What is a 5-year relative survival rate?

A **relative survival rate** compares people with the same type and stage of pancreatic neuroendocrine tumor (NET) to people in the overall population. For example, if the **5-year relative survival rate** for a specific type and stage of pancreatic NET is 90%, it means that people who have that cancer are, on average, about 90% as likely as people who don't have that cancer to live for at least 5 years after being diagnosed.

## Where do these numbers come from?

The American Cancer Society relies on information from the SEER\* database, maintained by the National Cancer Institute (NCI), to provide survival statistics for different types of cancer.

The SEER database tracks 5-year relative survival rates for pancreatic NET in the United States, based on how far the cancer has spread. The SEER database, however, does not group cancers by [AJCC TNM stages](#) (stage 1, stage 2, stage 3, etc.). Instead, it groups cancers into localized, regional, and distant stages:

- **Localized:** There is no sign the cancer has grown outside of the pancreas.
- **Regional:** The cancer has grown outside the pancreas into nearby tissues or has spread to nearby lymph nodes.
- **Distant:** The cancer has spread to distant parts of the body such as the lungs, liver or bones.

## 5-year relative survival rates for pancreatic NET

(Based on people diagnosed with pancreatic NET between 2009 and 2015.)

SEER Stage	5-year Relative Survival Rate
Localized	93%
Regional	77%
Distant	27%
All SEER stages combined	54%

### Understanding the numbers

- **These numbers apply only to the stage of the cancer when it is first diagnosed.** They do not apply later on if the cancer grows, spreads, or comes back after treatment.
- **These numbers don't take everything into account.** Survival rates are grouped based on how far the cancer has spread, but your age, overall health, how well the cancer responds to treatment, [tumor grade, tumor function](#)<sup>1</sup>, and other factors can also affect your outlook.
- **People now being diagnosed with pancreatic NET may have a better outlook than these numbers show.** Treatments improve over time, and these numbers are based on people who were diagnosed and treated at least five years earlier.

\*SEER= Surveillance, Epidemiology, and End Results

### Hyperlinks

1. [www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/about/what-is-pnet.html](http://www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/about/what-is-pnet.html)

### References

Howlader N, Noone AM, Krapcho M, et al (eds). SEER Cancer Statistics Review, 1975-2016, National Cancer Institute, Bethesda, MD, [https://seer.cancer.gov/csr/1975\\_2016/](https://seer.cancer.gov/csr/1975_2016/), based on November 2018 SEER data submission, posted to the SEER website, April 2019.

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## Questions to Ask About Pancreatic Neuroendocrine Tumor

It's important to have honest, open discussions with your cancer care team. They want to answer all your questions, so that you can make informed treatment and life decisions. For instance, consider these questions:

### When you're told you have a pancreatic neuroendocrine tumor

- What [kind of pancreatic neuroendocrine tumor](#)<sup>1</sup> do I have?
- Has my cancer spread beyond where it started?
- What is the [stage](#) of my cancer and what does that mean?
- Is my cancer resectable (removable by surgery)?
- Are my symptoms because the cancer is making too many hormones?
- Will I need any other tests before we can decide on treatment?
- Will I need to see other doctors or health care professionals?
- If I'm concerned about the costs and insurance coverage for my diagnosis and treatment, who can help me?

### When deciding on a treatment plan

- How much experience do you have treating this type of cancer?
- What are my [treatment options](#)<sup>2</sup>?
- What do you recommend and why?
- What is the goal of the treatment?
- Should I get a [second opinion](#)<sup>3</sup>? How do I do that? Can you recommend a doctor or cancer center?
- How is treatment likely to help me?
- What risks or side effects might I expect? Are there things I can do to reduce these side effects?

- Should I think about taking part in a [clinical trial](#)<sup>4</sup>?
- How quickly do I need to decide on treatment?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What are the chances the cancer will [recur](#)<sup>5</sup> (come back) with these treatment plans?
- Will treatment affect my daily activities? Can I still work full time?
- What would my options be if the treatment doesn't work or if the cancer comes back?
- What if I have [transportation problems](#)<sup>6</sup> getting to and from treatment?

## During treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply to you, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything I can do to help manage [side effects](#)<sup>7</sup>?
- What symptoms or side effects should I tell you about right away?
- How can I reach you on nights, holidays, or weekends?
- Do I need to change what I eat during treatment?
- Are there any limits on what I can do?
- Can I exercise during treatment? If so, what kind should I do, and how often?
- Can you suggest a mental health professional I can see if I start to feel [overwhelmed, depressed, or distressed](#)<sup>8</sup>?

## After treatment

- Are there any limits on what I can do?
- Do I need a special diet after treatment?
- What symptoms should I watch for?
- What kind of exercise should I do now?
- What type of [follow-up](#)<sup>9</sup> will I need after treatment?
- How often will I need to have follow-up exams and tests? Will I need any blood tests?

- How will we know if the cancer has come back? What should I watch for?
- What will my options be if the cancer comes back?

Along with these sample questions, be sure to write down some of your own. Keep in mind that doctors aren't the only ones who can give you information. Other health care professionals, such as nurses and social workers, can answer some of your questions. To find out more about speaking with your health care team, see [The Doctor-Patient Relationship](#)<sup>10</sup>.

## Hyperlinks

1. [www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/about/what-is-pnet.html](http://www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/about/what-is-pnet.html)
2. [www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/treating.html](http://www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/treating.html)
3. [www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/seeking-a-second-opinion.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/seeking-a-second-opinion.html)
4. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
5. [www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html](http://www.cancer.org/treatment/survivorship-during-and-after-treatment/understanding-recurrence.html)
6. [www.cancer.org/treatment/support-programs-and-services/road-to-recovery.html](http://www.cancer.org/treatment/support-programs-and-services/road-to-recovery.html)
7. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html)
8. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/changes-in-mood-or-thinking.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/changes-in-mood-or-thinking.html)
9. [www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/after-treatment.html](http://www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/after-treatment.html)
10. [www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/the-doctor-patient-relationship.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/choosing-your-treatment-team/the-doctor-patient-relationship.html)

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