



cancer.org | 1.800.227.2345

EASY READING

If You Have a Pancreatic Neuroendocrine Tumor (NET)

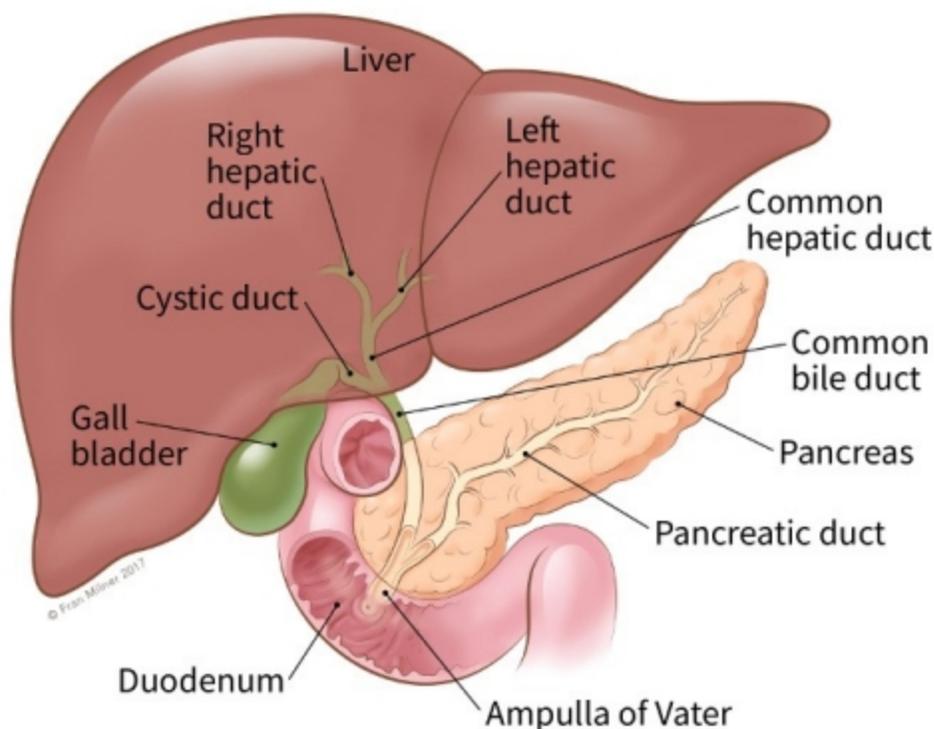
What is a pancreatic neuroendocrine tumor?

A pancreatic neuroendocrine tumor (NET) is a type of cancer that starts in the pancreas. It happens when *endocrine cells* (a type of cell found in the pancreas) start to change and grow out of control, crowding out normal cells.

Your pancreas has 2 jobs:

- It makes a substance that helps break down (digest) the food you eat.
- it makes hormones that help control the levels of sugar, insulin, and other substances in your blood.

Pancreatic NETs start in the type of cells that make hormones (*endocrine cells*). But there's another, [more common type of pancreatic cancer](#)¹ that starts from the cells that help digest food (*exocrine cells*). **If you've been diagnosed with pancreatic cancer, ask your doctor which type you have. The two types of pancreatic cancer are treated differently and have different outlooks.**



Ask your doctor to use this picture to show you where your cancer is located.

Pancreatic NETs can spread to other parts of the body. When cancer does this, it's called *metastasis*. But the type of cancer is based on the type of cells it started from. So even if a pancreatic NET spreads to your liver, for example, it's still called a pancreatic NET, not liver cancer.

Questions to ask the doctor

- Why do you think I have cancer?
- Is there a chance I don't have cancer?
- Would you please write down the kind of cancer you think I might have?
- What will happen next?

How does the doctor know I have a pancreatic neuroendocrine tumor?

Sometimes it can be hard to find a pancreatic NET when it's still small. Not all pancreatic NETs cause [signs and symptoms](#)², but some make different types of

hormones that might cause problems that you notice.

Tests that may be done

The doctor will ask questions about your health and do a physical exam. The pancreas is deep inside the body, so it can be hard for the doctor to see or feel something wrong if the cancer is still small. If signs are pointing to pancreatic NET, more tests will be done. Here are [some of the tests you may need](#)³:

Biopsy: The doctor takes out a little bit of tissue or some cells to check for cancer. A biopsy is the only way to tell for sure if you have cancer. There are different ways to do biopsies, so ask your doctor which type of biopsy you will have.

CT or CAT scan: This test uses x-rays to make pictures of your insides. This can show clear pictures of the pancreas and the area around it to see if the cancer has spread.

MRI scan: This test uses radio waves and strong magnets instead of x-rays to make clear pictures of the inside of the body. This test may be used to learn more about the cancer's size and spread. Special types of MRI scans can also be used to look at ducts and blood vessels in and around the pancreas.

Endoscopic ultrasound (EUS): This test uses sound waves to make pictures of the inside of your body. A small ultrasound on the tip of a thin tube is passed down your throat, into the stomach, and then into the first part of the small intestine. The ultrasound tip can be pointed to look at the pancreas. It can also be used to take out a little bit of tissue that can be checked for cancer.

Endoscopic retrograde cholangiopancreatography (ERCP): A small camera on the tip of a thin tube is passed down your throat, into the stomach, and then into the first part of the small intestine. This test can check if the ducts are blocked due to pancreatic NET. It can also be used to help open a blocked duct or take out some cells.

Radionuclide scans: These are tests that use a small amount of radiation and special cameras to find where the pancreatic NET is located or spread. They are also helpful to choose certain drugs for treatment and to see if treatment is working.

Liver function tests: These are blood tests to see how well the liver is working.

Tumor marker tests: Your blood might be checked for proteins or hormones that certain types of pancreatic NETs make. This test can help your doctor find out the kind of pancreatic NET that you have.

Other blood tests: You might have other tests to help find out if you have any other health problems such as kidney disease or bone marrow problems.

Questions to ask the doctor

- What tests will I need to have?
- Who will do these tests?
- Where will they be done?
- Who can explain the tests to me?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

How serious is my cancer?

Staging the cancer

If you have a pancreatic NET, the doctor will want to find out [how far it has spread](#)⁴. This is called *staging*. Your doctor will want to find out the stage of your cancer to help decide what treatment is best for you. Your cancer can be staged 1, 2, 3 or 4. The lower the number, the less the cancer has spread.

Grading the cancer

Grading means checking the cancer cells from your biopsy test to see how much they look like normal cells. This helps doctors tell how fast the cancer is likely to grow and spread. Your tumor will be given a grade between 1 and 3. The lower the number, the more the cancer cells look like normal cells and tend to grow more slowly. The tumor grade helps the doctor decide which treatment is best for you, so ask your doctor to explain your cancer's grade and what it means for your treatment.

Questions to ask the doctor

- Do you know the stage of the cancer?
- If not, how and when will you find out the stage of the cancer?
- Would you explain to me what the stage means in my case?
- Based on the stage of the cancer, how long do you think I'll live?
- What is the grade of the cancer and what will that mean for treatment?

- What will happen next?

What kind of treatment will I need?

The main [ways to treat pancreatic NET⁵](#) are surgery, radiation therapy, chemotherapy or other drugs. Ask your doctor what treatments can help you. Even for cancers that are more advanced and harder to cure, treatment can often make symptoms better and slow down the cancer's growth. Talk with your doctor to find out your options.

The treatment plan that's best for you will depend on:

- The stage and grade of the cancer
- The chance that a type of treatment will cure the cancer or help with symptoms
- Your age
- Other health problems you have
- Your feelings about the treatment and the side effects that come with it

Surgery

If the cancer is small and has not spread, surgery is done to try to take all of it out. Sometimes, surgery can be done to take out only the cancer, and leave the rest of the pancreas alone. But often, depending on how large the cancer is, parts, or even all, of your pancreas and other organs might need to be removed, too. Ask your doctor what kind of surgery you will have. If the cancer is too large or has spread too far, surgery might not be possible, and other treatments might be done instead.

Side effects of surgery

Surgery for pancreatic NET can be a small or very big operation, but all surgery can have risks and side effects. Be sure to ask the doctor what to expect, and let your doctor know if you have any problems after surgery. Possible problems from surgery are:

- Leaking inside the body
- Infection
- Bleeding
- Trouble eating

- Weight loss
- Changes in bathroom habits
- Diabetes

Tumor ablation and embolization

Tumor ablation or embolization can help if a pancreatic NET has spread to the liver. It destroys the tumor without taking it out by surgery. It may be done if you are too sick to have surgery. There are many ways to do this, such as heating the tumor with radio waves or microwaves, freezing the tumor, or killing the tumor by blocking the blood supply that feeds the liver. Talk to your doctor about what to expect.

Radiation Therapy

Radiation uses high energy x-rays to kill cancer cells or shrink tumors. Radiation might be used if the cancer has grown too much to be taken out by surgery. It might also be used after surgery if all the cancer was not removed and is still causing problems. Radiation can also help make symptoms better, such as pain caused by the cancer.

Side effects of radiation therapy

If your doctor suggests radiation, ask about what side effects might happen. The most common side effects of radiation are:

- Skin changes where the radiation is given
- Feeling very tired
- Feeling sick to your stomach
- Losing weight

Radioactive drugs

Sometimes special drugs that have small amounts of radiation inside are used to treat pancreatic NETs. These drugs can bring radiation straight to the cancer, without hurting as many healthy cells.

The most common side effects of radioactive drugs are nausea, kidney and liver problems, low white blood counts, and vomiting.

Chemo

Chemo is the short word for chemotherapy, the use of drugs to fight cancer. These drugs are mainly used for pancreatic NETs that have spread, are growing fast, are causing bad symptoms, or when other drugs have not worked.

Some chemo drugs are given through a needle into a vein (called an *infusion*), and others are taken as pills. These drugs go into the blood and spread through the body. Chemo is given in cycles or rounds. Each round of treatment is followed by a break to allow your body to get better from the side effects. Different kinds of chemo drugs can be used together or alone, and often with other types of drugs, too. Treatment often lasts for many months.

Side effects of chemo

Common side effects are:

- Hair loss
- Mouth sores
- Not feeling like eating
- Diarrhea
- Feeling sick to your stomach
- Infections
- Bruising and bleeding easily
- Tiredness

These problems usually go away after treatment ends, and there are ways to treat most chemo side effects. If you have side effects, be sure to talk to your cancer care team so they can help.

Targeted Therapy

Targeted therapy drugs work differently from chemo drugs. These drugs affect mainly cancer cells and not normal cells in the body. They may work even if other treatments don't. The types of targeted therapy drugs that are used for pancreatic NETs are taken as pills. The side effects will depend on which targeted therapy drug you are given, so talk to your doctor what to expect. Often, the side effects are different than the side effects for chemo.

Other drugs

Octreotide and lanreotide: These drugs are helpful in treating the symptoms caused by many pancreatic NETs. Sometimes they can temporarily shrink these tumors, but they can't cure them. These drugs are given as shots (injections) just under the skin.

Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

Clinical trials are one way to get the newest cancer treatment. They are the best way for doctors to find better ways to treat cancer. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)⁶ to learn more.

What about other treatments that I hear about?

When you have cancer you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be [vitamins, herbs, special diets, and other things](#)⁷. Some of these are known to help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

Questions to ask the doctor

- What treatment do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the cancer?
- Will treatment include surgery? If so, who will do the surgery?
- What will the surgery be like?
- Will I need other types of treatment, too? What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- How soon do I need to start treatment?

- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

What will happen after treatment?

You'll be glad [when treatment is over](#)⁸. For years after treatment ends, you will see your cancer doctor. Be sure to go to all of these follow-up visits. You will have exams, blood tests, and maybe other tests to see if the cancer has come back. At first, your visits may be every 3 to 6 months. Then, the longer you're cancer-free, the less often the visits are needed.

Sometimes treatments may not cure your cancer. You may need to keep getting treatment and care. From time to time tests will be done to see how your treatment is working.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. Call us at 1-800-227-2345 or talk to your cancer care team to find out what you can do to feel better. You can't change the fact that you have cancer. What you can change is how you live the rest of your life.

Hyperlinks

1. www.cancer.org/cancer/pancreatic-cancer.html
2. www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/detection-diagnosis-staging/signs-and-symptoms.html
3. www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/detection-diagnosis-staging/how-diagnosed.html
4. www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/detection-diagnosis-staging/net-staging.html
5. www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/treating.html
6. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html
7. www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html
8. www.cancer.org/cancer/pancreatic-neuroendocrine-tumor/after-treatment.html
9. <http://www.cancer.org>

Words to know

Ablation (ab-lay-shun): Treatment that removes or destroys all or part of a cancer; can also be used to remove or stop the function of an organ. For example, removing the ovaries or testicles or taking medicines that cause them to stop making their hormones would be called ablation. Besides surgery and drug treatment, other ways of ablating body tissues and tumors include extreme heat, freezing, and chemicals.

Chemotherapy (key-mo-THER-uh-pee) : Treatment with drugs that kill cancer cells. Chemotherapy is often used, either alone or with surgery and/or radiation, to treat cancer that has spread or come back (recurred), or when there is a strong chance that it could come back. Often called chemo.

Embolization (em-buh-li-ZAY-shun): A type of treatment that reduces the blood supply to the cancer by injecting materials to plug up the artery that supplies blood to the tumor.

Endocrine cells (EN-doh-krin): Cells in the pancreas that produce hormones (such as insulin) that help control sugar in the blood.

Exocrine cells (EK-soh-krin): Cells in the pancreas that make special juices that help your body digest food after you eat.

Pancreas (Pan-kree-us): An organ that lies behind the stomach and contains 2 different types of gland cells. One type makes enzymes which are released into the intestines to help digest food. The other type makes insulin and glucagon, which help regulate blood sugar. See also enzyme, glandular cells.

Targeted therapy: These drugs affect mainly cancer cells and not normal cells in the body. These drugs often have milder side effects than chemo.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org (<http://www.cancer.org>)⁹. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

Last Medical Review: October 30, 2018 Last Revised: October 30, 2018

Written by

The American Cancer Society medical and editorial content team
(www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

Our team is made up of doctors and oncology certified nurses with deep knowledge of cancer care as well as journalists, editors, and translators with extensive experience in medical writing.

American Cancer Society medical information is copyrighted material. For reprint requests, please see our Content Usage Policy (www.cancer.org/about-us/policies/content-usage.html).

cancer.org | 1.800.227.2345