



# Understanding Your NET

Your guide to living with a  
neuroendocrine tumor



[www.netpatientnetwork.ie](http://www.netpatientnetwork.ie)

## Stay informed, and stay involved in your care

Understanding Your NET is a brochure with information for people affected by neuroendocrine tumors (NET) and their loved ones.

There are 9 topics covered in this brochure. They are divided into 2 sections, called “About NET” and “Living with my condition.”

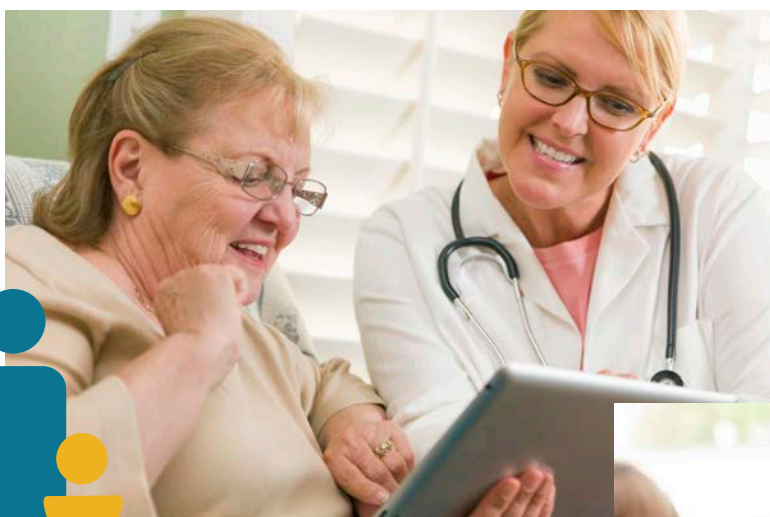
“About NET” provides information about how NET form and grow, and the different ways they can affect your body.

“Living with my condition” provides practical tips about managing your symptoms, working with your health care team, and finding support groups.

The topics covered in each section are shown in the Table of Contents on the facing page. Each topic is tabbed to help you find information quickly and easily.

When you talk to your doctors about your NET, they may use words or terms you haven’t heard before. Important medical terms appear **like this** in this brochure, and their definitions are in the glossary in Section 10.

Visit [www.netpatientnetwork.ie](http://www.netpatientnetwork.ie) for more information or visit our private Facebook discussion groups at [www.facebook.com/NETPatientNetwork](https://www.facebook.com/NETPatientNetwork).



### Mission Statement

**“To give a voice to NET patients in Ireland, to advocate for best medical practice and best service levels, and to connect patients within a supportive familial atmosphere utilising past patient experiences.”**



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### Notes

#### Testing and nutrition factsheets

This brochure is designed to answer some questions you may have about NET.

It can also be used as an aid for talking with your health care team so you can get the best possible care.

We hope it will help you feel more comfortable with your condition.

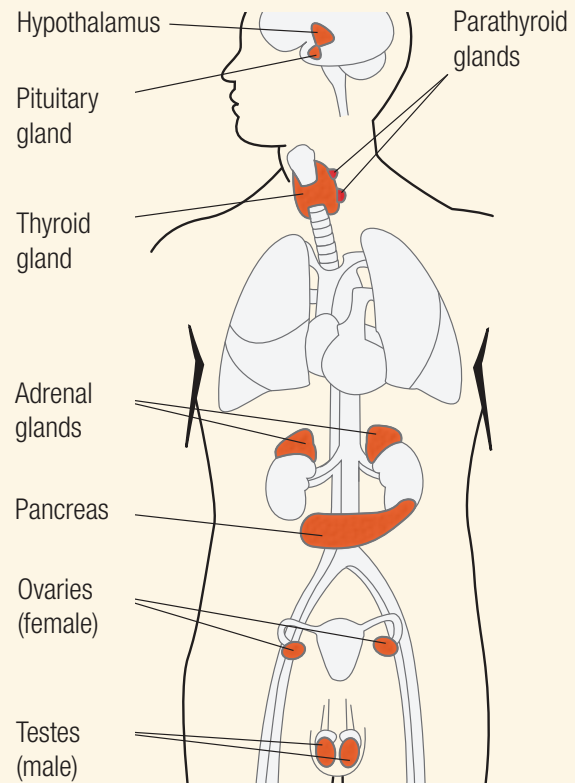
# What is the neuroendocrine system?

## Major glands of the endocrine system

The neuroendocrine system is made up of the nervous system and the **endocrine system**

- The nervous system is controlled by your brain. Your brain sends messages through your body using the nervous system
- Some messages reach your endocrine system. Your endocrine system is made up of a group of glands and organs, like the **pancreas, thyroid** and parathyroid, and **adrenal glands** (see the picture at right)
- The glands and organs in your endocrine system release **hormones**. Hormones control different body functions, like growth and reproduction, and how your body responds to stress or injury

Figure reprinted from The Merck Manuals Online Medical Library.



## How does the neuroendocrine system work?

Your nervous system and endocrine system are made up of neuroendocrine cells.

Neuroendocrine cells are located throughout your body. They release hormones that send messages to other cells.

- For example, after you eat and your body needs to digest food, your brain sends a message to release the hormone **serotonin**. Serotonin tells the muscles in your digestive tract to start working.
- **Insulin**, adrenalin, estrogen, and testosterone are other important hormones you may have heard about.

Like other types of cells in your body, neuroendocrine cells can sometimes turn into cancer. This can lead to serious medical problems, like neuroendocrine **tumors** (NET).

# How are tumors formed?

## How do cells become tumors?

Cells make up the tissue and organs in your body. Cells are always aging, dying, and being replaced by new cells.

Sometimes, this 3-stage process doesn't happen, and cells may not grow the way they are supposed to. That is when **tumors** may form.

## Do all tumors mean cancer?

Not all tumors mean cancer. It depends on what type of tumor it is: benign or malignant. Look at the table below to learn about the difference between benign and malignant tumors.

Benign tumors	Malignant tumors
<p><b>Are not</b> considered cancer</p> <p>Are generally harmless</p>	<p><b>Are</b> considered cancer</p> <p><b>Grow</b> uncontrollably</p>
<p><b>Are not</b> very different from surrounding tissue</p>	<p><b>Are</b> different from surrounding tissue</p>
<p><b>Don't</b> spread to nearby tissue</p>	<p><b>May</b> invade nearby tissue or spread (<b>metastasize</b>) to other parts of the body</p>

## What kind of tumor is a neuroendocrine tumor (NET)?

NET are malignant tumors. They vary in size and in how fast they grow.

NET start in cells throughout the body called neuroendocrine cells. Neuroendocrine cells release **hormones**. Some NET may also release hormones.

NET can spread to other parts of the body, like the liver or bone. By the time they are found, more than 50% of NET have already spread to other parts of the body. This can happen because some NET

- Are hard to find until they have grown or spread
- Don't cause symptoms until they have grown or spread
- Cause symptoms that make them seem like other diseases, so they may take longer to be diagnosed

Some NET may be found during regular doctor visits or during surgery for other conditions. In these cases, doctors may be able to diagnose the NET at an early stage of disease.

## What is differentiation?

**Differentiation** is a word doctors use to describe how a tumor looks under a microscope. Doctors view a tumor this way to see how it looks compared with the tissue around it. The table below explains more.

If your NET is well differentiated, it...	If your NET is poorly differentiated, it...
May not grow or spread quickly	Often grows and spreads quickly
May be called low or intermediate <b>grade</b>	May be called high grade
Probably will not be called <b>aggressive</b>	May be called aggressive



# What does the term “NET” mean?

NET stands for “neuroendocrine tumor.” It is a label for many specific types of malignant **tumors**. Your doctor may describe your NET using words shown in the table below.

- |  |  |
|--|--|
| <ul style="list-style-type: none"><li>• <b>Carcinoid</b></li></ul>   | <ul style="list-style-type: none"><li>• A NET that may release <b>serotonin</b> and other chemicals that cause a certain set of symptoms called <b>carcinoid syndrome</b></li></ul>  |
| <ul style="list-style-type: none"><li>• <b>Gastroenteropancreatic NET (GEP-NET)</b></li></ul>  | <ul style="list-style-type: none"><li>• A NET found in the <b>gastrointestinal (GI) tract</b> or the <b>pancreas</b></li></ul>   |
| <ul style="list-style-type: none"><li>• Islet cell tumor</li><li>• Gastrinoma, glucagonoma, insulinoma, or <b>vasoactive intestinal peptide</b> tumor (VIPoma)</li></ul> | <ul style="list-style-type: none"><li>• A term used for a pancreatic NET</li><li>• Types of pancreatic tumors that release <b>hormones</b> that cause different symptoms and sets of symptoms (<b>syndromes</b>)</li></ul> |
| <ul style="list-style-type: none"><li>• Merkel cell <b>carcinoma</b></li></ul>   | <ul style="list-style-type: none"><li>• A type of skin cancer</li></ul>  |
| <ul style="list-style-type: none"><li>• Medullary <b>thyroid</b> carcinoma</li></ul>   | <ul style="list-style-type: none"><li>• A NET found in the thyroid gland</li></ul>   |
| <ul style="list-style-type: none"><li>• Small-cell lung carcinoma</li></ul>  | <ul style="list-style-type: none"><li>• Malignant form of lung cancer that may be considered a NET</li></ul>   |



## Where do NET start?

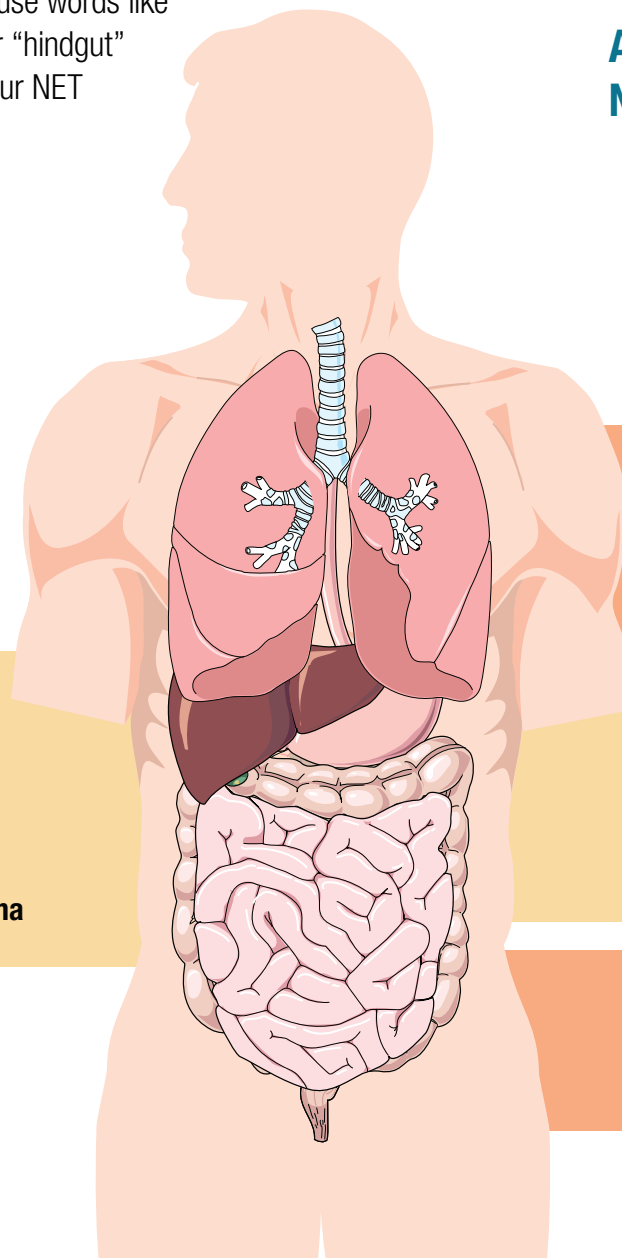
Doctors may refer to a NET based on where it started in the body.

NET start in neuroendocrine cells, which are found all through your body. Most NET can be found in organs of the GI tract, like the stomach or intestines, or in the pancreas. They are called GEP-NET.

NET can also appear in your lungs, ovaries, testes, and other glands, like the **thymus** and **adrenal gland**. See the diagram in Section 1 of this brochure.

Your doctor may also use words like “foregut,” “midgut,” or “hindgut” when talking about your NET (see picture).

## Areas in your body where NET may appear



### Pancreatic NET

- Gastrinoma
- Insulinoma
- Glucagonoma
- VIPoma
- Somatostatinoma
- Pancreatic polypeptidoma

### Carcinoid tumors\*

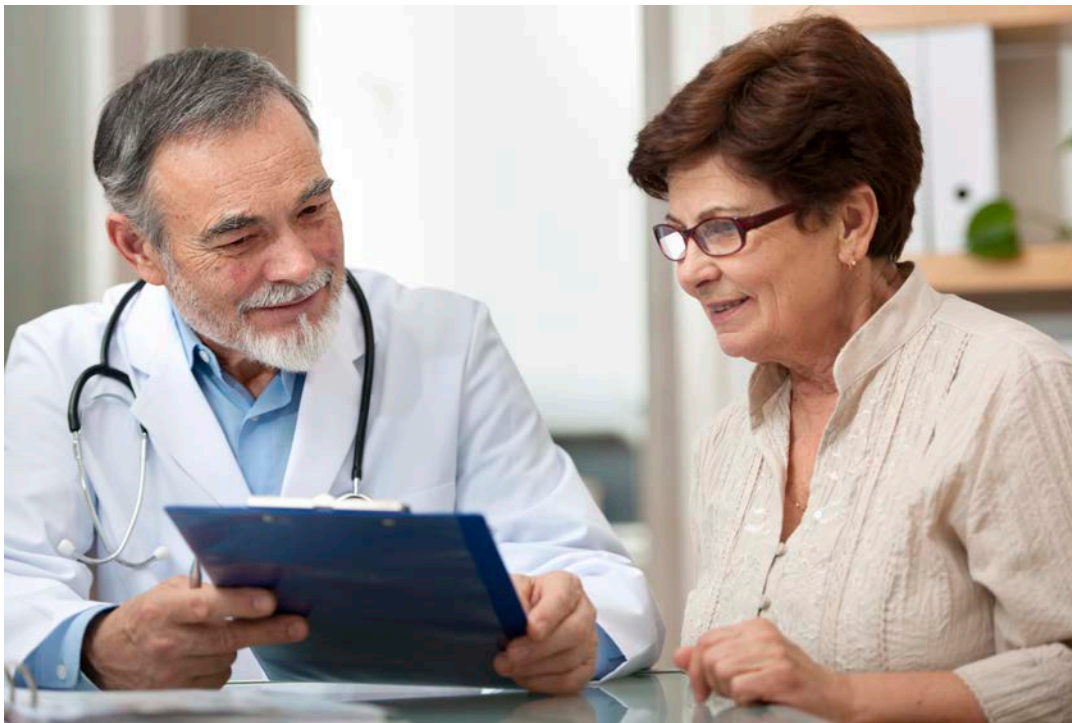
- Foregut**
  - Lungs
  - Stomach
  - Thymus
  - First part of duodenum
- Midgut**
  - Second part of duodenum
  - Jejunum
  - Ileum
  - Right colon
- Hindgut**
  - Transverse, left, sigmoid colon
  - Rectum

\*Certain NET that appear in these areas may be called carcinoid tumors.

## How else might my doctor describe my NET?

Your doctor may talk about whether or not your NET releases **hormones**. It's another way doctors can describe the type of NET you have.

- **Functional** NET, or secretory **tumors**, produce hormones
  - A NET can cause different symptoms depending on the hormones it releases, or secretes
- **Nonfunctional** NET, or nonsecretory tumors, don't produce hormones
  - Symptoms like pain may happen as the tumor grows



# How can I learn to live with my neuroendocrine tumor (NET)?

## Like any cancer, NET can change your life.

Having a NET means you have a type of cancer that is not as well known as other types of cancer. It is normal to feel overwhelmed, confused, afraid, and even angry about your condition. Your family and friends may feel the same way.

It's important to learn how to live with your condition. It's also important to keep yourself as comfortable as possible. Here are some tips.

## Understand your journey

Your journey as a person with a NET started when you were diagnosed. It continues as you and your doctors work together to manage your condition.

Be sure to take an active role in your journey. Try to

- Get the best possible care
- Stay on top of your care plan
- Keep track of your disease
- Talk about your symptoms
- Feel confident about your health
- Stay positive

## Talk openly with your doctors and nurses

Take control of your health.

- Share details about your symptoms. Be sure to include information about changes in your symptoms, too. If they are happening more often or become more intense, tell your doctors. Also be sure to talk about any new symptoms you have
- Share information about allergies, what you eat, and medicines you are taking
- Ask questions. Write the answers down so you can read them again later

## Prepare for your doctor visits

- Bring test results or any other paperwork from previous visits with you
- Ask questions and take notes using the notepad included with this brochure
- Take a caregiver with you, when you can. They can give you emotional support and help make sure you don't miss anything
- Understand the role of each of the specialists on your health care team
- Use the glossary in this brochure to help you understand some of the words your health care team may use

## Make some changes

Your doctor may suggest things you can do to make living with a NET easier.\*

- Eat foods that can help ease your symptoms or prevent them from occurring. Tips to help you with your diet are included on a fact sheet at the end of this brochure
- Do regular, mild exercise, like walking
- Get plenty of sleep, and take naps when you can
- Avoid stress



**Eat foods that can help ease your symptoms or prevent them from occurring.**

\*Patients must consult with their health care providers before making any changes to their diet or daily habits.

## **Connect with others**

Always remember, you are not alone. There are other people like you and many groups that want to help. NET Patient Network is a patient support and advocacy group for NET patients in Ireland. NET Patient Network organises patient support meetings and distributes information specific to Ireland. Find us on [www.netpatientnetwork.ie](http://www.netpatientnetwork.ie) or on Facebook at [www.facebook.com/NETPatientNetwork](https://www.facebook.com/NETPatientNetwork).

A list of all other groups is in Section 8 of this brochure. The list includes ways to contact them as well.

## **Manage your health coverage**

The bills and paperwork you receive from your doctor and hospital visits can be confusing. It's important to keep track of it all and keep it organized.

# Who will help me manage my neuroendocrine tumor (NET)?

Your doctor or your oncologist may talk to other doctors who are experts in managing NET. Sometimes a team of medical experts will come together to provide the best possible care for people with NET. You may see one or more of the types of doctors listed in the table below.

Type of health care professional	What they do
Oncologist	Expert in <b>tumors</b> and how to manage them
Gastroenterologist	Expert in diseases of the digestive tract and their symptoms
Endocrinologist	Deals with diseases of the <b>endocrine system</b> (see Section 1 for more about the endocrine system)
Surgeon	Performs surgery and removes tumors
Pathologist	Uses a powerful microscope to look at samples of tumors. A sample of a tumor is called a <b>biopsy</b>
Nuclear medicine specialist	Takes medical pictures of tumors. This process is called “imaging”
Interventional radiologist	Treats tumors that have spread to other parts of the body with <b>radiation</b>
Nutritionist	Suggests changes in diet and nutrition that may help improve a patient’s health
Nurse Social worker Case manager	Care for and understand the special needs of patients with NET

## Why might I want to see so many different doctors?

Here are just a few reasons why you may want to see different types of doctors:

- NET are found in different areas of the body. You may want to see a doctor who is an expert in that area
- NET appear and grow in different ways
- NET cause different symptoms and can lead to other medical issues
- NET may or may not spread to other parts of the body





## What tests might my doctor order?

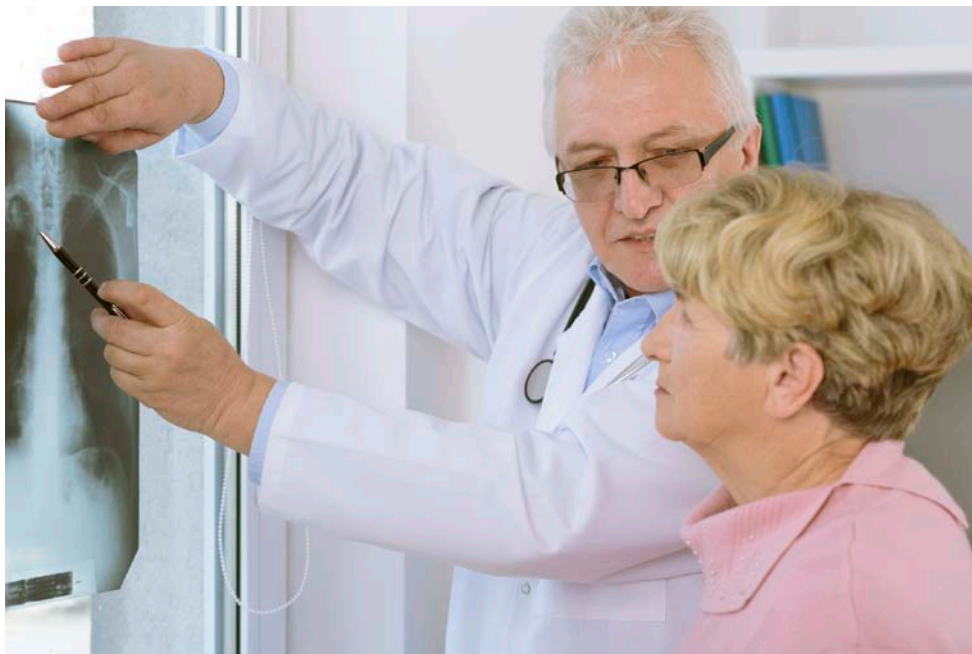
There are a number of tests your doctor might order. Some tests help to find a neuroendocrine tumor (NET). Some help to track changes in your NET over time.

Your family doctor may order some tests. Or, you may go to another doctor for certain tests. Your doctor will decide which tests are best for you and how often you will need them.

Two types of tests your doctor might order for you are

- Biochemical tests
  - Look at a sample of blood or urine
  - Measure the amounts or levels of certain substances in the sample
- Imaging tests
  - Use special machines to look at your internal organs or tissues
  - Your doctor does not need to take a sample of blood, urine, or tissue for these tests

Information about different kinds of biochemical and imaging tests can be found on a fact sheet at the end of this brochure.



## What is causing my symptoms?

Your doctor may order tests depending on the symptoms you have. NET can cause many types of symptoms. They include diarrhea, stomach pain, weight gain or loss, skin rash or flushing, and many others. Your doctor can talk to you more about your specific symptoms.

There are different reasons why you may have certain symptoms, which are described below.

- Is your NET **functional** ?
  - Releases **hormones** that cause symptoms
  - When symptoms happen at the same time it is called a **syndrome**
- Is your NET **nonfunctional** ?
  - Does not release hormones
  - Causes symptoms like pain as the **tumor** grows
- Where is your NET located?
  - The location of the NET in your body may play a part in the type of symptoms you have

Remember to keep detailed notes of your symptoms, tests you've had, and the test results. You can print and use the notepad at the end of this brochure to keep track of the details. Be sure to ask your doctor about your test results and what they mean. If you have a test more than once and the results change, ask your doctor what this means. You will want to keep notes of your doctor's answers, too.



# What are the options for managing my neuroendocrine tumor (NET)?

Some of the options your doctors may discuss with you appear below and on the following page.

Option	May remove tumor	May reduce tumor size	Helps ease symptoms	Hospitalization needed
<p><b>Surgery</b></p> <ul style="list-style-type: none"> <li>• Surgery is the first option for many people with NET. Surgeons may try to remove the NET entirely or control the growth of the <b>tumor</b></li> <li>• If disease has spread to other parts of the body, surgery may be an option to help reduce symptoms</li> </ul>	X	X	X	X
<p><b>Chemotherapy</b></p> <ul style="list-style-type: none"> <li>• <b>Chemotherapy</b> is the use of drugs to kill cancer cells or stop them from growing</li> <li>• There are many different kinds of chemotherapy drugs. Some are pills that you can take by mouth. Some drugs can be given by an injection into your body</li> </ul>		X		Maybe
<p><b>Chemoembolization</b></p> <ul style="list-style-type: none"> <li>• Chemoembolization is when drugs are injected directly into a tumor. This stops the blood supply to the tumor for a short time. It also lets the drug stay in direct contact with the tumor longer</li> <li>• Chemoembolization may be used when disease has spread to the liver</li> </ul>		X		Maybe
<p><b>Radiofrequency ablation</b></p> <ul style="list-style-type: none"> <li>• Radiofrequency ablation is when radio waves are used to heat and kill tumor cells</li> <li>• Radiofrequency ablation may be used to shrink the size of a tumor. It may also be used when disease has spread to the liver and cannot be removed with surgery</li> </ul>		X	Maybe	

## What are the options for managing my neuroendocrine tumor (NET)? (cont)

Option	May remove tumor	May reduce tumor size	Helps ease symptoms	Hospitalization needed
<b>Radiotherapy</b> <ul style="list-style-type: none"> <li>Radiotherapy uses <b>radiation</b> to kill cancer cells and shrink tumors. The radiation may come from a machine, or from a substance containing radiation that is placed in your body</li> <li>Radiotherapy may be used when disease has spread. It may help control certain symptoms</li> </ul>		X	X	Maybe
<b>Targeted radionuclide therapy</b> <ul style="list-style-type: none"> <li>A radionuclide is a chemical that releases radiation. Radionuclides are injected into your body with a liquid and collect in specific areas</li> <li>One type of this treatment is called <sup>131</sup>I-MIBG. It can be used to help control symptoms in some people who have disease that has spread or cannot be removed with surgery</li> <li>Another type of treatment is called peptide receptor radionuclide therapy (PRRT). It is only available in certain medical centers</li> </ul>			X	Maybe

### Are there any other options for me?

Medicines are also used to treat some people with certain kinds of NET. Your doctor may discuss these options with you, depending on your personal circumstances.

Remember, you should always work closely with your doctor and the other members of your health care team to decide on the best way to manage your condition.

## What do I need to tell my doctor?

Be sure to tell your health care team everything about your disease, including

- Symptoms
- Allergies
- Foods you eat
- All medicines you are taking (prescription or over-the-counter)
- Any changes in your daily habits

### How will my doctors know how to manage my NET?

Your doctors will consider many things when making decisions about managing your NET, including (but not limited to)

- Where your tumor is located in your body
- The **grade** and **stage** of your tumor
- Whether your tumor is **functional** or **nonfunctional**
- Symptoms you may have
- How you're feeling and your overall health

Be sure to share information about your daily life with your doctors. They will need these details to create a plan for you to manage your NET.

# Where can I find information and support?

**Because a neuroendocrine tumor (NET) is not a common condition, it is even more important for you to get as much support as possible**

Your health care team should be your first source of information. They understand your specific medical needs. But there are also other ways to learn more about NET and connect with people who have the same condition.

Whether you use the Internet or a large or small support group, you are not alone. There are many people who can help you cope with the challenges of living with a NET.

## NET patient groups\*

### Australia

The Unicorn Foundation  
[www.unicornfoundation.org.au](http://www.unicornfoundation.org.au)

### Canada

Carcinoid-Neuroendocrine Tumour Society – Canada (CNETS-Canada)  
[www.cnetscanada.org](http://www.cnetscanada.org)

### France

APTED: L'Association des Patients porteurs des Tumeurs Endocrines Diverses  
<http://apted.fr/Pages/default.aspx>

### Germany

Netzwerk Neuroendokrine Tumoren  
[www.glandula-Net-online.de](http://www.glandula-Net-online.de)

Bundesorganisation NET  
[www.net-shg.de](http://www.net-shg.de)

### Ireland

NET Patient Network  
[www.netpatientnetwork.ie](http://www.netpatientnetwork.ie)  
[www.facebook.com/NETPatientNetwork](https://www.facebook.com/NETPatientNetwork)

## **Netherlands**

Stichting NET-groep  
[www.net-kanker.nl/](http://www.net-kanker.nl/)

## **Norway**

CarciNor  
[www.carcinor.no](http://www.carcinor.no)

## **Poland**

Stowarzyszenie Pacjentow/Osob Wspierajacych chroych na Guzy Neuroendokrynne  
[www.rakowiak.pl/statut.htm](http://www.rakowiak.pl/statut.htm)

## **Singapore**

Carcinoid & Neuroendocrine Tumor Society (CNETS) Singapore  
[www.cnets.org/index.htm](http://www.cnets.org/index.htm)

## **Sweden**

CARPA (The Carcinoid Patient Association)  
[www.carpapatient.se/](http://www.carpapatient.se/)

## **United Kingdom**

NET Patient Foundation  
[www.netpatientfoundation.org](http://www.netpatientfoundation.org)

## **United States**

Carcinoid Cancer Awareness Network  
[www.carcinoidawareness.org](http://www.carcinoidawareness.org)

The Carcinoid Cancer Foundation  
[www.carcinoid.org](http://www.carcinoid.org)

Caring for Carcinoid Foundation  
[www.caringforcarcinoid.org](http://www.caringforcarcinoid.org)



Please note that this is not a comprehensive list of all NET patient groups. Other NET patient groups may be available.

## **Clinical trials involving NET**

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)



## NET awareness (sponsored by Novartis Pharmaceuticals Corporation) education

The NET Community  
[www.thenetalliance.com](http://www.thenetalliance.com)

Worldwide NET Cancer Awareness Day  
[www.netcancerday.org](http://www.netcancerday.org)

CarcinoidLink  
[www.carcinoid.com](http://www.carcinoid.com)

## General cancer information and advocacy groups

American Cancer Society  
[www.cancer.org](http://www.cancer.org)

APOZ and Friends in Bulgaria  
[www.oncobg.info](http://www.oncobg.info)

Association for International Cancer Research  
[www.aicr.org.uk](http://www.aicr.org.uk)

Ayrshire Cancer Support  
[www.ayrshirecs.org](http://www.ayrshirecs.org)

Canadian Cancer Society  
[www.cancer.ca](http://www.cancer.ca)

Cancer Adventures  
[www.canceradventures.org](http://www.canceradventures.org)

CancerCare, Inc.  
[www.cancercares.org](http://www.cancercares.org)

Cancer Research UK  
[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

Cancer Society of New Zealand  
[www.cancernz.org.nz](http://www.cancernz.org.nz)

Danish Cancer Society  
[www.cancer.dk](http://www.cancer.dk)

Irish Cancer Society  
[www.cancer.ie](http://www.cancer.ie)

National Cancer Institute (NCI)  
[www.cancer.gov](http://www.cancer.gov)

Oncolink  
[www.oncolink.org](http://www.oncolink.org)

Rarer Cancers Foundation  
[www.rarercancers.org.uk](http://www.rarercancers.org.uk)

Swedish Cancer Society  
[www.cancerfonden.se](http://www.cancerfonden.se)

Ulster Cancer  
[www.ulstercancer.org](http://www.ulstercancer.org)

# What can caregivers expect when a loved one has a neuroendocrine tumor (NET)?

For many people, NET are not going to go away. Like any cancer, NET can change your life. Your loved one may need surgery or other treatments. There may be times when there are no symptoms. Or there may be times when symptoms suddenly get worse.

You will be with your loved one through the ups and downs of this journey. Let your loved one know often that you care about his or her well-being and that you are there to help.

## How can I help?

Caregiving can mean helping to perform daily activities or helping your loved one cope with feelings. The most important thing you can do is be there for your loved one. Being there will help him or her feel less alone on this journey. Here are a few other tips:

### Understand the condition

NET are all very different and affect people differently. It may be helpful for you to learn about these tumors.

- Go with your loved one to doctor visits. Your loved one may appreciate the company. The doctor is a reliable source of information about the condition. You can also help take notes and keep track of appointments and paperwork
- Use the Internet. There are many good sources of information listed in Section 8

### Encourage healthy habits

The doctor may suggest some tips for your loved one. You can help your loved one make some of these changes and stick with them.\*

- Eat foods that can help ease your symptoms or prevent them from occurring
- Do regular, mild exercise, like walking
- Get plenty of sleep, and take naps when you can
- Avoid stress

Be sure to take care of yourself, too. Caregiving can be tiring, and you can't be there for your loved one if you are not feeling well yourself.

### What if I need support?

Talking to others in situations like yours may help you through some of the challenges of caregiving. There are plenty of support groups for people who care for cancer patients.

- Ask your loved one's doctor or hospital to help you get in touch with these groups
- Use the Internet. But be careful, not all information about NET is accurate. Some of the groups listed in Section 8 also give support to caregivers

**Remember: You are not alone! Help is available.**

\*Patients must consult with their health care providers before making any changes to their diet or daily habits.

# Glossary of terms

Use this glossary to find the meanings of important terms your doctor may use. Some of the terms are highlighted in this brochure.

**Adrenal gland:** A gland near the top of the kidney that creates hormones, like adrenaline and cortisol. Your body has 2 adrenal glands.

**Adrenocorticotrophic hormone (ACTH):** A hormone also known as corticotropin. It is produced by the anterior pituitary gland.

**Aggressive:** A term used to describe the speed or extent to which a tumor grows and spreads.

**Biopsy:** A procedure where a small amount of tissue is removed from the body and examined under a microscope or using other tests to find out if there is a tumor.

**Carcinoid:** Has the same meaning as NET or GEP-NET (see below). The words may be used in place of one another.

**Carcinoid syndrome:** A set of symptoms that occur when a functional NET that releases the hormone serotonin begins to spread or metastasize. The symptoms may be sudden or severe.

**Carcinoma:** Cancer that starts in the skin or in tissues that line or cover internal organs.

**Chemotherapy:** The use of drugs to destroy cancer cells, usually by affecting their ability to grow.

**Differentiation/differentiated cells:** In normal cells, differentiation is the process that changes a general, less specialized cell to a more specialized cell that has a specific job in the body. In tumor cells, differentiation refers to how developed the cells are. Differentiated tumor cells look like normal cells. Undifferentiated, or poorly differentiated, tumor cells don't have the structure of normal cells, and don't work the way normal cells do. Poorly differentiated tumor cells usually have a better chance of being malignant.

**Duodenum:** The first part of the small intestine, connected to the stomach. The duodenum gets enzymes from the pancreas and chemicals from the liver and the gallbladder to help with digestion.

**Endocrine system:** A group of glands and organs that control different body functions by producing and releasing hormones.

**Functional NET:** A NET that releases hormones and may cause many different symptoms. Also called a secretory NET.

**Gastrin:** A hormone released by the pancreas that tells your stomach to produce digestive acids and enzymes.

**Gastroenteropancreatic NET (GEP-NET):** A NET that most often starts in the gastrointestinal tract or pancreas.

**Gastrointestinal (GI) tract:** Another name for the digestive system. It includes the mouth, throat, esophagus, stomach, small intestine, large intestine, rectum, and anus.

**Glucagon:** A hormone released by the pancreas that raises glucose (sugar) levels in your blood.

**Grade:** A system of classifying tumor cells. The cells are graded based on how they look under a microscope and how quickly the tumor is likely to grow and spread. Low-grade tumors (grades 1 and 2) look like the tissue around them. They are less aggressive. High-grade tumors (grades 3 and 4) do not look like the tissue around them. They are more aggressive.

**Growth hormone-releasing factor (GRF):** A chemical released by the brain that tells the pituitary gland to produce growth hormone.

**Hormone:** A substance, usually a protein, that is released and travels through the bloodstream to different organs. Hormones help control how some of the organs in the body work.

**Hyperglycemia:** The condition of having high levels of glucose (sugar) in your blood. Symptoms include dry mouth, thirst, frequent urination (including at night), blurry vision, and dry, itchy skin.

**Hypochlorhydria:** The condition of having low levels of hydrochloric acid in your stomach. Symptoms include halitosis (bad breath), heartburn, bloating or belching, gas right after eating, and indigestion.

**Hypoglycemia:** The condition of having low levels of glucose (sugar) in your blood. Symptoms include dizziness, headache, tiredness, and confusion.

**Hypokalemia:** The condition of having low levels of potassium (salt) in your blood. It may be caused by diarrhea.

**Insulin:** A hormone released by the pancreas that lowers glucose (sugar) levels in your blood.

**Lesions:** Areas of abnormal tissue that may or may not be cancerous.

**Metastasize:** To spread from one part of the body to another. The words “localized,” “regional,” and “distant,” are sometimes used to describe how much a NET has spread, or metastasized.

**Nonfunctional NET:** A NET that doesn’t release hormones. This type of NET may only cause symptoms when it grows. Also called a nonsecretory NET.

**Pancreas:** An organ that produces hormones and enzymes that help your body digest food.

**Pellagra:** A condition caused by low levels of niacin (a B vitamin) in your blood. Symptoms include diarrhea, scaly skin rash, mental confusion, and inflamed mucus membranes.

**Proteins:** The basic building blocks of tissue and other structures in the body. An enzyme is a kind of protein that causes chemical changes in your body.

**Radiation:** A form of therapy used to kill cancer cells by damaging their DNA. Radiation can damage normal cells too, so treatment should be carefully planned to decrease side effects.

**Radiology:** The use of radiation to treat or diagnose disease.

**Radiotherapy:** The use of high-energy radiation to destroy cancer cells and shrink tumors. The radiation may come from a machine outside the body or from radioactive material that is placed in the body near cancer cells.

**Serotonin:** A hormone made by certain types of cells in the body, mostly in the gastrointestinal tract. Serotonin helps with various functions, including digestion.

**Somatostatin:** A hormone that stops the release of other hormones, including gastrin, insulin, glucagon, and serotonin (see definitions for these hormones in this glossary).

**Specialized cells:** Cells that have specific jobs in the body. They start as unspecialized cells, also known as stem cells, which are present in babies still in the womb. Unspecialized cells can turn into any kind of cell. The DNA in the cell determines the kind of cells they will become. The cells then grow and change shape, becoming specialized cells.

**Stage:** How far cancer in the body has progressed. Staging is usually based on the size of the tumor, whether lymph nodes in the body contain cancer, and whether the cancer has spread from the original site to other parts of the body.

**Syndrome:** A set of symptoms that occur together. A syndrome may be a sign of a certain disease. Or it may mean there's an increased chance of developing the disease. For example, hypoglycemia syndrome may be caused by a type of NET called an insulinoma, and Zollinger-Ellison syndrome may be caused by a type of NET called a gastrinoma.

**Thymus:** An organ near the base of the neck that produces infection-fighting cells.

**Thyroid:** A small gland in the neck, just under the skin below the Adam's apple. It produces thyroid hormones, which help control metabolism.

**Tumor:** An abnormal growth or mass in the body caused when cells grow out of control or don't die when they are supposed to.

**Tumor burden:** The number of cancer cells, size of a tumor, or the amount of cancer in a person's body.

**Ulcer:** A round sore where the lining of the stomach or duodenum has been eaten away by stomach acid and digestive juices.

**Unspecialized cells:** Also known as stem cells. These cells are present in babies still in the womb. They can turn into any kind of cell. The DNA in the cell determines the kind of cells they will become. The cells then grow and change shape, becoming specialized cells with specific jobs in the body.

**Vasoactive intestinal peptide (VIP):** A substance released by the pancreas that causes watery diarrhea.

**Wheezing:** A whistling sound made during breathing that happens when airways become partially blocked. Some tumors can squeeze an airway and cause the blocking.











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