Irish Cancer Society

Understanding

Neuroendocrine tumours (NETs)

Caring for people with cancer

Understanding

Neuroendocrine tumours (NETs)

This booklet has information on:

- Treatments
- Side-effects and how to manage them
- Coping with the emotional side of cancer
- Financial and practical matters

Useful numbers

Specialist nurse

Family doctor (GP)

Endocrinologist

Gastroenterologist

Surgeon

Medical oncologist

Radiation oncologist

Dietitian

Medical social worker

Hospital clinic

Emergency:

National Centre for NET email: **netcentre@svuh.ie**

Hospital medical records number (MRN):

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Fast facts

Can my cancer be treated? Page 41

Yes. There are lots of treatments for NETs. It's important that the right treatment is given at the right time. If a tumour is found early, it may be possible to remove it with surgery and sometimes this may cure the cancer. More often, NETs are treated to keep the disease and its symptoms under control, often using drugs.

Will I get side-effects or symptoms? Page 99

NETs often cause symptoms – the symptoms depend on the type of NET and where it is in your body. You may also get side-effects from certain treatments. See page 57 to learn about treatments and their possible side-effects.

What's the prognosis? Page 38

With the right treatment, many people can live full lives with a NET, with their symptoms controlled. It can be hard to predict exactly what will happen with your disease. The best thing to do is to talk to your NET team.

Clinical trials Page 87

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you.

We're here for you Page 137

If you or your family have any questions or worries, want to know where to get support, or if you just need to talk, you can talk to one of our cancer nurses.

Ways to get in touch

- Call our Support Line on 1800 200 700
- Drop into a Daffodil Centre to speak to a nurse. Email daffodilcentreinfo@irishcancer.ie to find your local Daffodil Centre.
- Email us: **supportline@irishcancer.ie**

See page 137 for more about our services.

Reading this booklet

This booklet is to help you throughout your treatment and afterwards. You will probably find different sections useful at different times, so keep it for reference.

If you need more information or don't understand something, ask your doctor or nurse. You can also ask one of our cancer nurses:

- Call our Support Line on Freephone 1800 200 700
- Visit a Daffodil Centre
- Email the nurses at supportline@irishcancer.ie

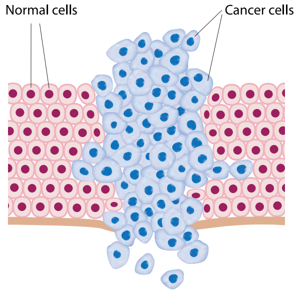
About our information

While we make every effort to ensure the information in this booklet is correct and up to date, treatments and procedures in hospitals can vary.

You should always talk to medical team about your treatment and care. They know your medical history and your individual circumstances. We cannot give advice about the best treatment for you.

About NETs

What is cancer?



- **Cancer is a disease of the body's cells.** Cancer cells are abnormal cells that grow without control. They can form a tumour.
- **Cancers are named after the organ or cell where the cancer starts.** Neuroendocrine cancers start in the neuroendocrine cells. Different types of NETs are named after the site of the original tumour, e.g. pancreatic NET or small intestine NET.
- **Cancers sometimes spread.** If a tumour is cancerous (malignant), a cell or group of cells can be carried by your blood or lymph fluid to another part of your body, where it can form a new (secondary) tumour. This is called metastasis.

What causes cancer?

We don't know exactly what causes many cancers, but there are things that can increase your risk of getting cancer. If you want to know more about why cancer happens, see our website **www.cancer.ie** or talk to a cancer nurse – call our Support Line or visit a Daffodil Centre.

Some NETs are inherited

If there is a history of certain conditions in your family, such as multiple endocrine neoplasia type 1 and Von Hippel-Lindau disease, then there may be an increased risk of developing a NET. Your family may wish to talk to their GP about the benefit of genetic testing.

What are NETs?

NET stands for neuroendocrine tumour. NETs are rare slow-growing cancers (neuroendocrine cancers) that affect cells in your neuroendocrine system.

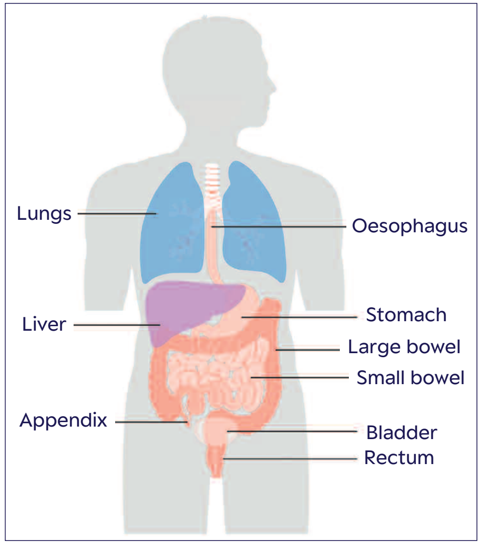
Ways to describe neuroendocrine cancers

Neuroendocrine cancers and neuroendocrine neoplasms (NENs) are umbrella terms covering cancers that start in neuroendocrine cells.

NETs (neuroendocrine tumours) and NECs (neuroendocrine carcinomas) are types of neuroendocrine cancers.

NETs is the term most commonly used at the moment.

Neuroendocrine cells are special cells that make hormones in your body. Hormones help to control many of the functions in your body. Examples of hormones are serotonin and insulin. Some NETs make extra hormones that can cause symptoms. These are called functioning NETs. Non-functioning NETs do not produce extra hormones.



Picture courtesy of CRUK (Wikimedia Commons)

The term NETs can be used to refer to different types of tumours. For example, gastroinstestinal NETs, pancreatic NETs, and lung NETs.

What are the types of NETs?

There are a number of different types of NETs and ways of describing them.

The type you have depends on the type of cell that the cancer started in. Most NETs are found in your digestive system. This includes your oesophagus, stomach, bowel, back passage (rectum) and appendix.

NETs can also affect other areas of the body. These include your lungs, pancreas, kidneys, ovaries and testicles.

Functioning and non-functioning NETs

- **Functioning NETs:** Produce extra hormones that cause symptoms.
- **Non-functioning NETs:** Do not cause hormone-related symptoms

Indolent and aggressive NETs

- **Indolent:** The tumour grows slowly.
- **Aggressive:** The tumour grows more quickly and is more likely to spread quickly to other parts of the body.

Where did the NET develop?

Gastrointestinal (GI) NETs

GI NETs start in organs in the gastrointestinal (digestive) system tract. This includes the small bowel (small intestine), back passage (rectum), stomach, colon, oesophagus and appendix. GI NETs are a common type of NET. Most GI NETs grow slowly.

Types of GI NETs

- **Functional GI NETs:** Functional GI NETs are tumours that release excess hormones (particularly serotonin) and other chemicals into the blood. This can cause a group of symptoms known as carcinoid syndrome. See below for more about GI NET symptoms and carcinoid syndrome.
- **Well-differentiated GI NETs:** The cells look like normal cells. These tumours may be slow-growing (indolent) or faster-growing. Low-grade NETs are slower growing than high-grade NETs. Read more about grading NETs (see page 37).
- **Poorly differentiated GI NETs:** The cells look very abnormal compared to normal cells. They tend to grow quickly and are more likely to spread.

Symptoms of a NET in the digestive system (gastrointestinal NET)

Symptoms depend on which part of the digestive system is affected by the NET.

- Diarrhoea
- Constipation
- Nausea
- Vomiting
- Bleeding from the rectum
- Fatigue
- Weight loss
- Abdominal (tummy area) pains
- Blockage in the intestine
- Carcinoid syndrome (see page 13)

Carcinoid syndrome

Carcinoid syndrome is a group of symptoms caused by a NET releasing large amounts of a hormone-like substance called serotonin or other chemicals into the blood.

Most patients with a NET do not have carcinoid syndrome. It is most common with small bowel NETs but it can sometimes happen with some other types of NETs. The signs or symptoms of carcinoid syndrome include:

- Flushing (hot and reddened) skin, mainly in the face and upper chest area
- Diarrhoea
- Breathing difficulties, wheezing
- Fast or irregular heartbeat, palpitations
- Low blood pressure
- Heart damage (carcinoid heart disease)

See page 108 for tips on coping with carcinoid syndrome

Lung NETs

Lung NETs start in the lungs or the airways. For example, the bronchi that lead to the lungs from the windpipe. Lung NETs are a common type of neuroendocrine tumour.

Types of lung NETs

There are 4 types of lung NETs:

- **Typical carcinoid tumours** usually grow slowly (indolent) and don't often spread to other parts of the body. The cells look and act much like normal cells.
- **Atypical carcinoid tumours** tend to grow slowly, but they may spread to other parts of the body. The cancer cells look and act much like normal cells (well differentiated).
- **Large cell lung neuroendocrine carcinomas** tend to grow quickly and are more likely to spread to other parts of the body. The cancer cells are very abnormal compared to normal cells (poorly differentiated).
- **Small cell lung neuroendocrine carcinomas,** or small cell lung cancers, are also very abnormal compared to normal cells (poorly differentiated). They tend to grow quickly and often spread to other parts of the body.

Your medical team may use different terms to describe lung NETs. For example, bronchial NET, pulmonary NET. Ask them if you have any questions about your diagnosis.

Symptoms of lung NETs

- Coughing up blood
- Wheezing
- A persistent cough
- Difficulty breathing
- Pneumonia
- Fatigue (extreme tiredness)

Most lung NETs are discovered incidentally.

Functioning lung NETs cause symptoms related to hormones, for example, carcinoid syndrome (see page 13) and Cushing syndrome. Cushing syndrome is caused by too much of the hormone cortisol. It is rare and causes symptoms such as weight gain and a round, red face.

Your team will give you information about symptoms if you have a functioning lung NET.

Pancreatic NETs (pNETs)

Pancreatic NETs can be functioning or non-functioning

- **Functioning:** The NET cells produce excess hormones, which can cause symptoms (see below).
- **Non-functioning:** The NET cells don't produce excess hormones.

Symptoms of functioning pNETs

The symptoms depend mainly on the type of hormone released by the tumour.

Insulinoma (releases insulin – causes a drop in blood sugar levels)

- Sweating, shaking, dizziness, heart palpitations, hunger, forgetfulness and confusion (caused by low blood sugar levels - hypoglycaemia)

Gastrinoma (releases gastrin – increases stomach acid)

- Heartburn, indigestion, pain in the chest or tummy, stomach ulcers, nausea, diarrhoea, weight loss

Glucagonoma (releases glucagon - raises blood sugar)

- Extreme thirst, needing to urinate (pee) a lot, tiredness, dry mouth, nausea, weight loss, red rash, anaemia

Somatostatinoma (releases somatostatin – controls the level of other hormones)

- Symptoms of diabetes, diarrhoea, steatorrhoea (fatty pale bowel motions) and weight loss.

VIPoma (releases vasoactive intestinal peptide - relaxing certain muscles, controlling some functions of the pancreas and gut, controlling release of hormones from the hypothalamus in the brain)

- Severe watery diarrhoea, which may lead to electrolyte imbalances in the blood such as low potassium (hypokalaemia) and low chloride (hypochorhydria), weakness and fatigue.

Well-differentiated/poorly differentiated pNETs

pNETs can also be grouped by how the cells look compared to normal cells and how fast the cells are growing:

- **Well-differentiated pNETs:** The cells are similar to normal cells. They tend to grow slowly.
- **Poorly differentiated pNETs:** The cells are very abnormal compared to normal cells. They tend to grow quickly and have often spread to other parts of the body when they're diagnosed.

Other neuroendocrine tumours

NETs can happen in other parts of the neuroendocrine system, but these NETs are very rare. For example:

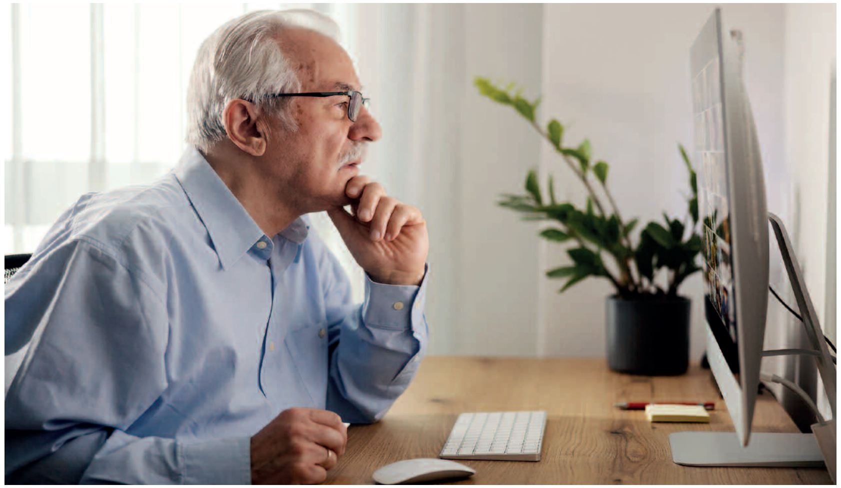
- Adrenal glands (pheochromocytoma and paraganglioma)
- Thyroid gland (medullary carcinoma, parathyroid adenoma)
- Pituitary gland
- Thymus (thymic NET)
- Ovaries or testicles
- Skin (Merkel cell carcinoma)

Ask your treating team about how these NETs may affect you.

Preparing for your hospital appointments

Preparing for your hospital appointments

Preparation is key to getting the most out of your hospital appointments. Being prepared also helps the doctors and nurses get the information they need to plan your care.



Before your appointment

- Write down a list of questions and things you would like to discuss.
- Know where you are going and plan your journey (build in extra time for unexpected delays, such as parking).
- Dress in warm comfortable clothes and shoes – sometimes you can be waiting around for a while. Layers are best, as the temperatures in hospitals can vary a lot. Loose-fitting clothing will be easier to manage if you are having your blood pressure taken, blood tests or a physical examination.
- Try to drink clear fluids (water or juice without pulp) if you are having a blood test and you aren't fasting. This can make it easier for the nurse or doctor to find a vein.
- Always try to bring someone with you. Ask a friend or family member to go along for extra support.

What to take to your appointment

Put together a list of things you might need to bring for your visit, including:

- Your medical card, if you have one
- Your private health insurance details, if you have insurance
- The appointment letter from the hospital, if you got one
- A referral letter or GP letter, if you got one
- Your GP's name and contact details
- Your medical history – remember, your doctor will likely ask you lots of questions so it's a good idea to have everything written down beforehand
- Your list of questions
- A notebook and pen to take notes. (Some healthcare professionals/nurses may be happy for you to record the meeting, but make sure you ask for their permission before doing so)
- A list of your medications or the medication itself – ask your pharmacist to print off a list of your medication. Hand-written lists can be hard to read or inaccurate
- Be aware of when your prescription is due, so you can ask for a prescription before you leave, if needed
- Medications and any medical supplies you may need that day, in case you are delayed
- A light snack and drink if you are likely to have to wait for some time. (Make sure you are not meant to be fasting – check with the hospital beforehand if you are not sure)
- Your phone and your phone number
- Contact details of the person to call in an emergency
- Your glasses and hearing aid, if you use them
- A book or something to listen to (including headphones) to pass the time while you wait

Before leaving the appointment

- Make sure you feel satisfied that your questions were answered and that you have written down what you need to know
- Make sure you know what will happen next
- Ask for the name or number of someone you can contact in case you have further questions
- Ensure you are booked in for your follow-up appointment before you leave

After the appointment

- Arrange any tests in advance of your next appointment as soon as you can, for example, a blood test – if your healthcare professional has asked for it.

Note: If you have to cancel your appointment...

If you are unable to attend your appointment, contact the hospital in advance and they will try to arrange a new appointment for you. If you don't go to your appointment or contact the hospital, you may have to return to your GP and go back on the waiting list for a new appointment.

Questions to ask your doctor

Here is a list of questions that you might like to ask. Never be shy about asking questions. It is always better to ask than to worry.

What tests will I need?

Will I have to stay in hospital for the tests?

How long will I have to wait for the test results?

What type of NET do I have?

What type of treatment do I need? Why is this best for me?

How successful is this treatment?

How long will treatment last?

What are the risks and possible side-effects of treatment?

Will I get symptoms from my NET?

Do I have to eat special foods?

Who do I contact if I have a problem when I go home?

What support services are available to help me cope?

Diagnosis and further tests

Being diagnosed with a NET

After your NETs diagnosis you may be feeling:

- **Upset and overwhelmed** by your emotions
- **Confused** by all the information being given to you
- **Worried** about what will happen next
- **Angry** that this is happening to you

However you feel, you are not alone. If you need to talk to someone, or if you want support or advice:

- Ask to speak to the cancer (oncology) liaison nurse or the medical social worker at the hospital. They can help you and your family to cope with your feelings and advise you about practical matters
- Talk to one of our cancer nurses in confidence – visit a Daffodil Centre or call our Support Line on 1800 200 700. You can email the nurses at supportline@irishcancer.ie
- Speak to an Irish Cancer Society Peer Support volunteer who has had a similar cancer experience and is fully trained to provide emotional and practical cancer support in a safe, responsible and kind way. Our cancer nurses can put you in touch with a volunteer.
- Talk to other people affected by cancer. NET Patient Network is a patient support and advocacy group for NETs patients in Ireland. It provides information on NETs and organises patient support meetings. **www.neuroendocrinecancer.ie**
- Join our online community at **www.cancer.ie/community** or the NET Patient Network's online support page at **www.facebook.com/NeuroendocrineCancerIreland**
- Go to your local cancer support centre. For more information, see page 144.

Telling people about your diagnosis

A diagnosis of NETs can be hard to talk about, as people may not have heard of NETs before, and each diagnosis is very individual. It may be hard for you to explain, especially when it is new to you too. You can ask your medical team if your friends and family have questions you don't know the answer to.

Telling people about your diagnosis can help you to get support from friends and family. But you may feel you don't want to tell people straight away. You may be unsure how to break the news or need a little time to adjust before you talk about it. You may also worry about how other people will react. For example, they may fuss over you or be upset.

If you would like to talk things over with a cancer nurse, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a copy of our booklet ***Understanding the emotional effects of cancer***. It can help you find ways to talk about your cancer and to ask for the help and support you need.

What tests might I have?

You might need more tests after you have been diagnosed with a NET.

The tests give doctors more information about your cancer:

- The size of the tumour
- Where exactly is the cancer?
- Has the cancer spread to any other parts of your body?

This is called staging.

The tests you have help to ensure that your team has all the information they need recommend the best treatment for you. Some tests may also be used to see how well you are responding to treatment.

Blood tests

CgA test: This measures the level of a protein called chromogranin A (CgA) in the blood. It can be used to help diagnose NETs, as people with a NET may have a raised level of CgA. It can also be used to monitor how you are responding to treatment. This test needs to be put on ice when taken by the phlebotomist.

PRoBNP test: A test used for people with carcinoid syndrome. It measures a peptide in your blood which gives your team information about your heart function.

Blood tests can also measure:

- Kidney function (urea and electrolytes)
- Liver function
- Thyroid function
- Pituitary hormones (e.g. adrenocorticotrophic hormone (ACTH), prolactin, growth hormones and cortisol)
- Serum calcium, parathyroid hormone levels (as a simple screening test for MEN-1 syndrome)
- Levels of other hormones
- Levels of vitamins and minerals

Urine test

5HIAA urine test

This test measures a substance called 5HIAA, which is found in the urine if your tumour is producing high levels of serotonin. By measuring 5HIAA, doctors can work out the amount of serotonin in the body. This is to confirm a diagnosis of carcinoid syndrome and is also used to monitor patients with carcinoid syndrome.

For 24 hours, every time you pee you will collect it in a container and then you will return the urine collected to the hospital. The hospital will advise you on how to collect and store the urine.

They will also advise you on foods and medicines to avoid before the test, as they can affect the results.

Scans

CT scan

This is a type of X-ray that gives a detailed 3D picture of the tissues inside your body. It can show the position and size of tumours. You may have regular scans to find out more about the rate of tumour growth and how the tumour is responding to treatment.

You might be asked to fast (not eat) for a few hours before the test. You may also be given an injection or a special drink to help show up parts of your body on the scan. The injection may make you feel hot all over for a few minutes. During the scan you will lie on a table which passes through a large doughnut-shaped machine. The scan is painless and takes between 10 and 30 minutes. You'll probably be able to go home as soon as the scan is over.

PET scan

A PET scan can show if the cancer has spread to other tissues and organs. A low dose of radiotracer (radioactive sugar) is injected into your arm. An hour or so later you will have a scan. The PET scan uses the radiotracer to highlight cancer cells in the body.

Before the scan, you may have to fast (not eat) and drink only plain unflavoured water for a few hours. You may also be asked to avoid strenuous exercise the day before and the morning of the scan.

During the scan, you will lie on a table that moves through a scanning ring. The scan usually lasts between 20 and 60 minutes. You will be asked to stay still during the scan.

Gallium-68 (Ga68) PET scan

This a special type of PET scan that is more sensitive. This test can help reveal the size and position of NET tumours in the body. It can also show if your NET might respond to targeted treatments, such as PRRT (see page 82) or targeted drug treatments (see page 74).

You may have to travel to a specialist centre to have a PET scan or a Gallium 68 scan, as not every hospital has these scanners.

You will be slightly radioactive after the PET scan. You should avoid close contact with pregnant women, babies or young children for a few hours after the scan.

Drink plenty of fluids and empty your bladder regularly after the scan; this can help flush the radiotracer from your body.

For most scans you will be alone in the treatment room, but the medical team can still see you, hear you and speak to you. Just speak or raise your hand if you need anything.

MRI scan

This is a scan that uses magnetic energy and radio waves to create a picture of the tissues inside your body. An MRI scan can be used to see where a tumour is. Further tests may be needed to confirm the type of tumour. You will need to complete a form before the test to ensure that it is safe for you to have an MRI scan.

During the test you will lie inside a tunnel-like machine for 40-60 minutes. The length of time depends on the number of images that are needed and the area of the body being scanned. Some people are afraid they will feel claustrophobic inside the tunnel. Tell the radiographer if you're feeling anxious. An MRI can also be noisy, but you will be given earplugs/headphones to wear.

You might get an injection (tracer) before the scan to highlight tumours. It is important that you keep as still as possible during the scan.

During the scan you cannot wear metal jewellery. If you have any medical device in your body, like a pacemaker or pin, you may not be suitable for the test.

Usually you can go home soon after the scan. You shouldn't need to stay in hospital.

Scoping tests

Scoping tests use a tube with a camera and a light attached which is passed into your body. Your doctor or nurse can see inside your body and check for any abnormal areas. Samples of tissue (biopsies) can also be taken during a scoping test.

Usually you will have a mild sedative to help you feel more relaxed. Or you may fall asleep. If you have a general anaesthetic, you may have to stay overnight in hospital.

Each test takes about 20-30 minutes. You may feel a little discomfort during or after the test, but you shouldn't have any pain.

You should be able to go home once the sedation has worn off. Make sure you arrange for someone to take you home, as you're not allowed to drive for 24 hours after having sedation. Tell your doctor if you have any problems like pain, bleeding or fever afterwards.

- **Endoscopy (gastroscopy):** Endoscopy is a scoping test that looks inside your body. It often refers to a test that examines your upper digestive system (oesophagus, stomach, start of the small intestine). This can also be called a gastroscopy. The tube with the camera is inserted down the back of your throat. You will have to fast (not eat) for a few hours before this test. The hospital will explain this and any other preparations you need. Sometimes an ultrasound probe is attached to the tube. This is called an EUS – endoscopic ultrasound. It can give a clearer view of the tumour and surrounding areas.

- **Colonoscopy:** A colonoscopy looks at your large intestine (colon) and rectum. The tube with the camera is inserted into your back passage. You will have to fast (not eat) for a few hours before the test and drink a special drink the day before and/or on the morning of your test to help clear out your bowels. The hospital will explain what you need to do.

Biopsy

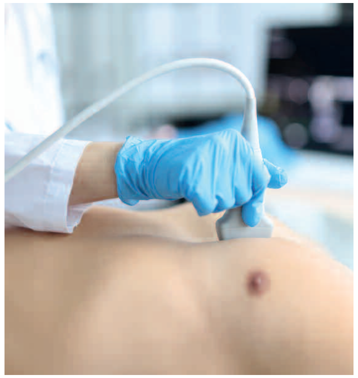
Taking a sample of the tumour using a fine needle. This may be done during a scoping test, where a tube is passed into your body. Sometimes this may be guided using ultrasound or another method to help ensure the targeted tumour is biopsied.

The sample is examined in a laboratory by a specialist called a histopathologist to give information about what type of NET cancer it is, and how it is growing.

Echocardiogram

This is a type of ultrasound scan, which uses sound waves to build up a picture of your heart.

A gel will be spread over the area the doctors are checking. A small device like a microphone is moved back and forth over your skin to take the scan. This can be used to check for heart issues which may occur due to carcinoid syndrome.



Waiting for test results

It can take a number of weeks for all the test results to come back. Usually your consultant or specialist nurse will discuss your test results with you at your next hospital visit.

Waiting for results can be an anxious time for you. It may help to talk things over with the specialist nurse or with a relative or close friend. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Staging and grading NETS

- Staging cancer means finding out its size and if it has spread
- Grading means looking at the cancer cells to see how they might grow
- Staging helps your doctor to plan the best treatment for you
- Your prognosis is what your doctor expects to happen with your cancer

The tests you have after diagnosis help the doctor to give your cancer a stage and a grade.

Staging describes **where the cancer is** in your body – its size and if it has spread.

Grading describes **the cancer cells** – what they look like under the microscope and how they might grow.

Knowing the stage and grade helps your doctor to decide the best treatment plan for you.

How are NETs staged?

Staging means finding out about the size of the tumour and if it has spread to other parts of your body. Staging will help your doctor to plan the best treatment for you.

The staging system normally with NETs is called TNM. This stands for:

- **Tumour (T):** The size of the tumour
- **Node (N):** Is there cancer in your lymph nodes?
- **Metastasis (M):** Has the cancer spread to other parts of your body?

Your doctor often uses this information to give your cancer a number stage – from 1 to 4.

A higher number, such as stage 4, means a more advanced cancer, where the cancer has spread to other parts of the body.

Staging can be hard to understand, so ask your doctor and nurse for more information if you need it. You can also call our Support Line on 1800 200 700.

Staging allows your doctor to decide the best treatment for you.

How are NETs graded?

Grading describes how quickly the cancer may grow and spread and how it might respond to treatment.

A special doctor called a pathologist looks at a tissue sample (biopsy) from the tumour under a microscope to see:

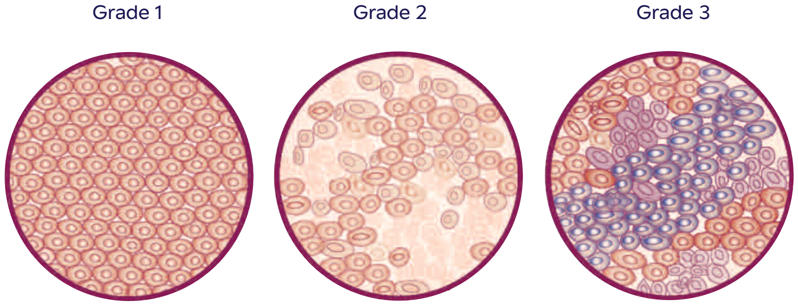
- How often the cells of the tumour are dividing (called the mitotic count)
- How much of a protein called Ki67 the cells make when they divide (called the proliferative index or Ki67 labelling index)
- The number of dead cells or tissues that are present (necrosis)

The pathologist gives the NET a grade from 1 to 3.

Grade 1 – Low grade: The cells of the tumour are slow growing. The Ki67 index is 2% or less

Grade 2 – Intermediate grade: The cells of the tumour are growing and dividing more quickly than normal cells. The Ki67 index is between 3% and 20%

Grade 3 – High grade: The cells of the tumour are growing quickly. These tumours are more likely to spread than grade 1 and grade 2 tumours. They are described as high grade. The Ki67 index is more than 20%



Knowing the stage and grade helps your healthcare team plan your treatment.

Asking about your prognosis

Your prognosis includes information about how your cancer is likely to progress, including average survival times or life expectancy.

It's not always easy for doctors to answer a question about life expectancy. Everyone is different, so what happens to you might be quite different from what the doctor expects.

Should I ask about my prognosis?

If your prognosis is better than expected, you may feel more hopeful about your illness and your future. You may feel more in control by having as much information as possible. Or you may not want to know about your prognosis. You may prefer not to think about the future too much or you may worry how you will cope if you get bad news.

If you decide you want information on your prognosis:

- Think carefully about how you will cope with the information before asking for your prognosis.
- Get information on prognosis from your doctor. They know your individual circumstances. Your doctor can also support you in understanding the information and answer any questions you have.
- Ask a friend or family member to go with you, if you would like some support
- Be careful with online information. It may be hard to understand or it may be incorrect. Also, the information may not really apply to your situation or to your particular cancer type. Ask your doctor or nurse specialist for recommended websites.
- Accept that you will need some time to think about what you have been told. You may forget some things or there may be things you didn't understand. You may need to talk to your doctor or nurse again after you have thought about everything.

If you feel upset or anxious about your prognosis you can get support from friends, family or your hospital team. You can also call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie. Our cancer nurses can give you support, information and advice. They can also tell you about free counselling and other services that can help you.

Treatment overview

How are NETs treated?

- Treatments for NETs include surgery, drug treatments, radiotherapy and liver treatments.
- The best treatment plan for you depends on the type of NET.
- A team of healthcare professionals will be looking after you (multidisciplinary team).

The type of treatment your doctor will recommend for you will depend on:

- Where the tumour is and its size
- If it has spread and where it has spread
- How fast the cancer cells are growing
- Your symptoms
- Whether or not the tumour is producing hormones (functional or non-functional)
- Your general health

Treatments for NETs include

Active surveillance (watch and wait)

If the NET is not causing you problems, you may not start treatment straight away. Instead, your medical team will monitor your cancer closely with tests such as scans and blood tests. You can start treatment if the cancer starts to grow, spread or cause problems. See page 59 for more about active surveillance.

Surgery

Removing some or all of the tumour. For early-stage tumours, surgery may cure the disease. Surgery can also be given for later stage NETs to improve symptoms. There are many different types of surgery, depending on the type of NET and where the cancer is. See page 61 for more about surgery.

Drug treatments

- Somatostatin analogue drugs: Drugs that can lower the amount of hormones produced by some types of NET. These injections help control cancer spread in many patients.
- Chemotherapy drugs: Drugs used to kill cancer cells or slow their growth.
- Targeted therapy drugs: Drugs that target certain parts of cancer cells to stop or slow their growth.
- Supportive care drugs: Drugs to improve or prevent side-effects such as diarrhoea, high blood pressure, fast or irregular heart rate and high levels of certain hormones.

See pages 70–80 for more about drug treatments.

Liver-directed therapy

Used to treat NETs that have spread to the liver. It is mainly used when surgery can't be done, to control symptoms and the growth of the cancer in the liver. Liver-directed therapy works by slowing or blocking the blood supply to the tumour. See page 81 for more about liver treatments.

Peptide receptor radionuclide therapy (PRRT)

PRRT is a type of internal radiotherapy. PRRT may be used for NETs that have spread. A radioactive substance is put into your bloodstream through a drip. See page 82

External beam radiotherapy

External beam radiotherapy may be used to control symptoms such as bone pain, to help you feel better. See page 86 for more about radiotherapy.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating cancer or reducing side-effects. Ask your consultant if there are any trials suitable for you. See page 87 for more about clinical trials.

Your treatment plan

The treatment or treatments your doctors recommend for you are based on the latest research and international guidelines about the best ways to treat NETs.

You may notice that other people with NETs are not getting the same treatment as you. Their cancer may not be the same type or at the same stage as yours, so your treatment plan may be different. Your plan is individual to you and your particular needs. Talk to your doctor or nurse if you have any questions about your treatment plan.

Specialist cancer centres

NETs are treated at specialised centres in St Vincent's University Hospital in Dublin, Mercy University Hospital Cork in the south and Galway University Hospital in the west. The staff at these centres have a lot of experience in managing patients with NETs. As a result, you may be transferred to another hospital from the one where you received your diagnosis, depending on your diagnosis and your suggested treatment plan. Or a NET specialist from one of these centres may be consulted for their opinion on your treatment plan.

Multidisciplinary team

A multidisciplinary team (MDT) is a team of specialists involved in caring for your type of NET. For example, a surgeon, endocrinologist, specialist nurse, radiologist and oncologist (cancer doctor). The team will meet to discuss your test results and your suggested treatment plan.

Who might be involved in my care?

Consultant (NET specialist): An expert doctor. They are in charge of your treatment. They have a team of doctors working with them.

Endocrinologist: A doctor who specialises in illnesses that affect the endocrine (hormone) system, including NETs.

Gastroenterologist: A doctor who specialises in treating diseases of the digestive system.

Surgeon: A doctor who specialises in surgery and who can remove a tumour from your body.

Medical oncologist: A doctor who specialises in treating cancer patients using chemotherapy and other drugs.

Radiation oncologist: A doctor who specialises in treating cancer patients using radiotherapy.

Radiation therapist: A specially trained person who delivers radiotherapy and gives advice to cancer patients about their radiation treatment.

Radiologist: A doctor who specialises in interpreting X-rays and scans such as ultrasound, CT, MRI and PET.

Advanced nurse practitioner (ANP): ANPs give expert information and support and are specially educated and trained to carry out tests and help to review your treatment.

NET nurse / clinical nurse specialist: A specially trained nurse who works in a cancer care unit. They give expert advice and information to you and your family from diagnosis and throughout treatment.

Medical social worker: A person trained to help you and your family with your social, emotional and practical needs. They can also give advice on benefits and financial matters and on practical supports and services available to you.

GP (family doctor): While your medical team will be your main point of contact, your GP is still very much a part of your care and can be a great support to you. You can contact your GP about any worries you have or if you are finding it hard to cope.

Physiotherapist: A therapist who treats injury or illness with exercises and other physical treatments related to the illness.

Dietitian: An expert on food and nutrition. They are trained to give advice on diet during your illness and can support you to make changes to your diet to try and help symptoms.

Psycho-oncology team: These are specialists in psychological care and support for cancer patients. Usually the team includes psychiatrists, clinical psychologists and nurses.

Community health services: These include family doctors, public health nurses (who can visit you at home), welfare officers and home-help organisers. Your local health centre or the medical social worker in the hospital can advise you about these services.

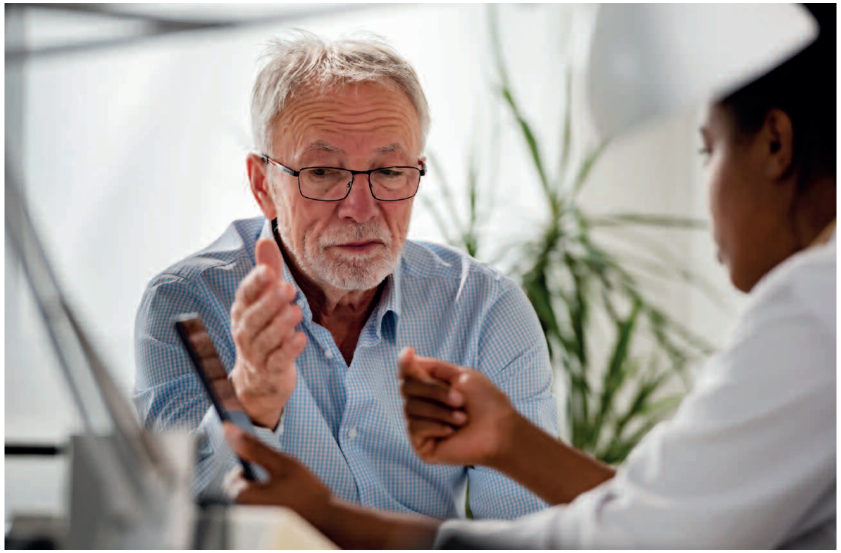
Pharmacists: Pharmacists – in hospital and in your local pharmacy – dispense chemotherapy and other cancer drugs. They can give advice on cancer drugs, such as how to take them, side-effects, and possible interactions between your cancer drugs and other medicines, food and drink, and supplements such as herbs and vitamins.

Palliative care team: This team is experienced in managing pain and other physical symptoms. They can help you and your family cope with any emotional distress. They are sometimes known as the symptom management team. A specialist palliative care service is available in most hospitals. Palliative care teams also work in the community.

Understanding your treatment

Your doctor and nurse will explain your treatment options. Ask as many questions as you like. You could write down any questions you have in advance, so you don't forget anything. You could use the fill-in page at the back of this booklet for your questions and answers.

If you do forget something or need more explanations, ask your specialist nurse or talk to one of our cancer nurses – call our Support Line on 1800 200 700 or visit a Daffodil Centre.



Time to think: It may feel as if everything is happening too fast. You may feel under pressure to make a decision. You can always ask for more time to decide about the treatment, if you are unsure when it's first explained to you.

Second opinion: You might also find it reassuring to have another medical opinion to help you decide about your treatment. Your treating doctor or GP will refer you to another specialist for a second opinion if you feel this would be helpful.

Accepting treatment: You have the right to find out what a treatment option means for you, and the right to accept or refuse it. If you want to refuse a particular treatment, let your doctor or nurse know your concerns first. It may help to talk to your GP as well. The important thing is that you are fully aware of the benefits and risks.

Giving consent for treatment

Before you start any treatment, you should be asked to sign a consent form saying that you understand what the treatment is for and that you give permission for treatment to be given. Before treatment, you should have been given full information about:

- What the treatment is for
- The type and amount of treatment you will have
- The benefits and risks of the treatment
- Possible side-effects from treatment
- Any other treatments that may be available

If you are confused about the information given to you, let your doctor or nurse know straight away. They can explain it to you again. Some treatments can be hard to understand and may need to be explained more than once. You can still change your mind after you have started treatment. Talk to your doctor or nurse if you have any worries about your treatment plan.

Waiting for treatment to start

Not everyone diagnosed with a NET will need treatment straight away. If you do need treatment, you may be anxious to start right away. You may worry that the cancer will spread during this time.

If needed, treatment should start soon after diagnosis. But for most cancers, waiting for scans or treatment for a few weeks does not usually affect how well the treatment works. It may take your doctors some time to decide on the best and individual treatment for you.

If you are worried, talk to your doctor. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre to speak to a cancer nurse.

Ask your specialist nurse or visit a Daffodil Centre for information on our pre-treatment education workshops. The workshops give information on certain treatments, including what to expect and how to manage side-effects.

How can I help myself?

It can be very difficult to cope with a cancer diagnosis and all the changes that this can bring. Your healthcare team can offer you different types of support, but there are also things you can do yourself to prepare for treatment and help you to feel as well as possible.

Eat well

If you can, eating well when you have a NET may help you feel better. It can help you to:

- Keep up your energy and strength, so you can continue to do everyday tasks.
- Maintain your weight and avoid muscle loss. This is important, even if you are not having any treatment.
- Cope better with side-effects and tolerate your treatment better
- Reduce your risk of infection and other complications
- Recover faster

You can ask to talk to the dietitian at the hospital for advice on the best diet for you. You can also read our booklet ***Understanding diet and cancer***. To get a copy, call our Support Line on 1800 200 700, visit a Daffodil Centre or download it on our website **www.cancer.ie**

Stay active

If you are able, it can really help to be active before, during and after your treatment. Keeping up or increasing your activity levels can help to:

- Reduce tiredness and some treatment side-effects
- Reduce anxiety and depression
- Improve your mood and quality of life
- Strengthen your muscles, joints and bones
- Reduce the risk of other health issues

Always talk to your doctor or nurse before starting or increasing the amount of exercise you take. They can advise you on the type and amount of exercise that is safe for you.

Quit smoking

If you are coping with a cancer diagnosis, you may find it stressful to quit smoking.

However, research tells us that:

- Non-smokers are likely to have fewer or less severe side-effects during cancer treatment. For example, chest infections
- Smoking can reduce how well radiotherapy and some other anti-cancer treatments work
- Not smoking can help you to heal better after surgery
- Quitting reduces your chance of further illness

If you would like advice or support on quitting, call the HSE Quit Team on Freephone 1800 201 203, visit www.QUIT.ie or Freetext QUIT to 50100. Some hospitals have a stop-smoking service, with advisors who can help and support you.

Other ways to help yourself

Get information about your cancer and treatment

Understanding cancer and its treatment and knowing what to expect can help to relieve anxiety and stress. If it makes you anxious, you could ask a friend to research for you and tell you anything important. Make sure you get your information from trustworthy sources such as:

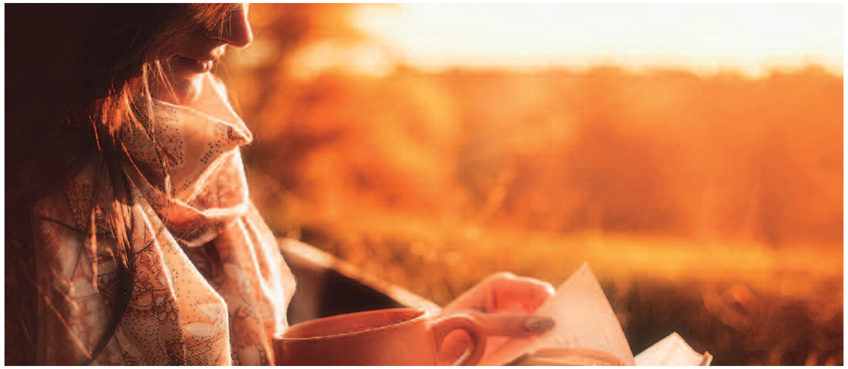
- Your medical team
- The Irish Cancer Society
- The International Neuroendocrine Cancer Alliance **www.incalliance.org**
- The HSE

Involve your family and close friends

Don’t keep worries or physical problems secret from the people closest to you. Ask someone close to you to come with you when you are visiting the doctor and when treatments will be discussed. Your friends and family will be affected by your diagnosis too, so try to talk openly and find ways to support each other.

Use your support network

Don’t be shy about asking for help. Family and friends may not know the best way to help you, so tell them what you need. For example, lifts to the hospital, practical help at home, child-minding or just some company or support. Telling people what you need and how they can help means you will get the right amount of support to suit you.



Try relaxation and stress management techniques

Therapies like meditation or yoga can help you to cope with stress. Some cancer support centres provide groups to help you learn these techniques.

Accept change in your life

Accept that you may not be able to carry on exactly as before. Give yourself time to adjust to your new routine.

Be aware that there will be ups and downs

Sometimes people feel they have to be brave or positive all the time, but it’s normal to have bad days. Get help if you are finding it hard to cope.

Try to cope day by day

Don’t think about the future too much. Concentrate on the present and getting through each day of tests or treatment. That way, you may find it easier to cope with your illness.

Types of treatment

Active surveillance (watch and wait)

Active surveillance means holding off treatment and instead monitoring your condition closely with tests, such as blood tests and scans. You can start treatment as soon as you need it, but you may not need treatment for many years, if at all.

Active surveillance means you can avoid or delay unnecessary treatment and treatment side-effects that can affect your quality of life.

What are the benefits of active surveillance?

- No treatment-related side-effects
- Does not interfere with your everyday life
- You can avoid unnecessary treatment

What are the drawbacks of active surveillance?

- You may feel anxious or worried about your cancer changing
- You may need repeat tests and investigations, which can be stressful
- The cancer may grow more quickly than expected
- The tests are usually good at picking up changes, but there's a slight chance that changes in your cancer may not be picked up

Who can have active surveillance?

Active surveillance is usually only recommended for slow-growing (low-grade or low-risk) cancers.

If you feel anxious…

During the surveillance, you may feel anxious or worry about your cancer changing. This can be worse at times leading up to scans and follow-up appointments.

If active surveillance makes you feel very anxious it may not be the best choice for you. Or you may need extra support to help you manage your feelings. Support groups, complementary therapies, like mindfulness or massage, and counselling may all help you.

If you change your mind after starting surveillance you can talk to your doctor about starting treatment.

Questions to ask about active surveillance

- What tests will I have?
- How often will I need to have tests?
- What changes in my tests mean I will be advised to start treatment?
- What treatments could I have if my cancer grows?
- Can I start treatment if I change my mind?

Surgery

There are different types of surgery depending on where the NET is and if it has spread. You may be treated by a surgeon who specialises in a particular area of the body, for example hepatobiliary, colorectal, pancreatic and cardiothoracic surgeons.

Types of surgery

Surgery to remove the tumour (resection)

Resection means surgery to remove the tumour. It is the most common treatment for NETs.

If the NET has not spread (local tumour) it can often be successfully treated by surgery.

The surgeon will remove the tumour and some healthy tissue around the tumour, to reduce the risk of any cancer cells being left behind. This might mean removing part of an organ containing the tumour or the whole organ. If the cancer has not spread and surgery is successful, you may not need any more treatment.

Surgery to remove lymph nodes (lymph node dissection)

If cancer spreads, it often spreads to lymph nodes first. Your surgeon may remove nearby lymph nodes at the same time as surgery to remove the tumour.

Surgery to improve your symptoms (palliative surgery)

You may have surgery to control your symptoms and help you to feel better. For example:

- **Cytoreductive surgery (debulking):** Removing a large amount of the cancer or as much cancer as possible.
- **Bypass surgery**: Making a passage around a blocked area to improve symptoms.
- **Stenting:** Putting a metal mesh tube inside an organ or duct to stop a blockage causing symptoms.

Surgery and carcinoid syndrome

Surgery and anaesthesia can trigger a carcinoid crisis. If you have carcinoid syndrome, ask your surgeon about how they will manage this. The NET Centres of Excellence can provide a "Carcinoid Crisis Risk Card" to patients who are at risk of carcinoid crisis in the event of an emergency.

Treatment before surgery

Sometimes you will have treatment before surgery to shrink the cancer so it's easier to remove. For example, radiotherapy or chemotherapy. This is called neo-adjuvant treatment.

Ways of doing surgery

The two main types of surgery are open surgery and keyhole surgery:

Open surgery: Open surgery means making a cut (incision) in your body. Your surgeon removes the tumour or other tissue through this cut.

Keyhole surgery (laparoscopic surgery): Keyhole surgery usually involves making a few small cuts in your body. Your surgeon will put a tube with a tiny telescope and light inside your body through a very small cut. Special instruments can then be used to remove the tumour. There is usually a quicker recovery with keyhole surgery and you may spend less time in hospital than with open surgery.

Keyhole surgery is not suitable for everyone and is not available in all hospitals. Your consultant will tell you if it's an option for you.

Before surgery

Tests before surgery

To make sure you are fit for surgery you will have some extra tests. These might include:

- Blood tests
- A chest X-ray
- Heart tests (ECG and echocardiogram)
- Breathing tests

The tests will depend on what type of surgery is planned and where the NET is.

Understanding your surgery

Your medical team is in the best position to answer any queries you have about your surgery, as they will know you and your individual case. You can also talk to our cancer nurses by visiting a Daffodil Centre or calling our Support Line on 1800 200 700.

Risks of surgery

Most people come through their surgery without serious problems, but surgery always involves some potential risks. Possible risks include:

- Bleeding during or after surgery
- Wound/chest infection
- Blood clots (also known as DVT or deep vein thrombosis)
- Carcinoid crisis (see page 110)

Your surgeon will talk to you about any possible risks before your surgery. If you do have complications, they can be treated by your surgeon.

Be prepared for side-effects

It's important to know how the surgery might affect you afterwards. Depending on where you're having surgery you might have short-term effects while you are recovering. Surgery can also result in long-term or permanent changes. For example, changes to how you look, changes to your sex life or to how you eat or go to the toilet. Ask your consultant about this.

Preventing problems

A physiotherapist may show you how to do deep breathing exercises either before you go for the surgery or soon after. These will help to prevent a chest infection or blood clots after surgery. You may also be given a pair of elastic stockings to wear or receive an injection of a drug called heparin to prevent blood clots.

After surgery

You may spend a short time in an intensive care or high-dependency unit (HDU) after your operation. You will be closely watched before returning to the ward. When you wake up, you may have some tubes attached to your body. The type of tubes will depend on the type of surgery you had. Don't be alarmed as they are normal after surgery.

Pain relief

You may have some pain after the operation, especially when you cough or move. Your nurse can give you medicine to control the pain and stop you feeling or getting sick, if you need it. You may have an epidural tube in your back to relieve pain after the surgery. If you have a patient-controlled analgesia pump (PCA), your nurse will show you how to use it. Always ask for help before the pain or sickness gets too bad.

Infection

After surgery, there is a risk you may get an infection. Your nurse will check your wound and the tubes twice a day. Let them know if any leakage happens at the wound or tube sites or if you feel hot or unwell.

Your bladder and bowel after surgery

Sluggish bowels: Surgery can slow down your bowels; some people experience constipation after surgery.

Catheters: After surgery, you may have a thin, flexible tube called a catheter in your bladder for a day or two. It drains your urine into a bag and you can walk around with this. The tube will be removed once you are drinking normally and your urine looks fairly clear. Removing the tube is not painful but may be a little uncomfortable. This usually happens a couple of days after the surgery.

Getting up and about

A physiotherapist may visit you regularly for the first few days. These visits are to help you with breathing and leg exercises. Doing the exercises can help to prevent a blood clot.

For some types of surgery you will have to be careful to avoid strenuous activity like gardening, vacuum cleaning or lifting anything heavy for at least 3 months. Your team will advise you about this. You may also be advised not to drive for a few weeks. Ask your doctor about any precautions you should take.

Pathology report

During your surgery samples of tissue, including from lymph nodes, will be taken. The samples will be tested by a doctor called a pathologist to see how effective the treatment has been and help your doctors to decide if you need further treatment.

Your doctor will discuss the results of these tests with you, and any plans for more treatment or monitoring your condition. Usually this happens at your first follow-up appointment, when you have had a chance to recover.

Eating difficulties after surgery

Sometimes, you may not be able to eat normally after your surgery. This will often depend on the type of surgery you have had. If you can’t eat normally after surgery, your dietitian will discuss your nutritional needs with you and your doctors and help to make sure you get enough nutrition in other ways.

These include temporary feeding through a tube through your nose into your stomach (nasogastric tube feeding), short-or longer-term feeding through a tube directly into your stomach (PEG tube feeding) and giving nutrition directly into your veins (parenteral feeding).

Weight loss

If you can’t eat normally, it is likely that you will lose some weight in the first few weeks after your surgery. This should slow down once you begin eating well again. If your weight loss continues, it is important to let your medical team know, as you may require further support from a dietitian.

Going home

You may be in hospital for up to 14 days, depending on the type of surgery, but often it isn't this long. How long you have to stay in hospital and the type of side-effects you might get depend on:

- Where the surgery was
- What type of surgery you had (for example, keyhole surgery vs open surgery)
- If you have any side-effects from surgery that need to be managed in hospital. For example, eating difficulties or problems going to the toilet
- Your general health

The nurse will give you advice about how to manage at home. For example, if you have a catheter, stoma or a feeding tube, your nurse will give you advice about how to care for them.

Before you go home, you will be given a date to come back for a check-up about 4–6 weeks later. You may also have to attend the hospital regularly so that your wound can be checked.

Help at home

If you live alone or have problems getting around the house, talk to your nurse or the medical social worker on your ward as soon as you are admitted to the hospital. That way, they can organise any community services you may need after you leave hospital. This may include visits from your local public health nurse or home help. The medical social worker can also advise you about social welfare benefits or entitlements you can apply for.

Getting better

Having surgery can take a lot out of you. It may be weeks and even months before you feel fully recovered.

When you get home, you may feel physically and emotionally exhausted. Try to get plenty of rest, take some gentle exercise and eat a well-balanced diet. Get some emotional support if you feel you need it. Sometimes it's not until after treatment that the emotional effect of a cancer diagnosis hits you.

Driving

Your doctor will tell you when you can start driving again but it is usually about 4 to 6 weeks after surgery. You won't be able to drive if you're still on strong painkillers that might make you drowsy. Check that your car insurance covers you to drive after your surgery.

Who to contact if you have any problems

You will be given contact numbers so that you can reach your surgical team at any time. Contact them as soon as possible if have any worry or symptom that is causing you concern.

Remember it will take about 3 months to recover from your operation and about a year to get back to your normal routine.

Drug treatments

Somatostatin analogues

Somatostatin analogues are drugs that can:

- Lower the amount of hormones produced by some types of NET. In this way they can reduce the symptoms caused by the hormones, such as diarrhoea and hot, flushing skin
- Control the growth of some types of NETs.

Examples of somatostatin analogue drugs are lanreotide and octreotide.

These drugs are given by injection, usually once a month. Your GP or practice nurse will give you the injection. Patients or carers can also be shown how to do it. You will stay on these drugs as long as they continue to control your tumour and your symptoms.

Side-effects of somatostatin analogues

Side-effects vary from person to person. Sometimes side-effects are worse for a time when you start taking the drugs and then go away or improve. Possible side-effects of somatostatin analogues include:

- Changes to the way your bowel works – diarrhoea or constipation
- Headaches and dizziness
- Loss of appetite
- Feeling sick or vomiting
- Stomach pain or cramping
- Tiredness (fatigue)
- Changes to your blood sugar levels
- Steatorrhea, which causes pale, oily, floating and/or foul-smelling bowel motions

Most side-effects settle down with time. You can ask your NET team about possible side-effects from your medication and let them know if you have any side-effects that are troubling you. See page 75 for advice on coping with side-effects.

Hints and tips: Somatostatin analogues

- **Keep a note of what you eat and how it affects you** – see if any particular foods cause symptoms or make them worse.
- **Plan ahead before travelling** to make sure you get your injections on schedule.
- **If you have been prescribed pancreatic enzymes to help you absorb fat, always follow advice about how to take your tablets correctly,** e.g. with food.

Follow the advice from your NET team about how to take and store your medicines correctly. You should also check the information leaflet that comes with your medicine about how to take and store it. Ask your NET team if you have any questions.

Chemotherapy

Chemotherapy drugs may be given for some fast growing (poorly differentiated) NETs or for cancer that has spread. You may also have chemotherapy after surgery, to reduce the risk of the cancer coming back or spreading, depending on the drug. You may have chemotherapy along with other treatments.

How often will I have chemotherapy?

Chemotherapy is given in cycles with a rest period between treatments. This rest period allows your body time to recover from the side-effects of treatment. The number of treatments and cycles can vary, depending on your cancer type and how well it is responding to treatment.

How is chemotherapy given?

Chemotherapy may be given as an infusion into a vein or as tablets that you take at home, depending on the drug. You may have a central venous access device fitted. This is a thin tube (line) which goes directly into a vein and stays in place until your treatment is over. This saves you having repeated injections. There are different types of central venous access devices, such as ports, Hickman lines and PICC lines. Usually your treatment will be given in the oncology day ward.

What kinds of drugs are used?

There are several chemotherapy drugs used to treat NETs. Your doctor or nurse will discuss your treatment with you. Usually, you will have a combination of different drugs, depending on the type of tumour.

Hints and tips: Understanding your drug treatment

It’s important that you understand the drugs you have been given. Ask your doctor or specialist nurse for more information about your drug treatment and any possible side-effects. They should give you a printed sheet to take home with you.

If you know the name of your drug, you can visit the Health Products Regulatory Authority’s website at **www.hpra.ie** for information about the drug and possible side-effects.

If you have any questions or need any more information, you can speak to our cancer nurses by calling our Support Line on 1800 200 700.

Targeted therapy drugs

These drugs target certain parts of cancer cells that make them different from normal cells. They can block substances that help the cancer to grow or stop the blood supply to the tumour. They are usually used to control cancer that has spread.

They may be used for treatment of advanced NETs of the GI tract, lung and pancreas when surgery can't be done, and the cancer continues to grow and spread. Examples of targeted therapy drugs used for some types of NETs are sunitinib (Sutent) and everolimus (Afinitor). They are taken as pills. Some targeted therapy drugs are given into a vein through a drip.

New targeted therapy drugs

New targeted therapies are being developed all the time and existing therapies are being used in new ways. You may also be offered a targeted therapy drug as part of a clinical trial (see page 87). Ask your doctor if there are any targeted therapies available to treat your cancer or if there are any trials that are suitable for you.

Coping with side-effects of drug therapies

The side-effects of drug therapies vary from person to person. Some people have fewer side-effects than others. The type of side-effects you might get and how severe they are mainly depend on the drugs used and the dose.

Most side-effects can be helped by medication. Usually, the side-effects go away when the treatment ends or soon after.

The list below includes possible side-effects from different types of drug treatments – somatostatin analogues, chemotherapy drugs and targeted therapy drugs, but not all side-effects happen with all drugs. Ask your NET team about possible side-effects from your own drug treatment.

- **Fatigue:** Fatigue is very common. It can make you feel tired and weak. For more information see page 101.
- **Nausea and vomiting:** Cancer drugs can cause nausea (feeling sick) and vomiting (getting sick). There are anti-sickness medicines that work well to prevent nausea and vomiting. Take them as prescribed, even if you don't feel sick, as they can stop the sickness from happening. Tell your doctor or nurses if the anti-sickness medication is not working for you.
- **Risk of infection:** You may be more at risk of infections. You will be given a number to call if you have signs of infection. These signs include feeling shivery and unwell, having a high or low temperature, having a cough or sore throat, or pain passing urine. It's important to call straight away so you can be treated, if necessary.

- **Anaemia:** Chemotherapy can cause the bone marrow to make fewer red blood cells. Having fewer red blood cells is called anaemia. Anaemia can make you feel tired and breathless. Regular blood tests to measure your red cell count will be done during treatment. You may need a blood transfusion to treat your anaemia.

- **Bleeding and bruising:** Some drugs stop your bone marrow from making enough platelets. Platelets help make your blood clot and stop bleeding. With fewer platelets you may bleed or bruise very easily. Tell your doctor if you have any bruising or bleeding that you can't explain, such as nosebleeds or bleeding gums.
- **Mouth and throat problems:** You may have mouth and throat problems, such as a dry mouth, ulcers or gum infections. There are many mouthwashes and medications to help, which your doctor can prescribe for you.
- **Changes to your hair:** Your hair may change colour or get thinner. Some drugs can cause hair loss from all over your body. This can be very distressing. It can affect your confidence and make you feel self-conscious about your cancer. How much hair falls out depends on the drug given, the dose and your own reaction to it. Hair will grow back 3-6 months after you stop treatment.

- **Constipation:** You may need to drink more clear fluids or eat more fibre. Getting some exercise can help to move your bowels too. In some cases, your doctor may have to adjust your treatment.

- **Diarrhoea:** Tell your doctor or nurse immediately if you have loose or watery poos more than 3 times over and above your normal pattern over a 24-hour period. Your doctor or nurse will give you advice over the phone on how best to treat this diarrhoea. See page 104 for more.
- **Skin and nail changes:** Skin may become dry, flaky and itchy. The colour or texture of your skin may change too. For example, it may feel rougher. Some drugs can cause hand foot syndrome, which causes the skin on your feet and hands to become sore, red or peel. Moisturise your skin, but always use products recommended by your medical team, to avoid irritation. Nails may become dark, yellow or brittle.
- **Taste changes:** Food may taste strange, for example, you may experience a metallic taste in your mouth or you may find it hard to identify the taste of different foods. You may not want to eat things you used to enjoy. Your team can give you tips to help. There are also tips in our booklet, ***Understanding diet and cancer.*** Your taste should return to normal a few weeks after treatment.

- **Peripheral neuropathy:** Some drugs can affect your nerve endings. It's important to tell your doctor if you have numbness or a tingling or burning sensation in your hands and feet. This is known as peripheral neuropathy.

- **Changes in kidney or liver function:** Some drugs can irritate or damage kidney and liver cells. Decreased urination, swelling of the hands or feet (oedema) or headaches are some of the signs of kidney damage; yellowing of the skin or eyes (jaundice) can be a sign of liver problems. Tell your doctor if you have these or any other changes in your body. Blood tests will check your kidney and liver function regularly.
- **Allergy:** On rare occasions people can have a reaction to certain drugs. Reactions can include rash, itching, low blood pressure and shortness of breath. It's important to tell your medical team immediately if you have any of these side-effects, as allergic reactions can be serious.

- **Blood clots:** A blood clot may cause pain, redness and swelling in your leg, or breathlessness and chest pain. Contact your hospital immediately if you have any of these symptoms, as blood clots can be serious. Usually they are treated with medication to thin your blood.
- **Swelling in your hands or feet:** This happens when fluid builds up. Tell your doctor or nurse if you have any swelling.
- **Blood pressure changes:** Tell your doctor or nurse if you have headaches, nosebleeds, changes to your vision, such as blurred vision, feel dizzy or faint, as these can be signs of blood pressure problems. Your medical team will check your blood pressure regularly during treatment.
- **Changes in blood sugar levels:** Some drugs can affect how your body controls the level of sugar in your blood. You will have regular tests to check your blood sugar level if your drug treatment might have this side-effect. High blood sugar can make you feel thirsty or tired. You may lose weight, pee a lot or have blurred vision. Low blood sugar can make you feel tired, dizzy, hungry or shaky. Your lips may tingle or you may have a pounding heartbeart or look pale.
- **Changes in thyroid hormones:** Low levels of thyroid hormones can make you feel tired, cold or depressed. You may gain weight or your voice may deepen. You will have regular tests to check your thyroid hormones if your drug treatment might have this side-effect.
- **Breathing problems:** Some cancer drugs can cause inflammation of your lungs, so you may feel short of breath and cough. It is important to know what is normal for you – your baseline – if you already suffer with breathlessness. If you notice you're starting to feel more breathless than usual, especially if you have to stop when climbing the stairs, or you are becoming more breathless walking on a flat surface, talk to your team. They may need to check your lungs for a drug side-effect.
- **Hepatitis B:** Some drugs can make the Hepatitis B infection active again, so tell your doctor if you have had hepatitis B in the past.

- **Steatorrhea:** Somatostatin analogues can cause steatorrhea. This occurs as a result of difficulty digesting fat, which is then excreted in your stools (poo), causing them to become pale, oily, floating, frothy and/or foul smelling. If you are having these symptoms, it is important to mention it to your doctor or dietitian, as you may require pancreatic enzymes to help with this.
- **Gallstones:** People treated with somatostatin analogies often get gallstones, but specific treatment is only needed if they cause symptoms, which is quite rare.

If you have any symptoms that are troubling you or you feel unwell, tell your doctor or nurse straight away. You will be given contact details of who to contact before you start your treatment.

For more information on the side-effects of cancer drugs or a copy of the booklet ***Understanding chemotherapy and other cancer drugs***, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also look at our website, **www.cancer.ie**, for tips on coping with different side-effects.

Liver-directed therapy

Hepatic arterial embolisation (HAE)

HAE blocks or slows the blood supply to the tumour by injecting tiny particles called microspheres into the main blood vessel to the liver (hepatic artery). The microspheres are passed into the artery through a thin catheter tube. Without a blood supply, the tumour will shrink or die.

This procedure is done with a local anaesthetic and sedation. You should be able to go home once the sedation has worn off.

Transcatheter arterial chemoembolisation (TACE)

This is similar to HAE, but chemotherapy drugs are injected into the artery during the embolisation procedure. You will probably stay in hospital after TACE.

Radiofrequency ablation (RFA)

RFA uses heat to destroy cancer cells.

PRRT (peptide receptor radionuclide therapy)

PRRT delivers radiation therapy directly to any tumours in your body that are visible on your PET/CT scan.

Some neuroendocrine cancer cells have proteins (receptors) on the outside of them called somatostatin receptors. PRRT works by specifically targeting these receptors. The drug contains somatostatin (a hormone) and Lutetium-177 (a radioactive substance). When injected into the bloodstream, somatostatin attaches to these receptors and the Lutetium-177 then enters the cancer cells and releases radiation that destroys the cells from the inside. By delivering a high radiation dose directly to cancer cells, PRRT minimises the damage to surrounding healthy cells.

PRRT will only be considered if you have receptors on your cancer cells that allow them to be targeted by the radiation.

Before PPRT treatment

It is important that any long-acting somatostatin analogue injections are stopped ideally 2-4 weeks before to PRRT, and short acting somatostatin analogue injections are stopped ideally 24 hours prior to PRRT. This is because these drugs may block the receptors that the therapy is designed to target. This could potentially reduce the success of the treatment. **The referring NET consultant will decide whether or not you should stop these injections before PRRT.**

Before starting your course of PRRT, you will have a consultation with the NET consultant and the PRRT nurse specialists at the outpatient PRRT clinic. You will also have a consultation with a radiologist/nuclear medicine physician and PRRT nurse specialist in the Nuclear Medicine department. They will explain the procedure in detail and address any concerns you may have and provide you with their contact details in case of issues afterwards.

A medical physicist will give you written and verbal instructions about the precautions you will need to take after each infusion to minimise the radiation exposure to others. For example, limiting contact with young children and pregnant women for up to 3 weeks after each treatment cycle.

It may also be necessary to avoid places of work where you are in close contact with other people for up to 2 weeks after therapy. A sick note will be provided if required.

You will also be given advice about pregnancy and breastfeeding. The drug can cause harm to an unborn child if given during pregnancy. It is advisable that women of child bearing age use effective contraception during the treatment and for 7 months afterwards. Men with partners of child bearing age should also use effective contraception during treatment and for 4 months afterwards.

Breastfeeding must be stopped before starting treatment.

Having PRRT treatment

A radioactive substance is put into your bloodstream through a drip. You can have PRRT in the NET Centre of Excellence at St Vincent's Hospital, Dublin.

Most patients have 4 treatments (infusions), about 8 weeks apart. The time between treatments may be longer, depending on how you are responding to treatment and availability of treatment. You will usually stay overnight in hospital for the first infusion. For the remaining 3 infusions you may stay in hospital overnight or go home the same day.

You will be checked at the PRRT clinic in between treatments. You will have a scan to check the amount of radioactivity delivered to certain organs. Your bloods will also be checked regularly, to make sure you are well enough to have the next infusion.

Side-effects of PRRT

Side-effects can happen for a short time. Others may last longer or even be permanent. Not all patients will experience any or all of these side-effects.

Possible short-term side-effects

- **Tiredness:** This is a very common but usually mild and may last for a few weeks after treatment.
- **Nausea/vomiting/decreased appetite:** Nausea and vomiting are very common during the treatment. You will be given anti-sickness medication before your treatment to help with this.
- **Fall in blood count:** This is very common and usually temporary, but could cause a delay in your next cycle of PRRT. A fall in blood count can leave you more prone to infection, bleeding and bruising or leave you feeling tired and short of breath. Your blood count will be checked before you start treatment and every 2 weeks while you are undergoing treatment. If you notice any bruising or bleeding it is important to contact the PRRT nurse specialist or the NET team. Some drops in blood count may require treatment with a blood transfusion.
- **Diarrhoea:** This is common but is usually mild and usually should not need any specific treatment.
- **Abdominal pain:** Stomach pain is common and may last for a few days after treatment. If you have persistent or severe pain you should contact the PRRT nurse specialist or the NET team.
- **Mild hair loss:** This is common but usually minimal. Hair will grow back after the treatment has finished.
- **Hormonal syndromes:** The treatment can cause a sudden release of hormones. This is uncommon but if left untreated can result in a hormonal crisis. This is most likely to occur in the first 48 hours after your treatment. You will be monitored closely while you are in hospital. You might need additional medications or a longer stay in the hospital to treat that. You will be advised to watch for hormonal symptoms after you return home and what to do in case of emergency.
- **Tumour lysis syndrome:** When a lot of cancer cells break down really fast in the body following the infusion, this can result in tumour lysis syndrome, which can cause an irregular heartbeat, kidney problems or seizures. If you develop any muscle cramps or weakness, confusion or shortness of breath, it is important to contact the PRRT nurse specialist of the NET team.
- **Infertility:** Treatment may cause infertility which can be temporary or permanent.
- **Allergic reaction:** Allergy is uncommon and you will be monitored for this during and after your infusion.

Possible long-term side effects

Some of the possible side-effects can happen after some time. These include impaired kidney or liver function and a small increase in the risk of other cancers.

- **Impaired kidney function:** This is common and some patients have experienced kidney failure. The risk of this is minimised by giving you amino acids during the therapy.
- **Impaired liver function:** If cancer has spread to your liver you may be more at risk of impaired liver function.

  Your kidney and liver function will be checked before treatment and every 2 weeks during treatment, as well as routine monitoring after treatment.
- **Blood cancer:** A bone marrow disease known as myelodysplastic syndrome of the bone marrow (usually a forerunner of leukaemia) and acute leukaemia have been noted in about 2% of patients. Your blood counts will be checked before treatment and every 2 weeks during treatment, as well as routine monitoring after treatment.

- Cancer risk: Radiation is associated with increased risk of cancer. Because having PRRT means you are being exposed to radiation, it contributes to the total amount of radiation you have been exposed to over your lifetime, which can affect your risk of other cancers. Your team will make every effort to minimise your radiation exposure and you will be advised about precautions you should take to minimise the risk of exposure to your household contacts..

External beam radiotherapy

External beam radiotherapy may be used to control symptoms such as bone pain, to help you feel better. With external beam radiotherapy, the radiation comes from machines which aim rays directly at your tumour or the tumour site.

You will have a planning (simulation) appointment, which includes a CT scan, to pinpoint the area to be treated. The treatment field or area will then be marked carefully on your skin, usually using tiny tattoo dots. The dose of radiation will be decided and tightly controlled for your treatment.

How much external beam radiotherapy will I need?

For pain relief (palliative radiotherapy), you will usually only need a short course of radiotherapy. You may have a single dose or a dose divided into a few sessions.

Side-effects of external beam radiotherapy

Side-effects tend to affect the area of the body being treated. Some side-effects appear during the treatment, while others can develop after the treatment. With a short course of radiotherapy any side-effects are usually mild and reversible. For more information on or a copy of our booklet ***Understanding Radiotherapy***, call our Support Line on 100 200 700 or visit a Daffodil Centre.

If you feel unwell or have any other side-effects or symptom – during or at any time after treatment – tell your doctor, nurse or radiation therapist.

Clinical trials

Clinical trials are research studies that try to find new or better ways of treating or diagnosing tumours or reducing side-effects. They can also help improve a person's quality of life, when living with a diagnosis.

Patients are sometimes asked to take part in a clinical trial. This means that instead of the standard treatment, you get a new trial drug. Or you may be given existing treatments used in different ways. For example, you may be given a different dose of a drug or you may be given 2 treatments together. Because the drugs are still in trial, you'll be very closely monitored and may have extra tests and appointments.

Trials often investigate very specific features of a particular type of tumour or treatment, so you may not be suitable for a trial. Your doctor can advise you about this.

More information

It's best to talk to your doctor if you're interested in taking part in a clinical trial. For more information, you can read our factsheet ***Cancer and Clinical Trials***. It's available to read or download on our website, **www.cancer.ie**. You can also get a free copy by calling our Support Line on 1800 200 700 or by dropping into a Daffodil Centre. You can see a list of current cancer trials at **www.cancertrials.ie**

After treatment for NETs

Follow-up

No matter what type of treatment you have, you will still need regular check-ups. This may involve having a physical exam, blood tests and scans.

If you are between check-ups and have a symptom or problem that is worrying you, call your doctor or specialist nurse for advice or to make an appointment, if necessary.

If you become suddenly unwell and can’t contact your specialist nurse or hospital team, go to your GP or the emergency department at the hospital.

Living with a NET

For many people, having a NET is a long-term condition. Most people have a good quality of life living with a NET, but it may take a bit of time to adjust. It is important to learn how to live with your condition and keep yourself as comfortable as possible. Here are some tips to help:

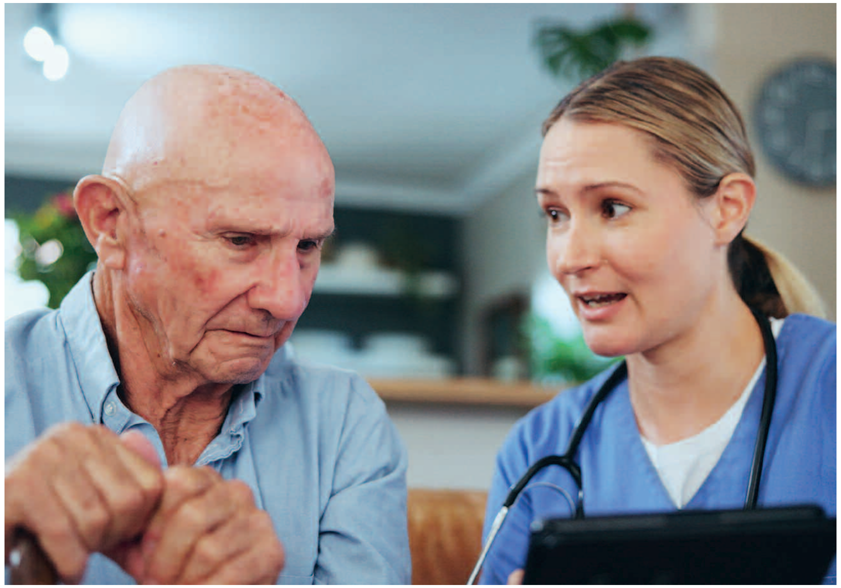
Be involved in your healthcare

- Learn about NETs so you understand your treatment and know what to expect.
- Don't be afraid to ask questions. The team will be happy to answer them.
- Keep all your appointments. Put reminders in your phone or calendar or use notes in visible places so that you don't forget.
- Let your doctor know straight away if you have any new symptoms or any symptoms that are bothering you.
- Don't feel like you have to wait until your next appointment if you have any health problems or worries. Get a name and number from the hospital so you know who to contact if you have any worries or questions.

Take your medication

It's important to take any medication as prescribed, even if you feel well. Ask your doctor or pharmacist if you have any questions about your medication.

Depending on your type of NETs, you may need to keep a regular medication schedule or take medication before and after you eat. You may need to keep a supply of some medications with you when you are away from home. It can be hard to adjust to this, but keeping reminders on your phone or using a pill dispenser can help.



Take care of your health

Watch out for any signs of infection or other problems and contact the hospital straight away if you have any symptoms that are troubling you.

If you need treatment for another medical condition, tell the person treating you that you have a NET and about any medication you're taking.

Have regular dental and eye check-ups. Take good care of your mouth, teeth or dentures, as they can be a source of infection. Check with your medical team before having dental treatment and let your doctor or nurse know if you have any discomfort or pain in your mouth. If you have carcinoid syndrome or are taking bone-strengthening drugs, tell your dentist before you go for checks or treatment.

Vaccinations

You will probably be advised to get the flu vaccine each winter and the pneumonia vaccine every 5 years. Some vaccinations may not be suitable for you, if your immune system is low. For example, live vaccines. Ask your doctor about any vaccinations you should have and make sure you get them.

Eat for health

If you can, eating well when you have a NET may help you feel better. Some types of NETs and some treatments can result in low levels of certain vitamins and minerals. In most cases, your dietitian and medical team can request blood tests to check your levels. It is important that you only take supplements following advice from your dietitian or medical team. It is not advised to take high doses of any single or multivitamins or minerals due to the potential risk of toxicity.

Try to get some exercise

Taking some exercise is one of the best things you can do to feel as well as possible. It can:

- Improve fatigue and other side-effects
- Increase your energy levels
- Help anxiety and depression
- Improve your mood and quality of life
- Help you to keep a healthy weight
- Strengthen your muscles, joints and bones
- Help with coordination, balance, stamina
- Reduce the risk of other health issues

Talk to your doctor about becoming more physically active. They can tell you what is safe and suitable for you and may be able to recommend a special exercise programme.

Exercise and carcinoid syndrome

If you have carcinoid syndrome, certain activities may trigger symptoms, so talk to your doctor about this.

Leading a healthy lifestyle

Many people want to live a healthy life after a diagnosis of NETs. Having a healthy lifestyle is important as it can help you to:

- **Feel better**
- **Cope better with the side-effects of treatment**
- **Keep up your energy and strength**

A healthy lifestyle includes:

- **Avoiding alcohol**
- **Protecting yourself from the sun and checking your skin for any changes**
- **Having all the recommended cancer screening tests**
- **Exercising**
- **Taking vitamin supplements as advised by your doctor,** if blood tests show you have a deficiency
- **Staying at a healthy weight**
- **Not smoking**

If you want more information or advice, call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also go to our website **www.cancer.ie** for tips and publications on healthy living.

NET Patient Network
www.neuroendocrinecancer.ie

NET Patient Network is a patient support and advocacy group for NETs patients in Ireland. It provides information on NETs and organises patient support meetings.

Mind your mental health

Living with a NET and coping with any symptoms can be stressful. The following may help:

- Try to avoid additional stress wherever possible. Spend time with your friends and family. Make time to relax and do the things that you enjoy.
- Use stress-management techniques if you do feel stressed. Try complementary therapies and relaxation techniques like yoga, meditation, mindfulness or aromatherapy. See page 114 for more about complementary therapies.
- Counselling or a short course of medication may also help you, if you are finding it hard to cope. See page 119 for more information.
- Having the support of loved ones, healthcare professionals and other people going through a similar diagnosis can also make a big difference. See page 120 for more about getting support.

Connect with others

Sharing experiences and advice can be helpful. There are other people like you and many groups that want to help and support you.

Work and activities

Once you are on treatment and start to feel well, you should talk to your doctor about returning to work or study and carrying on with your usual activities like socialising, sports and hobbies.

Holidays and insurance

You may decide to go on a holiday once your NET is under control. If you are planning a holiday, ask your doctor about any special precautions you need to take, supplies you need to bring and vaccinations you should have before you go. It is best to have travel insurance too. We have information on travel insurance on our website, **www.cancer.ie**. You can also contact our Support Line on 1800 200 700 or visit a Daffodil Centre for more details.

Managing side-effects and symptoms

Managing side-effects and symptoms

People with a diagnosis of NETs may have side-effects and symptoms. These can be caused by:

- The cancer itself – for example it may be producing hormones that create symptoms
- The treatment
- The stress and strain of coping with cancer – for example, fatigue may be related to your mood, as well as to other things.

If you have carcinoid syndrome, this can also cause symptoms.

Fatigue

Fatigue means feeling extremely tired. Fatigue is very common with cancer. Usually fatigue starts to improve once treatment is over, but it can carry on for some people. Tell your doctor or nurse if fatigue is affecting you, so that they can help you.

Fatigue when you have cancer can be caused by many things, including:

- The cancer itself
- Tests and treatments for cancer
- Not eating well
- Low levels of red blood cells (due to the cancer or its treatment)
- Dealing with difficult emotions and feeling anxious or depressed
- Not sleeping well
- Symptoms like pain, breathlessness or fluid retention

Finding out what is causing your fatigue makes it easier to treat. For example, if you have a low red blood cell count, a transfusion can make you feel better. If you are not eating well, ask to speak to a dietitian who may be able to give you some advice to help you.

Hints and tips: Fatigue

- **Ask your doctor about exercising.** Being active can help with fatigue. Your doctor may also be able to recommend an exercise programme for you.
- **Plan your days:** Get to know when your energy levels tend to be better. You may have to decide which tasks are important to finish and do them over the course of the day or when you have most energy.
- **Ask for help at work or at home** with any jobs that you find tiring.
- **Try to eat a well-balanced diet.** If your appetite is poor, try to eat little and often. Our booklet ***Understanding diet and cancer*** has tips to help.
- **Try to avoid stress.** Talk to friends and family about any worries you have and take time to enjoy yourself. Counselling may help too (see page 119).
- **If you are not sleeping well, have a good bedtime routine and try relaxation techniques.** Avoid stimulants like caffeine and alcohol in the evening and try not to use electronic devices for an hour before bedtime.
- **Short naps (less than an hour) and rest periods can be helpful,** as long as they don't stop you from sleeping at night.
- **Try complementary therapies** like meditation, acupuncture or massage, if your doctor says they're safe for you.

Our booklet ***Coping with Fatigue*** has more advice. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy. It's also on our website **www.cancer.ie**

Diet-related symptoms

There is no single recommended diet for everyone with a NET. However, there are some symptoms associated with NETs that can be improved with diet, so some people may need to adjust their diet to help with symptoms. For example, if you have diarrhoea, have trouble digesting fats, are losing weight or have diabetes.

Because the symptoms of NETs can vary depending on your individual diagnosis and treatment, it is important to speak to a dietitian, who can give you the best advice on adjusting your diet to help manage your symptoms.

Diarrhoea

There are many possible causes of diarrhoea if you have a NET, such as hormones, treatment, infection or intolerance to certain foods. If you are having diarrhoea, it is important to talk your medical team about it so that they can try to find out the cause and make sure it is treated appropriately.

Hints and tips: Managing diarrhoea

- **Try to drink plenty of clear fluids** (1½ to 2 litres spread out over the day) to avoid dehydration
- **Try to separate food and fluids** - take liquids 30 minutes to 1 hour after your meal and/or between meals
- **Try to eat small amounts of food more frequently** during the day, instead of 3 large meals
- **Try to avoid or reduce your intake of the following foods** as they can make diarrhoea worse:
  - **Drinks with caffeine** like coffee, tea, cola and hot chocolate
  - **Fatty, greasy and fried foods**
  - **Fizzy drinks**
  - **Foods containing the artificial sweetener sorbitol**, such as chewing gum and diet or low-calorie products
- **Ask your doctor or dietitian about probiotics.**
- **If appropriate, your doctor may prescribe something to control the diarrhoea.** Take this as advised.

Call your doctor if the diarrhoea continues or gets worse, or if your stools (poos) are red or dark in colour. If you have severe diarrhoea, you may become dehydrated and need to be admitted to hospital for intravenous fluids.

Carry the card

The Irish Cancer Society has a ‘Medical need toilet card’, which explains to a business owner that you would like to use the toilet due to a medical condition. Call our Support Line on 1800 200 700 or visit a Daffodil Centre if you would like one.

Fat malabsorption (steatorrhoea)

When we eat and drink, the pancreas produces enzymes which allow the body to properly digest and absorb the nutrients from the food that we eat, particularly fat. If you have a NET, this process can be affected by the NET itself, treatments (e.g. somatostatin analogues) or surgery (e.g. if you have had parts of or all of your pancreas removed). This can result in steatorrhoea, where fat is excreted in your stools, causing them to become pale, oily, floating, frothy and/or foul smelling.

If you are having these symptoms, it is important to tell your medical team, as you may require pancreatic enzymes to help with this. These enzymes are prescribed by a doctor, and your dietitian can advise you on how to take them appropriately.

Fat malabsorption and fat-soluble vitamin deficiency

If you are not absorbing fat properly from your diet, it can lead to deficiencies of certain vitamins, such as vitamins A, D, E and K. If there is a concern that you may be low in any of these vitamins, your dietitian and medical team can request blood tests to check your levels. If your levels are low, you may be started on a vitamin and mineral supplement to correct this. It is important that you only take supplements following advice from your dietitian or medical team. It is not advised to take high doses of any single or multivitamins or minerals due to the potential risk of toxicity.

Weight loss

Sometimes weight loss can occur due to the NET itself, as a consequence of treatments and their side-effects or following surgery. If you are continuously losing weight, it is important to speak to your doctor or dietitian, as it may affect your ability to tolerate your treatment, as well as your quality of life. Here are some tips which may help to increase your intake and prevent further weight loss:

- Try to eat 'little and often' - 3 small meals and 3 snacks a day. It may help to use a smaller plate if it seems less daunting.
- Don't skip meals. Try to eat something even if you are not hungry. Choose something that you know you will enjoy.
- Have protein (meat, fish, egg, dairy, beans, lentils, nuts, tofu) at least 3 times a day.
- Use foods that require little preparation, such as ready meals, tinned food, breakfast cereals.
- Drink milk with your meals.
- Minimise intake of low-calorie drinks, e.g. tea, coffee, thin soups and diet drinks, as these are filling and have little nutrition.
- Try to have a dessert or pudding once or twice a day, e.g. ice cream, custard, rice pudding.

You may also benefit from a nutritional supplement drink. These can be prescribed by your doctor or dietitian.

Bowel obstruction or narrowed bowel

Sometimes if you have a small intestine NET or have had previous bowel surgery, you may get obstructions (blockages) in your bowel. These blockages cannot always be completely prevented with diet, but the following tips may help to reduce your risk of blockages:

- Cook food very well so that it is easy to mash.
- Eat slowly and in a relaxed setting, chewing food well.
- Eat small amounts often throughout the day - aim for 5-6 smaller meals.
- Avoid alcohol, caffeine, fried and greasy foods as they can increase bloating and cramping.
- Eating a modified low-fibre diet may improve symptoms and prevent a blockage. The amount and type of fibre you can eat will depend on the severity of your symptoms. Your dietitian will be able to give you advice about this.
- Drink plenty of fluid with all meals and snacks to keep your stool soft. You should aim for a minimum of 8-10 glasses per day.
- Only eat what you feel comfortable eating. Don't force yourself.
- If you are struggling to eat enough you may need a multivitamin and/or high protein nutritional supplement drink. Speak with your dietitian or doctor about this.
- Some people need to have pureed/liquidised foods to reduce symptoms along with lots of fluids. Your dietitian will discuss this with you if it is advised.

If you have severe abdominal pain and are concerned that you may have a bowel obstruction, you should go to your nearest emergency department.

Coping with carcinoid syndrome

Carcinoid syndrome is a group of symptoms caused by a NET releasing large amounts of a hormone-like substance called serotonin or other chemicals into the blood.

Carcinoid syndrome can cause symptoms such as:

- Flushing – skin feeling warm and turning red. This may be related to triggers such as alcohol, certain foods, exercise and emotions.
- Diarrhoea and tummy cramps. It usually does not respond to anti-diarrhoea medications or other treatments prescribed for irritable bowel syndrome.
- Tummy pain
- Tiredness
- Low blood pressure
- Tiny blood vessels showing on the skin
- Wheezing
- Heart disease, which may cause shortness of breath and swelling of the legs

Flushing and diarrhoea are the most common symptoms.

It is important to ensure that your diet has increased amounts of protein foods (which contain tryptophan) and niacin if you have carcinoid syndrome. This is because with carcinoid syndrome, the process of making the hormones it releases uses tryptophan (an amino acid), which is needed to make niacin (vitamin B3). As a result, levels of both of these can become low.

Some suggestions to ensure that you are getting enough dietary protein and niacin include:

- Having at least 4 sources of high-protein foods daily. For example, fish, poultry, lean meat, eggs, dairy foods, beans, lentils, tofu, nuts and seeds.
- Ask your doctor or dietitian about taking a daily niacin-containing tablet and for recommendations about the best one to take.

Learn your triggers

Stress, exercise and certain foods can trigger carcinoid syndrome symptoms. In time you will learn what affects you and how to manage. For example, strenuous activities, large meals, getting stressed or certain foods may lead to symptoms.

Food and drinks that can make symptoms worse include:

- A large or very high-fat meal
- Alcohol
- Spicy foods
- Foods moderate to high in amines such as aged cheese, smoked/salted fish and meat, yeast, fermented tofu, miso and sauerkraut
- Foods moderate in amines such as large doses of caffeine, chocolate, nuts, coconut, bananas, raspberries, soybean products (including soya sauce and tempeh) and broad beans

It may be helpful to keep a food diary to see how these or other foods affect you, to try to identify possible triggers. If you are making changes to your diet, it is important to work with a dietitian to ensure that you are not missing any key nutrients.

Carcinoid crisis

Carcinoid crisis is a severe case of carcinoid syndrome symptoms such as flushing, low or high blood pressure, breathing difficulties, altered mental state, diarrhoea and palpitations. Your medical team will take extra precautions to avoid this if you are having treatment.

Having a general anaesthetic, surgery or other treatments can trigger a carcinoid crisis. Stress can also trigger a carcinoid crisis. Carcinoid crisis is serious and may be life-threatening.

A somatostatin analogue drug such as octreotide (Sandostatin) should be given either before and/or during a procedure to reduce the risk of carcinoid crisis. These drugs can also be given to treat a carcinoid crisis if it happens.

The NET Patient Network website (**www. neuroendocrinecancer.ie**) has a carcinoid crisis card that you can print and carry with you to let doctors and other people know you're a NET patient who may need octreotide infusions in urgent or emergency circumstances.

Carcinoid crisis – Advice for carers

It's important for carers to understand carcinoid crisis and what to do if it happens. Carers can also help the patient by telling treating doctors about what happened and about the patient's illness.

Will treatment affect my sex life?

Cancer can affect how you feel about sex and your relationships. Coming to terms with the fact that you have cancer can take quite a while. It can be hard to relax as well when you have a lot of worries on your mind. You may also be feeling tired from the effects of treatment and lose interest in sex as a result.

There is no right or wrong way to feel about your sexuality and sex life. Even if you do not feel like having sex, you can still enjoy a close and loving relationship with your partner. Touching and holding each other can help you to stay physically close.

You may find that talking about your feelings may ease any worries you have. If you find it hard to express your feelings to your partner or a close friend, talk to your doctor or nurse. Our Support Line 1800 200 700 and our Daffodil Centres can help you to find supportive information and accredited therapists if you would like to talk to someone. Therapy can help you and your partner deal with a change in your sexual relationship and find ways of being close again.

There is no set time for you to be ready to have sex again. It varies from person to person. Some people fear that cancer can be passed on to a partner during sex. There is no truth to this.

Contraception

If you are having sex and you are fertile, you should use a reliable method of contraception during and for some time after treatment. Some treatments may harm a developing baby, so it’s important to avoid pregnancy during treatment and for a time after treatment. Ask your NET team’s advice about this.

Many specialists recommend that you wait for up to 2 years after treatment before trying to start a family or having more children. This time gives your body a chance to recover from the effects of the cancer and its treatment.

Ask your doctor's advice about contraception or if you are thinking about having children after treatment.

Asking for advice

If you have any questions about how treatment may affect your sex life, you can ask your doctor or nurse. Your doctor and nurse are well used to talking about these matters, so try not to feel embarrassed. You can also call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can discuss any worries you might have with a nurse in confidence. Or email the nurses at supportline@irishcancer.ie

Will treatment affect my fertility?

Your fertility may be affected by some of the treatments so that you may not be able to have a child in the future. Discuss any worries you have about infertility with your doctor before treatment starts. They can tell you if there are any options open to you. For example, it may be possible to freeze your eggs or sperm before treatment begins. Your doctor can refer you to a specialist fertility clinic for advice, counselling and support if this is an option for you.

Cancer and complementary therapies

Complementary therapies are treatments and activities that you can have along with your standard medical treatment to try and feel better. For example, massage and counselling. Complementary therapies can't treat or cure cancer, but some people say that complementary therapies help them to feel more relaxed and better able to cope with their illness and the side-effects of treatment.

It's very important to talk to your doctor if you're thinking of using complementary therapies. Some can interfere with your treatment or be harmful to you, even if you have used them safely before your diagnosis.

Integrative care

Integrative care means combining (integrating) your standard treatment with complementary therapies to try to feel as well as possible and to cope better with your illness.

What's the difference between complementary and alternative therapies?

Complementary therapies are used **together with** standard medical treatment.

Alternative therapies are used **instead of** standard medical care.

Modern medical treatments are very effective. An unproven alternative could harm your health, or you might miss out on a treatment that could really help you.

More information

To find out more about complementary therapies, you can talk to one of our cancer nurses — call our Support Line on 1800 200 700 or visit a Daffodil Centre. You can also ask for a free copy of our booklet ***Understanding cancer and complementary therapies***, or download it from our website **www.cancer.ie**

Coping and emotions

How can I cope with my feelings?

Some people say that trying to cope with their thoughts and feelings is the hardest part of having cancer.

You may find it hard to come to terms with your diagnosis, you may blame yourself, resent other people who are healthy or feel very anxious or depressed.

Feelings like sadness, fear, grief, hopelessness, anxiety and anger can happen at different times.

NETs patients often live long lives with their condition. It can be stressful to live with a long-term (chronic) illness, even if you are feeling well.

A cancer diagnosis can be hard on you – mentally and emotionally. Give yourself time and space to deal with your emotions and get help if you need it.

A helpful booklet that discusses in detail how you may be feeling is called ***Understanding the Emotional Effects of Cancer***. Call our Support Line on 1800 200 700 or visit a Daffodil Centre for a free copy.

Anxiety and depression

If you feel that anxiety or low moods are getting the better of you or you're finding it hard to cope, it's important to get help. Try to talk with someone you know who is a good listener, join a support group or tell your GP. Medical social workers can also offer support to you and your family.

Your doctor may also suggest medication to help with anxiety or depression. Often a short course of medication can work well. Professional counselling can also be very helpful.

> "Counselling has helped me with every part of my life."

> It's not a sign of failure to ask for help or to feel unable to cope on your own.

Counselling

If you're feeling very distressed or finding it hard to cope, a trained counsellor who is not involved in your situation can help you to express your feelings, worries and fears and make sense of them. Counselling can also give you emotional support, help you to make decisions and learn ways to cope better.

The Irish Cancer Society funds one-to-one counselling remotely and through many local cancer support centres. To find out more about counselling, call our Support Line on Freephone 1800 200 700, visit a Daffodil Centre or email the nurses at supportline@irishcancer.ie

> "Talking about cancer made it less awful and helped ease my fears. I learned to cope and understand myself better."

Ways to get emotional support

Find out about cancer support services in your area: Most provide a range of helpful services like counselling, complementary therapies, exercise programmes and other activities. They can also give you practical advice and support. See page 144 for more about cancer support services.

Join a support or educational group: You might find it reassuring to talk to other people with cancer who are facing similar challenges. The NET Patient Network organises patient support meetings. Many cancer support centres have activities and groups where you can meet other people affected by cancer.

Ask about psycho-oncology services at the hospital: Psycho-oncology services give cancer patients emotional and psychological support to help them cope. Your healthcare team can refer you to psycho-oncology services if they're available at your hospital.

Get online support: Special websites called online communities let you write questions, share stories, and give and receive advice and support. Visit **www.cancer.ie/community** to join the Irish Cancer Society online community.

Talk things through: It can be a great weight off your mind to share your feelings and worries. You could talk to a friend or family member if you feel comfortable doing so. You could also speak to the medical social worker at the hospital or to one of our cancer nurses.

Seek spiritual support: For some people spiritual and religious beliefs can bring comfort and hope. Practices such as prayer or meditation may help you to focus on what has value and meaning in your life.

If you need more information or help with finding support, call our Support Line on 1800 200 700 or drop into a Daffodil Centre.

Peer Support

Peer Support is the Irish Cancer Society's one-to-one support programme. You can be put in contact with a trained volunteer who has had a similar cancer experience to you. Volunteers give support, practical information and reassurance. Call 1800 200 700 for more information or visit a Daffodil Centre.

Positive feelings

In time, some people say they can find positive things in their cancer experience. They say that cancer brought them closer to the people around them or made them appreciate what's important in life. Or it opened up new experiences and relationships.

Getting support, such as counselling, may help you to come to terms with your diagnosis and feel more positive.

> "I am very happy and content … even though I have to live with this."

You and your family

Every family deals with cancer in its own way. You may feel that you don't want your illness to upset family life, feel guilty that you can't join in as much as before, or that you're letting down your partner or children. You may also worry about the emotional impact your illness will have on your loved ones. Our booklet ***Understanding The Emotional Effects of Cancer*** can help to you find ways to talk about your cancer and to ask for the help and support you need.

If you or your family members need more support or advice, speak to the medical social worker at the hospital or get in touch with one of our cancer nurses. Call us on 1800 200 700 or visit a Daffodil Centre. The nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet ***Talking to Children about Cancer***, which has practical advice about how to talk to children of different ages.

Changing relationships

You may feel that people are treating you differently. Some people may withdraw and not contact you as much because they are afraid of doing or saying the wrong thing. Others may not understand that you feel too unwell to go out. Try to talk openly to your friends and family if there are any misunderstandings or problems. Tell them how you feel. If you find it hard, ask another family member or friend to talk to them.

Talking to children and teenagers

Saying nothing

You may feel it's best not to tell your children anything. You may be worried about what to say or how they will react. But children and teenagers can often sense that there is a problem. If no one explains to them why things have changed, they may imagine something worse or blame themselves. By talking openly you can answer their questions and help them to cope with their emotions.

How to tell your children

It's best that you or your partner tell your children about your cancer diagnosis. How you discuss your cancer and treatment with them will depend on their age and character. Your specialist nurse and our cancer nurses can also support you if you have children and aren't sure what to say to them. You could also read our booklet ***Talking to Children about Cancer***, which has practical advice about how to talk to children of different ages. It also has information on supporting children and teenagers and helping them to deal with their emotions.

The booklet is available free of charge from Daffodil Centres or by calling our Support Line. It's also available on our website **www.cancer.ie**.

Further information and support

If you want more advice and support, you can ask your nurse or medical social worker. Or call our Support Line on 1800 200 700 or visit a Daffodil Centre to talk to a cancer nurse in confidence.

Supporting comeone with cancer

Supporting someone with cancer

Finding out someone you love has cancer and trying to care for them can be difficult. You might be unsure about how best to support the person with cancer, practically or emotionally. You might also be struggling with your own feelings and responsibilities.

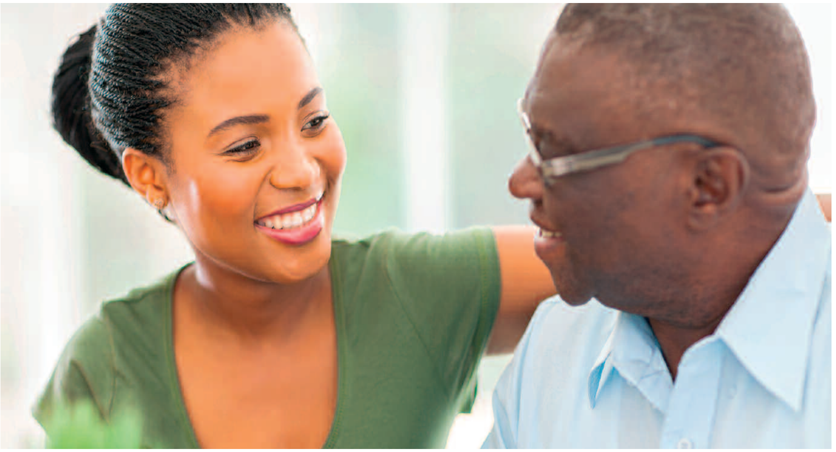
Here are some things that can help to make life a little easier:

Learn about NETs

Try to go to hospital visits and also read any information from the hospital so you can understand your loved one’s illness and treatment, how it might affect them, physically and emotionally, and how you can best support them. If your loved one has carcinoid syndrome, you should understand the symptoms and what to do in the event of a carcinoid crisis (see page 110). Visit our website **www.cancer.ie** or call our Support Line for free copies of our cancer information booklets.

Share worries

If you are feeling anxious or overwhelmed, share your worries with someone else. Call our Support Line on 1800 200 700 or drop into a Daffodil Centre if you want to chat to a cancer nurse in confidence.



Be kind to yourself

Your health and happiness matter too. Make some time for yourself, stay in touch with your friends and don't be afraid to let other people help out with the caring.

Try counselling

You might find it helpful to talk to a counsellor. The Irish Cancer Society funds one-to-one counselling for friends and family members remotely and through many local cancer support centres. Talk to your GP or see page 119.

Find out about support for carers

Find out about groups and organisations especially for carers of people with cancer. Many local cancer support centres have services for carers too.

How to talk to someone with cancer

When someone close to you has cancer, it can be hard to know what to say. You may find it difficult to talk about their cancer. Or you may be afraid of saying the wrong thing. Often what people with cancer want most is someone to listen to them.

If you want advice on how to support a friend or loved one with cancer, call our Support Line on 1800 200 700. Ask for a copy of our booklet ***Caring for someone with cancer.*** The booklet gives advice on talking to someone with cancer. It also has tips to help you to feel more confident about supporting your friend or relative. You can also pick up a copy of the booklet at any Daffodil Centre, or download it at **www.cancer.ie**

Support for you

Our cancer nurses are there to support you. Call our Support Line on 1800 200 700, visit a Daffodil Centre or email supportline@irishcancer.ie for confidential support, advice and information.

Our booklet, ***Caring for someone with cancer***, has lots of information on:

- Getting organised
- Managing and giving medications
- Giving personal care
- Practical and money matters
- Relationships with other people
- Looking after yourself
- Life after caring

Free copies are available from our Daffodil Centres and our Support Line, or download it from our website **www.cancer.ie**

Support resources

Money matters

- If you have cancer, you may not be able to work for a time. You may also have extra expenses.
- You may have to pay for some of your cancer treatment.
- You might be entitled to certain social welfare payments.
- There are services to help you if you're finding it hard to manage.

A diagnosis of cancer often means that you will have extra expenses, such as car parking during hospital visits, medication, travel, heating and childcare costs. If you can't work or you are unemployed, this may cause even more stress. It may be harder for you to deal with cancer if you are worried about money.

Practical and financial solutions from the Irish Cancer Society

We provide individualised financial support and practical solutions for people living with cancer. This includes:

- **Understanding your welfare entitlements**
- **Advice on accessing extra childcare**
- **Telling your boss about your diagnosis**

We can tell you about public services, community supports and legal entitlements that might help you and your family. We can also act as advocates for patients and their families who may need extra support after a diagnosis. This might include having a Practical and Financial Officer present when discussing your diagnosis with your employer or at meetings with your financial provider to help them understand your diagnosis.

To be referred, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre. Our nurses will chat with you and confirm if a discussion with one of our Practical and Financial Officers might help.

Medical expenses

Medical expenses that you might have to pay include:

- Visits to your family doctor (GP)
- Visits to hospital
- Medicines
- Medical aids and equipment (appliances), like wigs

How much you pay towards your medical expenses depends on whether or not you qualify for a medical card and what type of health insurance you have, if any.

If you have a medical card, you will probably have very little to pay for hospital and GP (family doctor) care or your medication. If you are over 70, you can get a free GP visit card.

Medical cards are usually for people on low incomes, but sometimes a card can be given even if your income is above the limit. For example, if you have a large amount of medical expenses. This is known as a discretionary medical card.

An emergency medical card may be issued if you are terminally ill and in palliative care, irrespective of your income.

If you don’t have a medical card you will have to pay some of the cost of your care and medication.

If you have health insurance, the insurance company will pay some of the costs, but the amount will depend on your insurance plan. It’s important to contact your insurance company before starting tests or treatment to check you’re covered.

Benefits and allowances

There are benefits that can help people who are ill and their family. For example, Illness Benefit, Disability Allowance, Invalidity Pension, Carer’s Allowance, Carer’s Benefit, Carer’s Leave.

If you want more information on benefits and allowances, contact:

- The medical social worker in the hospital you are attending
- Citizens Information – Tel: 0818 074 000
- Department of Employment Affairs and Social Protection – Tel: 0818 662 244 or ask to speak to a DSP representative at your local health centre or DSP office.

Always have your PPS number to hand when you are asking about entitlements and benefits. It’s also a good idea to keep a copy of completed forms, so take a photo or photocopy them before posting.

If you have money problems

If you are getting into debt or you are in debt, the Money Advice and Budgeting Service (MABS) can help you. MABS can look at your situation, work out your budget, help you to deal with your debts and manage your payments. The service is free and confidential.
Call the MABS Helpline 0818 07 2000 for information.

If you are finding it hard to cope financially, contact your medical social worker in the hospital or your local health centre for advice. The Irish Cancer Society can also give some help towards travel costs in certain cases. See page 141 for more details of our **Transport Service** and the **Travel2Care** fund.

You can also call our Support Line 1800 200 700 or visit a Daffodil Centre and the nurse will suggest ways to help you manage.

Money and finances

Go to **www.cancer.ie** and see our **Managing money** page for information on:

- Medical costs and help available
- Benefits and allowances that you or your family may qualify for
- Travel services
- Ways to cope with the cost of cancer

Our Benefits Hub on our website has lots of information on government supports for people who are unwell and their carers. It also has advice on how to apply.

Irish Cancer Society services

We provide a range of cancer support services for people with cancer, at home and in hospital, including:

- Support Line
- Daffodil Centres
- Telephone Interpreting Service
- Peer Support
- Patient Education
- Counselling
- Transport Service
- Night Nursing
- Publications and website information
- Support in your area
- Practical and financial solutions (see page 134)

Support Line Freephone 1800 200 700

Call our Support Line and speak to one of our cancer nurses for confidential advice, support and information for anyone affected by cancer. Our Support Line is open Monday to Friday, 9am–5pm. You can also email us any time on supportline@irishcancer.ie or visit our Online Community at **www.cancer.ie/community**

The Support Line service also offers video calls for those who want a face-to-face chat with one of our cancer nurses. From the comfort of your own home, you can meet a cancer nurse online and receive confidential advice, support and information on any aspect of cancer.

Our cancer nurses are available Monday to Friday to take video calls on the Microsoft Teams platform. To avail of the service, please go to **https://www.cancer.ie/Support-Line-Video-Form.**

One of our nursing team will then email you with the time for your video call. The email will also have instructions on how to use Microsoft Teams on your phone, tablet or computer.

Daffodil Centres

Visit our Daffodil Centres, located in 13 hospitals nationwide. The centres are staffed by cancer nurses and trained volunteers who provide face-to-face advice, support and information to anyone affected by cancer. The service is free and confidential.

This is a walk-in service; you do not need an appointment. For opening hours and contact details of your nearest Daffodil Centre, go to **www.cancer.ie** and search 'Daffodil Centres'.

Who can use the Daffodil Centres?

Daffodil Centres are open to everyone – just call in if you want to talk or need information on any aspect of cancer including:

- Cancer treatments and side-effects
- Chemotherapy group education sessions
- Emotional support
- Practical entitlements and services
- Living with and beyond cancer
- End-of-life services
- Lifestyle and cancer prevention
- Local cancer support groups and centres

Telephone Interpreting Service

We make every effort to ensure that you can speak to our Support Line and Daffodil Centre nurses in your own language through our Telephone Interpreting Service.

If you would like to speak to us using the Telephone Interpreting Service, call our Support Line on Freephone 1800 200 700, Monday to Friday 9am-5pm, or contact your nearest Daffodil Centre.

Tell us in English the language you would like. You will be put on hold while we connect with an interpreter. You may be on hold for a few minutes. Don't worry, we will come back to you.

We will connect you to an interpreter.

The interpreter will help you to speak to us in your own language.

Peer Support

Peer Support is a free and confidential telephone service connecting people with similar cancer experiences. Peer Support volunteers are fully trained to provide emotional and practical cancer support in a safe, responsible and kind way.

To be referred to a Peer Support volunteer, call Freephone 1800 200 700 or contact your nearest Daffodil Centre.

For more information on Peer Support, search 'peer support' at **www.cancer.ie**

Patient Education

At our free patient education workshops, our cancer nurses provide tailored information before and after cancer treatment.

The workshops take place in person, in one of our 13 Daffodil Centres nationwide, or online. To register for a place at one of our patient education workshops, call our Support Line on 1800 200 700, contact your nearest Daffodil Centre or email patienteducation@irishcancer.ie

Counselling

The Society funds professional one-to-one counselling for those who have been affected by a cancer diagnosis. Counselling is available for the person who has been diagnosed, family members and close friends. The services we provide are:

- Remote counselling nationwide, by telephone or video call.
- In-person counselling sessions in cancer support centres around the country.

For more information, call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Support in your area

We work with local cancer support centres and the National Cancer Control Programme to ensure patients and their families have access to high-quality confidential support in a location that's convenient to them.

For more information about what's available near you, visit **www.cancer.ie/local-support**, contact your nearest Daffodil Centre or call our Support Line on Freephone 1800 200 700.

Transport Service

We provide transport and financial grants for patients in need who are in cancer treatment.

- Transport is available to patients having chemotherapy treatments in our partner hospitals who are having difficulty getting to and from their local appointments.
- We have recently opened a pilot service for patients having radiotherapy treatment at University Hospital Cork and the Bons Secours Hospital, Cork.
- Travel2Care is a fund for patients who are having difficulty getting to and from their appointments for diagnostic tests or cancer treatments. Patients can apply for this fund if they are travelling over 50 kilometres one way to a national designated cancer centre. Travel2Care is made available by the National Cancer Control Programme.

To access any of these supports, please contact your hospital healthcare professional, Freephone 1800 200 700 or contact your nearest Daffodil Centre.

Night Nursing

We provide end-of-life care for cancer patients in their own home. We offer up to 10 nights of care for each patient. Our service allows patients to remain at home for the last days of their lives surrounded by their families and loved ones. This is a unique service in Ireland, providing night-time palliative nursing care to cancer patients, mostly between 11pm and 7am.

For more information, please contact the health professional who is looking after your loved one.

> “We were really lost when we brought Mammy home from the hospital and the night nurse's support was invaluable. She provided such practical and emotional support.”

> “Our night nurse was so caring and yet totally professional. We are so grateful to her for being there for Dad and for us.”

Publications and website information

We provide information on a range of topics, including cancer types, treatments and side-effects and coping with cancer. Visit our website **www.cancer.ie** to see our full range of information and download copies. You can also call our Support Line on Freephone 1800 200 700 or contact your nearest Daffodil Centre for free copies of any of our publications.

To find out more about the Irish Cancer Society’s services and programmes:

- **Visit us at www.cancer.ie**
- **Call our Support Line on Freephone 1800 200 700**
- **Email our Support Line at supportline@irishcancer.ie**
- **Contact your nearest Daffodil Centre**
- **Follow us on:**
  Facebook
  X
  Instagram
  LinkedIn

Local cancer support services

The Irish Cancer Society works with cancer support services all over Ireland. They have a range of services for cancer patients, their partners, families and carers, during and after treatment, many of which are free. For example:

- **Professional counselling.** The Irish Cancer Society funds one-to-one counselling remotely and through many local support services
- **Support groups,** often led by professionals like social workers, counsellors, psychologists, or cancer nurses
- **Special exercise programmes**
- **Stress management and relaxation techniques,** such as mindfulness and meditation
- **Complementary therapies** like massage, reflexology and acupuncture
- **Specialist services** such as prosthesis or wig fitting and lymphoedema services, such as education, exercise, self-management and manual lymph drainage
- **Mind and body sessions,** for example, yoga and tai chi
- **Expressive therapies** such as creative writing and art
- **Free Irish Cancer Society publications** and other high-quality, trustworthy information on a range of topics

Cancer support services usually have a drop-in service where you can call in for a cup of tea and find out what's available.

You can call our Support Line on Freephone 1800 200 700 to find your nearest cancer support centre. Or go to **www.cancer.ie** and search 'Find support'.

What does that word mean?

Carcinoid tumours: A term used to describe gastrointestinal NETs or gastroenteropancreatic NETs (GEP-NETs)

ECG: A test that measures your heart's electrical activity, including the rate and rhythm using sticky patches called electrodes attached to your body.

Echocardiogram: A type of ultrasound scan that produces detailed pictures of your heart and nearby blood vessels.

Gallium-68: A radioactive substance that is injected into the body to show up specific neuroendocrine cancer cells during a PET scan.

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

Glucagon: A hormone that raises blood sugar levels. It is released by the pancreas.

Hormones: Hormones act as chemical messengers. They control many functions in the body.

Hypothalamus: A gland in your brain that controls your hormone (endocrine) system.

Insulin: A hormone that lowers blood sugar levels. It is released by the pancreas.

MEN1 syndrome: MEN1 syndrome causes tumours, which are mainly benign (non- cancerous). The tumours commonly affect the endocrine glands, which produce hormones.

Neuroendocrine carcinomas: A faster growing type of neuroendocrine cancer where the cell changes are called poorly-differentiated – the cells look very abnormal. They are likely to grow more quickly and spread.

Neuroendocrine neoplasms (NENs): Tumours that develop from the neuroendocrine cells. NENs include neuroendocrine tumours (NETs) and neuroendocrine carcinomas (NECs).

Phlebotomist: A medical professional who takes blood samples from patients, which are examined in a laboratory.

Pituitary gland: A gland in the brain It releases hormones that carry messages around the body via the bloodstream. It controls several hormone glands in the body.

Notes/questions

Notes/questions

Notes/questions

Notes/questions

Acknowledgments

The Irish Cancer Society has produced this booklet to meet the need for improved communication, information and support for cancer patients and their families throughout diagnosis and treatment. We would like to thank all those whose support and advice made this publication possible.

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The following sources were used in the publication of this booklet:

- *National Cancer Strategy 2017-2026*, National Cancer Control Programme
- *Cancer in Ireland 1994-2020: Annual statistical report of the National Cancer Registry* (2022)
- *Understanding your NET* (2016) NET Patient Network, Ireland
- *Your Guide to Neuroendocrine Tumours* (2017), IPSEN
- https://www.hse.ie/eng/services/list/5/cancer/profinfo/medonc/peptide-receptor-radionuclide-therapy-prrt-/prrt-pil-short.pdf
- https://bestpractice.bmj.com/topics/en-gb/296
- https://www.esmo.org/guidelines/guidelines-by-topic/esmo-clinical-practice-guidelines-endocrine-and-neuroendocrine-cancers

Published in Ireland by the Irish Cancer Society.

Join the Irish Cancer Society team

If you want to make a difference to people affected by cancer, join our team! Visit our website www.cancer.ie if you want to get involved.

Support people affected by cancer

Reaching out directly to people with cancer is one of the most rewarding ways to help:

- Help people needing lifts to hospital by becoming a volunteer driver
- Give one-on-one support to someone newly diagnosed with cancer as part of our Peer Support programme
- Give information and support to people concerned about or affected by cancer at one of our hospital-based Daffodil Centres

Share your experiences

Use your voice to bring reassurance to cancer patients and their families, help people to connect with our services or inspire them to get involved as a volunteer:

- Share your cancer story
- Tell people about our services
- Describe what it's like to organise or take part in a fundraising event

Raise money

All our services are funded by the public's generosity:

- Donate direct
- Take part in one of our fundraising events or challenges
- Organise your own event

Did you like this booklet?

We would love to hear your comments or suggestions.
Please email reviewers@irishcancer.ie

Our cancer nurses are here for you:

- Support Line Freephone **1800 200 700**
- Email **supportline@irishcancer.ie**
- Contact your nearest Daffodil Centre

Irish Cancer Society

www.cancer.ie