Neuroendocrine Cancer.

A Guide for Patients.

NeuroEndocrine
Cancer New Zealand

Contents.

Welcome.

If you're reading this booklet it means either you, or a loved one, has found out they have neuroendocrine (NET) cancer. We know what a tough time you're having right now. Neuroendocrine Cancer New Zealand was set up in 2013 and is dedicated to helping every Kiwi living with neuroendocrine cancer. We have information, support and resources to suit everyone, at every stage. Here are just some of the ways that we can help you:

- Our website is packed with information and links to help you understand and manage your cancer.
- Our regular newsletter is packed with information about how to manage NET cancers, upcoming educational events to learn more about NETs and other useful advice.
- Our specialist neuroendocrine cancer nurses offer free help to explain and answer your questions.
- For Facebook users, we have a patient-only Facebook page where you can get top tips and advice from peers, and be first to know about upcoming events.
- In the main centres we run catch ups at local cafes so you can meet other NET cancer patients and supporters.
- Monthly zoom education series, where we invite guest experts to answer your questions.
- In-person annual patient education day with New Zealand's leading NET cancer experts so you can learn more about your cancer.
- Information booklets covering an array of topics - such as diet and nutrition - are available in print and online.
- We connect with and support research projects that help address ongoing challenges with NET cancer diagnosis, management and treatment.

Neuroendocrine Cancer New Zealand is New Zealand's only national charity dedicated to supporting neuroendocrine cancer patients and their families. We are committed to keeping all our support services free for all patients and whānau. Thanks to our incredible donors and supporters you can rely on us for help, whenever you need it.

For more details about us and how we can help you, see our website **www.neuroendocrinecancer.org.nz**

About this guide.

This guide has been put together for neuroendocrine cancer patients and their families. If there is any information in here that you do not understand please ask your medical team, or contact the Neuroendocrine Cancer New Zealand team with your questions. We are here to help.

There are many types of neuroendocrine cancer, so after reading this you will likely want to know more about your specific cancer. Please get in touch with us and we can help point you in the right direction to get the information you need. We encourage you to discuss any information you find on the internet with your healthcare team.

We hope this guide will be a helpful resource throughout the coming weeks, months and years.

This is a general guide and all information provided can also be found on our website **www.neuroendocrinecancer.org.nz**

What is Cancer?

The body is made up of many different types of cells. Normally these cells divide and copy themselves in a controlled manner. Cancer begins when one type of cell starts to divide and grow uncontrollably. These uncontrolled cells form into lumps (also called masses or tumours) that invade nearby parts of the body or can spread to more distant parts of the body through the lymphatic and blood systems. Not all tumours are cancerous, the non-cancerous or benign tumours do not spread throughout the body.

What are Neuroendocrine Cancers?

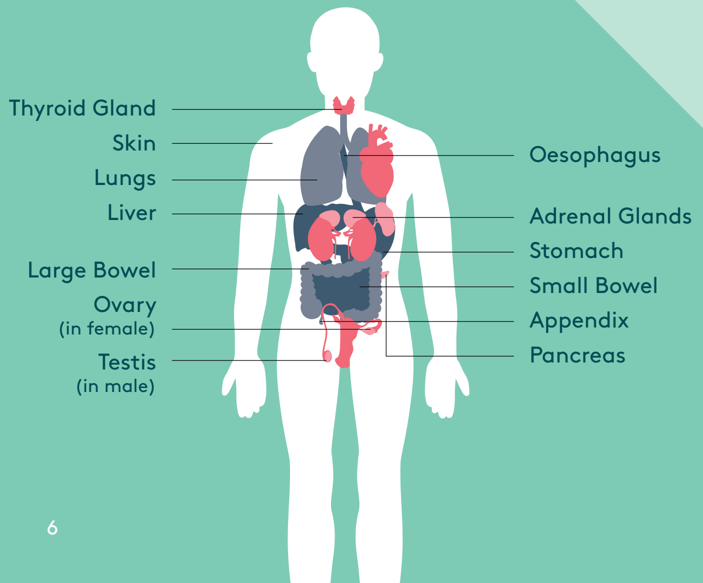
Neuroendocrine cancers are often referred to as neuroendocrine tumours or NETs, and they arise from neuroendocrine cells. Neuroendocrine cells are special cells whose normal job is to make hormones and proteins that control different organs in the body. They are often connected and controlled by very fine nerves.

In the same way that other cancers form, NETs occur when a single neuroendocrine cell loses control of the way it grows, and forms a lump called a neuroendocrine tumour. If this tumour invades the surrounding organ and sometimes spreads around the body it is called malignant or cancerous. But neuroendocrine tumours do not always spread.

Where do Neuroendocrine Cancers occur?

Neuroendocrine cells can be found in many areas of the body, which means neuroendocrine tumours can form in any of these sites.

For example, in the lungs neuroendocrine cells control air and blood flow, and in the gastro-intestinal (GI) tract they control food moving through the gut, stomach acid production and blood sugar levels. When the body is healthy, each neuroendocrine cell releases one kind of hormone. For example pancreatic neuroendocrine cells release insulin, and GI neuroendocrine cells release serotonin. When a neuroendocrine cell becomes a neuroendocrine tumour, it might start making large amounts of one or more hormones. If this happens, the tumour can cause symptoms due to the high hormone level.

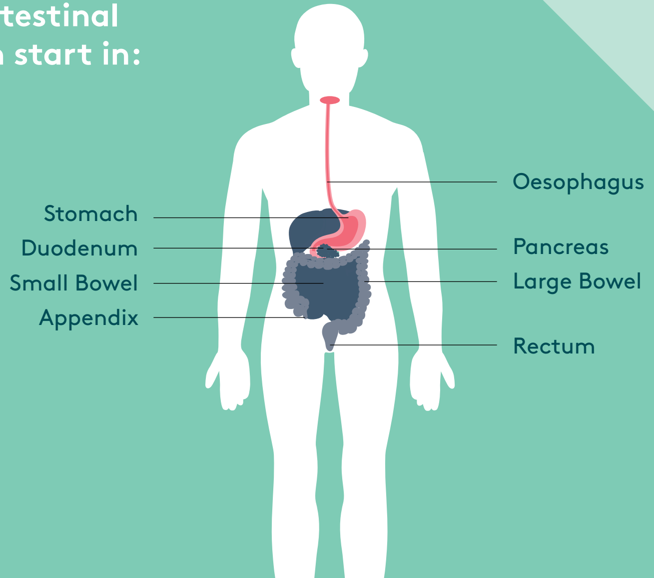


Different types of NET cancers.

There are many different types of NETs. They can start in different places, have different symptoms, and all look a little different under a microscope.

Doctors like to describe NETs according to the areas they are found, as this helps choose the right treatment. The place in the body where the NET appears first is called the “Primary Site”. If the NET spreads to other parts of the body these are often called “secondary” tumours or metastases. For example, the liver is a common place where metastases are found.

Gastrointestinal NETs can start in:



NETs that start in the pancreas or duodenum

These NETs are named after the hormone that the tumour secretes:

- Gastrinoma
- VIPoma
- Insulinoma
- Glucagonoma
- Somatostatinoma

NETs that start in endocrine organs

These NETs are referred to by a different name. For example:

- Adrenal Glands are called a Phaeochromocytoma
- Autonomic (this happens without us knowing about it) Nervous system (special nerves called sympathetic and parasympathetic nerves) are called Paraganglioma
- Thyroid Glands are called Medullary Thyroid Cancer

NETs that start in other sites

- Lungs and their airways or bronchi are often referred to as Carcinoid Lung
- Thymus
- Skin also called Merkel Cell Carcinoma
- Ovaries and testes.

Sometimes doctors refer to NET types by the syndrome or set of symptoms that result from the extra hormone production it may cause (see table opposite).

It can be confusing with so many different names for NETs. Most people need clarification, so please ask your specialist doctor to explain your NET.

Syndrome /Name	Caused by hormone	Symptoms it may cause
Carcinoid syndrome	Serotonin	Flushing, wheezing, diarrhoea, Carcinoid Heart Disease (CHD).
Insulinoma	Insulin	Confusion, sweating, weakness, unconsciousness, relief with eating.
Gastrinoma	Gastrin	Severe peptic ulceration and diarrhoea.
VIPoma	Vasoactive intestinal polypeptide	Watery diarrhoea with marked hypokalaemia (low potassium).
Glucagonoma	Glucagon	Erythema (skin rash), weight loss, diabetes, stomatitis (sore mouth), diarrhoea.
Somatostatinoma	Somatostatin	Cholelithiasis (gall stones), weight loss, diarrhoea, steatorrhoea (fatty stools), diabetes.
SIADH	Antidiuretic hormone	Water retention, confusion.
PTHrP	Parathyroid related peptide	Increased calcium leading to nausea, constipation, lethargy, pain.
Cushings Syndrome	Cortisol	Weight gain, a red round face, high blood pressure, muscle weakness, increased hair growth on face and body, high blood sugar.

What causes NET cancers?

It is not fully understood what causes NETs. Researchers do not know why some neuroendocrine cells start growing abnormally.

Most neuroendocrine cancers are NOT passed down through families (inherited).

The risk factors for NETs are not well known and most NETs occur without any known cause.

Tell your doctor if you are aware of other family members who have developed cancers or endocrine problems. For families that are more likely to develop NETs, this can be caused by an abnormal gene that gets passed down through the family.

Some NETs are linked with a hereditary cancer or tumour syndrome such as:

Multiple endocrine neoplasia (MEN Type 1)

Multiple endocrine neoplasia (MEN Type 2)

Von Hippel-Lindau disease

Adrenal corticol carcinoma (ACC)

Succinate dehydrogenase enzyme (SDH)

SDHD

Familial Medullary Thyroid Carcinoma (FMTC)

If you are worried about NET cancers in your family, please talk to your doctor.

What is known about NET cancers?

NETs can range from being very slow growing cancers in some people, through to fast growing cancers in other people. Most NETs grow slowly, and some people can have one or more tumours for years, often without symptoms, before they are diagnosed. Slow growing NETs are sometimes found at the time of surgery or during investigation for other problems. At first it can be hard for your doctor to know whether you have a slow or fast growing NET.

When you are diagnosed with any type of NET your specialist may take a small piece of the tumour, called a biopsy sample, and give your tumour a 'proliferative index'. This is a measure of the number of cells in the tumour that are dividing (proliferating) at any one time. The most common proliferative index is called Ki-67. A Ki-67 of less than 2% means that the tumour is very slow growing. The higher the number, the faster the growth. Sometimes doctors like to grade your tumour according to the speed at which it is growing.

Unlike some other cancers the grading is not based on whether the NET has spread from its original site or not.

Each type of NET affects people in different ways in terms of how the tumour grows, the symptoms produced, whether or not they spread and how they spread.

Ki67 < 2%	Low grade	Grade1
Ki67 3-20%	Intermediate Grade	Grade 2
Ki67 >20%	High grade	Grade 3

Diagnosing NET cancers.

NETs are hard to diagnose. The symptoms take about 3 to 5 years to show up, and even then symptoms are often non-specific and vague. International experience shows that the time from first symptoms to diagnosis is about 6 to 7 years.

Just like all cancers an early diagnosis can mean a better outcome, which is called prognosis.

Tests.

Like all cancer patients, if you have a NET you can expect to have a lot of tests and scans that will tell your doctor about your disease, its spread and the rate of growth. Some of the tests you might have are the same as any cancer and some are just for understanding NETs.

Biopsy

This involves taking a piece of tissue from the suspect tumour and having it tested in the laboratory by a specialist called a pathologist. It helps to confirm if you do have a neuroendocrine tumour and how fast it is growing.

Blood tests

Blood will also be collected for a range of tests.

You may be asked to have a fasting blood test to check your Chromogranin A which is often high in people with NETs. This is a type of test called a tumour marker because it can act as a guide to the amount of cancer that is present.

Doctors may also look for other markers of NETs, depending on where your NET starts, and what symptoms you have. This is because some NETs keep making the normal hormones (for example gastrin, insulin, glucagon, adrenalin, noradrenaline or dopamine), but in higher than normal levels and this can cause specific symptoms.

Blood tests will also check how well your kidneys and liver are functioning.

Some other tests may be needed if your doctor is concerned about whether your NET could run in your family, at which point you can ask to speak to a genetic counsellor.

Urine tests

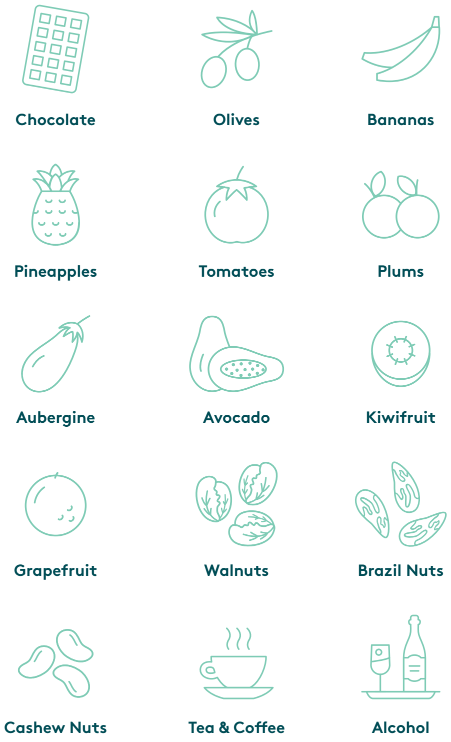
When some hormones produced by NETs are broken down inside the body, the waste products are excreted in the urine as a substance called 5-hydroxyindoleacetic acid (5-HIAA). Serotonin is produced by some NETs, and this is broken down to 5-HIAA, and so higher than normal levels of 5-HIAA can be a sign of a NET.

You may be asked to collect all your urine for 24 hours so that your 5-HIAA levels can be checked. Some foods and drugs can give a false high result.
You will need to avoid these for 3-7 days before collecting your urine sample.

Foods to avoid are:

Chocolate, olives, bananas, pineapple and its juice, all tomato products, plums, aubergine/eggplant, avocado, kiwi fruit, grapefruit, walnuts, brazil nuts, cashew nuts, tea, coffee and alcohol. You will also be asked to avoid certain cough, cold and flu remedies.

This is because they contain substances that might artificially raise 5-HIAA levels and give a false test result.



Scans.

There are a number of scans you may be asked to have. These will help determine the exact size and position of the tumour or metastases. You may not need all types of scans as it will depend on the tumour location and grade. Your medical team will advise which type of scan is appropriate, but if you are not sure ask your doctor. Scans for ALL cancers include:

Endoscopy

This is a way of looking into your GI tract (digestive system) using a flexible fibre optic tube called an endoscope. The tube can be inserted down the back of the throat and down into the stomach, which is called a gastroscopy. Or it can be inserted into the colon via the anus (back passage), which is called a colonoscopy. You will be offered sedation before the process, and the doctor may remove tiny biopsy samples of any suspicious areas for testing in the laboratory. Sometimes a small ultrasound scanner is placed at the tip of the endoscope, so that pictures of a tumour can be taken from inside the body, very close to the cancer. This tool can also be used to take a biopsy sample.

CT scan

A computerised tomography (CT) scan makes a two dimensional picture of the inside of the body. It can be used to find out the position and size of NETs. Regular scans are useful to find out the rate of tumour growth.

MRI scan

A magnetic resonance imaging (MRI) scan can help reveal where the tumours are positioned. It uses magnetism rather than X-rays to take pictures of the inside of the body.

FDG PET scan

A type of 'whole body' scan that picks up spots of very high cell growth. This type of scan is not very useful if your NET is slow growing, but might be useful in fast growing tumours.

Bone scan

A bone scan looks for abnormalities in bones that might be caused by cancer metastases. You will be given a small injection of radioactive tracer that will be absorbed into your bones over time. It takes about three hours for this to occur. Pictures of your bones are then taken using a special camera that detects the location of the tracer (called a gamma camera), and you will be asked to return for a second set of pictures three hours later. For this second set of pictures you will again be asked to lie or sit in front of the gamma camera. The scan will take approximately 30-45 minutes. These are not commonly used for NETs.

Ultrasound scan

Ultrasound imaging or sonography, uses high-frequency sound waves to produce pictures of the inside of the body. These scans do not use radiation like x-rays. Because ultrasound images are captured in real-time, they can show the structure and movement of the body's internal organs, as well as blood flowing through blood vessels. Ultrasounds might be used by your GP when you are first diagnosed but they are no longer used to follow up people with NETs.

Specialised Scans for NET cancers.

Octreotide scan (OctreoScan or Tektrotyd Scan)

This is a useful test that can help reveal the site of NET tumours. It works because some NET cells have special structures on the outside called somatostatin receptors. Octreotide is a man-made version of the natural hormone somatostatin, and can stick to these receptors. Octreotide is combined with a mildly radioactive agent which can be seen with a special kind of scanner. A whole body scan is taken after a few hours, and doctors look at the scan to see the location(s) of the NETs.

GaTate PET or Ga68 PET Scan

This type of scan is like an OctreoScan. It uses a different kind of camera and is often combined with a CT scan. The pictures often give a more accurate picture of where the NET is located than an octreotide scan.

MIBG scan

This type of scan is also like the OctreoScan, but it uses a different compound linked to the radioactive tracer. An MIBG scan will show up tumours which have receptors for meta-iodobenzylguanidine (MIBG) on the surface. This scan is often used if your doctor thinks you may have a paraganglioma or phaeochromocytoma.

Further testing (if required)

There are further tests that you may need to have, such as:

- Pill cam for finding small intestinal NETs (a camera inside a large pill, that you swallow, and pictures are taken as the pill moves through your GI tract (digestive system).
- Bronchoscopy for lung NETs (a type of endoscopy, but for the lungs)
- Kidney function test – a test done before some treatments to ensure your kidneys are working properly.

If you need these tests ask your specialist nurse or doctor for more information.

Treatments you may be offered.

Most people with NET cancer will be looked after by a specialist multidisciplinary team. Every patient will have an individual treatment plan. The treatment options depend on the type and location of your NET, and your general well-being.

Surgery

Surgery is usually the first choice of treatment if the tumour can be completely cut out. This is the case when the tumour is contained (or localised) in one area. If the tumour has spread (or metastasized) to other parts of the body, then surgery may not be the best choice. Your surgeon will consider the pros and cons carefully.

Curative surgery

This is when the cancer has not spread outside the organ or area where it first started. If the tumour can be removed whole and intact with a surrounding margin of normal healthy tissue, then surgery might be a cure with no other treatment needed. A follow-up plan will be put in place after surgery.

Palliative surgery

If a NET has already spread, or become too large to remove completely, surgery might still be an option. If the NET is causing symptoms by pressing on other organs, or by releasing hormones you may need surgery. The goal is to reduce the symptoms by removing (or 'debulking') a large chunk of the tumour that is causing the problems.

Pre-emptive surgery

Surgery might be needed if a NET is close to a vital structure in the body that might become blocked as the tumour grows, such as a blood vessel or the bowel. This will not cure the disease. But it can prevent future problems by removing tumours from areas where a vital structure could be damaged or blocked.

Cardiac surgery

Some NETs cause carcinoid heart disease. Patients may need surgery to replace their heart valve.

IMPORTANT NOTE:

NETs are uncommon and complex tumours. It is best to have a team of experts working together to decide which treatment is best for each patient. If your surgeon is planning to operate they might talk with an expert team at the MDM. This might include oncologists, gastroenterologists, endocrinologists, nurses, radiologists and doctors, each with special skills in managing NET cancers. Any patient can ask their doctor to refer their case to the NET MDM for review.

Treatments targeting NET cancers throughout the body.

Somatostatin Analogues

Somatostatin is a natural hormone that is made in the brain and digestive tract. It acts like an 'off' switch for some of the normal processes in the gut. NETs can make excess hormones that cause symptoms such as flushing, wheezing and diarrhea.

Somatostatin analogues are man-made versions of somatostatin. Injections of these analogues can stop the tumour from making hormones and improve quality of life. These injections also help slow tumour growth in some slower growing NETs.

Chemotherapy

Chemotherapy is either given through a drip (intravenous), or a course of tablets to swallow. Your oncologist will talk to you about the best option for you. To pick the right treatment, your oncologist will look at the proliferative index of your tumour (Ki-67, refer to What is known about NETs).

NETs need to be growing for chemotherapy to work. If you have a slow growing NET, you won't be given chemotherapy. For intermediate growing NETs you may get a combination of drugs called Temozolomide and Capecitabine. These come as tablets to swallow. Sometimes the combination Streptozocin and Doxorubicin (or 5FU) is given through a drip. Fast growing NETs are often treated with Carboplatin and Etoposide through a drip.

You may be asked if you want to be part of a clinical trial. These are studies to find out which combinations of chemotherapy drugs work best for different types of NETs.

Chemotherapy is most often used as a palliative option for people with aggressive NETs. The word palliative means the cancer can't be cured. The aim of the treatment is to slow the cancer down as much as possible. It is also to reduce symptoms so that your quality of life is better.

Molecular Targeted Therapies

There are drugs available that are not funded in New Zealand. The only way to get these drugs is through insurance, or paying for it yourself. Examples are Sunitinib and Everolimus that are used for pancreatic NETs.

Interferon

Interferon is a hormone that is made in the body to help fight infection. Injections of interferon turn on the body's immune system and some NET patients might get interferon injections. In can be given on its own, but it is usually combined with a somatostatin analogue. Because of side effects, this is not a common treatment.

Peptide Receptor Radionuclide Therapy (PRRT)

PRRT works like an OctreoScan, except that a higher dose of radioactive tracer is attached to the octreotide. This high dose is enough to kill the tumour cell that the octreotide binds to. To find out if this therapy will work for you, a Ga68 PET scan is needed. People with intermediate or aggressive NETs will also need a FDG PET scan. These scans will tell your medical team if your NET has enough receptors on the outside of your tumour cells for PRRT to work.

From 1 July 2021 New Zealand has a national PRRT service at Auckland city hospital. Access to PRRT is based on clinical need, which is decided by a nationwide multidisciplinary meeting (called the NET MDM).

Treatments that target liver metastases.

If the NET is mostly in the liver, there are targeted treatments. The three main ways are surgery, embolisation (blocking the blood supply to parts of the liver) or ablation (directly targeting individual tumour spots in the liver).

Embolisation Types

Hepatic artery embolisation (HAE).

In HAE, a catheter is put in a blood vessel in the groin (femoral artery). From here, the catheter is threaded up to the hepatic artery that supplies blood to the liver. Next the blood vessels that feed the tumour are targeted. Tiny particles (or microspheres) are injected through the catheter into these arteries. The particles block the blood supply to the tumour, which can shrink or even kill the tumour. HAE is done by a specialist called an interventional radiologist. Patients are either sedated or under a general anaesthetic for the treatment.

Hepatic Artery Chemoembolisation (HACE).

This treatment is the same as HAE, but the tiny microspheres are loaded with chemotherapy.

Selective Internal Radiation Therapy (SIRT)

This treatment is like HAE, but the tiny microspheres are loaded with radiation. When the spheres get stuck in the tumour they shrink it with local radiation damage. Before having SIRT patients need to have a planning angiogram, where a test dose is delivered. Currently SIRT is not publicly funded in NZ.

Ablation

This is used when a patient has relatively few secondary tumours (metastases). A needle is put into the centre of each tumour then heated to kill the cells. It is very useful in treating small tumours that are not touching major blood vessels.

Watch and wait.

Watch and wait is a frequent approach for NET cancers. It can be especially hard for patients as it feels like nothing is being done. However, your specialist will be aiming to maximise the impact of any treatment, which often means waiting until there is enough tumour mass so that the treatment has enough disease to target. This can also minimize the chance of unwanted side effects. For patients under a watch and wait approach, anxiety levels can be high so make sure you talk to your specialist about support for this.

Multidisciplinary Care.

The care of NET cancers is often complex. Most patients will get a wide range of tests and treatments. They will see a lot of healthcare professionals and feel plenty of strong emotions.

There can be more than one treatment option. To make the best choice for the patient this means medical experts from a lot of different fields need to work together.

This team work is called a multidisciplinary team (MDT), and the place they meet is called a multidisciplinary meeting (MDM). This approach is being used worldwide to deliver the best care for cancer patients.

An MDT has specialists with expertise and interest in NETs. The specialists involved are usually pathologists, endocrinologists, oncologists, radiologists, nuclear physicians, surgeons and cardiologists.

A patient may see some or all of the following people:

- Medical Oncologist
- Surgeon
- Endocrinologist
- Radiology staff
- Radiation Oncologist
- Nuclear medicine physician
- Dietitian
- Nurse Specialist
- Palliative Care Team and Hospice Team
- Pain Team
- General Practitioner /Practice Nurse
- Counselling Staff
- Various Technicians
- Clinic Nurses and Staff

It helps to know the best possible treatment plan is in place. Patients can feel happier if all aspects of their care have been considered. A well co-ordinated MDT is essential for the best quality of life for NET cancer patients.

Communicating with the Health Care Team.

Being told you have cancer is a confusing and frightening time for you and your loved ones. Your healthcare team will do their best to support you. But your medical appointments can be stressful so here are some tips to get the most out of each appointment.

A few things to keep in mind:

- The most important part of your healthcare team is YOU
- YOU know more about YOU than anyone else does
- Your doctor can help YOU more if you are an active partner in your treatment

Tips

Bring a trusted friend or family member with you to the appointment if you can. If you are worried, you may not hear everything that is said, or ask all the questions you wanted to. It helps to have someone else to listen, and to help make sure your concerns are brought up.

Try taking notes on what symptoms you are feeling and when. Take these notes along to your appointments as it may help your medical team.

Write down a list of questions you want to ask. If you don't understand the answers to any of your questions, don't be shy about asking for the answer to be repeated or explained in a different way. Make sure you know who your point of contact is and how to get hold of them, in case you have questions later.

Deciding on a treatment strategy can be difficult so asking your doctor to seek opinions from other specialists can be helpful. This is often done during discussion at a Multidisciplinary Meeting (MDM). Doctors are usually very open to this because they know that making the best treatment choice for people with NETs can be hard. You can always ask that your case be discussed at an MDM.

You can choose how much you want to know about your own cancer. This includes you overall treatment strategy, what the future might hold (prognosis) and what options are available to you if initial treatments do not get your cancer under control.

You have the right to make decisions for yourself, even if the choice is against medical treatment or the choice is to end medical treatment.

Living with NET cancer: Diet, Exercise and Psychological Support.

Diet

Dietary advice on what to eat and avoid is different for each NET patient. But all patients should try to eat a varied diet to keep their weight stable and meet their body's energy and nutritional needs. Problems such as loss of appetite or diarrhoea can make this hard to do. Sometimes talking with a dietician can help. Your specialist doctor or nurse can arrange this for you.

Exercise

Keeping active will help with your well-being. It also helps to keep your body functioning, your muscles strong and may reduce the side effects of treatment. Some gyms offer cancer support programs to help maintain your well-being.

Psychosocial Support

Being diagnosed with a cancer is a challenge that can change your view of life. For people with NETs that produce extra hormones, this can provide additional challenges as these can affect normal bodily functions. Having an understanding of your disease and its effects on your body can be helpful in developing ways to cope.

There are support people around to help you understand your disease. Sometimes it is helpful to talk with a counselor or psychologist to help you develop ways of coping with your particular concerns.

Relationships

A diagnosis of cancer can bring you closer to your family and friends, but it can also put increased pressure or strain on those relationships. You may feel like a burden or your NET has become such a focus of your life. Your supporters may want to try do something to help but are unsure of what to do, or how to support you. Whatever your situation, remaining honest and talking openly can really help. Explaining what you need and getting issues out in the open without blame or criticism can help. Talking to your partner, family, children and friends about your diagnosis can be tough. Supporters often ask questions in different ways – we all process information differently and you may have to repeat information several times for them to understand your situation.

Make time to enjoy doing the things you have always enjoyed. You might have cancer but this does not need to define who you are.

Helping your GP to help you.

Neuroendocrine cancers are not common. Most GPs will never have had a patient with NETs so, just like you, they need to access information and resources to provide the best care. Thanks to the amazing support of Neuroendocrine Cancer Australia, we have a free GP education model available. It is endorsed by the Royal New Zealand College of General Practitioners and worth 4 CME points. Show your GP this QR code so they can check out this amazing course.

Further support and sources of information.

It is important to understand as much as possible about your NET cancer. Neuroendocrine Cancer New Zealand is here to help you find the information you need, and we have specialist nurses that can help explain anything confusing and answer general questions.

Neuroendocrine Cancer New Zealand | www.neuroendocrinecancer.org.nz

We are a national charity helping neuroendocrine cancer patients and their families. We also help doctors and nurses that work with NET cancer.

We run support services and activities online and around New Zealand to suit everyone. Our regular newsletter is packed with information and is completely free. Sign up on the website or email hello@neuroendocrinecancer.org.nz

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We have many ways to help, so whether you or someone you love has been recently diagnosed, or you have had NETs for years we are here for you. We'd love to hear from you, and we will do our best to help you in any way. Send your specific NETs questions to support@neuroendocrinecancer.org.nz for a personal answer from our specialist NET nurse.

NETwork!

This is website run by the research team in Auckland that is trying to better understand NETs and improve treatment.
www.network.ac.nz

Neuroendocrine Cancer - Australia

Sister organisation to Neuroendocrine Cancer New Zealand, providing excellent information. Please be aware that some treatments available in Australia are either not available or not funded in New Zealand.
www.neuroendocrine.org.au

Neuroendocrine Cancer - UK

This is a UK-based patient foundation, which also has very reliable information and resources.
www.neuroendocrinecancer.org.uk

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