Neuroendocrine Tumours

A guide for patients





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INTRODUCTION

This booklet has been developed to provide information about neuroendocrine tumours (NETs) for patients and their families. If there is any information in the guide that you do not understand please feel free to discuss it with a member of your medical team.

Further or more detailed information about your type of neuroendocrine cancer may also be available so please do not hesitate to ask for this as well.

We encourage you to discuss any information you find on the internet with your healthcare team.

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

This is a general guide and all information provided can also be found on the following website:

www.unicornfoundation.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. In cancer 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 TUMOURS?

Neuroendocrine Tumours (NETs) arise from neuroendocrine cells. Neuroendocrine cells are highly specialized cells that normally release hormones and peptides into the bloodstream and control different organs in the body. They are often connected and controlled by very fine nerves.

In the same way that other cancers develop, NETs occur when a single

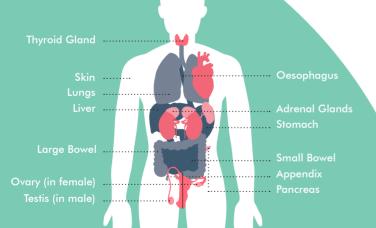
neuroendocrine cell loses control of the way it grows, and forms a lump called a neuroendocrine tumour. Sometimes this tumour is malignant (cancerous) and invades the surrounding organ, and sometimes it spreads around the body. However sometimes it will not spread.

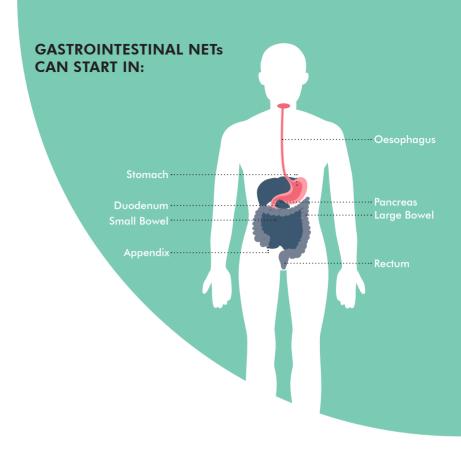
WHERE DO NEUROENDOCRINE TUMOURS OCCUR?

Neuroendocrine cells can be found in many areas of the body, and therefore neuroendocrine tumours can potentially develop in any of these sites.

For example, in the lungs they control air and blood flow and in the gastro-intestinal tract (GI) they

control the movement of food through the aut, 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 or GI cells release serotonin. When a neuroendocrine cell becomes a neuroendocrine tumour, the cell might release massive amounts of one or more hormones. If the level of the hormone is high enough, this might cause symptoms directly related to the high hormone level.





DIFFERENT TYPES OF NETs

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.

TYPE OF NETS THAT CAN ARISE IN THE PANCREAS OR DUODENUM

(Named after the hormone that the tumour secretes):

- Gastrinoma,
- VIPoma,
- Insulinoma
- Glucagonoma
- and Somatostatinoma

NETS THAT START IN ENDOCRINE ORGANS

Are often referred to by a different name. For example, those that start in the:

- Adrenal Glands are called a Phaeochromocytoma
- Autonomic 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 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 and if you need clarification please ask your specialist doctor.

TABLE: NET TYPES

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)
Glugagonaoma	Glucagon	Erythema, weight loss, diabetes, stomatitis, diarrhoea
Somatostatinoma	Somatostatin	Cholelithiasis (solid concentrations in the gall bladder), weight loss, diarrhoea, steatorrhoea (fatty stools), diabetes.
SIADH	Antidiuretic Hormone	Water retention, confusion
PTHrP	Increased Calcium	Nausea, constipation, lethargy, pain
Cushings Syndrome	ACTH	Cholelithiasis, weight loss, diar- rhoea, steatorrhoea (fatty stools), diabetes.

WHAT CAUSES NETs?

It is not fully understood what causes NETs. It is unclear what triggers the process of abnormal cell growth of neuroendocrine cells.

Some families have a higher than normal rate of certain types of cancer due to inheriting an abnormal gene. It is important to know the majority of NETs are NOT hereditary. The risk factors for NETs are poorly understood and most NETs occur without any known cause.

However, let your doctor know if you are aware of other family members who have developed cancers or endocrine problems. Occasionally families will be found to have a tendency to develop NETs, and this can sometimes be caused by an inherited gene.

Some NETs are associated 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 cortical carcinoma (ACC)

Succinate dehydorgenase enzyme (SDH)

SDHD

Familial Medullary Thyroid Carcinoma (FMTC)

If you are concerned please talk to your main health care provider or contact Unicorn Foundation NZ.

WHAT IS KNOWN ABOUT NETs?

NETs can range from being very slow growing cancers in some people, through to fast growing cancers in other people. The majority of 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 discovered 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 review a biopsy sample (a small piece taken from the tumour) 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.

Ki67 < 2%	Low Grade	Grade 1
Ki67 3-20%	Intermediate Grade	Grade 2
Ki67 > 20%	High Grade	Grade 3

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

Different NETs affect different people in different ways in terms of how the tumour grows, the symptoms produced, whether or not they spread and how they spread.

DIAGNOSING NETS

NETs are difficult to diagnose. The onset of symptoms takes an average of 3 to 5 years, and even then symptoms are often non-specific and vague. International experience shows that the average time from first symptoms to

diagnosis is approximately 6 to 7 years.

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

TESTS

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

BIOPSY

This involves taking a piece of tissue from the suspect tumour and having it analysed in the laboratory by a specialist called a pathologist. It helps to establish the diagnosis of 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 called a Chromogranin A which is often elevated in people with NETs. This type of test is 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 kidney and liver are functioning. Some other tests may be requested 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 (5HIAA). 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 your urine over a 24 hour period so that your 5HIAA levels can be checked. The test result however can be falsely raised by certain foods and drugs, so for 3-7 days prior to collecting urine these need to be avoided.

This includes: chocolate, olives, bananas, pineapple and its juice, all tomato products, plums, aubergine/egaplant, avocado, kiwi fruit, arapefruit, 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 5HIAA levels and give a false test result.



SCANS

There are a number of scans you may be asked to have. These will 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, however if you are not sure ask your lead health professional. Scans for ALL Cancers include:

ENDOSCOPY

This is a way of examining 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, a procedure called a gastroscopy. Or it can be inserted into the colon via the anus (back passage), a procedure known as a colonoscopy. You will be offered sedation before either of the procedures, and the doctor may remove tiny biopsy samples of any suspicious areas for analysis. 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 provides a two dimensional picture of the inside of the body. It can be used to determine the position and size of NETs, and regular scans are useful to find out the rate of tumour growth.

MRI SCAN

This 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

This type of 'whole body' scan picks up spots of very high cell growth. This type of scan is therefore not very useful if your NETs are low grade / or 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 which over time will be absorbed into your skeleton. It takes about 3 hours for this to occur. Pictures of your skeleton 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 3 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 around 30-45 minutes. These are not commonly used for NETs.

ULTRASOUND SCAN

Ultrasound imaging, also called ultrasound scanning or sonography, uses high-frequency sound waves to produce pictures of the inside of the body. Ultrasound exams do not use ionizing. radiation (as used in 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 in the initial diagnosis by a GP but are no longer used to follow up people with NETs.

Specialised Scans for NETs include:

OCTREOTIDE SCAN (OR TEKTROTYD SCAN)

This is a useful diagnostic test that can help reveal the site of NET tumours. Some NETs have special receptors on their cell surfaces called somatostatin receptors. Octreotide is a manufactured version of somatostatin, and can stick to these receptors. Octreotide is combined with a mildly radioactive agent which are visible to 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 similar to an octreoscan, but uses a different kind of camera, and is usually combined with a CT scan. The pictures often give a more accurate picture of where the NET is located compared to an octreotide or tektroyd scan.

MIBG SCAN

This is a similar type of scan to the

OctreoScan, except a different substance is connected to the radioactive tracer. An MIBG scan will show up those tumours which have receptors for meta iodo benzyl guanidine (MIBG) on the surface. This scan is usually used when a paraganglioma or phaeochromocytoma is suspected.

FURTHER TESTING (IF REQUIRED)

There are further tests that you may need to have, for example:

- Pill cam for finding small intestinal NETs - this is where a camera inside a large pill is swallowed, 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 required your specialist nurse or doctor can provide you with more information about these.

TREATMENTS YOU MAY BE OFFERED

Patients should ideally be treated within a specialist multi disciplinary team (MDT). Each patient will have an individualised treatment plan: there are a number of options available, depending on the type and location of your NET, and your general well-being.

SURGERY

Surgery is usually the first choice of treatment when it is possible to remove the tumour completely. This is the case when the tumour is contained (or localised) in one area. If the tumour has already spread (or metastiasized) to other parts of the body, the pros and cons of surgery have to be considered 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 the surgery might be curative and no other treatment may be necessary. A follow-up plan will need to be put into place after surgery.

PALLIATIVE SURGERY

If a NET has already spread, or become too large to remove completely, then surgery may be considered in specific situations. Surgery may be performed if the NET is causing symptoms by pressing on other organs, or by releasing hormones. In this instance surgery aims to reduce the symptoms by removing (or 'debulking') a large chunk of the tumour, or bypassing the part of the disease that is causing the problems.

PRE-EMPTIVE SURGERY

This can occur when an area of tumour is critically placed close to an important structure that might become blocked as the tumour grows, such as a blood vessel or the main bile duct, or the bowel. Even though this will not cure the disease, it can prevent immediate problems by removing turmours from key areas, before the vital structure has been damaged or blocked.

CARDIAC SURGERY

This involves heart valve replacement and may be required for patients with carcinoid heart disease.

Important Note:

Most planned surgery for NETs should be done after the surgeon has been able to talk to a team including oncologists, gastroenterologists, endocrinologists, nurses, radiologists and docstors all of whom have particular expertise in managing NET cancers. These are rare and complex tumours so it is best of have a dedicated team of experts jointly involved in helping to decide which treatment is best for each patient.

TREATMENTS TARGETING NETS THROUGHOUT THE BODY

SOMATOSTATIN ANALOGUES

Somatostatin analogues are synthetic versions of somatostatin, a naturally occurring hormone produced in the brain and digestive tract that acts like an 'off' switch for some of the normal processes in the gut.

Injections of these analogues can stop the overproduction of hormones that cause symptoms such as flushing, wheezing and diarrhea and therefore improve quality of life.

Injections are also used to help slow tumour growth in some slower growing NETs.

CHEMOTHERAPY

Chemotherapy regimens involve either intravenous drugs (this means given through a drip), or oral tablets or drugs and your oncologist will discuss the most appropriate option with you. The proliferative index of the tumour (the Ki-67 mentioned earlier) may help the oncologist decide the type of treatment you receive.

Chemotherapy is not useful for slow growing NETs. Intermediate growing NETs may be treated with a combination of oral drugs called Temozolomide and Capecitabine or alternatively another intravenous combination Streptozocin and doxorubicin (or 5FU) is sometimes used. Fast growing NETs are often treated with intravenous Carboplatin and Etoposide.

You may be asked to be involved with clinical trials that look into different combinations of chemotherapy agents that are most appropriate for different types of NETs.

Chemotherapy is most commonly used as a palliative option for patients with aggressive NETs. The term palliative is used when a cancer cannot be cured, but the aim of the treatment is to slow the cancer down as much as possible, and take away any symptoms that are caused by the cancer,

so that your quality of life is better.

MOLECULAR TARGETED THERAPIES

Drugs such as Sunitinib and Everolimus are used for Pancreatic NETs.Currently there is no public funding for these in New Zealand.

INTERFERON

This is a naturally occurring substance that is produced by the body's immune system. Taking extra injections of interferon activates the body's immune system and is used to treat some patients with NETs. In some patients it is given on its own, but more often it is given as a combination therapy with a somatostatin analogue. This is only used in specific situations because of the side effects that some people experience.

PEPTIDE RECEPTOR RADIONUCLIDE THERAPY PRRT

These treatments work in a similar way to 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 decide whether this therapy is suitable, you will be asked to take a Ga68 PET scan. Intermediate and aggressive NET patients will also need a FDG PET scan. The results of these scans will indicate whether or not your

NET has enough receptors present on tumour cells, and whether this sort of therapy would be an option. This treatment is not available in NZ but Unicorn Foundation NZ are working with various parties to ensure this happens. At present if you are a suitable candidate you will be referred to a centre in Australia by your NET team. At the moment funding is not available for this treatment.

For more information on PRRT, please contact the Unicorn Information and Support Managers.

TREATMENTS THAT TARGET LIVER METASTASES

For people with NETs that are mostly sitting in the liver, it makes sense to target the liver directly. The three main ways of doing this are surgery, embolization (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 this procedure, a catheter is placed in a blood vessel in the groin (femoral artery), to gain access into the arterial system. A catheter is then threaded up to the hepatic artery that supplies blood to the liver and the branches supplying the tumour are able to be targeted. Tiny particles (or microspheres) are injected through the catheter into these arteries. The particles block the blood supply to the tumour, which can cause it to shrink or even die.

This procedure is done by a specialist called an interventional radiologist. Patients are either

sedated or under a general anaesthetic for treatment.

HEPATIC ARTERY CHEMOEMBOLISATION (HACE)

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

SELECTIVE INTERNAL RADIATION THERAPY (SIRT)

This treatment is similar to HAE, but the microspheres are loaded with radiation. The spheres once lodged into the tumour then cause localised radiation damage. To ensure that patients are suitable for SIRT they require a planning angiogram, where a test dose is delivered. Currently SIRT is not funded in the public sector in NZ.

ABLATION

Used when a patient has relativley few secondary tumours (metastases). A needle is inserted into the centre of each tumour, and thermal energy (heat) is then delivered into the tumour to kill the cells. It is very useful in treating small tumours that are not touching major blood vessels.

MULTIDISCIPLINARY CARE

The care of NET cancers can be complex, and for the patient the journey can encompass a whole host of emotions, as well as a wide range of investigations, treatments and healthcare professionals.

The very fact that there is often not just one treatment option at diagnosis and throughout the patient journey, means that there has to be a collaboration among all key healthcare professional groups, who are making clinical decisions for individual patients.

This collaboration has been termed an MDT (multidisciplinary team), and the place they meet is called a multidisciplinary meeting (MDM). This is a formula that is now being used across the world in the care of cancer patients.

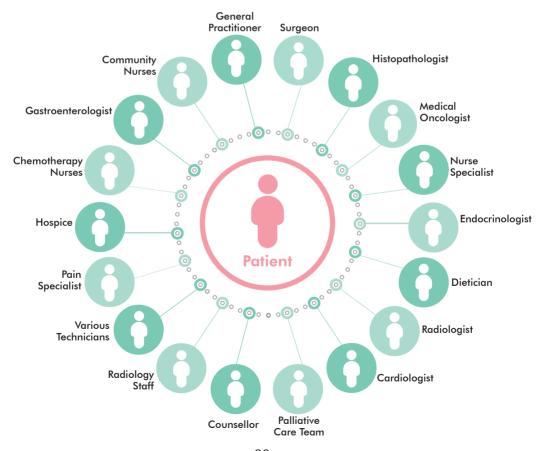
An MDT will usually be formed by particular specialists with expertise and interest in NETs. The specialists involved are commonly pathologists, endocrinologists, oncologists, radiologists, nuclear physicians, surgeons and cardiologists.

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

Patients can feel more confident in the knowledge that all aspects of their care have been discussed and that the best possible treatment plan will be formulated. A well coordinated and disciplined MDT is a very important aspect for care when striving to achieve the best quality of life and the best outcome for NET cancer patients.



COMMUNICATING WITH THE HEALTH CARE TEAM

Being diagnosed with cancer can be a confusing and frightening time for you and your loved ones. Although your healthcare team will do their best to support you, medical appointments can be stressful, and it is worthwhile to be reminded of ways 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 if you can. If you are feeling anxious, you may not hear everything that is said, or ask all the questions you wanted to. It helps to have additional ears there to listen, and your guest may help to make sure your concerns are brought up.

Try taking notes on how you are feeling and when, and 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 embarrassed to ask for the answer to be rephrased. 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 encouraging your doctor to seek opinions from other specialists can be valuable. This is often done during discussion at a Multidisciplinary meeting. Physicians are usually very open to this because they appreciate the fact that making an effective treatment choice for people with NETs can be very challenging. You can always request that your case be discussed at an MDT.

You have the right to know as much about your own prognosis as you wish and you have the right to know the overall treatment strategy, including what options are available to you if initial treatments do not work to stabilise your disease.

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

LIVING WITH A NET

Diet, Exercise & Psychological Support

DIET

Dietary advice will vary from patient to patient since patients with NETs have different symptoms. One general piece of advice is that all patients are encouraged to eat a varied and proper diet so that energy and nutritional requirements are met and weight is kept stable. When problems such as loss of appetite or diarrhoea occur this can be difficult. Sometimes talking with a dietician can be very helpful, which your specialist doctor or nurse can arrange for you.

EXERCISE

Regular physical activity improves well-being, functional ability, muscular strength, and may counteract side effects of treatment. These factors in combination improve a patients' quality of life. In NZ some gyms offer cancer support programs to help maintain your well-being.

PSYCHOSOCIAL SUPPORT

Being diagnosed with a cancer can change your view of life. Being diagnosed with a cancer can be a challenging life situation. 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 coping strategies.

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 strategies for 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/how to do so. Whatever your situation is remaining honest and having open lines of communication can really help. Explaining what you need and aetting 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.



FURTHER SUPPORT & SOURCES FOR INFORMATION

It is important to understand as much as possible about your NET cancer. Below is a list of websites or contacts that you may find useful.

UNICORN FOUNDATION NZ

Only NZ organisation focused on NETs. Provides support and information to patients, families, supporters and medical professionals. Opportunities to meet other patients either online or in person.

www.unicornfoundation.org.nz

UNICORN FOUNDATION AUSTRALIA

Sister organisation to Unicorn NZ, providing excellent information. Please be aware some treatments that are available in Australia are not available in NZ.

www.unicornfoundation.org.au

NET PATIENT FOUNDATION UK

This is a UK based foundation, which also has very reliable information and resources. www.netpatientfoundation.org

NETWORK! RESEARCH GROUP

This is a website run by the research team in Auckland who are trying to understand NETs and improve treatment.

www.network.ac.nz

INTERNATIONAL NEUROENDOCRINE CANCER ALLIANCE

Alliance of NET cancer patient advocacy groups form across the globe.

www.incalliance.org

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Seeking the cure for Neuroendocrine Cancers

www.unicornfoundation.org.nz

