

Understanding Neuroendocrine Tumours (NETs)

A guide for people affected by cancer

This fact sheet has been prepared to help you understand more about neuroendocrine tumours (NETs).

Many people look for support after being diagnosed with a cancer that is rare or less common than other cancer types. This fact sheet includes information about the different types of NETs, how they are diagnosed and treated, as well as where to go for additional information and support services.

Many people feel shocked and upset when told they have cancer. You may experience strong emotions after a cancer diagnosis, especially if your cancer is rare or less common like a NET. A feeling of being alone is usual with rare cancers, and you might be worried about how much is known about your type of cancer and how to manage it. You may also be concerned about the cancer coming back after treatment. Linking into local support services (see last page) can help overcome feelings of isolation and will give you information that you may find useful.

What are NETs?

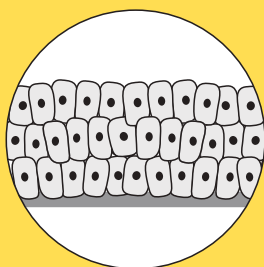
The neuroendocrine system is a network of glands and nerve cells that make hormones and release them into the bloodstream. These hormones help control normal body functions, for example digesting food.

Neuroendocrine cells are found throughout the body, but mainly in the gastro-intestinal tract (including large bowel and small bowel), pancreas and lungs.

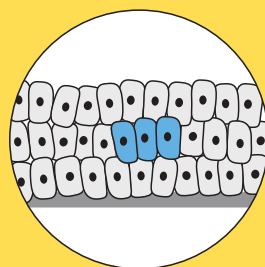
NETs are an uncommon type of tumour that forms in these cells. The type is generally defined by where the abnormal cells come from and can range from low grade (slow growing) to high grade (fast growing). NETs that produce extra amounts of hormones can cause certain symptoms and are referred to as functional tumours. However, not all NETs produce extra hormones (non-functional).

Malignant (cancerous) tumours have the potential to spread to other parts of the body through the blood stream or lymph vessels and form another tumour at a new site. This new tumour is known as secondary cancer or metastasis.

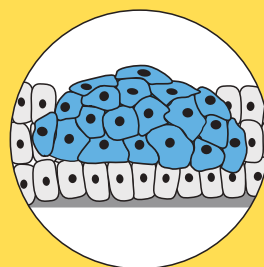
How cancer starts



Normal cells

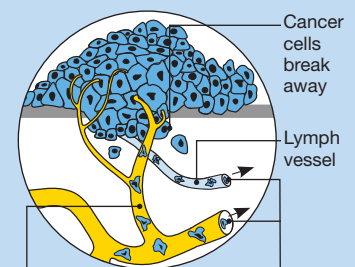


Abnormal cells



Abnormal cells multiply

How cancer spreads



Blood vessel

Cancer cells travel to lymph nodes and other parts of the body (metastasis)

Understanding Neuroendocrine Tumours (NETs)

Types of NETs

Gastro-intestinal

These start in the large bowel and small bowel.

Types of gastro-intestinal NETs include:

- gastric NETs, in the stomach
- duodenal NETs, in the duodenum (the first section of the small bowel)
- small bowel NETs, including the jejunum and ileum
- large bowel NETs, in the colon
- appendiceal NETs, in the appendix
- rectal NETs, near the anus.

If functional, these NETs may release high levels of hormones such as serotonin, which can be associated with symptoms of diarrhoea, flushing and tiredness.

Pancreatic

Pancreatic NETs begin in the endocrine cells of the pancreas and make up approximately 7% of the more common pancreatic (adenocarcinoma) cancer diagnoses. About 90% of pancreatic NETs do not produce extra hormones.

Functional pancreatic NETs are very rare and most are named after the hormone they overproduce:

- insulinomas, produce too much insulin (causing low blood sugar levels)
- glucagonomas, produce too much glucagon (causing high blood sugar levels)
- gastrinomas, produce too much gastrin (causing stomach ulcers)
- somatostatinomas, produce too much somatostatin (causing abdominal discomfort and weight loss)
- VIPomas, produce too much vasoactive intestinal peptide (causing severe watery diarrhoea).

Lung

The four types of NETs that develop in the lung include:

- typical carcinoid
- atypical carcinoid
- large cell neuroendocrine carcinoma
- small cell lung neuroendocrine cancer.

Merkel cell carcinoma

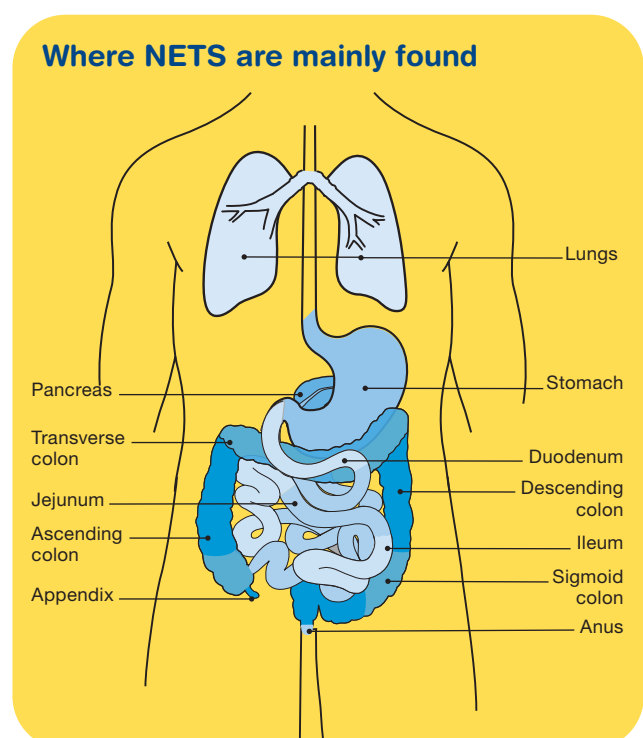
Also known as neuroendocrine carcinoma of the skin, this is a rare cancer involving the Merkel cells in the top layer of the skin. Merkel cell carcinoma grows quickly and often returns and spreads. More information is available from the Australasian Merkel Cell Carcinoma Interest Group (AMIGOs): amigos.org.au and the Australian Cancer Research Foundation: acr.com.au

Neuroblastoma

This tumour typically starts in the adrenal glands (above the kidneys), but can also be found near the spinal cord. It affects immature or developing nerve cells in children. More information is available from Neuroblastoma Australia: neuroblastoma.org.au

Other NETs

More information on all the different types of NETs (including others such as thymic, testicular, prostate, ovarian and endometrial, multiple endocrine neoplasia, pheochromocytoma, paraganglioma and medullary thyroid carcinoma) is available from NeuroEndocrine Cancer Australia: neuroendocrine.org.au.



Understanding Neuroendocrine Tumours (NETs)

How common are NETs?

NETs are not common but the number of people being diagnosed is slowly increasing. There is an almost equal risk for males and females.

- Around 3700 Australians are diagnosed with a NET each year; with most new cases being diagnosed in people aged 40 years or over.¹
- Australia has the highest number of Merkel cell carcinoma cases in the world, with older men most at risk.
- Neuroblastoma is more likely in children under the age of 5 years.

What are the risk factors?

The causes of most NETs are not known. However, there are several risk factors:

Genetic factors

Some rare, inherited diseases can put people more at risk of NETs. These include multiple endocrine neoplasia (MEN 1, MEN 2), Von Hippel-Lindau (VHL) syndrome, tuberous sclerosis complex and neurofibromatosis.

Other factors

Some NETs may be linked to pre-existing conditions such as:

- peptic ulcers (in the stomach or duodenum) may increase the risk of NETs in these areas
- diabetes – people with diabetes may be more likely to develop pancreatic NETs.

Merkel cell carcinoma is linked to overexposure to the sun and ultraviolet light; it may also be caused by the Merkel cell polyomavirus (MCV).

What are the symptoms?

Most NETs develop slowly over several years but they can also be aggressive and grow quickly, spreading to other parts of the body and causing problems.

In the early stages NETs may not cause symptoms. If you do have symptoms, it will depend on where in the body the tumour is and if the tumour cells are producing hormones. You may experience general symptoms such as fatigue and loss of appetite.

Gastro-intestinal

Symptoms may include:

- abdominal (tummy) pain and bloating
- changes in bowel or bladder habits, including diarrhoea
- bowel obstruction or bleeding from the anus
- facial flushing and asthma-like wheezing.

Pancreatic

Functional NETs – produce extra amounts of hormones, and the first symptoms will often be related to this excess hormone production.

Symptoms may include:

- low blood sugar levels (hypoglycaemia) causing shaking, sweating, confusion, dizziness and rapid heartbeat
- high blood sugar levels (hyperglycaemia) which may cause increased urination, excessive thirst and blurred vision
- indigestion (heartburn) and stomach ulcers
- rash in the groin area
- unexplained weight loss
- nausea or vomiting
- changes in bowel habits, including diarrhoea or pale, foul-smelling stools that are hard to flush away.

Non-functional NETs – do not produce extra hormones and rarely cause symptoms in the early stages. Symptoms often appear only once the cancer is large enough to affect nearby organs, or has spread (most commonly to the liver). As the tumour grows it may also cause pain in the upper abdomen, side or back.

Lung

Symptoms may include:

- repeated pneumonia or chest infections
- coughing up blood
- shortness of breath; wheezing
- chest pain.

Merkel cell carcinoma

This usually occurs as a painless hard nodule (tumour) in the skin that grows rapidly and is often red, purple or blue, or can be flesh-coloured. Some patients feel the nodule is under (rather than in) the skin. The most common location is skin that has been exposed heavily to the sun such as the face, head and neck.

Understanding Neuroendocrine Tumours (NETs)

Neuroblastoma

Symptoms may include:

- painless lump or swelling in the tummy, chest or neck
- swollen legs, arms, upper chest, neck and face
- loss of appetite or feeling full
- weight loss
- changes in bowel or bladder habits
- difficulty breathing or swallowing
- headaches or dizziness
- drooping eyelid
- trouble feeling or moving arms and legs.

Carcinoid syndrome

When NET tumours produce excess hormones (such as serotonin) it can cause a group of symptoms known as carcinoid syndrome.

Some of these symptoms include facial flushing, diarrhoea, wheezing and carcinoid heart disease leading to shortness of breath.

It is most common in people with gastro-intestinal NETs, including duodenal and small bowel, and lung NETs that have spread (metastasised) in the body. However, not all people with these NETs will develop the syndrome.

More information is available from NeuroEndocrine Cancer Australia: neuroendocrine.org.au.

Diagnosis

NETs can be difficult to find and are sometimes diagnosed when patients are undergoing tests for a different condition.

Many doctors may not have seen or treated Merkel cell carcinoma before, so diagnosis is often delayed. It is a good idea to seek urgent review by a specialist connected with a skin cancer multi-disciplinary team – see section below.

If your doctor thinks that you may have a NET (or one of the syndromes associated with NETs) they will take your medical history, perform a physical examination and carry out certain tests. If the results suggest that you may have a NET, your doctor will refer you to a specialist who will carry out further tests such as:

- **Blood tests** – including a full blood count to measure your white blood cells, red blood cells and platelets and chromogranin A (a hormone marker).
- **Urine tests** – to measure serotonin production (which can be produced by NETs).
- **Endoscopy** – a flexible tube with a camera on the end (endoscope) is inserted under sedation down the throat into the stomach, or into the anus and large bowel to view your gut.
- **Bronchoscopy** – a thin, tube-like instrument with a light and a lens for viewing (bronchoscope) is inserted through the nose or mouth to view your lungs. The bronchoscope is also able to remove tissue to obtain a diagnosis.
- **CT (computerised tomography) or MRI (magnetic resonance imaging) scans** – special machines are used to scan and create pictures of the inside of your body. Before the scan you may have an injection of dye (called contrast) into one of your veins, which makes the pictures clearer. During the scan, you will need to lie still on an examination table. For a CT scan the table moves in and out of the scanner which is large and round like a doughnut; the scan takes about 10 minutes. For an MRI scan the table slides into a large metal tube that is open at both ends; the scan takes about 30–90 minutes. Both scans are painless.
- **PET (positron emission tomography) scan** – before the scan you will be injected with a small dose of radioactive glucose (sugar) solution. Many cancer cells will show up brighter on the scan. You will be asked to sit quietly for 30–90 minutes to allow the glucose to move around your body. The scan will take around 30 minutes to perform. There are two different types of PET scans used in NETs – Gallium-68 Dotatate (also called Gatate scans) and fluorodeoxyglucose (FDG). Which scan you have will depend on the type and grade of tumour.
- **Biopsy** – removal of some tissue from the affected area for examination under a microscope. The biopsy may be done in one of two ways. In a needle biopsy, a local anaesthetic is used to numb the area, then a thin needle is inserted into the tumour

Understanding Neuroendocrine Tumours (NETs)

under ultrasound or CT guidance. An open or surgical biopsy is done under general anaesthesia. The surgeon will cut through the skin to expose the affected area and take a tissue sample.

- **Echocardiogram** – a painless ultrasound to examine your heart valves, which can sometimes be affected, and takes around 30–60 minutes.

Finding a NETs specialist

NeuroEndocrine Cancer Australia can be contacted for a directory of specialists in NET care and treatment: neuroendocrine.org.au.

Australasian Merkel Cell Carcinoma Interest Group (AMIGOs) can be contacted for a directory of specialists in Merkel cell carcinoma care and treatment: amigos.org.au

Treatment

You will be cared for by a multi-disciplinary team of health professionals during your treatment for NETs. These may include a surgeon, medical oncologist (to prescribe and coordinate a course of systemic therapy which includes chemotherapy), radiation oncologist (to prescribe and coordinate a course of radiation therapy), nuclear medicine specialist, gastroenterologist, endocrinologist, lung physician, nurse and allied health professionals such as a dietitian, social worker, psychologist or counsellor, physiotherapist and occupational therapist. For neuroblastoma, the team will include childhood cancer specialists, including a paediatric oncologist.

Discussion with your doctor will help you decide on the best treatment for your tumour depending on:

- the type of NET you have, including if it is functional (hormone producing) and the symptoms you have
- where it is in your body
- the grade of the tumour, if known
- whether or not the NET has spread (stage of disease)
- your age, fitness and general health
- your preferences.

The main treatment options for NETs include surgery, chemotherapy, targeted therapy, theranostics – peptide receptor radionuclide therapy (PRRT) and drug therapy (to control any symptoms caused by extra hormones). Merkel cell carcinoma may also be treated using radiotherapy. Treatments can be given alone, in combination or one after the other. This is called multi-modality treatment. If the NET is slow-growing and not causing any symptoms you may not need immediate treatment.

Surgery

Surgery is the main treatment for most types of NETs, especially for people with early-stage disease who are in otherwise good health. Surgery usually involves removing the cancer and some healthy tissue around the cancer to ensure the tumour is completely removed. It is important to have your surgery in a specialist centre with surgical and anaesthetic experience with NETs.

The type of operation depends on the size of the tumour and where it is located (see next page). For Merkel cell carcinoma the surgery may also involve removing the lymph nodes close to the tumour.

Surgery for early-stage NETs is often given with the aim of cure, although there can also be benefits from removing areas of tumour, even if the cancer has spread (e.g. to reduce the risk of bowel obstruction in small bowel NETs). However, there are risks and potential complications involved in surgery. Your surgeon will discuss the type of operation you may need and the benefits and impacts of surgery.

- ▶ For a free copy of Cancer Council's booklet *Understanding Surgery* visit your local Cancer Council website or call 13 11 20.

Somatostatin analogues (SSAs)

The body produces a hormone called somatostatin, which controls how organs release several other hormones. SSAs are medicines that are similar to somatostatin. SSAs can slow down or prevent tumour growth, as well as slow down the release of hormones from NETs. They may be used to help control symptoms associated with carcinoid syndrome such as facial flushing and diarrhoea. The main SSAs used in Australia are octreotide LAR and lanreotide. These are generally given as monthly injections, but may be given more often if required.

Understanding Neuroendocrine Tumours (NETs)

Surgery for non-functional pancreatic NETs

Early-stage

As with more common types of pancreatic cancer, surgeries include:

Whipple procedure	treats tumours in the head of the pancreas and removes the pancreas, the first part of the small bowel, the gall bladder and bile duct. Also called pancreaticoduodenectomy.
Distal pancreatectomy	removes tumours in the tail or body of the pancreas and often also removes the spleen.
Total pancreatectomy	removes the entire pancreas and spleen. This may be the best option if the cancer is large, or in multiple places in the pancreas.

Advanced

Surgery can be used to treat blockages caused by the tumour and to reduce the size of the tumour.

Stenting	If the tumour has blocked the common bile duct or duodenum (first part of the small bowel), a small tube called a stent can be inserted.
Debulking	If the whole tumour can't be removed, the surgeon may try to remove some of it. This surgery, called debulking, is not always possible and will depend on the tumour's position and size.

More information on these surgeries is available from NeuroEndocrine Cancer Australia: neuroendocrine.org.au.

Theranostics – peptide receptor radionuclide therapy (PRRT)

PRRT, a form of radiation treatment, may be offered to some people with NETs. You will have PET scans first to assess if you are suitable for this treatment. PET scans will show whether your tumours take up the radiation. This treatment uses a radioactive compound bound together with a small molecule that attaches strongly to NET cells. This allows high doses of radiation to be delivered to specific sites of tumours wherever they have spread throughout the body. The most common form of PRRT is ¹⁷⁷Lu-Dota-octreotate (LuTate) therapy. PRRT is available only in certain specialised treatment centres in each state (generally in metropolitan areas). You will usually see a nuclear medicine specialist and a medical oncologist.

You may have a dose of chemotherapy in tablet form before PRRT as a combined treatment. PRRT is injected into your vein via a cannula, with a session lasting around four hours. Most people have four sessions about 8–12 weeks apart. Re-treatment with PRRT is possible in selected cases. A video on PRRT is available on the NeuroEndocrine Cancer Australia website: neuroendocrine.org.au.

Chemotherapy

Chemotherapy (sometimes just called “chemo”) is the use of drugs to kill or slow the growth of cancer cells. You may have one chemotherapy drug, or a combination of drugs. This is because different drugs can destroy or shrink cancer cells in different ways. Your treatment will depend on the grade and type of tumour you have. Chemotherapy is more often given to treat high-grade NETs. Your medical oncologist will discuss your options with you.

Chemotherapy is given through a drip into a vein (intravenously) or as a tablet that is swallowed. Chemotherapy is commonly given in treatment cycles which may be daily, weekly or monthly. For example, one cycle may last three weeks where you have the drug over a few hours, followed by a rest period before starting another cycle. The length of the cycle and number of cycles depends on the chemotherapy drugs being given.

► For a free copy of Cancer Council's booklet *Understanding Chemotherapy* visit your local Cancer Council website or call 13 11 20.

Understanding Neuroendocrine Tumours (NETs)

Targeted therapy

Targeted therapy uses drugs that work in a different way to chemotherapy drugs. While chemotherapy drugs affect all rapidly dividing cells and kill cancer cells, targeted therapy drugs attack specific molecules within cells and work by blocking cell growth. People with advanced pancreatic NETs may be offered targeted therapies such as sunitinib (Sutent) and everolimus (Afinitor) to slow the growth of the tumour. Everolimus may also be used to treat advanced gastro-intestinal, pancreatic and lung NETs. These drugs are in capsules that you swallow.

► For a free copy of Cancer Council's fact sheet on *Targeted Therapy* visit your local Cancer Council website.

Treatment for liver tumours

NETs, particularly gastro-intestinal and pancreatic, often spread to the liver. The tumours in the liver are called metastases. Treatments to control these liver lesions may include:

Radiofrequency ablation (RFA) and microwave ablation – Using an ultrasound or CT scan, a needle is inserted through the abdomen into the liver tumour. The needle sends out radio waves or microwaves that produce heat and destroy the cancer cells.

Transarterial chemoembolisation (TACE) –

In this procedure, a catheter is inserted into the hepatic artery, which supplies blood to the liver. A chemotherapy drug together with tiny particles (called microspheres) is released into the artery, which blocks the flow of blood into the tumour. This may cause the tumour to shrink. The procedure is performed by an interventional radiologist. Sometimes the injection may involve using microspheres alone without the chemotherapy component, called transarterial embolization (TAE).

Selective internal radiation therapy (SIRT) –

Also known as radioembolisation, this is done by an interventional radiologist. The radiologist inserts a catheter into the liver's main artery and then delivers tiny radioactive beads (SIR-spheres) to the liver through the catheter. The beads give a direct dose of radiation to the tumour.

PRRT can also be used to treat liver lesions in selected cases (see previous page).

External beam radiation therapy

Radiation therapy (also known as radiotherapy) uses high energy rays to destroy cancer cells, where the radiation comes from a machine outside the body. NETs may be treated with external beam radiation therapy in selected cases, depending on the location of tumours and your symptoms. It may be used:

- if the cancer can't be removed with surgery
- if the cancer has spread to other parts of the body
- after surgery, to destroy any remaining cancer cells and stop the cancer coming back (such as for Merkel cell carcinoma).

Radiation therapy can shrink the cancer down to a smaller size. This may help to relieve symptoms such as pain. Sometimes chemotherapy is given as well as radiation therapy, for example to treat lung NETs.

Radiation therapy does not hurt and is usually given in small doses over a period of time to minimise side effects.

► For a free copy of Cancer Council's booklet *Understanding Radiation Therapy* visit your local Cancer Council website or call 13 11 20.

What about clinical trials?

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, GP, clinical trials nurse or get a second opinion. If you do take part in a trial, you can withdraw at any time.

For more information visit:

- australiancancertrials.gov.au
 - NeuroEndocrine Cancer Australia: neuroendocrine.org.au
 - Australasian Gastro-Intestinal Trials Group (AGITG): gicancer.org.au.
 - Neuroblastoma Australia: neuroblastoma.org.au
 - Melanoma and Skin Cancer (MASC) Trials: masc.org.au and melanoma.org.au
- For a free copy of Cancer Council's booklet *Understanding Clinical Trials and Research* visit your local Cancer Council website or call 13 11 20.

Understanding Neuroendocrine Tumours (NETs)

Complementary therapies and integrative oncology

Complementary therapies are designed to be used alongside conventional medical treatments (such as surgery, chemotherapy, targeted therapy and radiation therapy) and can increase your sense of control, decrease stress and anxiety, and improve your mood. Some Australian cancer centres have developed “integrative oncology” services where evidence-based complementary therapies are combined with conventional treatments to create patient-centred cancer care that aims to improve both wellbeing and clinical outcomes.

Complementary therapy	Clinically proven benefits
acupuncture	reduces chemotherapy-induced nausea and vomiting; improves quality of life
aromatherapy	improves sleep and quality of life
art therapy, music therapy	reduce anxiety and stress; manage fatigue; aid expression of feelings
counselling, support groups	help reduce distress, anxiety and depression; improve quality of life
hypnotherapy	reduces pain, anxiety, nausea and vomiting
massage	improves quality of life; reduces anxiety, depression, pain and nausea
meditation, relaxation, mindfulness	reduce stress and anxiety; improve coping and quality of life
qi gong	reduces anxiety and fatigue; improves quality of life
spiritual practices	help reduce stress; instil peace; improve ability to manage challenges
tai chi	reduces anxiety and stress; improves strength, flexibility and quality of life
yoga	reduces anxiety and stress; improves general wellbeing and quality of life

Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

- ▶ For a free copy of Cancer Council’s booklet *Understanding Complementary Therapies* visit your local Cancer Council website or call 13 11 20.



Alternative therapies are therapies used *instead* of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Nutrition and exercise

If you have been diagnosed with a NET, both the cancer and treatment will place extra demands on your body. Research suggests that eating well and exercising can benefit people during and after cancer treatment. Eating well and being active can help you cope with some of the common side effects of cancer treatment, speed up recovery and improve quality of life by giving you more energy, keeping your muscles strong, helping you maintain a healthy weight and boosting your mood.

Some people with NETs, especially pancreatic NETs or those who have had bowel surgery, may need specific dietary advice. The symptoms of carcinoid syndrome (facial flushing, diarrhoea) may be triggered by certain foods and drinks, and some vitamin deficiency syndromes may be more common. You can discuss individual nutrition and exercise plans with health professionals such as dietitians, exercise physiologists and physiotherapists.

More information on the nutritional needs of people with NETs is available in the *Nutrition and Neuroendocrine Tumours* booklet available from NeuroEndocrine Cancer Australia: neuroendocrine.org.au.

- ▶ For free copies of Cancer Council’s booklets on *Nutrition and Cancer* and *Exercise for People Living with Cancer* visit your local Cancer Council website or call 13 11 20.

Understanding Neuroendocrine Tumours (NETs)

Side effects of treatment

All treatments can have side effects. The type of side effects that you may have will depend on the type of treatment and where in your body the cancer is. Some people have very few side effects and others have more. Your specialist team will discuss all possible side effects, both short and long-term (including those that have a late effect and may not start immediately), with you before treatment begins.

One issue that is important to discuss before you undergo treatment is fertility, particularly if you want to have children in the future.

- For a free copy of Cancer Council's booklet *Fertility and Cancer* visit your local Cancer Council website or call 13 11 20. To speak to a health professional about treatment side effects call 13 11 20.

Common side effects

Surgery	Bleeding, damage to nearby tissue and organs (including nerves), drug reactions, pain, infection after surgery, blood clots, weak muscles (atrophy), lymphoedema
SSAs	Loss of appetite, nausea, vomiting, bloating, bowel issues such as constipation or diarrhoea, abdominal pain, gallstones, fatigue
PRRT	Nausea, vomiting, fatigue, short-term hair loss, kidney damage and blood disorders, loss of fertility
Chemotherapy	Fatigue, loss of appetite, nausea, bowel issues such as constipation or diarrhoea, hair loss, mouth sores, skin and nail problems, increased chance of infections, loss of fertility
Radiation therapy	Fatigue, loss of appetite, nausea, bowel issues such as diarrhoea, abdominal cramps and excess wind, bladder issues, hair loss, dry mouth, skin problems, lymphoedema, loss of fertility

Making decisions about treatment

It can be difficult to know which treatment is best for you. It is important that you speak with a NET specialist team before making decisions. Ask them to give you a clear plan of your treatment options, including information about side effects. Some people prefer to seek several opinions before feeling confident to go ahead with treatment. If you are confused or want to check anything, ask your specialist questions. This will make sure you have all the information you need to make decisions that you are comfortable with.

You may have to attend many appointments. It's a good idea to take someone with you. They will be able to listen, ask questions and remember what the doctor says. It may help to take a list of questions with you, take notes or ask the doctor if you can record the discussion (many mobile phones have a recording function or you can use the CAN.recall app – visit rarecancers.org.au for more information). There are some suggestions for questions you could ask at the end of this sheet.

- Cancer Council's podcast *Making Treatment Decisions* can be downloaded from your local Cancer Council website.

Looking after yourself

There is no right way to feel if you have been diagnosed with a cancer such as a NET. Feeling a range of emotions is normal and you may feel overwhelmed, anxious, fearful, angry, sad or lonely. Many people need emotional support before, during and after treatment, particularly if they have ongoing symptoms and side effects that are hard to manage.

Adjusting to living with visible scars, changes to your physical appearance, changes to your lifestyle and bodily function can be hard and take time. If this is affecting you or likely to affect you, it's important to seek help. It can help to talk things through with a counsellor, psychologist, friend or family member. Talk to your medical team, visit the NeuroEndocrine Cancer Australia website for support groups or call Cancer Council 13 11 20 about what support services are available.

- For a free copy of Cancer Council's booklet *Emotions and Cancer* visit your local Cancer Council website or call 13 11 20.

Understanding Neuroendocrine Tumours (NETs)

Practical and financial support

There are many services that can help you manage with practical or financial issues caused by NETS. Benefits, pensions and hardship programs can help pay for prescription medicines (for example the Australian Government's Pharmaceutical Benefits Scheme [PBS]), transport costs or utility bills. Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

For additional income, you may be able to access your superannuation early in certain circumstances, or claim on insurance policies such as income protection, trauma, and total and permanent disability (TPD).

Managing your ability to work or study, particularly during cancer treatment, is important to consider and will depend on your personal situation.

► For free copies of Cancer Council's booklets on *Cancer and Your Finances* and *Cancer, Work & You* visit your local Cancer Council website or call 13 11 20.

If you don't have a care plan, ask your specialist for a written summary of your cancer and treatment and make sure a copy is given to your GP and other health care providers.

NeuroEndocrine Cancer Australia has a template for a Treatment and Wellness Care Plan for people with NETs which can be used to document your cancer and ongoing management: neuroendocrine.org.au.

► For a free copy of Cancer Council's booklet *Living Well After Cancer* visit your local Cancer Council website or call 13 11 20.

If the cancer comes back

For some people a low-grade NET can be successfully removed with surgery, and there is a good chance it won't come back after treatment. However, regular check-ups will be needed over a long period. Unfortunately, NETs are difficult to treat and they can come back after treatment. This is known as a recurrence. If the cancer does come back, treatment will depend on where the cancer has returned in your body and your symptoms.

For Merkel cell carcinoma, major breakthroughs recently in understanding the cancer and how to treat it make long-term survival possible.

In many cases of advanced NETs, treatment will focus on controlling the tumour, managing any symptoms such as pain and improving your quality of life without trying to cure the disease. This is called palliative treatment. Palliative care can be provided in the home, in a hospital, in a palliative care unit or hospice, or in a residential aged care facility. Services vary in each state and territory.

When cancer is no longer responding to active treatment, it can be difficult to think about how and where you want to be cared for towards the end of life. However, it's essential to talk about what you want with your family and health professionals, so they know what is important to you. Your palliative care team can support you in having these conversations.

► For free copies of Cancer Council's booklets on *Understanding Palliative Care*, *Living with Advanced Cancer* and *Facing End of Life*. visit your local Cancer Council website or call 13 11 20.



If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Life after treatment

Once your treatment has finished, you will have regular check-ups including physical examinations and you may have further imaging scans. Let your doctor know immediately of any health problems between visits.

Some cancer centres work with patients to develop a "survivorship care plan" which includes a summary of your treatment, sets out a schedule for follow-up care, lists any symptoms to watch out for and possible long-term side effects, identifies any medical or psychosocial problems that may develop and suggests ways to adopt a healthy lifestyle. Eating well and being physically active are all important.

Understanding Neuroendocrine Tumours (NETs)

Questions for your doctor

If you have a NET, asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your list. Here are a few suggestions:

Diagnosis

- What type of NET do I have? Where is it located?
- How far has it spread? What stage of cancer do I have?
- What grade is my tumour/tumours?
- Have you treated this type of cancer before?

Treatment, side effects and follow-up care

- What are the treatment options for me? What do you recommend and why?
- What is the goal of treatment for my type of NET?
- What are the possible risks and side effects of my treatment? How will these be managed?
- What impact will treatment have on my fertility?
- How long will treatment take?
- Is this treatment covered by Medicare/private insurance? Will there be extra expenses?
- If the cancer comes back, how will I know?

If you are thinking of taking part in a clinical trial, here are some questions you could ask:

- What are the possible benefits and risks to me?
- What is being tested and why?
- How many people will be involved in this trial?
- If I cannot get onto a clinical trial can I still pay for a drug that is currently in trial?

Reference

1. Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: *Neuroendocrine tumours*, AIHW, Canberra, 2018.

A web-based resource for Australians with less common cancers project is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government. Website: canceraustralia.gov.au

Acknowledgements

This information is based on clinical practice guidelines and has been developed with help from health professionals and people affected by neuroendocrine tumours. It was reviewed by: Dr David Chan, Medical Oncologist, Royal North Shore Hospital, NSW; Leslye Dunn, Consumer; Prof Gerald Fogarty, Radiation Oncologist, St Vincent's Hospital, NSW; Katie Golden, Consumer; Dr Grace Kong, Nuclear Medicine Physician, Peter MacCallum Cancer Centre, VIC; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Elizabeth Paton, Melanoma and Skin Cancer Trials Group, NSW.

Note to reader

Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

Support services

- Cancer Council: visit your local Cancer Council website (see below for details) or call **13 11 20**
- NeuroEndocrine Cancer Australia: neuroendocrine.org.au or call **1300 287 363**
- Rare Cancers Australia: rarecancers.org.au or call **1800 257 600**
- Australasian Merkel Cell Carcinoma Interest Group (AMIGOs): amigos.org.au
- Neuroblastoma Australia: neuroblastoma.org.au or email info@nb.org.au
- Talk to a nurse, social worker or Cancer Council **13 11 20** about what is available in your area.

Where to get help and information

Call Cancer Council **13 11 20** for more information about NETs. Trained health professionals can listen to your concerns, provide information, and put you in touch with local services and support groups. Ask for free copies of booklets that may be relevant to you, or download digital versions from your local Cancer Council website:

ACT..... actcancer.org
 NSW cancercouncil.com.au
 NT cancer.org.au/nt
 QLD cancerqld.org.au
 SA cancersa.org.au
 TAS cancertas.org.au
 VIC cancervic.org.au
 WA cancerwa.asn.au
 Australia..... cancer.org.au

A summary of information about NETs is also available from Cancer Australia: neuroendocrine-tumours.canceraustralia.gov.au



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.