Information for people affected by VIPomas, Glucagonomas or Somatostatinomas

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What are neuroendocrine tumours (NETs)?

Neuroendocrine tumours (NETs) are a complex group of tumours that develop predominantly in the digestive or respiratory tracts, but can occur in many areas of the body. These tumours arise from cells called neuroendocrine cells.

Like all cancers, NETs develop when the specialised cells undergo changes causing them to divide uncontrollably and grow into an abnormal tissue mass (tumour).

Neuroendocrine tumours can be benign or malignant. Back in 1907, when neuroendocrine tumours were first classified, they were named ‘carcinoid’ (meaning ‘cancer-like’) as they seemed to grow slowly and were therefore not thought to be truly cancerous. The use of the term ‘carcinoid’ is being phased out in medical literature, as we now know that these tumours can be malignant. Current terminology is either simply neuroendocrine tumours (or NETs) or your NET will be named dependent on the site of your primary tumour, for example a bronchial (lung) NET, a bowel NET or a pancreatic NET.

Where do neuroendocrine tumours occur?

For information about other types of NETs, please visit our website at www.netpatientfoundation.org

Examples of where NETs can occur as primary sites or as metastases (spread)
What are Functioning Pancreatic NETs?

Pancreatic NETs are divided into two groups. Those in the functioning group are so named as they produce a recognisable syndrome related to where the tumour is found. Examples are Insulinoma, Gastrinoma, VIPoma, Glucagonoma, and Somatostatinoma.

VIPomas
VIPomas are very rare neuroendocrine tumours that affect a type of hormone-secreting cell mostly found in the pancreas. These cells produce the hormone VIP (vasoactive intestinal polypeptide), which plays a part in the digestive process. Its role in healthy people is not fully understood, but it is thought to affect the transport of water into the digestive system and control gut movements during digestion. The cells that make VIP are found scattered throughout the pancreas and elsewhere in the digestive tract. A tumour develops when the cells begin to grow abnormally, producing too much VIP. This causes a great deal of watery diarrhoea and possibly flushing of the face.

Two American doctors named Verner and Morrison first classified a group of symptoms (syndrome) caused by VIPomas in 1958. You may still hear the term Verner-Morrison in connection with VIPomas. VIPomas can affect children as well as adults although extremely rarely. One American study of 19 children found the average age of discovery to be two and a half years. In adults the average age of onset is in the 40s or 50s.

Glucagonomas
Glucagonomas are rare tumours that develop predominantly in the tail of the pancreas. There have been few reports of the tumours originating outside the pancreatic gland. The tumours usually develop from pancreatic alpha-cells often found at the base of the pancreas (called the tail) that are responsible for making the hormone glucagon.

This hormone helps to regulate the amount of glucose (sugar) circulating in the bloodstream. When the cells develop into tumours the amount of glucagon circulating in the bloodstream can rise dramatically. Most cases arise sporadically (they develop without any genetic influence), although a small percentage (up to 17%) are linked to the genetic, inherited syndrome called MEN1. (For further information about this syndrome see the NPF/AMEND leaflet on MEN1). Rarely they are associated with another inherited condition called adenomatous polyposis.

Glucagonomas can develop into quite large tumours and do have the ability to be malignant (spreading to other areas of the body). Around 80% of glucagonomas will have spread, mainly to the liver, at the time of diagnosis.

The condition is most often found in patients over 40, although if tumour development is linked to MEN1 it may be picked up at an earlier age.

Like other NETs, glucagonomas may grow ‘quietly’ and without obvious symptoms for some years.

By the time symptoms develop and become troublesome between 60% and 80% of patients may have experienced a spread of the disease beyond the pancreas usually to the liver. However, even when there is disease spread most patients will still be able to look forward to a good quality of life, with the right care and treatment.

Somatostatinomas
Somatostatinomas are rare tumours that can develop in the pancreas or small bowel.

Somatostatinomas develop in hormone producing cells called islet cells. There are different types of islet cells, each producing different hormones. Delta islet cells make the hormone somatostatin.

Somatostatin cuts off production of other hormones by the pancreas and controls how the gut works. Somatostatinomas produce extra somatostatin, which eventually leads to symptoms.

These tumours are extremely rare. Most are cancerous (malignant) and the rest are benign (non cancerous) tumours. It may not always be possible to tell if you have a benign or a malignant tumour. The tests you have such as an MRI or CT scan may show if the tumour has spread to the nearby lymph nodes or elsewhere. But it may not be until you have surgery that you know for certain if it is benign or malignant.

Somatostatinomas are usually slow growing and symptoms tend to develop slowly. People who have an inherited syndrome called Multiple Endocrine Neoplasia Type 1 (MEN1) or neurofibromatosis have a higher risk of somatostatinoma, although these still occur rarely in these syndromes.

For more information about MEN1, please see our website or www.amend.org.uk
What are the symptoms of these tumours?

These tumours are all functioning pancreatic NETs, which means that they cause an over-production of certain hormones. This in turn causes a particular set of symptoms, or syndrome.

VIPomas

**The key symptoms are:**

- Watery diarrhoea
- Abnormally low levels of potassium in the blood (a condition called hypokalaemia)
- A deficiency of hydrochloric acid in the stomach, where normally this acid helps digest food (a condition called achlorhydria)

This collection of symptoms is known as WDHA (standing for watery diarrhoea hypokalaemia achlorhydria).

The diarrhoea is unrelated to eating or consuming any particular type of food or drink, and can happen at any time, without warning. In some severe cases a patient may have continuous, extreme diarrhoea. This can lead to weight loss and severe dehydration.

You may also have noticed a ‘colicky’ type of abdominal pain and muscle cramps. If the disease has spread, there may also be some discomfort in the liver region.

The symptoms may have developed very gradually over time.

**Glucagonomas**

The larger the tumour grows the more glucagon and other peptides are produced and this can cause a number of key symptoms and conditions to develop. (Looking back, you may find you have been treated for the following conditions separately).

- NME (seen in 65-80% of patients) - a striking rash known as necrolytic migratory erythema (NME for short). The rash tends to spread from one part of the body to another migrating from the groin to the buttocks, chest, lower legs and occasionally over areas of minor trauma. In some cases the rash is mistaken for eczema and is treated accordingly to no good effect. The rash can become crusted and blister, and over time may cause a change in skin pigmentation. The affected areas may also be susceptible to infection. The rash can extend to the mouth and create a burning sensation. There are however a few cases reported where patients have not developed NME.
- Weight loss (seen in 70-80% of patients)
- Diabetes (seen in 75% of patients)
- Diarrhoea (seen in 15-30% of patients). Other gastrointestinal symptoms include: abdominal pain, cramps, constipation and anorexia
- Cracked surface of the tongue
- Thickened nails
- Inflammation of the inner lining of the cheeks and lips
- Chapped lips
- Anaemia
- There is predisposition to forming blood clots and there may be a history of blood clots in the lungs (pulmonary embolism) or legs (deep vein thrombosis)
- There may be some hair loss
- Women may experience inflammation of the vagina or vulva - a condition called vulvovaginitis
- There are however often non specific symptoms or no symptoms at all.

Somatostatinomas

The symptoms are caused by an increase in the amount of the hormone somatostatin. They may start slowly and become worse. They include:

- Gallstones
- Weight loss
- Diarrhoea
- Fatty stools (steatorrhoea)
- Yellowing of the skin and whites of the eyes called jaundice, which is more common if the tumour develops in the small bowel
- Abdominal pain
- Blockage in the bowel
- Diabetes mellitus
- There are however often non specific symptoms or no symptoms at all.

Symptoms of diabetes mellitus include feeling thirsty, a dry mouth, passing urine frequently, weight loss, tiredness, and blurred vision.

Between 20-40% of patients may also have raised levels of the hormone gastrin or vasoactive intestinal peptide (known as VIP) that has a role in the digestive process.

The cause of the NME rash is unknown although there is speculation it is associated with a deficiency of certain trace elements such as zinc, or low levels of certain amino or fatty acids, and/or a deficiency in Vitamin B and other nutrients as a result of excessive glucagon in the body.
How are these tumours diagnosed?

Like all NET patients you can expect to face numerous tests and scans that will provide your doctor with information about the disease, its spread and the rate of growth.

**Biopsy**

This involves taking a piece of tissue from the suspect tumour and having it analysed in the laboratory by a specialist called a histopathologist. Biopsies are usually taken during medical tests (an endoscopy for example) or operations. The biopsy sample is sent to the laboratory and the cells are looked at very closely under the microscope to see if they are normal or cancer cells. NET cells look quite different to normal cells. Doctors can sometimes tell from biopsies where in the body a cancer has started.

Biopsies are very important in medicine. It is virtually impossible to diagnose some types of cancer any other way. Often, the only way to be sure of the diagnosis is to actually look for cancer cells under the microscope.

**Blood tests**

You will be asked to have a fasting gut hormone blood test, and blood will also be collected for a range of other tests.

Doctors will be looking for certain NET markers, particularly chromogranin A and B, and for evidence of a rise in certain peptides and hormones in the blood, as well as checking how well your kidneys and liver are functioning.

In a person with a VIPoma levels of VIP might be up to ten times higher than those found normally, providing conclusive confirmation of the diagnosis. If a VIPoma is suspected, you will also have a blood test to measure potassium levels. This is because low levels of electrolytes, particularly potassium, can occur and would need to be treated.

If you have a Glucagonoma, the tests will show increased levels of glucagon, and decreased levels of plasma amino acids.

In a person with a Somatostinoma, levels of somatostatin will be higher than normal.

**Blood tests may include:**
- Full blood count
- Kidney function test (urea and electrolytes)
- Liver function tests
- Thyroid function tests
- Pituitary hormone screen e.g. adrenocorticotropic hormone (ACTH), prolactin, growth hormone and cortisol
- Serum calcium, parathyroid hormone levels (as a simple screening test for MEN-1 syndrome)

You may also be asked to give an extra blood sample for use in research studies. You should always be informed of this and asked to sign a consent form.

**Urine tests**

When serotonin breaks down in the body, it is converted first to 5-HT and then to 5HIAA, which is excreted into the urine. A urine sample is collected, and the level of 5HIAA in the urine is measured. Higher than normal levels of serotonin produced by NET patients show up as raised levels of 5HIAA in their urine. You may be asked to do a urine collection over a 24 hour period so that your 5HIAA levels can be checked.

You will be asked to avoid certain foods prior to and during the test including chocolate, olives, bananas, pineapple and its juice, all tomato products, plums, aubergine, avocado, kiwi fruit, walnuts, brazil nuts, cashew nuts, tea, coffee and alcohol. You will also be asked to avoid certain cough, cold and flu remedies 3 to 7 days prior to the test. This is because they contain substances that might artificially raise your serotonin levels and so give a false test result.

For further information see the NET Patient Foundation Factsheets on The 5HIAA Test and Fasting Gut Hormone Profile.

**Endoscopy**

This is a way of examining your digestive tract using a flexible fibre optic tube called an endoscope. The tube can either be inserted down the back of the throat, a procedure called a gastroscopy, or into the colon via the rectum (back passage), a procedure known as a colonoscopy. You will be offered sedation before either of the procedures, and the doctor may remove samples of any suspect areas of tissue for analysis.
How are these tumours diagnosed?
(continued)

**Wireless Capsule Endoscopy**
This involves swallowing a small capsule (the size of a large vitamin pill), which contains a colour camera, battery, light source and transmitter. The camera takes two pictures every second for eight hours, transmitting images to a data recorder about the size of a portable CD player that patients wear around the waist.

**Endoscopic ultrasound**
This is usually carried out under sedation and involves looking at the digestive tract with a flexible camera. The test can help pick up small tumours that might not be clearly visible on a scan.

**Octreotide scan**
This is a useful diagnostic test that can help reveal the site of tumours. Some NETs have special receptors on their surfaces called somatostatin receptors. Octreotide is a somatostatin analogue, a substance that copies or mimics the action of somatostatin. When octreotide is combined with a mildly radioactive agent and then injected via a vein in the arm, it sticks to somatostatin receptors on the tumour surface and the tumours light up on the screen as radioactive ‘hot spots’. This investigation is done on a machine called a SPECT CT.

**CT scan**
A computerised tomography (CT) scan provides a three dimensional picture of the inside of the body. It can be used to determine the position and size of neuroendocrine tumours and regular scans are useful to find out the rate of tumour growth.

**MRI scan**
This ‘whole body’ 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. For some parts of the body and for some types of tumour, it can produce clearer results than a CT scan. For other situations, a CT scan is better. Your own doctor will know which is the best type of scan for you.

**PET scan**
There are different types of Positron emission tomography (PET) scan that may be used for NET patients. PET scanners are used in many cancer types. The scan looks for the activity of the cell tissue and the growing speed of the cells.

Like the octreotide scan a special tracer (most commonly called FDG [18F]-fluorodeoxyglucose) is injected intravenously and the PET camera then produces a 3-dimensional image, highlighting any abnormal activity.

More recently a PET scan is used in combination with a CT camera which is a more advanced diagnostic tool.

A PET scan is not required for everyone but more likely to be used in more aggressive disease.

Another type of PET scan is the GA-DOTA-octreotate PET scan, which has been shown to have a higher sensitivity (can see more) for NETs compared to the octreotide scan.

Not only is this a more sensitive scan but it is also much quicker than the octreotide scan and results are available in a shorter time. This is new technology and an advancement in NET scanning but at present there are only a few available in the UK.

**Bone scan**
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 taken in order to help your doctor determine whether there are any problems associated with it.

**Ultrasound scan**
Ultrasound imaging, also called ultrasound scanning or sonography, involves exposing part of the body to 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 your body’s internal organs, as well as blood flowing through blood vessels.
Patients should ideally be treated within a specialist multidisciplinary team (MDT). Each patient will have an individualised treatment plan: there are a number of options available, depending on the type and location of the tumour, and the general well-being of the patient.

Immediate treatments may be needed to get the symptoms under control. For example:

**VIPomas**

An anti-diarrhoea medication such as dephenoxylate or codeine may be prescribed to help the immediate problems. You may also need to be admitted to hospital for rehydration (replacement of the fluid lost due to diarrhoea). A high dose steroid regime may help to get immediate symptoms under control.

**Glucagonoma**

Hyperglycaemia can be controlled using insulin or oral blood glucose lowering drugs. Somatostatin analogues and zinc therapies may help with the NME rash. Simple measures, such as applying gentle skin creams or emollients to soothe and hydrate any crusting or blistering of the skin, combined with treatment for diabetes, can improve matters considerably.

Because Glucagonoma patients are more prone to forming blood clots, you may be recommended aspirin or blood thinning tablets.

Here are some of the other treatments that your team may discuss with you.

**Surgery**

If the tumour is contained in one area (localised), or if there has been only limited spread, surgery is usually the first choice of treatment. If it is possible to remove the tumour completely, no other treatment may be necessary.

If the tumour has spread to other parts of the body (metastatic), surgery may still be possible to remove the part of the tumour that is producing too many hormones. This is often referred to as tumour debulking.

**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 clear, healthy tissue then the surgery is potentially curative and no other treatment may be necessary. A follow-up plan will need to be put into place after surgery.

If the tumour is caught early, you may be a candidate for a type of surgery known as the Whipple procedure,

*See Factsheet on Whipple procedure.*
Palliative surgery
When the tumour or tumours have already spread or become too large to remove completely, then surgery may still be considered. If the tumours are causing symptoms by pressing on other organs or by releasing hormones then surgery may be performed to reduce the symptoms by removing or bypassing the part of the disease that is causing the problems.

Pre-emptive surgery
This is when an area of tumour is critically placed close to an important structure such as a blood vessel or the bile duct or bowel. Even if the disease cannot be cured, removing the tumour may prevent problems in the future by removing disease from key areas before the vital structure has been damaged or blocked.

Cyto-reductive surgery
All of the many medical treatments for NETs aim to reduce symptoms and prolong survival by cyto reduction.

This means reducing the number of living tumour cells inside the patient. Operations can also be used to achieve this when the disease has already spread, by surgically removing bulky areas of tumour to reduce the total number of cancer cells inside the patient. Cyto-reduction often involves other treatments used in combination with surgery.

Somatostatin Analogue
Daily or monthly injections of somastostatin analogues are available to control some of the unpleasant symptoms caused by the tumours. Somatostatin analogues are synthetic versions of somatostatin, a naturally occurring hormone produced in the brain and digestive tract that inhibits the release of several other hormones and chemicals from our internal organs.

Injections of these analogues can stop the overproduction of hormones that cause symptoms such as flushing and diarrhoea. There is good evidence now demonstrating that these injections also slow down the growth rate of tumours.

Targeted Peptide Receptor Radionuclide Therapy PRRT
These treatments are sometimes referred to as ‘magic bullet’ therapies. The treatments are based on using different radiolabelled peptides which target receptors on the tumour surface. In PRRT for neuroendocrine tumours, the radionuclides commonly used are indium-111, lutetium-177 and yttrium-90. The basis for which treatment is suitable for which patient is the diagnostic tracer imaging. To decide whether this therapy is suitable, you will be asked to take an Octreotide, PET or MIBG scan as described in the diagnosis section. The results of these scans will indicate whether or not you have the correct receptors present and whether this sort of therapy would be an option.

SIRT
SIRT stands for Selective Internal Radiation Therapy. It is a new way of using radiotherapy to treat liver metastases which cannot be removed with surgery. The doctor inserts a thin tube called a catheter into the hepatic artery. This is the main artery which supplies blood to the liver. They then send tiny beads called microspheres down the catheter and these get stuck in the small blood vessels around the tumour. The microspheres contain a radioactive substance which give a dose of radiation to the tumour. The microspheres are also called SIR-spheres and the radioactive substance is called yttrium-90. This therapy is currently of very limited availability in the UK.

Embolisation
If the tumour has spread to the liver, you may be offered hepatic artery embolisation (HAE). In this procedure, a catheter is placed in the groin and then threaded up to the hepatic artery that supplies blood to the tumours in the liver. Tiny particles called embospheres (or microspheres) are injected through the catheter into the artery. These particles swell and block the blood supply to the tumour, which can cause the tumour to shrink or even die. This treatment can also be combined with systemic treatments in some patients where the tumour has spread. It is a procedure that would be carried out by a specialist called an interventional radiologist. The patient would be sedated for the treatment.

Sometimes this embolisation process is combined with chemotherapy (called HACE (Hepatic Artery Chemoembolisation) or TACE (Transcatheter Arterial Chemoembolisation) or radiotherapy (RMT or SIRT).

Radiofrequency Ablation (RFA)
This may be used when a patient has relatively few secondary tumours (metastases) in the liver. A needle is inserted into the centre of the tumour and a current is applied to generate heat which kills the tumour.
Treatments (continued)

Chemotherapy
This may be an option for NET patients especially those with pancreatic, bronchial or high grade NETs. Not all NETs respond equally to chemotherapy, therefore careful selection of patients is imperative so as to maximise the chance of response and avoid unnecessary toxicity. Many chemotherapy treatments involve intravenous drugs, however there are now also oral chemotherapy agents and your NET doctor will discuss the most appropriate option with you. The histology of the tumour i.e. how it looks down the microscope after biopsy or operation, may help determine the type of treatment you receive.

Chemotherapy may sometimes be recommended after surgery (adjuvant therapy). You may be asked to be involved with clinical trials currently underway which are looking into the different combinations of chemotherapy agents that are most appropriate for different types of NETs.

Sutent (Sunitinib)
Sutent is a medication that comes in capsule form. It is mainly used in patients with pancreatic neuroendocrine tumours. It works mainly by blocking a process called angiogenesis. Angiogenesis is the process of making new blood vessels. Tumours need a good blood supply to grow and Sutent helps stop that process. The drug comes under an umbrella group of drugs known as mTOR inhibitors.

Clinical Trials
Clinical trials are medical research trials involving patients. They are carried out to try to find new and better treatments. Carrying out clinical trials is the only sure way to find out if a new approach to cancer care is better than the standard treatments currently available.

You can find out more about current NET trials at: www.netpatientfoundation.org/category/patient-resources/research/

No treatment
No treatment or watchful waiting may be suitable for you if your NET is not currently causing you any symptoms or problems and the tumour(s) are stable. You may also have other health conditions that would make the NET treatment inadvisable.

Follow up
The follow-up intervals are highly variable depending on the clinical situation, functionality (whether any syndrome is present), stage, grade and time since diagnosis. Intervals may vary, but generally follow-up should be tailored to individual needs and is usually every 3-6 months initially.

Affinitor (Everolimus)
Affinitor is another medication for patients with pancreatic neuroendocrine tumours. It also comes in a capsule form and is a type of drug that interferes with the process of new cancer growth. The drug comes under an umbrella group of drugs known as mTOR inhibitors.

Clinical Trials
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Mutidisciplinary teaming

The care of NETs can be complex, and for the patient the journey can encompass not only a whole host of emotions, but also a whole 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 between all key healthcare professional groups, who are making clinical decisions for individual patients.

This collaboration has been termed an MDT (multidisciplinary team). 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 a particular specialist with expertise and interest in NETs and other adrenal tumours. This specialist is commonly an endocrinologist or oncologist.

A patient may see some of or all of the following people:
- Gastroenterologist
- Oncologist
- Surgeon
- Endocrinologist
- Cardiologist
- Radiotherapy staff
- Nuclear medicine physician
- Dietician
- Nurse Specialist
- Palliative Care Team
- Pain Team
- General practitioner/ Practice Nurse
- Counselling Staff
- Various Technicians
- Clinic Staff
- Hospital Staff
- Hospice Team
Multidisciplinary teams (continued)

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 patients.

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 member of the 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
- If you are dissatisfied with the care that you receive, and discussion with your doctor does not resolve the situation, you can ask for a second opinion - how you feel about the care you receive is the most important thing.

Tips:

Bring a trusted friend or family member with you to the appointment if you can. If you are feeling anxious, you may not hear everything that’s 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 to get into the practice of taking notes on how you are feeling, and take these notes into your appointments.

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 repeated or 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 choosing to get a second opinion is quite common. Physicians are usually very open to this because they appreciate the fact that making an effective treatment choice can be very challenging.

If getting a second opinion through your specialist is not possible, you can get a referral from any of your physicians, including your general practitioner.

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 are not successful in stabilising your disease.

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

Further Support

NET Patient Foundation

From diagnosis and throughout treatment and beyond our services are here every step of the way. Below is an overview of all the services we offer to people living with and beyond NETs.

Helpline – 0800 434 6476

Our free, confidential helpline is for anyone who has questions about NETs (neuroendocrine tumours). Your call will be answered by one of our nurses or trained staff members with experience of NETs. Whatever your concern, you can be confident we will understand the issues you might be facing, and that the information you receive will be clear and up-to-date.

We will also let you know where else you can go for further support. The helpline is open 10am-2pm Monday to Friday. We operate a call-back service for those who wish to leave a message out of hours.

Website – www.netpatientfoundation.org

We know how important it is to understand as much as possible about your NET. Our website is here round-the-clock giving you instant access to information when you need it. As well as clinical information, you will find real life experiences and access to the largest online NET community in the UK, so you can share your questions or concerns with other people in a similar situation.

Discussion forums

Through our discussion forums you can exchange tips on coping with the side effects of treatment, ask questions, share experiences and talk through concerns online. Our dedicated areas for popular topics should make it easy for you to find the information you’re looking for. The discussion forums are easy-to-use. If you’re feeling anxious or just need to hear from someone else who’s been there, they offer a way to gain support and reassurance from others in a similar situation to you.

Information and support sessions

We run information and support sessions for people living with NETs. These meetings include talks from some of the country’s top NET specialists plus invaluable Question & Answer sessions and an opportunity to meet other NET patients. For information about meetings in your area, please see our website or call our helpline.

NET Natter groups

These are informal groups which meet locally on a regular basis. To find out if there is a NET Natter group in your area, or if you’d like to set one up, please visit our website.
Further Support (continued)

Information resources
Our free information resources are for anyone affected by NETs. They are here to answer your questions, help you make informed decisions and ensure you know what to expect. All of our information is written and reviewed regularly by healthcare professionals and people affected by NETs, so you can trust the information is up-to-date, clear and accurate. You can order our publications by sending us an email or calling the helpline. All our publications can also be downloaded from our website.

Other organisations
NHS Choices
Information on clinical trials and treatment centres, including reviews and ratings.
www.nhs.uk

Cancer Research UK
Trusted information on all cancer types.
www.cancerresearchuk.org

Macmillan Cancer Support
Macmillan Cancer Support provides practical, medical, emotional and financial support to people living with cancer and their carers and families. Over the phone, its cancer support specialists can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and are there if someone just wants to talk. Its website features expert, high-quality information on cancer types and treatments, emotional, financial and practical help, and an online community where people can share information and support. Macmillan also funds expert health and social care professionals such as nurses, doctors and benefits advisers.
www.macmillan.org.uk
General enquiries: 020 7840 7840
Helpline: 0808 808 0000
Textphone: 0808 808 0121 or Text Relay

You could make a difference to the lives of people living with neuroendocrine cancers...

We Support:
• Vital clinical research in the UK
• Education for healthcare professionals

We Fund:
• The provision of supportive care for patients and carers living with neuroendocrine cancers
• Research into patient focused issues related to patient experience and equality of care

To find out more or to make a donation please call us on 01564 785577 or visit our website www.netpatientfoundation.org
About us

The Foundation has the following aims:

- To provide support, education and information to anyone affected by neuroendocrine cancers
- To advocate for neuroendocrine cancer patients so that they may achieve the best possible outcomes
- To encourage standardised care for all NET patients
- To provide community supportive care to patients and their carers or family members
- To raise awareness of NETs throughout the UK
- To raise funds for clinical research projects.

If you found this booklet useful and would like to make a donation to the NET Patient Foundation, please contact us.

Did you know?

- Over 50% of patients are diagnosed when the cancer has already spread
- Early diagnosis significantly improves outcomes for patients
- There are dedicated NET clinics around the UK. Find out where at www.netpatientfoundation.org

Why the moth?

We have chosen the moth as our logo to symbolise this ‘camouflaged’ condition. We aim to encourage medical professionals to consider an uncommon alternative when symptoms persist (i.e. a NET rather than IBS).

“When you see an insect beating its brightly patterned wings against your window, don’t assume it’s a butterfly. It could be a moth.”