Gastrointestinal NETs

NET Patient Foundation
What are neuroendocrine tumours?

Neuroendocrine tumours (NETs) arise from neuroendocrine cells, also called neurosecretory cells. These are specialised cells, which release hormones and peptides into the bloodstream when required to affect the function of different organs in the body. Neuroendocrine cells can be found in many areas of the body.

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 know that these tumours can be malignant. Terminology used now is either simply neuroendocrine tumours (or NETs); or for tumours found in the GI tract are referred to as gastrointestinal neuroendocrine tumours (or GI NETs).

*For the purpose of this booklet, we will focus only on the malignant type.*
Where do neuroendocrine tumours occur?

Neuroendocrine cells are found in endocrine glands, and also in the mucosa of the lungs and the gastrointestinal tract. It is in these two regions that neuroendocrine tumours predominantly arise. When neuroendocrine cells are working well, they release a number of hormones, which fulfill various functions in the body. For example, in the lungs they regulate the air and blood flow, and in the gastrointestinal tract the cells can be involved in regulating gastrointestinal activity, including stomach acid production and blood sugar levels.

Tumours most commonly present in the areas listed below, but other rarer sites include ovaries, testes, skin, adrenal glands, thyroid and pituitary glands.

This booklet will focus on neuroendocrine tumours which arise in the gastrointestinal system (GI NETs). For information about other types of NET cancer, please visit our website at www.netpatientfoundation.org
How common are neuroendocrine tumours?

At the moment, we don’t have the data available to tell us exactly how many people are diagnosed with NETs each year in the UK, or how many people are living with the condition. Early data from the UK, Switzerland and Sweden shows that 2 to 3 people per 100,000 are diagnosed with a NET each year. What is known is that the number of people being diagnosed is reported to be rising significantly. The reasons for this increase is unknown, although it is likely to be related to improvements in scanning techniques, and to an increase awareness and understanding of NETs.

The prevalence of NETs (i.e. the number of people living with the condition at any time) is remarkably high. This is due to various factors, including the slow-growing nature of many types of NET cancer, and the availability of an increasing number of successful treatment options.

Types of GI NET

**Gastric NETs** - these are NETs of the stomach. They represent less than 1% of all gastric cancers, and there are four types of gastric NET:

- **Type I:** This is the most common and represents about 70-80% of all gastric NETs. These are associated with atrophic gastritis and can over-produce gastrin. Typically, the patient will present with polyps. These polyps may not be cancerous, but they may reoccur. Commonly they are removed, and a regular follow-up plan put in place.

- **Type II:** This group accounts for around 5% of gastric NETs. These occur as part of another condition known as Multiple Endocrine Neoplasia Type 1 (this is a familial condition which will be covered later in this course). An over-production of gastrin is also seen, which is known as Zollinger-Ellison Syndrome. The tumours are often quite small and can be managed well.

- **Type III:** This group accounts for 15-20% of gastric NETs. These tumours are often larger than Type II, and can metastasise.

- **Type IV:** This is a very rare type of gastric NET, with the poorest prognosis. Tumours are often large and advanced at diagnosis.

**Rectal NETs** - these account for about 27% of all GEP NETs and 16% of all NETs. In around half of the cases, the tumour is discovered incidentally. Patients may present with symptoms such as PR bleeding or change in bowel habit, but often they are asymptomatic. Patients may present with metastatic disease due to lack of symptoms.

**Appendiceal NETs** - these NETs are usually discovered incidentally, and quite often during surgery for a suspected appendicitis. If the tumours are less than 1cm in size, curative surgery is often performed. There is a group of tumours that arise from the appendix that are more aggressive. The cells of these tumours are shaped like a goblet under the microscope, and therefore are called goblet cell tumours. Patients often present with acute appendicitis, abdominal pain and mass, and 50% of all females also present with metastases in the ovary.
The symptoms of carcinoid syndrome vary, and can often be highly individual. Bowel Syndrome (IBS), Chron’s disease, peptic ulcer disease, gastritis or other digestive disorders.

Typical carcinoid symptoms include:
- flushing
- diarrhoea
- wheezing
- breathlessness and swollen ankles
- extreme cases, coma.

However, if the carcinoid tumour has spread there will be other more obvious symptoms. For example, you may have been told by your doctor that you may have Irritable Bowel Syndrome (IBS), Chron’s disease, peptic ulcer disease, gastritis or other digestive disorders.

The syndrome is caused by an excessive amount of certain hormones circulating in the blood. For example, adrenaline, dopamine, histamine, 5-hydroxytryptamine, noradrenalin, serotonin, bradykinin, chromogranin A, gastrin, glucagon and somatostatin.

Carcinoid tumours within the digestive tract are often very small. You may have no symptoms at all, or they may be very vague, which is why carcinoids are rarely diagnosed before the disease has already metastasised. About 20% of patients with a NET of the ileum have Carcinoid Syndrome.

Colon NETs - can be large and malignant, and patients may present with a bowel obstruction and bleeding. Initial diagnosis may be for the more common colon adenocarcinoma, however the patient may have flushing symptoms with a colon NET due to metastases in the liver. Flushing is part of a syndrome that may occur with any NET of the GI tract. This syndrome is still known as Carcinoid Syndrome, and is caused by over-production of hormones and peptides in the GI tract, such as serotonin. Colon NETs are rare, and they have a poor prognosis.

Duodenal NETs - there are many different types of duodenal NET. These NETs produce many hormones and peptides, such as serotonin, calcitonin and somatostatin. Patients may present with Carcinoid Syndrome, pain or anaemia.

Ileum NETs - these tumours are often slow-growing, which makes diagnosis in the early stages difficult. Patients may present with Carcinoid Syndrome, bowel obstruction or abdominal pain, but this may be at a time when the disease has already metastasised. About 20% of patients with a NET of the ileum have Carcinoid Syndrome.

Bronchial NETs - this is one of the more common NETs. Neuroendocrine tumours of the lungs are divided into four types - typical, atypical, small cell lung cancer and large cell neuroendocrine carcinoma. Around 70% of patients will have the atypical type. This type rarely spreads beyond the lungs. Atypical bronchial NETs behave more aggressively than typical ones, although metastases do develop in up to 20% of patients with typical bronchial NETs. They can occur at all ages.

Bronchial NETs can also cause various symptoms related to hormone overproduction. Patients with MEN 1 have an increased risk of developing bronchial NETs.

This booklet will focus on the first six types listed here. There is a booklet on Bronchial NETs available on our website at www.netpatientfoundation.org

Other types of NET
There are several other types of NET booklets and information about these are available on our website.

- Pancreatic NETs (PNETs) functioning and non-functioning
- Multiple Endocrine Neoplasia (MEN)
- Phaeochromocytomas – Paragangliomas
- Medullary Thyroid Cancer
- Merkel Cell Carcinoma
- Adrenocortical Carcinoma (ACC)

Neuroendocrine tumours may also occur in other organs such as the ovaries, cervix, testicles, spleen and breast, but these are very rare presentations.
What are the symptoms of GI NETs?

Neuroendocrine tumours within the digestive tract are often very small. You may have no symptoms at all, or they may be very vague, which is why NETs are sometimes know as the ‘quiet cancers’.

Early symptoms may include vague tiredness or digestive complaints, and your doctor may have told you that you have Irritable Bowel Syndrome, Crohn's disease, peptic ulcer disease, gallstones or other digestive disorders.

However, there may be other more obvious symptoms that make up what is known as ‘carcinoid syndrome’.

What is ‘carcinoid syndrome’?

When neuroendocrine tumours spread (‘metastasise’), the most common site for metastatic tumours (‘secondaries’) is the liver. Other areas of spread can, more rarely, include the bones, the lungs and the lymphatic system.

Many GI NETs have an associated syndrome caused when the neuroendocrine cells produce too many of a particular hormone or peptide. The most common of these is ‘carcinoid syndrome’, which is caused when too many hormones such as serotonin, histamine, somatostatin, chromogranin A and others are produced. The symptoms of carcinoid syndrome vary, and can often be highly individual.

Typical symptoms include:

- flushing
- diarrhoea
- wheezing
- fatigue
- skin changes

It is by no means certain that you will experience ‘carcinoid syndrome’. Not everyone with GI NETs will have this collection of symptoms, even if their disease has spread.
Complications

Carcinoid crisis

Sometimes patients may suffer a particularly bad episode of carcinoid syndrome triggered by stress, general anaesthetic or certain treatments.

Symptoms include intense flushing, diarrhoea, abdominal pain, wheezing, palpitations, low or high blood pressure, an altered mental state and, in extreme cases, coma.

Without treatment the complication can be life threatening, but if you are having any procedures your NET specialist will ensure you are monitored and may give you an infusion of a somatostatin analogue as a preventative measure. Your NET specialist will also liaise with any other team, for example a surgical team, and pass on the guidelines that are available as a preventative measure for patients at risk.

Carcinoid Heart Disease

The hormones released by the tumours into the bloodstream can affect the heart by causing deposits to build up on both the cardiac valves and the muscle. This can eventually impair the function of the heart valves and cause the valves to become leaky, which can cause symptoms such as breathlessness and swollen ankles. Carcinoid heart disease is detected by an echocardiogram.

For further information see the NET Patient Foundation booklet on Carcinoid Heart Disease.
How are GI NETs 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. Some of the tests you might undergo include:

**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

**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.

**Other biochemical tests may include:**

- Full blood count
- Kidney function tests (urea and electrolytes)
- Liver function tests
- Thyroid function tests
- Pituitary hormone screen e.g. adrenocorticotropic hormone (ACTH), prolactin, growth hormones and cortisol
- Serum calcium, parathyroid hormone levels (in all pancreatic NET patients, as a simple screening test for MEN-1 syndrome)

**Urine tests** - when certain hormones are broken down by the liver, it is excreted as a substance called 5-hydroxyindoleacetic acid (5HIAA) in the urine. 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 give a false test result.

**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.
There are a number of scans you may be asked to have. These will determine the exact site and size of the tumours.

**Octreotide scan** - this is a useful diagnostic test that can help reveal the site of tumours. Some GI 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’.

**MIBG scan** - This is a similar type of scan to the OctreoScan, except a different radioactive labelled substance is used. A radioactive MIBG will show up those tumours which have receptors for meta iodo benzyl guanidine (MIBG) on the surface.

**Endoscopic ultrasound** - this is usually done 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.

**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.

**PET scan** - this type of scan can show how body tissues are working, as well as what they look like. PET scanners are very expensive and only a few hospitals in the UK have one. This means that you may have to travel to another hospital for your scan. Not everybody who has cancer will need to have a PET scan. Other types of tests and scans may be more suitable.

**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. These pictures take about 10 minutes, and you will be asked to return for the 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 approximately 30-45 minutes.

**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 the body’s internal organs, as well as blood flowing through blood vessels.
Further testing

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

- Barium enema
- Wireless capsule enteroscopy
- Bronchoscopy for lung NETs

Treatments

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.

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.

Palliative surgery - When the tumour or tumours have already spread or become too large to remove completely, then surgery may be considered. If the tumours are causing symptoms by pressing on other organs or by releasing hormones then surgery maybe 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 we can see that 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 we can’t cure the disease by removing it all we can prevent future problems 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 NET cancers 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.

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

Most planned surgery for NET cancers should be done in specialist units where the surgeons work as part of a team including oncologists, gastroenterologists, nurses, radiologists and many other doctors all of whom have particular expertise in managing NET cancers. These are rare and complex tumours so it is best to have a dedicated team of experts jointly involved in deciding which treatment is best.

Somatostatin Analogues - Daily, fortnightly or monthly injections of somatostatin 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 other several 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.

These injections are also used to help stabilise tumour growth in some low grade tumours.
Treatments (continued)

**Targeted Peptide Receptor Radionuclide Therapy PRRT** - These treatments are sometimes to be referred to as magic bullet therapies. These treatments are based on using different radiolabelled peptides which will target receptors on the tumour surface. The basis for which treatment is suitable for which patient is the diagnostic tracer imaging. To decide whether this therapy is suitable, you be be asked to take an Octreotide 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.

**Interferon** - is a naturally occurring substance that is produced by the body's immune system. It is sometimes referred to as biological therapy or immunotherapy and is used to treat some patients with NETs. In some patients it is given on its own, but quite often it is given as a combination therapy with a somatostatin analogue.

**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 done 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)** - is used when a patient has relatively few secondary tumours (metastases). A needle is inserted into the centre of the tumour and a current is applied to generate heat, which kills the tumour.

**Chemotherapy** - may be an option for bronchial NET patients or patients with more aggressive GI NETs tumours. Many chemotherapy regimens involve intravenous drugs, however there are now also oral chemotherapy agents and your oncologist 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 NET cancer.
Multidisciplinary teams

The care of NET cancers 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 among 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 NET cancers and other adrenal tumours. This specialist is commonly an endocrinologist or oncologist.

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

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

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.
Effective Communication 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
- 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 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.

You can find out more about current trials at:

**Current Controlled Trials**
This website allows users to search, register and share information about randomised controlled trials. Covers multiple registers, including England, Scotland and the US.

http://www.controlled-trials.com/

**ClinicalTrials.gov**
This is a register of federally and privately supported clinical trials conducted in the United States and around the world.

clinicaltrials.gov

You can also search for research trials available to patients in the UK and Europe on these websites:

www.macmillan.org.uk

www.cancerhelp.org.uk

www.ctu.mrc.ac.uk (The Medical Research Council Clinical Trials Unit)

www.ncrn.org.uk (National Cancer Research Network)

www.eortc.be/ (European Organisation for Research and Treatment of Cancer)
Further support

**NET Patient Foundation**
From diagnosis, throughout treatment and beyond, our services are here every step of the way. Here is an overview of all the services we offer to people living with and beyond NET cancer.

**Helpline - 0800 434 6476**
Our free, confidential helpline is here for anyone who has questions about NET cancers (neuroendocrine tumours). Your call will be answered by one of our nurses or trained staff members with experience of NET cancer. Whatever your concern, you can be confident we will understand the issues you might be facing, and that the information you receive is 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 also 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 cancer. Our website is here round-the-clock giving you instant access to information when you need it. As well as clinical information, you’ll find real life experiences and access to the largest online NET cancer 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.

**Ask the nurse**
If you find it difficult to talk about your cancer, we can answer your questions by email instead. Our ‘ask the nurse’ service is available on the website - complete a short form that includes your question and we’ll get back to you with a confidential, personal response.

**Information and support sessions**
We run information and support sessions for people living with NET cancer. These meetings include talks from some of the country’s top NET specialists, invaluable Question & Answer sessions, as well as an opportunity to meet other NET patients. For information about meetings in your area, please see our website or call our helpline.
Information resources
Our free information resources are for anyone affected by NET cancer. 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 NET cancer, 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

Macmillan Cancer Support
89 Albert Embankment London SE1 7UQ
General enquiries: 020 7840 7840
Helpline: 0808 808 0000
Website: www.macmillan.org.uk
Textphone: 0808 808 0121 or Text Relay
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.

The Foundation has the following aims:

- To provide accurate and up-to-date information for people living with, or affected by, NET cancers
- To provide support for patients and others affected by NET cancers
- To provide education for healthcare professionals in the treatment and care of NET patients
- To raise awareness of NET cancers within the medical community, and amongst the general public
- To improve access to care for NET patients
- To raise funds, which will help to support research around the UK & Ireland

Did you know?
- 50% of patients are diagnosed when the cancer has already spread
- Early diagnosis significantly improves outcomes for patients
- Help us to make a difference. Donate now 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.”
About Us

The NET Patient Foundation incorporating Living with Carcinoid was formed at the start of 2006 and has Charity Commission status. The collaboration with Living with Carcinoid meant that the charity could spread its wings to include patients with all types of neuroendocrine tumour.

The Foundation has 5 main aims:

1. To provide accurate and up-to-date information for people living with, or affected by, neuroendocrine tumours. We do this through information and forums provided on the website (and links to other sources of information on the web).

2. To provide support for patients and others affected by neuroendocrine tumours. We offer a support line which is manned by an experienced healthcare professional; and organise patient support groups around the UK and Ireland.

3. To improve the quality of life for patients and their families. We can do this by providing support and information about services and treatments available, as well as by funding and publicising research and existing medical initiatives.

4. To raise funds, which will help to support research around the UK.

5. To raise awareness of neuroendocrine tumours throughout the UK and Ireland, within the medical community and the general public.

There is much campaigning work to be done. We don’t have the funding that breast or bowel cancer attracts, but our patients deserve exactly the same attention and research support.

**IF you found this booklet useful and would like to make a donation to the NET Patient Foundation, please contact us.**
This booklet is part of a series of publications for patients about neuroendocrine tumours and related conditions, treatments and tests.

It has been a generous donation from Angie Jones and friends.