

The NET Patient Foundation:  
supporting the neuroendocrine cancer community.

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## Surgery in Gastrointestinal and Pancreatic Neuroendocrine Tumours

## Introduction

This booklet provides information for anyone going into hospital for surgery. The first section covers some of the different surgical procedures that may be used for NET patients.

The second section covers what to expect before your admission to hospital, during your stay, when you have returned home and during your recovery from surgery.

It includes information about:

- The routine checks you will have before surgery (pre-assessment)
- What to take into hospital
- What to expect while in hospital
- Some of the immediate physical and psychological effects of surgery
- Your longer term physical and emotional recovery from surgery

It is important to follow any specific advice given by your hospital. This booklet aims to give general information that you may find useful, and should be used in addition to any information you have received from the hospital where you are being treated.

Some people may be given a choice about which surgical procedure to have. Others may be recommended a specific operation.

It is important that all your questions have been answered by your specialist team before you consent to surgery.

Making choices about surgery can be difficult and it is important that you feel any decisions you make are right for you. Whatever you decide, you don't have to be rushed into treatment. A little extra time to think about what is right for you, and a chance to discuss your options with your partner, friends, family or GP (local doctor), will make no difference to the outcome of treatment.

## Section I: Surgery and NETs

Surgery is just one of the many different treatments that can be considered for the very wide range of NETs that occur.

There are so many different types of NETs and they can arise in so many different organs that this booklet cannot claim to be comprehensive.

The team looking after any NET patient has to weigh up the different options and give the best advice on the pros and cons of these different treatments.

Surgery is never done lightly, and the surgeons doing the procedures will be very experienced consultants. The traditional approach to slow growing NETs was only to operate if it looked like the surgery was straightforward and had a high chance of curing the patient. However as surgical treatments have become safer and the number of effective treatments has increased surgery can now be considered in four different settings:

### Potentially 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 post surgery, as even with potentially curative surgery there is a risk of the tumour coming back.

### Surgery for symptom control

This is 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. The surgery is done to reduce the symptoms by removing or bypassing the part of the disease that is causing the problems.

### Pre-emptive surgery

In some cases your surgeon or NET team may recommend this type of surgery. Pre-emptive surgery 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 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 or debulking surgery

All of the many medical treatments (e.g. chemo) 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 such as medical or radiological treatment.

## Section I: Surgery and NETs *(continued)*

Most planned surgery for NETs 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 NETs.

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.

### **Surgical procedures used in the treatment of NETs and their associated symptoms**

*\*Please note that surgery may not be considered an effective option for all patients, and that it may be used alongside other therapies. For more information about the range of treatments available for you, please consult with your healthcare team, and have a look at our library of information at [www.netpatientfoundation.org](http://www.netpatientfoundation.org)*

## GI NETs

There are two main types of NET within this category: Gastrointestinal (GI) NETs, and pancreatic neuroendocrine tumours (PNETs).

### **Potentially curative surgery**

If the tumour is contained in one area (localised), or if there has been only limited spread, curative surgery is usually the first choice of treatment.

If the tumour is small or conveniently placed then this may be keyhole (laparoscopic or minimally invasive) surgery where under a full general anaesthetic telescopes and instruments are put inside the tummy through very small incisions. This speeds up the recovery after the operation.

If the tumour is bigger, in a more awkward place or has spread to the lymph glands then an open operation through a larger cut on the tummy is more likely.

Early tumours of the stomach, intestine, appendix and colon are most likely to be removed as a keyhole operation.

Most neuroendocrine tumours of the appendix are found by chance when the appendix has been removed as a keyhole operation for appendicitis. Normally no other treatment is required, but occasionally a second operation is required to remove more lymph glands or bowel at a later date. This decision is made after the tumour has been examined under the microscope by the pathologist to see whether it has all been removed, how big it is and how fast it has been growing.

The gold standard is surgical treatment with resection of the appendix. If the tumour is larger than 2 cm or located at the base of the appendix a wider resection has to be performed with right hemicolectomy (the removal of the right part of your large intestine).

### **Surgery for symptom control**

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

### **Pre-emptive surgery**

If a NET is starting to block an organ, such as the bowel, surgery may be helpful to relieve the blockage (obstruction). It is best to remove gut tumours, even if they have already spread because of the high chance of obstruction in the future if they are not treated.

Tumours arising in the gut often spread to the lymph glands that lie next to the blood vessels supplying blood to the intestine. When removing a gut tumour it is important that these glands are removed at the same time because if they are left they may block the blood vessels at a later stage which can cause major problems.

The secondary tumours in the glands are often bigger than the primary tumour in the gut wall. Sometimes removing the glands can be much more difficult than removing the piece of bowel, particularly if they are wrapping around the blood vessels at the root of the intestine.

## GI NETs (continued)

### Cyto-reductive or debulking surgery

If the tumour has spread to the liver, cyto-reductive surgery can be used to remove the parts of the liver containing the tumour. This is often done in combination with other treatments.

The large lumps in the liver are removed through surgery and smaller areas are treated with ablation or embolisation. These are other treatments that involve heating up tumours to kill the cancer cells (ablation) or blocking their blood vessels to starve the tumour of arterial blood and oxygen (embolisation).

Very occasionally, a liver transplant may be considered if there is low grade tumour in the liver, but no spread anywhere else.

Surgery may be used throughout the patient journey for many reasons, including in combination with other therapies.

### Goblet Cell Carcinoma

Goblet cell carcinoma starts in the appendix, however because this type of tumour is more aggressive than the usual neuroendocrine tumours found in the appendix, you will also be asked to consider a bigger operation to remove part of your large intestine to reduce the risk of the disease spreading. This procedure is called a right hemicolectomy, because it involves removing the right side of the colon and joining the ends back together.

In women if the spread is to the ovaries then you may be advised to have removal of one or both of your ovaries. Occasionally an operation may be recommended by some doctors even if there is no spread as a preventative measure.

In the case of spread to the abdomen you may be advised to have a right hemicolectomy, or other 'debulking' surgery to remove as much tumour spread as possible.

Occasionally some people have to adjust the type of foods they eat after a hemicolectomy in order to keep their bowels regular. Please talk to one of the nurses or doctors about this if you are in doubt.

Please note goblet cell carcinomas account for less than 5% of all NETs of the appendix and have a different disease pathway.

## PNETS (Pancreatic Neuroendocrine Tumours)

The group of pancreatic tumours that secrete hormones are called **functioning pancreatic neuroendocrine tumours**.

The different types have names that describe the hormone they secrete (e.g. insulinomas make insulin, glucagonomas make glucagon).

PNETs that do not have hormones that cause any syndromic symptoms are called non-functioning PNETs.

The principle intents of surgery for PNETs are the same as for other NETs i.e. curative, palliative, pre-emptive or cyto-reductive. All pancreatic surgery in the UK is done in designated specialist pancreatic cancer centres because the operations are complex and require specialist experience, support and after care.

There are many different pancreatic operations but the four most important for PNETs patients to know about are:

### Enucleation

This is often done as a keyhole (laparoscopic) operation. The tumour is identified and then carefully dissected away from the pancreas without damaging the pancreas. This is particularly useful for very small slow growing tumours like insulinoma.

### Distal Pancreatectomy

This is also usually a keyhole operation, it is for patients with tumours in the left side of the pancreas. It involves removing all or part of the left side of the pancreas (called the body and tail of the pancreas) and sometimes the spleen as well. The blood vessels to the spleen run immediately behind the pancreas so sometimes it is not safe or possible to separate them from the pancreas so the spleen is removed as well.

### Whipple's procedure (pancreatic duodenectomy)

This is a major operation to remove PNETs from the right side of the pancreas (pancreatic head). The head of the pancreas also contains the bile duct and is surrounded by the duodenum (the exit for the stomach) so when the head of the pancreas is removed these organs are removed too.

PNETs often involve some of the big blood vessels around the pancreas (portal vein and superior mesenteric vein), parts of these may need to be removed and repaired as well. This means that a lot of re-plumbing is required during the operation to join everything back together again. The operation usually takes 4 to 8 hours to complete. It may take a few months to fully recover from this surgical procedure.

## PNETS (Pancreatic Neuroendocrine Tumours) *(continued)*

### Multi-visceral pancreatic resection

These operations are very major procedures used to remove large slow growing PNETS that have grown into other organs inside the tummy (e.g. stomach, adrenal, liver, kidney, intestine or diaphragm). The tumour, the part of the pancreas it has started in and the parts of the other involved organs are removed all together, intact, as a block of tissue without disturbing the tumour.

It is often necessary to remove and repair any involved major blood vessels. This surgery is only done on younger, fitter patients because of the risks involved. However in carefully selected cases the long term results are good. These operations are only done by a handful of very experienced surgeons in a very few specialist pancreatic NET centres.

In some cases where the tumours have spread to the liver or other organs, pancreatic surgery may be considered in conjunction with an operation to remove part of the liver or other cyto-reductive treatments such as ablation, embolisation, radio-isotope treatment or chemotherapy.

Patients with pancreatic NETs should have their treatment in pancreatic cancer surgery centres with a specialist NET multidisciplinary team.

The pancreas controls blood sugar levels through the hormones insulin and glucagon as well as making pancreatic enzymes that form part of the digestive juices. After larger pancreatic operations some patients may become diabetic and require insulin or other medications to control their blood sugar levels. Some patients will also need to take pancreatic enzyme supplements as capsules before meals to make up for some of the reduced digestive juice production.

## Non-Functioning Pancreatic Neuroendocrine Tumour

There are many different types of surgical procedures which can be carried out when treating this type of tumour.

The surgeon will base their decision on many factors such as the size and site of the tumour, the rate of growth of the tumour, the presence of secondary spread and the intent of treatment (whether it is to try to cure the cancer, or improve symptoms and quality of life) and also on the medical condition of the patient.

Once the surgeon has made the decision about the appropriate operation they will provide detailed information.

## Functioning Pancreatic Neuroendocrine Tumours

### Gastrinomas

Surgery is the only treatment that can cure gastrinomas and should be performed by a surgeon experienced in treating these tumours. If the tumour has already spread to other organs such as the liver or if there are reasons why surgery cannot be performed, then other treatments may be considered.

### Glucagonomas

Surgery can offer the possibility of a cure if the disease is localised. Unfortunately, in most patients the disease may have already spread at the time of diagnosis and so it is not always appropriate to perform surgery.

However a surgical opinion should always be part of the review process as sometimes a two stage procedure might be considered, for example, surgery to remove a pancreatic tumour followed by another operation to remove a liver tumour. Additionally, the possibility of 'debulking' surgery may be considered if, for example, a surgeon can remove more than 90% of all tumour.

If the glucagonoma has spread (metastasised) the surgeon may still consider removing some of the tumours, a procedure called debulking, with the aim of reducing the levels of circulating glucagon that cause the unpleasant symptoms.

If the disease has spread to the liver (the most common site for secondaries of this type of tumour to be found) there may be options other than surgery (e.g. embolisation or ablation).

### Insulinomas

Complete surgical removal of the insulinoma from the pancreas can provide a cure. Most patients have single tumours that can be totally removed (enucleated) without even the need to cut away any part of the healthy pancreas. Often this can be performed via keyhole surgery (laparoscopically).

During surgery, the specialist may perform an intraoperative ultrasound to ensure there are no other small tumours close by or any affected lymph nodes.

If the tumour has spread (metastasised) it may still be possible to resect (surgically remove) part of the pancreas containing the tumour and also surgically remove any tumour which may have spread to the liver, which tends to be the main secondary site for these tumours.

# Functioning Pancreatic Neuroendocrine Tumours *(continued)*

## VIPomas

If the tumour is caught early you may be a candidate for a type of surgery known as the Whipple's procedure (see above), named after the doctor who first described it.

This involves removal of a large part of the pancreas, a portion of the bile duct, the gallbladder and the duodenum (the upper part of the small intestine), usually with part of the stomach.

Afterwards, the remaining pancreas, bile duct and stomach are rejoined to the intestine to allow pancreatic juice, bile and food to flow back into the gut, so that digestion can proceed normally.

If the tumour has spread (metastasised) to the liver then some 'debulking' surgery may be considered to help alleviate symptoms.

This means that the surgeon will remove as much of the tumour as possible.

## Phaeochromocytomas and Paragangliomas

These NETs very rarely affect the GI tract or pancreas, but it can be seen.

For further information, please see our Phaeochromocytomas and Paragangliomas booklet.

## 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 complications 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 Crisis cards are available from the NET Patient Foundation.

## Further reading

For further information, please see the Bowel Obstruction Factsheet and Whipple's Procedure Factsheet that can be found on our website.

Bowel Obstruction cards are available from the NET Patient Foundation.

### AT RISK - Bowel Obstruction

A bowel obstruction is a blockage in the bowel. Your bowel may become completely or partly blocked.

The symptoms of a bowel obstruction are a combination of:

- |                            |                          |
|----------------------------|--------------------------|
| 1 Feeling bloated and full | 4 Vomiting large amounts |
| 2 Severe Tummy Pain        | 5 Constipation           |
| 3 Feeling sick             |                          |

If you are worried you must contact your team during working hours. Weekends and out of hours you need to go the A&E

**Please seek medical advice immediately if you suspect that you have a bowel obstruction.**

Download a Bowel Obstruction Factsheet at [www.netpatientfoundation.org](http://www.netpatientfoundation.org)

### AT RISK - Carcinoid Crisis

I have a neuroendocrine cancer with 'carcinoid syndrome'. I am at risk of a carcinoid crisis if I have an invasive procedure.

I will need perioperative prophylactic treatment of intravenous octreotide for acute surgery. I may need additional intravenous octreotide if I still have symptoms. A lower dose can be given subcutaneously for more minor procedures.

ALL DOSAGES GIVEN ON THE REVERSE OF THIS CARD

[www.netpatientfoundation.org](http://www.netpatientfoundation.org)

## Section II:

# Your operation and recovery

*The following information has been taken from the Macmillan website*

### Before going into hospital

#### Pre-assessment

The general state of your health will be checked before your surgery. These checks are carried out before having a general anaesthetic for any reason. Some hospitals may ask you to visit a pre-assessment clinic before your surgery date. Others may do the assessment once you have been admitted to hospital for your operation.

If any health conditions are brought up by the pre-assessment, or you have any other health problems, you may require further assessment and tests. The time taken to complete any additional tests may delay your surgery for a short while. Although you might feel anxious about this delay, it should not make a difference to the outcome of your treatment.

#### What to take with you

Going into hospital may be a new experience for you and it can be worrying, particularly if you are not sure what to expect. Your hospital may provide you with a list of essential items to bring with you. However, you may also find the following information helpful.

#### Money and valuables

It is a good idea to take a small amount of money for a pay phone (which should be available on the ward) or to buy a phone card. In most cases you will be able to use your mobile phone, but do so with consideration for the other patients. It's best to put your phone on silent and try to avoid using it during rest times. In some cases, you or your visitors may be asked to turn off your mobile phones due to noise levels.

It is advisable to leave any valuables such as jewellery or credit cards at home. You will usually be able to leave a wedding ring on during your operation and it will be taped in place. If it is very loose you may be asked to remove it.

#### Books, magazines and music

Some people find it useful to bring something to read with them. Alternatively, there is usually a hospital shop where you can buy newspapers and magazines. In some hospitals, a trolley selling them will come to the ward.

A music player with headphones, such as a portable CD, iPod or mp3 player, or a radio can also be helpful

#### Food and drink

You can usually take some of your own food and drinks into hospital with you. Drinks and snacks are available in most hospital shops.

Most special diets are catered for in hospitals but let the ward staff know of any specific requirements. Sometimes visitors will be allowed to bring in takeaway or home-cooked food for you. You will need to discuss this with the ward staff first.

If you have specific cultural needs, for example if you need to fast while you are in the hospital, make sure you speak to your medical team about these before you are admitted.

#### Medicines

If you are taking medicines regularly, bring your medication with you into hospital. This can reduce any delay you might face if the ward staff need to get the medication from the hospital pharmacy. You should discuss any medicines or herbal supplements you are taking with a member of your care team before you are admitted to hospital.

#### Admission to hospital

You may need to ring the ward before going to the hospital to make sure that your bed is ready for you. You should receive instructions from your hospital about who you need to report to and when.

It might be useful to have someone with you when you are being admitted. If you still have any questions about your operation, write these down and take them with you so that you have all the information you want before the operation takes place.

Each ward has its own policy on visiting and how many people can visit at a time.

Young children and babies are not usually encouraged on the ward. You will need to discuss your hospital's visiting policy with the ward staff when you are admitted.

## Section II:

### Your operation and recovery (*continued*)

#### Before surgery

You will generally be admitted to the hospital either the morning before your operation or the previous evening. When you are admitted, your nursing team should introduce themselves to you.

A doctor from the surgical team will talk to you about your operation and discuss what they plan to do. This is a good time to ask any questions and talk about any concerns you may have. They will ask for your written consent to confirm that you fully understand what is going to be done and what you are agreeing to. If you are unsure, don't be afraid to ask the doctor to explain further.

If you have not had any tests done in advance (Pre-assessment) they will be done once you have been admitted.

The aim of this assessment is to check that you are fit for both surgery and a general anaesthetic.

It is important to follow any instructions you are given, such as when you can last have something to eat or drink before the operation. If there is anything you are unsure about, ask your doctor or nurse.

The surgical team may use a marker pen to draw on you, to indicate the site of the operation. Many people are given antiembolic stockings (elasticated support stockings) to wear during, and for a short time after, their operation. These reduce the risk of harmful

clots forming in the blood. Some people may be given a series of injections after their operation to further reduce this risk. If either of these are recommended for you, a member of your medical or nursing team will discuss them with you in more detail.

If you are feeling very anxious and would like something to relax you before the operation, discuss this with the anaesthetist. Sometimes medication can be given to help calm you.

Before going into the operating theatre for your surgery, the nursing staff will check:

- Your name band
- Whether you have any allergies
- When you last ate and drank
- That you have a theatre gown on
- If you have any jewellery or body piercings

If you do have any jewellery, the staff will discuss with you whether it can be secured with tape or will need to be removed before the operation.

If you have false teeth you will usually be allowed to keep these in, unless they are loose. If you wear glasses or use a hearing aid, you may be able to wear these to the anaesthetic room, where they will usually be taken off. It is advisable to have them clearly labelled with your full name.

#### After surgery

Everyone reacts differently to an anaesthetic. Some people wake very quickly, while others can feel very sleepy for several hours after an operation.

While you are waking from the anaesthetic you may be wearing an oxygen mask or nasal cannula (tubes inserted in the nose), to provide you with extra oxygen. You may also be given fluids via an intravenous drip until you are able to drink normally.

You may find this equipment restricting but you will usually only have it for a short time. Your blood pressure will be taken regularly and a nurse will also check your dressings frequently.

If you have had a longer operation, you may have a urinary catheter (a tube inserted in the bladder to collect urine). This will be removed as soon as possible, usually when you are able to get around on your own.

Following your surgery, and when you feel able, you can drink some water. It's best to start by taking a few sips and if you are okay with taking the sips then you will be encouraged to gradually drink more. Once you are drinking without any problems, you can then usually try to eat something.

It may be advisable to have something plain to eat after the operation, as food with a strong smell or taste might make you feel or be sick.

You will be encouraged to get out of bed when you feel able to. This will depend on how awake you are after your surgery and whether you feel dizzy. People can feel dizzy immediately after their operation because they may have lost some blood or because their blood pressure is low.

A member of your nursing team will be able to advise you on whether you need to call for help if you need to get out of bed and how far you should walk.



## Section II:

# Your operation and recovery (*continued*)

### What to expect after surgery (Normal Changes)

#### Pain and discomfort

You are likely to have some pain or discomfort after surgery but everyone's experience will be different.

There are different types and strengths of pain relief available, for example tablets or injections, and the type that you are given will vary according to your needs.

Some people find changing position and using pillows to support the wound can also help reduce pain or discomfort.

Sometimes pain relief may be given via a PCA (patient controlled analgesia). This is a special pump designed to give pain relief straight into your vein when you press a button. It is usually removed a day or two after surgery.

If you are in any pain, tell your nursing staff, as you may need a stronger dose or a different type of pain relief. Your specialist nurse, physiotherapist or ward staff will monitor your progress.

#### Bruising and swelling

Bruising is common after surgery but will gradually disappear. Swelling is also common. It is a normal part of the healing process and should lessen six to eight weeks after your surgery.

### Leaving the hospital

The length of your hospital stay will depend on what sort of operation you had, and how you recover from it.

You may be discharged within 24 hours and some hospitals may offer surgery as a day case. Your surgeon will advise when you will be able to go home.

It is important after you leave hospital that you follow any instructions you are given.

After a few days or weeks, you may have more discomfort and stiffness as you begin to become more active. This usually improves naturally over time. If you are still experiencing pain which is not controlled by pain relief, contact your nurse or your GP for advice.

### Recovering from your surgery

Recovery after surgery involves healing, both physically and emotionally, and the time taken varies from person to person.

Going home can bring mixed emotions. You may feel enormous relief that the operation is over but concerned about needing to go back for any results from tests on the tissue removed.

You may feel isolated or insecure because you no longer have the immediate support of the nurses, doctors and the hospital team.

Many hospitals will give you a contact number for the specialist nurse who you can get in touch with to talk through any issues.

### Physical recovery

The wound(s) should heal within two to three weeks. However, it may take several months for the affected area to feel 'normal' again.

Once you get home from hospital, try to do a little more physical activity each day. Try not to set yourself enormous tasks and remember to rest in between them; your body needs time and energy to recover.

Fatigue is something that most people will experience at some point during or after their treatment and it can last for weeks or even months.

Fatigue is different from normal tiredness and is more extreme and unpredictable. It can make a significant difference to how you feel and how you cope with everyday life.

Where possible, try to take things easy and don't be too hard on yourself if you can't do as much as you used to. Pace yourself if you can; for example, by taking up offers of help with shopping, transport, childcare or housework.

If you work, you might have the option of being able to work part-time for a while.

Gentle exercise can really help improve your feelings of fatigue, even if it feels like this would be unlikely.

Generally, you should be back to your usual level of activity after three to six months, depending on your individual circumstances. Some people may find that it takes longer and this will also depend on any further treatments you have.

If you drive, you can start to do this again once your wound(s) have healed. You should always wear a seat belt. If the area is still sensitive, you may need to put extra padding around it or the seat belt.

Depending on your individual circumstances, you will be encouraged to start gentle exercises one or two days after your surgery and increase to more challenging exercises as time goes on.

The nurses on the ward, or a physiotherapist, will be able to advise you on appropriate exercises to help prevent stiffness, and can offer guidance on when to start reintroducing any exercise or sport.

Sometimes taking pain relief approximately half an hour before starting exercise can make things easier.

## 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](http://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.

### 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](http://www.nhs.uk)

#### Cancer Research UK

Trusted information on all cancer types.

[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

#### A.M.E.N.D

Association for Multiple Endocrine Neoplasia Disorders

[www.amend.org.uk](http://www.amend.org.uk)

#### 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](http://www.macmillan.org.uk)

General enquiries: 020 7840 7840

Helpline: 0808 808 0000

Textphone: 0808 808 0121 or Text Relay

# Have you visited us online?



Our website is packed full of information that will help you find out more about the NET Patient Foundation and stay up-to-date with our services, campaigning and fundraising.

We provide high quality information and support for NET patients, their families and carers.

## Visit our website for...

- Information on NETs
- Support in your area
- Patient meetings and events
- NET clinics and research

## ...or get Social!

 @netpatientfound

 [www.facebook.com/NetPatientFoundation](http://www.facebook.com/NetPatientFoundation)

[www.netpatientfoundation.org](http://www.netpatientfoundation.org)



### 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](http://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 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.**