

# Neuroendocrine tumours and the treatments available to you

## Cancer Services

Information for patients

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### Introduction

The aim of this booklet is to help you understand more about neuroendocrine tumours (also referred to as NETs), and the treatments that are available to you.

### What are neuroendocrine tumours (NETs)?

These are rare tumours that form in cells that are part of both the body's system for producing hormones (endocrine system) and the body's nervous system. These specialised cells help us respond to changes in our environment, by controlling the levels of different chemicals in your body.

These tumours can be very slow growing and it can take several years before a diagnosis is made. They can also be either malignant (cancerous) or benign (non-cancerous).

### What are the different types of NET?

Some neuroendocrine tumours may also be referred to as carcinoids. Carcinoid tumours tend to be found in the appendix or small bowel. However, they may also occur in the pancreas, lung or kidney or elsewhere in the body.

Other neuroendocrine tumours may be referred to as gastroenteropancreatic tumours, or GEPs. GEPs can develop in the stomach, pancreas or intestines. Your consultant will tell you which type of neuroendocrine tumour you have and the grade of your tumour. Grade 1 is a slow-growing tumour, whereas Grade 3 is a more aggressive tumour.

**Health information and support is available at [www.nhs.uk](http://www.nhs.uk)  
or call 111 for non-emergency medical advice**

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## What causes neuroendocrine tumours?

The exact cause of neuroendocrine tumours is unknown. However, there is a slightly increased risk in people who suffer from a rare genetic syndrome called multiple endocrine neoplasia 1 (MEN1).

## How are neuroendocrine tumours diagnosed?

Sometimes the tumour is found by chance, particularly if you have had a scan for another reason. However, you may have had symptoms such as:

- Flushing of the skin
- Weight loss
- Wheezing
- Loss of appetite
- Diarrhoea
- Palpitations

With carcinoid tumours, a hormone called serotonin may be produced, leading to a condition known as carcinoid syndrome and this can cause you to experience the symptoms listed. However some people may have no symptoms at all.

## What tests might I have?

There are several tests that may be used to diagnosis neuroendocrine tumours. You may already have had some of these tests.

- **Blood tests** - to check that your liver and kidneys are working properly and that your blood cells are within normal range. Blood tests may also be taken to check for chemical activity that could indicate a tumour. These “tumour markers” are known as Chromogranin A and B.
- **Urine test** - a 24 hour urine collection in order to test for a hormone (serotonin) that is passed out in the urine as 5HIAA. The sample will be tested for raised levels of 5HIAA. Three days before starting this collection you will be asked to avoid certain foods. Once the collection is completed, you may restart your normal diet.
- **CT (computed tomography) scan** - an X-ray examination that gives more information than a normal X-ray. It produces detailed images of your organs and blood vessels. You will be asked to lie still on a scan table, while a circular scanner (like a large doughnut) moves up and down the table around you.
- **MRI (magnetic resonance imaging)** - a test that uses a powerful magnet and a computer to produce detailed images of your internal organs. The MRI scanner does not use X-rays. If you have anything metal inside your body, for example a pacemaker, you need to tell a member of staff before the test.

## What tests might I have? (continued)

- **Octreotide scan** - this scan gives us information about where your cancer has started, and where it may have spread to. A substance called octreotide is injected into your arm, and then you will be scanned to monitor the effects of this on the carcinoid cells. The scan is done in the Nuclear Medicine Department and takes place over three consecutive days. On the first day you will need to go to the department twice. In the morning you will have the injection. You are then usually free to leave the hospital if you would like to. In the afternoon you will have a scan using a gamma camera. The scan takes about an hour and during this time you will lie still on a bed. On the following two afternoons pictures will again be taken. This will take up to one and a half hours.
- **Pet scan** - a PET scan creates three- dimensional (3D) pictures of the inside of your body. PET stands for positron emission tomography. This type of scan can show how body tissues are working, as well as what they look like. It is used to help diagnose cancer and to help to find out where and whether cancer has spread.
- **Biopsy** - this involves you having a small sample of the tumour taken, either during surgery or as a procedure under local anaesthetic. This could be as part of an endoscopy examination or as a planned percutaneous (through the skin) biopsy by a consultant radiologist. The results of this take around five to seven days to come back.

## What treatments are available?

### Surgery

Whether surgery is recommended for you will depend on where the tumour is, and how far it has spread. If the tumour is limited to only one area, then it may be possible for the tumour to be fully removed, and for no further treatment to be necessary. If the tumour has spread to another area (metastasised), the surgery may still be advised, in order to slow down the rate of the tumour's growth.

If your doctor recommends surgery for you, written information will be given to you before you come in for your operation.

### Somatostatin analogues

You may be advised by your medical team to consider octreotide or lanreotide injections regularly. These work by reducing the amount of hormone that the tumour produces, as well as reducing the symptoms that you may be experiencing. These drugs are given as a monthly injection either by the nurse at the hospital or arranged to be done by yourself , or nominated person at home.

### Chemotherapy

Chemotherapy may be offered to you if your tumour is not responding to other forms of treatment. Chemotherapy is given in order to shrink the tumour, or to temporarily control the growth of the tumour.

### Peptide Receptor Radionuclide Therapy ( PRRT)

This is a targeted form of radiotherapy. When injected into the patient's bloodstream, the radiopeptide travels to and binds to neuroendocrine tumour cells, delivering a targeted high dose of radiation directly to the cancer cells in order to destroy them.

### Active monitoring

If your tumour is not causing you any symptoms, then you may decide, in discussion with you doctor, not to have any immediate treatment, but to take a 'watch and wait' approach. You will be regularly monitored in the Oncology Clinic for any changes in your condition. If these occur, you may be offered treatment.

## Your multidisciplinary meeting (MDT)

Your treatment plan will be decided by your doctor and several other specialists at a fortnightly meeting. This is called the Neuroendocrine Multidisciplinary Team (NET MDT) meeting. Members of the MDT include:

- surgeons—often hepatobiliary, colorectal or thorax consultants (doctors who specialise in operations involving the liver, pancreas, bowel or chest)
- a radiologist (a specialised X-ray doctor)
- a pathologist (a doctor who studies body tissues)
- an oncologist (a specialist cancer doctor)
- an endocrinologist ( a doctor specializing in treating disorders of the endocrine system)
- medical consultants
- neuroendocrine tumour nurse specialist (NET CNS)

## Clinical trials

Research continues into cancers and the treatments available. You may be asked by your doctor if you would like to take part in a clinical trial and this will be discussed fully with you. You will also be required to give written consent. If you decide that you do not want to take part in a clinical trial, this will not affect your treatment in any way.

## Support

You may experience a range of emotions from disbelief to anger. It is important that you talk through how you are feeling. You may wish to talk to family and friends, the health professionals looking after you, or other people who can offer you support. It is important to do what you feel is best to help you cope with your situation, and for you to be aware that help is available if you would like it.

You may find that you have more than one key worker as you meet one who deals with the area of the body that your tumour is in and one dealing with the neuroendocrine cells. Both are there to help you and work together in supporting you.

## What is a Holistic Needs Assessment (HNA)?

This is a chance for you to think about your concerns and discuss possible solutions with your key worker. It gives you the time to explore what resources, help and support are available.

Please ask your key worker for a Holistic Needs Assessment if you think that this would be helpful for you.

For more information go to [www.macmillan.org.uk](http://www.macmillan.org.uk) and search for “holistic needs assessment”.

## Other sources of information and support

### Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary, LE1 5WW

Opening hours Monday to Friday 9:30 am to 4:30 pm

**Telephone:** 0116 258 6189

**Email:** cancerinfo@uhl-tr.nhs.uk

**Website:** www.leicestershospitals.nhs.uk/cancerinfo

### Neuroendocrine Cancer UK

Offers support and information to all affected by neuroendocrine cancer.

**Helpline:** 0800 434 6476

**Website:** www.neuroendocrinecancer.org.uk

### AMEND

### Association for Multiple Endocrine Neoplasia Disorders

**Website:** www.amend.org.uk

### Macmillan Cancer Support

For information and support from cancer support specialists.

**Freephone:** 0808 808 00 00

**Website:** www.macmillan.org.uk

### Cancer Research UK

Ask specialist nurses about anything to do with cancer.

**Freephone:** 0808 800 4040

**Website:** www.cancerresearchuk.org

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