

# Neuroendocrine tumours and the treatments available to you

Cancer Services

Information for patients



## 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.

Other neuroendocrine tumours may be referred to as gastroenteropancreatic tumours, or GEPs. GEPs can develop in the stomach, pancreas or intestines. These tumours are known by the type of cell that the tumour started in and include:

- VIPomas
- Insulinomas
- Somatostatinomas
- Gastrinomas
- Glucagonomas

Your consultant will tell you which neuroendocrine tumour you have.

## 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 Chromagranin 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.

## What tests might I have? (continued)

- **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.
- **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 your 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.

## What treatments are available? (continued)

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 [macmillan.org.uk/recoverypackage](http://macmillan.org.uk/recoverypackage)

## Further information

### Macmillan Information and Support Centre

Osborne Building, Leicester Royal Infirmary, Leicester, LE1 5WW

Telephone: 0116 258 6189

Email: [cancerinfo@uhl-tr.nhs.uk](mailto:cancerinfo@uhl-tr.nhs.uk)

Website: [www.leicestershospitals.nhs.uk](http://www.leicestershospitals.nhs.uk)

### NET Patient Foundation

Offers information and advice to those affected by neuroendocrine tumours.

Freephone: 0800 434 6476

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

### AMEND

### Association for Multiple Endocrine Neoplasia Disorders

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

### Cancer Research UK

Ask specialist nurses about anything to do with cancer.

Freephone: 0808 800 4040

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

## Further information

### Macmillan Neuroendocrine Nurse Specialist

Sophie Noble 07950 888023

Working hours Monday to Friday 8am-4pm

Please ask for details of the local NET Support group.

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



Leicester's Hospitals is a research active trust so you may find research is happening on your ward or in your clinic.

To find out more about the benefits of research and become involved yourself, speak to your clinician or nurse, call 0116 258 8351 or visit [www.leicestersresearch.nhs.uk/patient-and-public-involvement](http://www.leicestersresearch.nhs.uk/patient-and-public-involvement)

For maps and information about visiting  
Leicester's Hospitals visit  
[www.leicestershospitals.nhs.uk](http://www.leicestershospitals.nhs.uk)

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format such as EasyRead or Braille, please telephone the  
number below or email [equality@uhl-tr.nhs.uk](mailto:equality@uhl-tr.nhs.uk)

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔

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**0116 250 2959**

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