



Welcome to Birmingham Neuroendocrine Tumour Centre A European Neuroendocrine Society certified Centre of Excellence

This booklet provides an introduction to our services, outlines what you can expect as a patient and details further information about neuroendocrine tumours.

Neuroendocrine tumours are cancers that are also called tumours, neoplasms or cancers. They are often referred to as '**NETs**' for short.

We have been a European Neuroendocrine Tumour Society (ENETS) certified Centre of Excellence since 2013 and are one of the largest centres managing patients with neuroendocrine tumours in the UK.

Patients who have been diagnosed with a neuroendocrine tumour are usually referred to an ENETS Centre of Excellence, where there are experts in the management of all aspects of NETs.

What are neuroendocrine tumours?

- They are relatively rare cancers. Although their incidence is increasing such that they are now the tenth most prevalent cancer in England.
- They are usually slow growing and they have been described as 'cancer-like' or benign.
- Although certain types of neuroendocrine tumours are slow growing, they can still spread to other areas in the body, this is called 'metastases'.
- They can develop anywhere in the body, although are more commonly found in the small bowel, lung, and pancreas.
- Some neuroendocrine tumours can produce hormones that may cause symptoms. The most common symptoms are diarrhoea and facial flushing. This is called 'carcinoid syndrome'.
- There will be a group of neuroendocrine tumours that need further treatment, surgery, continuous follow-up and surveillance with scans, blood and urine tests.
- There will be a group of neuroendocrine cancers that will not need further follow-up when they have been removed during surgery, such as many appendiceal neuroendocrine Tumours.
- Some neuroendocrine tumours will be faster growing, patients may be cared for by a NET team or an oncology team.
- Neuroendocrine carcinomas are a separate group of 'aggressive' cancers that are managed by oncology teams.

What to expect when you are referred to our centre

- The doctors looking after you or your general practitioner (GP) will send a referral over to us. They are known as the 'referrers'.
- Once we have received all the important information about you, we can then review your case with all the NET experts. This takes place in a multidisciplinary team meeting (MDT meeting), held once a week on a Thursday afternoon.
- There are additional specialist MDT meetings that also take place, when we need to discuss more complex issues that involve the heart and complex surgical cases.
- When we have completed all our discussions we email the MDT recommendation back to your referring team, who will then update you regarding the plan.
- We often then arrange to see you at our centre or ask your referring team to see you.
- The discussions and plan from the MDT meeting will be discussed with you at the clinic appointment.

Neuroendocrine Tumour Team

Dr Tahir Shah: Consultant Hepatologist and Liver Transplant Physician; Neuroendocrine Tumour Specialist and Lead for Birmingham NET Service.

Dr Ian Geh: Consultant Clinical Oncologist, Neuroendocrine Tumour Specialist and Deputy Lead Birmingham NET Service.

Dr Mohamad Roji: Consultant Clinical Oncologist, Neuroendocrine Tumour Specialist

Professor Shishir Shetty: Consultant Hepatologist, Neuroendocrine Tumour Specialist and Cancer Research UK Advanced Clinician Scientist.

Dr John Ayuk: Consultant Endocrinologist, Neuroendocrine Tumour Specialist.

Dr Hema Venkataraman: Consultant Endocrinologist, Neuroendocrine Tumour Specialist.

Dr Selva Selvaraj: Consultant Respiratory Physician - Respiratory Medicine and Neuroendocrine Tumour Specialist.

Mr Samuel Ford: Consultant Sarcoma and NET Surgeon.

Mr Bobby Dasari: Consultant Liver Transplant and HPB Surgeon.

Dr Simon Hughes: Consultant Nuclear Medicine Radiologist.

Dr Mohamed El-Sayed: Consultant Nuclear Medicine Radiologist.

Dr Salil Karkhanis: Consultant Interventional Radiologist.

Mr Maninder Kalkat: Consultant Thoracic Surgeon.

Ms Vanessa Rogers: Consultant Thoracic Surgeon.

Information for Patients

Professor Rick Steeds: Consultant Cardiologist and Carcinoid Heart Disease specialist.

Dr Shanat Baig: Consultant Cardiologist and Carcinoid Heart Disease specialist.

Mr Stephen Rooney; Consultant Cardiac Surgeon and Carcinoid Heart Disease Specialist.

Mr Ahmed Ashoub: Consultant Cardiac Surgeon and Carcinoid Heart Disease Specialist.

Mrs Elizabeth Bradley: Neuroendocrine Tumour Specialist Dietician.

Ms Stacey Smith: Neuroendocrine Tumour Clinical Nurse Specialist.

Mrs Suzanne Vickrage: Neuroendocrine Tumour Clinical Nurse Specialist.

Mrs Joanne Kemp-Blake: Neuroendocrine Tumour Clinical Nurse Specialist.

Mr Chris Coldham: Neuroendocrine Tumour and Nuclear Medicine Clinical Nurse Specialist.

Ms Jessica Vale: Neuroendocrine Tumour Administrator.

Neuroendocrine Tumour Clinics

Monday morning in the new Queen Elizabeth Hospital Birmingham building, Outpatient Area 2, reception 4B.

Monday afternoon monthly Carcinoid Heart Disease clinic. Centre for rare Diseases, Heritage Building based in the old Queen Elizabeth Hospital.

Tuesday afternoon in the Centre for Rare Diseases, Heritage Building based in the old Queen Elizabeth Hospital.

Wednesday afternoon monthly Oncology Liver Transplant clinic, in the Centre for Rare Diseases, Heritage Building in the old Queen Elizabeth Hospital.

There is an information stand in the clinic where you will find lots of useful information.

Support and information

- **Clinical Nurse Specialists** at your local hospital will often be your main contact and provide ongoing support.
- **The Neuroendocrine Tumour Clinical Nurse Specialist Team**, you will often meet us during the first clinic appointment. NET clinical Nurse Specialist working hours: Monday to Friday 8:00am -16:00pm.
- **All non-urgent queries should be discussed at the clinic appointment.** Call the office number on 0121 371 7993 and leave a message with your name, hospital number, contact

Information for Patients

number and what the call is regarding. If you do not have a response in 3 working days, please call again. If the call is regarding an urgent matter, we ask you to call your General Practitioner (GP), 111 or present at your local accident and emergency department.

- **General Practitioner (GP) Team** will often provide ongoing care and support you. This may be to help with health issues not related to your cancer or to help with some of the symptoms caused by the cancer. The GP team will be able to assess and discuss any psychological or social needs you may have and refer you to other support services.
- **Neuroendocrine Cancer UK (NCUK)** We work closely with the Neuroendocrine Cancer UK (NCUK) Charity. They provide lots of information and support for patients and carers. NCUK provide psychological support services, including counselling sessions, Mindfulness and Living Well with Neuroendocrine cancer programmes.

You can access this information online or speak to them over the phone.

Helpline: **0800 434 6476**

Website: [Home - Neuroendocrine Cancer UK](#)

- **The Patrick Room** is based in the Cancer Centre at Queen Elizabeth Hospital Birmingham. The team provide information and support to patients and carers. The Patrick Room is open from 10:00 to 16:00 Monday to Friday.

For more information, please telephone **0121 697 8417**.

- **MyHealth@QEHB** is available to patients at Queen Elizabeth Hospital Birmingham. It is a system where patients can access appointments, clinic letters and routine blood results. Please speak to a member of the team if you would like to register and use this service.
- **Macmillan Cancer Support**
[Macmillan Cancer Support | The UK's leading cancer care charity](#)
<https://www.macmillan.org.uk/get-involved/campaigns/telephone-buddies>
Available seven days a week, 8am-8pm on **0808 808 00 00**.
- **Help Harry Help Others Solihull and Birmingham.**
Patients can self-refer by calling 0121 783 5407.
- **Maggie's**
[The difference we make | Maggie's \(maggies.org\)](#)

Information for Patients

How did we do?

There are many ways you can provide feedback to the team:

Friends and Family test

You can provide feedback online [Friends and Family Test \(uhb.nhs.uk\)](https://uhb.nhs.uk/friends-and-family-test) or complete the paper feedback during the clinic visit.

You can provide verbal feedback or suggestions to the Neuroendocrine Tumour Team.

We ask all patients to consider providing patient satisfaction feedback received at our Centre to The European Neuroendocrine Tumour Society. Please see the QR code and link below:

URL: <https://qhweb.co.uk/enets/?UKBIR>

Or scan the QR code:



Neuroendocrine Tumour Charity Fund University Hospitals Birmingham: Improving care for our patients.

Donations to the NET Fund help improve services for our patients. Charity support has helped us bring new and advanced treatments to the centre.

We have included some information for those who wish to be involved or donate to our Neuroendocrine Tumour Fund.

There are a number of ways to get involved and raise funds for the NET charity such as considering a monthly contribution to our NET fund at Queen Elizabeth Hospital Birmingham or being involved in an organised event. Patients, family and friends may choose to donate in memory of a loved one or leave a donation in their Will.

Please see details below and ask a member of the team if you would like more information. You can also contact our hospital charity team for further information, please see details below:

QEHB Charity
Nuffield House
QEHB
B15 2TH

Information for Patients

Or donate online: www.hospitalcharity.org

Select- Neuroendocrine Tumour Fund

Cheques made payable: Queen Elizabeth Hospital Charity- Neuroendocrine Tumour Fund to above address.

Or directly via bank transfer:

Bank: Barclays

Sort code: 20-07-89

Account number: 83304124

Reference: 15-5-855 (the reference number relates to the neuroendocrine tumour fund)

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email: interpreting.service@uhb.nhs.uk