

# Neuroendocrine Tumour Service

## Information for patients

---

This leaflet is about the neuroendocrine tumour (NET) service and explains what we do and what you can expect from us. Please contact us using the telephone numbers below if you have any questions about your cancer or treatment plan. If we are not able to answer there is an answer machine on all numbers for you to leave a message and we will call you back.

Dr Lucy Wall	Consultant Medical Oncologist	0131 537 3039 (secretary)
Professor Mark Strachan	Consultant Endocrinologist	0131 537 2810 (secretary)
Dr Stuart Ritchie	Consultant Endocrinologist	0131 537 1753 (secretary)
Katie Gibson	Nurse Specialist	0131 537 3795

## What are NETs?

NETs are rare cancers that develop from neuroendocrine cells. The neuroendocrine system makes chemical messengers called hormones, which regulate the workings of different organs in the body. NETs sometimes make too much of certain types of hormone, which cause symptoms when they are released into the blood stream. The symptoms of a NET can vary depending on where it is and what hormones it is producing.

You can read more about NETs on these websites:

Neuroendocrine Cancer UK: [www.neuroendocrinecancer.org.uk](http://www.neuroendocrinecancer.org.uk)

MacMillan Cancer Support: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Cancer Research UK: [www.cancerresearchuk.org](http://www.cancerresearchuk.org)

## What we do

### NET clinic

The NET clinic is held on a Monday afternoon every 2 months in the Metabolic Unit at the Western General Hospital. You will meet with members of the NET team at the clinic, either one of the consultants or one of the trainee doctors that works alongside the team. The nurse specialist is in attendance at the clinic and the medical team will notify them of any patients who require additional support. We can have other health care staff working with us such as medical and nursing students.

We will ask about your general health and about any symptoms you are currently experiencing. We may also have scan results to discuss with you and may ask for some blood tests to be taken. We will give you as much or as little information about your cancer as you wish and will answer your questions openly and honestly. It can also be helpful to write down any questions you may have and bring these with you to clinic. You are very welcome to bring family or friends with you.

You may also be reviewed out with the specialist NET clinic by one of the consultants or at a clinic run by the nurse specialist.

## Cancer team meeting

The NET team meet on a monthly basis to discuss any new patients, review cases and discuss scan and test results. At this meeting the specialist doctors and nurse piece this information together to help us plan the best way to manage your cancer. This meeting is for NHS staff only. If your case is being discussed we will telephone you after the meeting to update you or will arrange to meet you in clinic to discuss. We also send a letter to your GP to let them know what was discussed at the meeting.

## Managing NETs

Sometimes we need to have more information before recommending a treatment and may arrange for you to have some more tests. We know that waiting for test results can be a worrying time so we will arrange to give you results as quickly as possible.

We will give you written information about any treatment and discuss the potential benefits and any side effects which may occur.

The most commonly used treatment for NETs are injections called Somatostatin Analogues. These work by slowing down the production of hormones from the cancer cells and can also slow the growth of the cancer itself. These are given every 4 weeks at the GP practice. There are other treatments available; your consultant will discuss these with you if these are appropriate.

## Other resources

The Ann Edgar Charitable Trust is the Scottish charity for patients diagnosed with a NET and has close links with the national NET Charity; The NET Patient Foundation. They run monthly support meetings in Edinburgh and Fife where you can meet with other patients and relatives. You may also wish to visit Maggie's Centre or the Macmillan Cancer Information and Support Centre for emotional and practical support and information including help with benefits and finances. Please ask us for details of any of these services or contact:

**Neuroendocrine Cancer UK** ([www.neuroendocrinecancer.org.uk](http://www.neuroendocrinecancer.org.uk))

Telephone: 0800 434 6376

**The Ann Edgar Charitable Trust (TAECT)** ([www.taect.scot](http://www.taect.scot))

Telephone: 07376251249

Email: [info@taect.scot](mailto:info@taect.scot)

**Maggies Edinburgh** (<https://www.maggies.org/our-centres/maggies-edinburgh/>)

The Stables, Western General Hospital, Edinburgh, EH4 2XU

Telephone: 0131 537 3131

**MacMillan Information and Support Centre**

South Corridor, Western General Hospital, Edinburgh, EH4 2XU

Telephone 0131 537 3907

We can also give you details of support services out with Edinburgh.

## Translation Services

This leaflet may be made available in a larger print, Braille or your community language.