

NET Patient Foundation

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NET Patient Foundation (NPF) is a UK wide charity solely dedicated to providing support and information to those affected by Neuroendocrine Cancer.

The Neuroendocrine System

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The Neuroendocrine System is made up of specific cells, found throughout the body, that help regulate normal bodily functions such as breathing and digestion.

Neuroendocrine Cancer

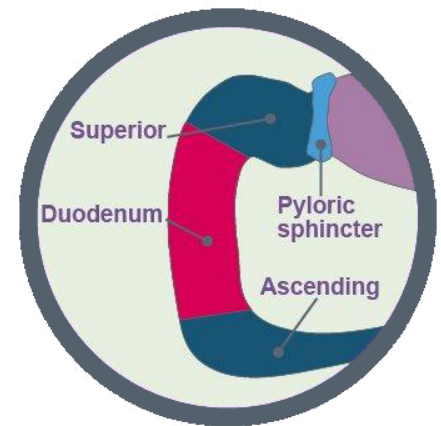
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Neuroendocrine Cancer is a term used to cover a group of cancers that start in neuroendocrine cells. These cancers may also be referred to as NETs, NECs, **NENs (Neuroendocrine Neoplasms)** or even Carcinoids. Neuroendocrine Cancer occurs when neuroendocrine cells stop working normally and start to grow or behave abnormally.

Further information about Neuroendocrine Cancer, including videos and support services can be found at www.netpatientfoundation.org

The Duodenum

The duodenum is the short tube that connects the stomach to the rest of the small bowel (aka small intestine). It is here that semi-digested food and stomach acid (chyme) is 'processed' so that nutrients can be absorbed as it passes through towards the large bowel. Key nutrients absorbed in the duodenum include iron, vitamins A and B1, calcium and other nutrients. Further information about nutrient absorption and dietary advice can be found in Section 5 of the NPF Handbook and in our Gut Surgery: How Diet can Help booklet - www.netpatientfoundation.org



Signs and symptoms of a duodenal NEN can be related to tumour position / size (1) and / or excess hormone production (2) :

1. Discomfort/pain, nausea +/- vomiting and jaundice (yellowing of skin and whites of the eye) - if blocking flow of bile
2. For example, Zollinger-Ellison Syndrome (ZES) - excess gastrin causing acid reflux, burping, potentially stomach/duodenal ulcers +/- chest pain.

NET or Neuroendocrine Tumour is neuroendocrine cancer with well-differentiated cells that usually has a slow to moderate growth rate.

NEC or Neuroendocrine Carcinoma is neuroendocrine cancer with poorly-differentiated cells that grow more rapidly.

Blood / Urine Tests

- Full blood count
- B12 (+ serum Iron)
- Liver and kidney function
- Biochemical :
- Chromogranin A (and B)
- Urinary 5-HIAA
- Gut Hormone Profile
- Thyroid function
- LDH
- MEN1 screen
- Consider Genetic testing (eg MEN1, VHL, etc).

Endoscopy

- Upper endoscopy – OGD +/- biopsy
- Endoscopic Ultrasound (EUS) +/- biopsy.

Scans

- CT or MRI
- Octreotide (SPECT) scan or Gallium-Dotatate PET/CT
- FDG-PET – if High Grade / rapidly progressing disease.

Pathology

- Differentiation and cellular morphology
- Synaptophysin
- Chromogranin
- Gut hormone (gastrin, etc)* - optional
- Ki67
- SSTR 2a (optional).
- * nb/may not have functional symptoms.

For all patients, there are many things to consider in planning treatments. Your treatment will be personalised to you and the type of NEN you have.

Even if you have a diagnosis that sounds the same as another patient, your treatment and follow up plan may be different.

Your care team will discuss your treatment options with you - giving you both written and verbal information - to help you make an informed choice. Together you can agree on the most appropriate treatment for you.

Information about the treatments that are used in NET and NEC can be found in the NPF Handbook - Your Guide to Living with Neuroendocrine Cancer - www.netpatientfoundation.org

There is consensus agreement that all Neuroendocrine Cancer patients should be reviewed by a Specialist Neuroendocrine Cancer MDT.

For patients with Grade 1 - 2 NET - who have had R0/1 resection:

- 3 - 9 monthly CT or MRI and biochemistry (type depending on pre-operative results) – extend interval as per stability of disease
- Endoscopic surveillance 12-24 months
- Functional imaging 18 - 24 months.

For Grade 3 NET/NEC:

- Resected disease - Contrast CT scan every 3 - 6 months for 2 - 3 years, and then every 6 - 12 months
- Residual / Advanced disease - Contrast CT scan every 2 - 3 months if on therapy
- Endoscopic surveillance : as clinically indicated – 6 - 12 months
- Functional imaging 18 - 24 months – or earlier if progression suspected
- Biochemistry if elevated at diagnosis.

Advanced disease:

- Follow up as per guidelines – nb should be guided by prognosis, expected treatment efficacy and treatment related toxicity (performance status and clinical indication for active intervention).

A big part of meeting with your doctors, or specialist nurse, is to make sure you get the information you need to understand what's happening, so that you can make an informed choice about your care. Asking questions can be difficult, especially if you're feeling nervous, confused, frightened or struggling to understand what you are being told. You might want to know as much as possible straight away or prefer to take things in small amounts at your own pace.

Suggestions that may help:

- Prepare a list of questions that are important to you
- Ask for simple explanations - do not be worried about asking your nurse or doctor to repeat what they have said
- Take someone with you or ask if you can record the conversation. Many mobile phones have a record function or an app you can download
- Ask for a copy of any letters sent to your GP and/or other care team(s)
- If you have a nurse specialist - keep in touch. They can be a great source of information and support for you.

Example questions:

- Who can I call if I have any questions? Who is my main point of contact?
- Who will be involved in my care?
- What are the treatment options for me? How might they affect me ?
- How often will I need to have scans and tests?
- Are there any flags or warning signs I need to look out for?

Further information about making the most of your consultations can be found in our handbook:
www.netpatientfoundation.org

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