

NET Patient Foundation

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

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

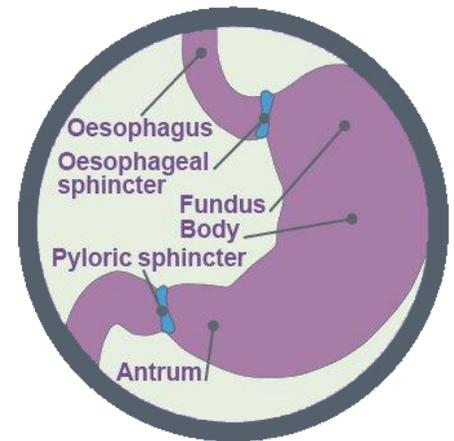
Neuroendocrine Cancer

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 Gastric (Stomach)

Once food is swallowed, it passes down the food pipe (oesophagus) into the stomach - and because we can put food into our body quicker than our body can digest and absorb it - we need a 'holding pouch' to store food temporarily - the stomach. While in the stomach, food can be



further broken down by acid and enzymes into a "mulch" called chyme, which then passes, in regular small amounts into the small bowel (duodenum, jejunum and ileum) where nutrients, including key vitamins can be more effectively absorbed. Specific cells called parietal cells within the stomach produce intrinsic factor, which is essential for the absorption of vitamin B12. Other gut hormones includes those responsible for stomach wall and small bowel muscle wall contraction (needed to move food through the gut), and those that stimulate hunger/ feeling full (satiety).

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.

Stomach NENs account for less than 1% of all stomach cancers. There are 3 confirmed types:

- **Type 1** : account for 70-80%, often associated with autoimmune chronic atrophic gastritis, achlorhydria (low levels of hydrochloric acid) and hypergastrinaemia (high levels of gastrin). Type 1 is rarely aggressive and unlikely to spread to other parts of the body (metastasise). Low vitamin B12 may be seen, along with Anti-parietal cell and anti-intrinsic factor antibodies. Gastric pH may be high (>4)
- **Type II** : approximately 7-10% , is associated with Zollinger-Ellison syndrome and Gastrinomas, often as part of MEN1. The lesions are usually small and multiple. Type II is predominantly low grade (1-2) and though metastases are rare, the potential is higher than with Type 1. Vitamin B12 may be normal, iron deficiency is common, anti-parietal cell antibodies may be negative, gastrin (off PPIs) is high but gastric pH may be low (<2)
- **Type III** : approximately 20% of all gastric NENs and is not typically associated with high gastrin, despite presence of ulceration. It may produce a solitary, larger lesion than seen in Types I & II, often >2cms. Type III is usually of a higher grade (G3), may be well (NET) or poorly (NEC) differentiated and is more likely to metastasise.



Diagnosis for Gastric (Stomach)

Blood / Urine Tests

- Full blood count
- B12 (+ serum Iron)
- Parietal cell and intrinsic factor antibodies
- Liver and kidney function
- Biochemical :
- Chromogranin A (and B)
- Urinary 5-HIAA
- Gastric pH
- Genetic analysis is recommended in case of suspected MEN-1

Endoscopy

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

Scans

- CT or MRI – for type III
- Octreotide (SPECT) scan or Gallium-Dotatate PET/CT : type II and III
- FDG-PET – if High Grade / rapidly progressing disease.
- Type 1 – biopsy background mucosa for dysplasia

Pathology

- Differentiation and cellular morphology
- Haematoxylin and oesin
- Synaptophysin
- Chromogranin

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.

Endoscopic follow-up is recommended for patients with g-NENs (stomach) following excision:

- Type I: Conservative management - Lab + clinical control every 6–12 months, as clinically indicated, with OGD + biopsies and/or polyp resection every 12–24 months.
- Type II tumours, endoscopy should be repeated yearly + lab. Polyps <1cm can be managed as per Type I.
- Type III (and IV), after gastrectomy, should follow programs indicated for gastric adenocarcinomas.
- Type III (and IV), inoperable or metastatic, should follow adenocarcinoma protocol as general health, symptoms, treatment options allow.
- 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

REFERENCES

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Management of patients with Gastric Neuroendocrine Neoplasms. Clinical Practice Page UKINETs. www.ukinets.org