

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

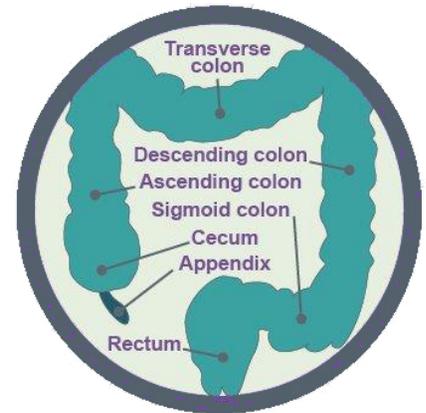
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Neuroendocrine Cancer is a term used to cover a group of cancers that start in neuroendocrine cells. These cancers may also be referred to as NETs, NECs, **NENs (Neuroendocrine Neoplasms)** or even Carcinoids. Neuroendocrine Cancer occurs when neuroendocrine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

The large bowel is also known as the large intestine or colon. It forms the last part of the digestive system leading to the rectum. As food passes through the digestive system it is broken down and the nutrients we need to survive are extracted. By the time it reaches the colon it is mostly fluid and waste



product. Bacteria in the colon breaks down any remaining substances and water is absorbed – whatever remains passes into the rectum to be excreted as waste ('stool'). Bloating, gas and pain may be experienced if the colon isn't working properly – diarrhea and/ or constipation can occur. Irritation of the lining of the colon or damage such as a tumour forming can lead to bleeding which may appear in the stools, as blood, or the stool may be black and tarry.

Colonic NENs are often aggressive, poorly differentiated and higher grade (G3) making them Neuroendocrine Carcinomas (NECs) rather than NETs, however some colon NENs may be lower grade and well-differentiated, therefore NETs.

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 / Iron/ ferritin/folate
- Liver and kidney function
- Biochemical :
- ChromograninA
- Urinary 5HIAA
- CEA
- $\beta\epsilon\alpha$ -HCG.

Endoscopy

- Colonoscopy +/- biopsy.

Scans

- Contrast CT chest/abdo/pelvis
- Octreotide (SPECT) scan or Gallium-Dotatate PET/CT
- FDG-PET.

Pathology

- Differentiation and cellular morphology
- Synaptophysin
- Chromogranin
- Ki67
- Low molecular weight keratins
- GLP
- PP/PYY
- CD56.

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.

Following surgery/endoscopic resection for minimum 10 years:

- G1/2 <1cm: no lymph nodes, no evidence of invasion: there is no data re recommended follow up.
- G3 <1cm: annual follow up with colonoscopy.
- G1/2 1-2cm: annual follow up with colonoscopy.
- Biochemistry alongside colonoscopy/scan.

ALL NETs/NECs >2cm require ongoing follow up – minimum 10 years (nb metastatic disease has been seen beyond this time):

- G1/2: annual colonoscopy + CT + biochemistry
- G3: 4 - 6 monthly colonoscopy + CT + biochemistry for the first year, then annually

If liver tumours present – for MRI or contrast multislice, triphasic CT concurrent with follow up timings.

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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