

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

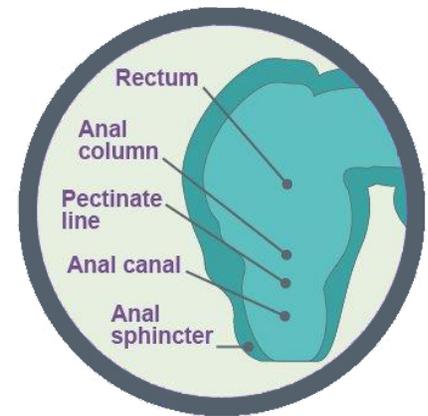
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Neuroendocrine Cancer is a term used to cover a group of cancers that start in neuroendocrine cells. These cancers may also be referred to as NETs, NECs, **NENs (Neuroendocrine Neoplasms)** or even Carcinoids. Neuroendocrine Cancer occurs when neuroendocrine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

The rectum is the final segment of the large intestine that connects the colon to the anus. It stores waste produced in the colon until the body is ready to eliminate the waste through the process of defecation. It is a hollow muscular tube about 8 inches (20 cm) in length and 2.5 inches in diameter at its widest point.



Although rectal NENs are one of the most commonly diagnosed intestinal NENs (in part related to colon cancer screening investigations) they are amongst the least common colorectal cancers (<1%).

They are often asymptomatic, but approximately 50% can present with rectal bleeding, changes in bowel habits, unexplained weight loss, or pain (on defecation).

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
- CEA
- β -HCG
- Pancreatic polypeptide.

Endoscopy

- Endo-anal Ultrasound
- Sigmoidoscopy / Colonoscopy +/- biopsy.

Scans

- Pelvic MRI
- Contrast CT : chest/abdomen/pelvis
- Gallium-Dotatate PET/CT (SRS SPECT/CT if Dotatate PET n/a)
- FDG-PET – if High Grade / rapidly progressing disease.

Pathology

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

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 :

- G1/2 <1cm: no lymph nodes, no evidence of invasion: there is no data re recommended follow up - Nb lesions <1% have a 4% chance of lymph node metastases
- G3 <1cm: annual follow up with endo-anal USS +/- colonoscopy
- G1/2 1-2cm: annual follow up with endo-anal USS +/-colonoscopy
- Biochemistry alongside endo-anal USS/colonoscopy.

ALL NENs >2cm require ongoing follow up:

- G1/2: annual endo-anal USS, colonoscopy + MRI + biochemistry
- G3: 4 - 6 monthly endo-anal USS + colonoscopy + MRI + biochemistry for the first year, then annually.

If liver tumours present – for MRI or contrast multi-slice, tri-phasic 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

REFERENCES

Neuroendocrinology (2016)103:139–143

doi: 10.1159/000443166

Ramage et al : ENETS Consensus Guidelines Update for Colorectal Neuroendocrine Neoplasms

Neuroendocrinology (2012) 95:88–97

doi: 10.1159/000335594

Caplin et al : ENETS Consensus Guidelines for the Management of Patients with Digestive Neuroendocrine Neoplasms: Colorectal Neuroendocrine Neoplasms

ESGE Guideline - Endoscopy (2013) 45: 842–851

doi: 10.1055/s-0033-1344548

Hassan et al : Post-polypectomy colonoscopy surveillance: European Society of Gastrointestinal Endoscopy (ESGE) Guideline

www.ukinets.org