

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.

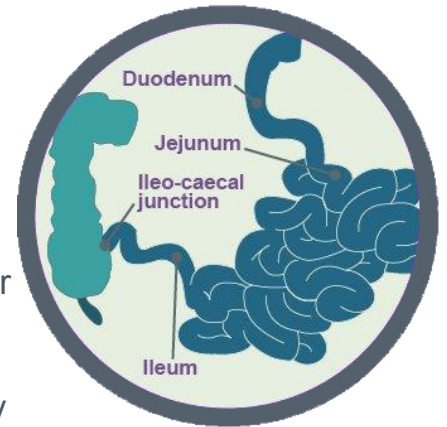
Neuroendocrine Cancer

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

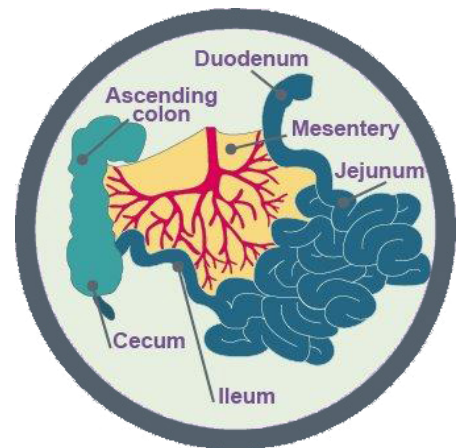
The Small Bowel

The small bowel (or small intestine) is the longest part of the digestive system. It is only about as big around as a middle finger (approximately 1 inch or 2.5 cms) and is from 20 to 25 feet (6 to 7.6 meters) long in an adult. The small intestine's major function is to absorb food and nutrients. Both the jejunum and the ileum have linings with many folds that increase the surface area of the small intestine for maximised nutrient absorption.



The small bowel is anchored within the abdomen by a double fold of peritoneum (lining of the abdomen) called the mesentery. The blood supply to the intestines and lymphatic system also run through this organ. It is not uncommon for small bowel NENs to be associated with or diagnosed because of a mesenteric mass.

Symptoms associated with a small bowel NEN may be acute – presenting as bowel obstruction or ischaemia - or chronic – where it may mimic other conditions such as IBS and/or be consistent with Carcinoid Syndrome (dry flushing, diarrhoea +/- wheeze). Nb Small bowel NENs may occur alongside IBS.



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

- (B12 + serum Iron)
- Liver and kidney function
- Biochemical :
- Chromogranin A (and B)
- Urinary 5-HIAA
- NT-Pro-BNP
- (Thyroid function)

- Echocardiogram : as a baseline in the presence of carcinoid syndrome / raised U5HiAA and / or elevated NT-Pro-BNP +/- clinical signs of heart valve impairment/R sided heart failure

Endoscopy

- Colonoscopy : may be useful in detecting distal ileal disease and for excluding synchronous colorectal tumours/cancer
- VCE – video capsule endoscopy

Scans

- CT thorax/abdo/pelvis or MRI abdo/pelvis
- CT enterolysis
- 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
- cdx-2, p53 and / or SSTR 2a (optional)

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:

- Grade 1 or 2:
 - surgery undertaken with curative intent: 6-12 monthly
 - non-curative surgery / residual disease: 3-6monthly
- Grade 3:
 - 3 monthly

Modalities: CgA, 5HiAA and tri-phasic CT.

Functional imaging if recurrence / progression suspected.

Inoperable disease: as per non-curative protocol nb high risk of sub-acute/acute small bowel obstruction and / or ischaemia.

Consensus guidelines recommend lifelong surveillance.

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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