

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.

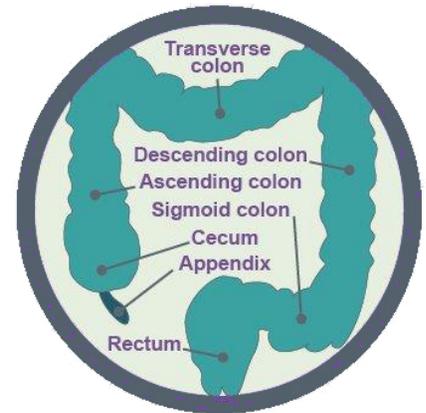
Neuroendocrine Cancer

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 Liver

The liver is the largest gland and the largest solid organ in the body, weighing some 1.8 kg in men and 1.3 kg in women. It holds approximately 13% (about one pint or 0.57 litres) of your total blood supply at any given time and has over 500 functions. It is divided into two main lobes (larger right and smaller left), which are made up of a total of eight segments, which themselves are made up of approximately 1000,000 small lobes or lobules. The liver receives its blood supply via the hepatic artery and portal vein.



Liver functions include: processing digested food from the intestine, combating infections, clearing the blood of particles and infections, including bacteria, neutralising and destroying all drugs and toxins, manufacturing bile, storing iron, vitamins and other essential chemicals, breaking down food and turning it into energy and manufacturing, breaking down and regulating hormones.

The diagnosis of Primary Liver NET is a medical challenge, requiring careful assessment and investigation to correctly identify the type and nature of tumour seen (e.g. has it grown from a liver cell, a bile cell, neuroendocrine cell or other? Is it primary or secondary disease?)

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.

- **Secondary Liver NEN is dependent on the primary tumour site, tumour extent (T-stage), histologic differentiation, and grading (G1-G3)**
- **Pancreas, right hemi-colon and small intestine are the most frequent primary sites associated with distant metastases at initial diagnosis**
- **80–90% with small intestinal and 60–70% of patients with pancreatic NEN show liver metastases**
- **Carcinoid syndrome is regularly associated with distant metastases.**

Blood / Urine Tests

- Full blood count
 - (B12 + serum Iron)
 - Liver and kidney function
- Biochemical :
- Chromogranin A (and B)
 - Urinary 5-HIAA
 - NT-Pro-BNP
 - (CEA, Alpha - Feta Protein, Ca19.9 optional).
- 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

- Dictated by primary site or may help identify primary - in secondary liver NET.

Scans

- Contrast CT : chest/abdomen/pelvis
- MRI Liver
- 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
- Additional staining as per primary site (secondary disease).

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.

Follow up is dependent on whether Liver NEN is confirmed as primary or secondary disease - and on tumour extent, histological differentiation (well-differentiated vs poorly differentiated) and proliferative activity (G1-3).

It may also be dictated by preservation or loss of normal liver function.

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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