

## 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

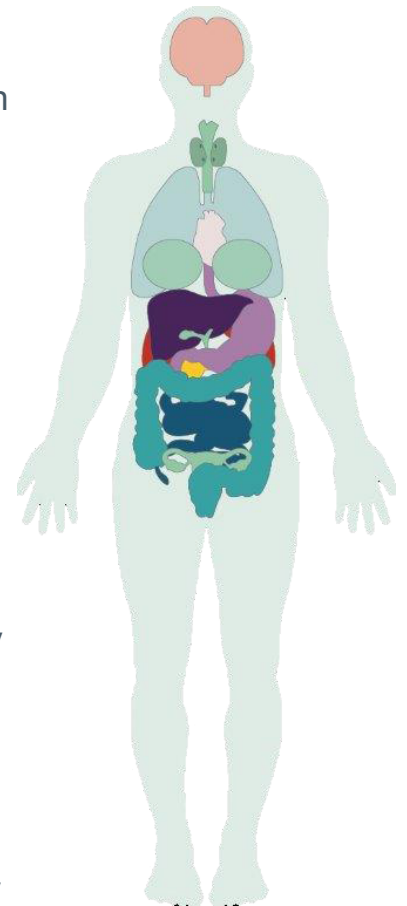
Neuroendocrine Cancer is a term used to cover a group of cancers that start in neuroendocrine cells. These cancers may also be referred to as NETs, NECs, **NENs (Neuroendocrine Neoplasms)** or even Carcinoids. Neuroendocrine Cancer occurs when neuroendocrine cells stop working normally and start to grow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

Further information about Neuroendocrine Cancer, including videos and support services can be found at [www.netpatientfoundation.org](http://www.netpatientfoundation.org)

## Unknown Primary

It is usually possible to work out where a cancer has started, by assessing symptoms and reviewing tests and scans, however sometimes confirmation is not always possible.

This may be due the way NENs develop, they start at a size similar to a grain of sand - and make take many months, possibly years to develop into the size that maybe detectable by scans. Despite small size (sometimes simply a few cells) NENs may still spread (metastasise) - this does not necessarily indicate an aggressive nature, indeed it may occur as a result of chronicity (that is, the primary collection of cells have been there so long, that over time, one or cells may enter the blood or lymph system and travel elsewhere in the body - usually the liver).



Cancer of unknown primary may or may not produce symptoms, if they occur they will depend on the type and site of the primary.

Your medical team may classify your cancer as being of unknown origin - or CUP (Cancer of Unknown Primary).

**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.

Investigations should be guided by presentation - that is, clinical signs and symptoms - and need to include assessing all potential primary sites

Pancreas, lung, right hemicolon and small intestine are the most frequent primary NEN sites associated with distant metastases at initial diagnosis.

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)
- Gut Hormone profile
- Calcium
- Thyroid function tests
- $\alpha$ FP, HCG, LDH, PSA, Ca19-9, Ca125, CEA
- Mid-stream urine sample
- Urinary 5HiAA

## Endoscopy

- as guided by examination / biomarker results

## Scans

- CT chest/abdo/pelvis
- MRI Liver
- Functional imaging : Gallium-Dotatate PET/CT (SRS SPECT/CT if Dotatate PET n/a)
- FDG-PET – if High Grade / rapidly progressing disease.
- Bone scintigraphy - if bone disease present/ suspected

## Biospy

- Biopsy

## Pathology

- Differentiation and cellular morphology
- Synaptophysin
- Chromogranin
- Ki67
- Additional IHC as clinically indicated including

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](http://www.netpatientfoundation.org)

There is consensus agreement that all Neuroendocrine Cancer patients should be reviewed by a Specialist Neuroendocrine Cancer MDT.

Follow up as per histology, grading and staging of disease - guided by results as per probable primary site.

Frequency as per disease status and potential for treatment.

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](http://www.netpatientfoundation.org)

#### REFERENCES

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