

## 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.

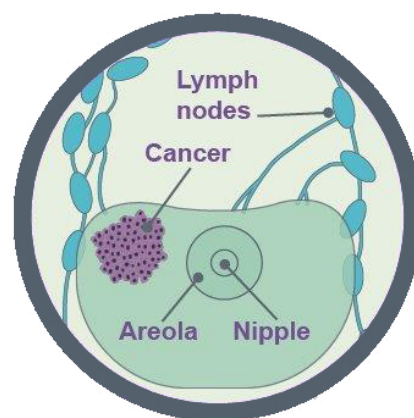
## Neuroendocrine Cancer

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)

## The Breast

Primary NENs of the breast (NECB) are rare, with an incidence of less than 5% of all breast cancers. They are usually diagnosed during tests or following surgery for breast cancer.



Vital to confirming diagnosis is accurate, expert histopathology review.

World Health Organisation (2012) classifies 3 subtypes :

- Well-differentiated neuroendocrine tumour (NET),
- Poorly differentiated neuroendocrine carcinomas or small-cell carcinomas (NEC)
- Invasive breast carcinomas with neuroendocrine differentiation - this is distinct from both NET and NEC.

There are no current standardised guidelines for treatment, but there is an agreement that care should be individualised and specialist opinion sought.

**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
- Liver and kidney function
- Lipid profile
- Breast cancer genetics
- Chromogranin A
- Urinary or serum 5HiAA (serotonin).

## Scans

- Mammogram
- Breast +/- axilla Ultrasound scan
- CT or MRI breast

If further disease or NEN suspected :

- CT chest & abdomen and / or CT chest & MRI abdomen
- Bone scintigraphy if suspect bone metastases.
- Octreotide (SPECT) or Gallium-Dotatate PET/CT.

## Pathology

- Differentiation and cellular morphology
- Synaptophysin
- Chromogranin.

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.

## Following treatment for early breast cancer:

- Annual breast screen for 5 years after treatment - with regular breast clinic review every 3 - 4 months for first 2 years, then every 6 months for years 3 - 5
- After 5 years: if 50 or older - NHS Breast Screening Programme timings. If under 50, annual breast screening until you reach 50, then follow NHS Breast Screening programme.
- Those with early invasive breast cancer do not routinely undergo tests for cancer elsewhere in the body unless they have symptoms of possible disease spread
- Women who have a high risk of developing breast cancer due to family history (including genetic mutations) may be offered additional screening, depending on their age and level of risk.

Breast NENs advice: follow both NHS Breast Screening programme and NEN surveillance as per grading (G1-3\*). Neuroendocrine Cancer of the breast can spread to multiple sites, even after routine follow up is completed, therefore longer-term follow up is recommended.

### \*Grade 1-2 (Ki67 <20%) NET:

- R0 resection - complete removal, no lymph node or distant metastases - contrast CT chest/abdo post surgery then follow NHS Breast Screening Programme.
- R1 or where there is evidence of lymph node +/- distant metastases - longer term follow up recommended, to include annual CT.

### \*G3 (Ki67 >20%) NET or NEC:

- R0 resection - complete removal, no lymph node or distant metastases - contrast CT chest/abdo 3 months post surgery, then follow National Breast Screening Programme.
- R1 or where there is evidence of lymph node +/- distant metastases - longer term follow up recommended, to include annual CT : nb every 2-3 months if on therapy.
- Biochemistry may be used as a surrogate marker in Primary Breast NEN.
- Biopsy is recommended in metachronous disease - especially if there has been a long disease-free interval.
- Secondary breast NEN to be followed up as per primary site guidelines.
- In secondary breast NEN use biochemistry of primary site as marker.

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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