

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

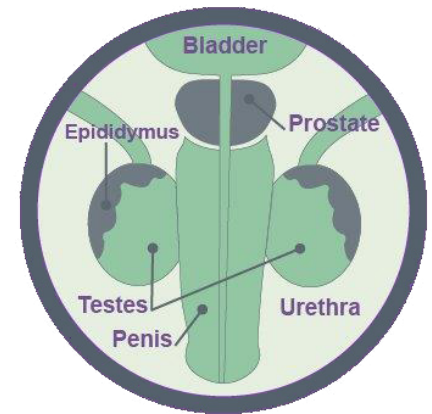
.....

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 Testicles

The testicles are 2 oval-shaped glands, that sit within the scrotal sac, just below the penis. They are responsible for producing and storing sperm, as well as several hormones - the key one being testosterone.



Testicular NENs account for less than 1% of all testicular tumours and can be divided into 3 subtypes:

1. Primary testicular NENs
2. Secondary NENs
3. Those associated with testicular teratoma.

The latter is a distinct disease entity where care and outcome is similar to those of testicular teratoma (a germ-cell type of testicular cancer).

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
- Biochemical :
- Chromogranin -A
- Urinary 5-HIAA
- α FP
- HCG
- LDH
- Mid-stream urine sample

- Testosterone, LH, FSH and semen analysis : consider fertility counselling incl sperm banking

- Clinical examination of testes.

Scans

- Testicular ultrasound +/- biopsy
- CT chest/abdomen/pelvis
- (MRI pelvis +/- spine)
- Bone scintigraphy - if bone involvement suspected
- 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
- Assessment for teratoma / germ cell components.

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.

For further information about testicular cancer, visit www.orchid-cancer.org.uk

Given the rarity of testicular NETs there are no consensus guidelines on follow up - however one can utilise guidelines for testicular cancer follow up - and suggestions from case reports :

- Physical exam and biochemical markers 3-4monthly for first 2 years, then 6 - 12monthly to annually
- CT at 3months, 9 months then 6-12monthly (MRI can replace CT depending on patient status)
- Functional imaging +/- re biopsy may be indicated in recurrent / progressive disease
- Further imaging as clinically indicated - e.g. CT chest.

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(2):172-85.
doi: 10.1159/000443167

Pavel et al :ENETS Consensus Guidelines Update for the Management of Distant Metastatic Disease of Intestinal, Pancreatic, Bronchial Neuroendocrine Neoplasms (NEN) and NEN of Unknown Primary Site.

Case Reports in Urology(2015), Article ID 687482,
<http://dx.doi.org/10.1155/2015/687482>

Petrossian et al : Primary Carcinoid Tumor of the Testis

<http://www.nhs.uk/conditions/Cancer-of-the-testicle/Pages/Diagnosis.aspx>

European Association of Urology :Actas Urol Esp. (2012) 36(3):127-145
Albers et al : EAU Guidelines on testicular cancer: 2011 update