

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.

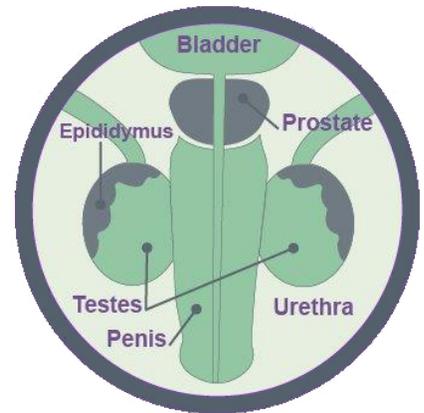
Neuroendocrine Cancer

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 Prostate

The prostate is a small gland about the size of a walnut that sits between the bladder and the penis, just in front of the rectum. The urethra (the tube through which urine is passed) runs through the prostate. The prostate produces seminal fluid, that helps to feed and protect sperm - during ejaculation the prostate secretes this fluid into the urethra, where it mixes with sperm and is expelled through the penis as semen.



True NENs of the prostate gland are rare: high-grade (small or large cell) and/or mixed cell neuroendocrine prostate cancers (<2% of all prostate cancers) are more likely to be seen than well-differentiated NET: diagnosis is ultimately based on histology.

Prostate NENs or Prostate Cancer with a high percentage of neuroendocrine differentiation are less likely to express PSA - however measurement is useful as this may aid diagnosis and direct therapy.

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
- PSA
- CEA
- Pending clinical presentation assessment for ectopic hormone secretion : ACTH, ADH, Thyroxine, Calcium and / or assessment for adrenal hyperfunction
- Mid-stream urine sample

- Digital rectal examination.

Scans

- Trans-urethral cystoscopy +/- biopsy.

Endoscopy

- Trans-rectal ultrasound +/- biopsy
- CT chest/abdomen/pelvis
- MRI pelvis +/- spine
- Bone scintigraphy - if bone involvement suspected
- FDG-PET.

Pathology

- Differentiation and cellular morphology
- Synaptophysin
- Chromogranin
- CEA / PSA
- Ki67
- Fluorescent in situ hybridisation (FISH)
- TMPRSS2-ERG gene rearrangement (present in 50% of patients) distinguishes PD-NECs of the prostate from small cell carcinomas of other primary sites.
- Gleason grade - based on adenocarcinoma component.

For all cancer patients, medical care including treatments need to be personalised not only to the specific type of cancer, but also the specific background medical history and current health status of the individual affected. So even if you have a diagnosis that sounds the same as someone else's, your care and treatment may be different. Your medical team will discuss your care and treatment options with you, so that, together, you can make an informed choice about your ongoing plan of care.

Further information about treatments 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 prostate cancer contact prostatecanceruk.org

There are no consensus guidelines for Prostate NEN:

- Absolute NEN is rare (limited case studies worldwide) - and advice is scant - PSA is usually within normal range however chromogranin A and other NEN biomarkers may be elevated.
- Follow up as clinically indicated.
- Small cell and large cell neuroendocrine carcinoma (NEC), and mixed NEC/acinar carcinoma (large and small cell) and adenocarcinoma with Paneth cell-like NE differentiation - would follow prostate cancer recommendations - with note taken of presence / absence of androgen receptor as this may affect treatment strategies.
- Follow up as per prostate cancer protocols / clinically indicated.
- 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

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