**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.
Diagnosis for Duodenum

Blood / Urine Tests

- Full blood count
- B12 (+ serum Iron)
- Liver and kidney function
- Biochemical :
  - Chromogranin A (and B)
  - Urinary 5-HIAA
  - Gut Hormone Profile
  - Thyroid function
  - LDH
  - MEN1 screen
  - Consider Genetic testing (eg MEN1, VHL, etc).

Endoscopy

- Upper endoscopy – OGD +/- biopsy
- Endoscopic Ultrasound (EUS) +/- biopsy.

Scans

- CT or MRI
- Octreotide (SPECT) scan or Gallium-Dotatate PET/CT
- FDG-PET – if High Grade / rapidly progressing disease.

Pathology

- Differentiation and cellular morphology
- Synaptophysin
- Chromogranin
- Gut hormone (gastrin, etc)* - optional
- Ki67
- SSTR 2a (optional).
* nb/may not have functional symptoms.

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Treatment for Duodenum

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 for Duodenum

As per national and international guidelines nb local policy may vary

For patients with Grade 1 - 2 NET - who have had R0/1 resection:
• 3 - 9 monthly CT or MRI and biochemistry (type depending on pre-operative results) – extend interval as per stability of disease
• Endoscopic surveillance 12-24 months
• Functional imaging 18 - 24 months.

For Grade 3 NET/NEC:
• Resected disease - Contrast CT scan every 3 - 6 months for 2 - 3 years, and then every 6 - 12 months
• Residual / Advanced disease - Contrast CT scan every 2 - 3 months if on therapy
• Endoscopic surveillance : as clinically indicated – 6 - 12 months
• Functional imaging 18 - 24 months – or earlier if progression suspected
• Biochemistry if elevated at diagnosis.

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).

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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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