Pancreatic NETs

The pancreas is a large gland that produces insulin and other hormones. Pancreatic NETs can be described as - **functioning and non-functioning.**

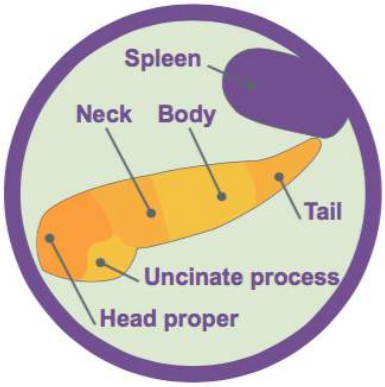
Functioning pancreatic NETs cause a specific set of symptoms (also known as a syndrome).

NETs in this category include insulinomas, gastrinomas, VIPomas, somatostatinomas and glucagonomas. (see The NET Handbook for more information on syndromes).

Non-functioning pancreatic NETs don't cause a specific syndrome (set of symptoms), but common symptoms include back pain, jaundice, stomach pain and weight loss.

Non functioning pancreatic NETs are rare but are the most common of the pancreatic NETs. They are often discovered between the ages of 40 and 60, but can occur in younger patients.

Between 20-40% of patients diagnosed with this condition have a genetically inherited condition called Multiple Endocrine Neoplasia Type 1. For further information see the NET Patient Foundation handbook. Pancreatic NETs may also be associated with Von Hippel-Lindau Disease, and Tuberous Sclerosis.



For more information and videos on NETs, diet and nutrition, tests, scans, treatments and side effects, please visit our website: www.netpatientfoundation.org and download 'The NET Handbook' and view our NET TV online channel.

NET Patient Foundation

Registered charity number 1092386

Diagnosis for Pancreatic NETs

Non Functioning

Blood / Urine Tests	Full blood count: - (B12 + serum Iron) - Liver and kidney function Biochemical: - Chromogranin A (and B) - Gut hormone profile (as baseline) - Urinary 5-HIAA
If inherited disorder present / suspected	Screen as per disorder e.g. MEN1, VHL, TS, NF1
Endoscopy	Endoscopic Ultrasound (EUS)
Scans	- Contrast CT / MRI *Gallium-Dotatate PET/CT (SRS SPECT/CT if Dotatate PET n/a) - FDG-PET – if High Grade / rapidly progressing disease
Pathology (tissue examined in the laboratory)	- Differentiation and cellular morphology - Synaptophysin - Chromogranin - Ki67

Treatment

For all NET Patients, treatments need to be completely personalised to the type of NET that you may have. Even if you have a diagnosis that sounds the same as another patient, your treatment plan maybe different, because you are unique. Your care team will discuss your treatment options with you so that together you can agree on the most appropriate treatment plan.

For information on all treatments currently utilised in the care of NET patients, please read the Treatments section in our NET Handbook - Your Guide to Life with a Neuroendocrine Tumour.

Follow-up

Follow up is dependent on grading and completeness of resection (if undertaken):

Grade 1	R0 resection / no lymph nodes : post operative check and evaluation
Grade 1 (R1/node positive) & Grade 2	- Follow up at 3, 6 and 12 months then annually if stable : labs & CT/MRI - EUS +/- Functional imaging (at 1 year then 3 yearly unless recurrence/ progression is suspected - optional)
Grade 3	Review 2 - 4 monthly if on ongoing (or may fit criteria) for treatment. FDG-PET as preferred mode of functional imaging in high grade disease
If inherited disorder present / suspected	Follow up as per disorder e.g. MEN1, VHL, TS, NF1

Diagnosis for Pancreatic NETs

Functioning

Blood / Urine Tests	Full blood count - (B12 + serum Iron) - Liver and kidney function Biochemical - Chromogranin A (and B) - Gut hormone profile incl gastrin, insulin, somatostatin, pancreatic polypeptide, VIP, - GRH, ACTH, PTHRP - Urinary 5-HIAA - Calcium, Calcitonin, Prolactin Gastrinoma* suspected/known - Fasting gastrin, Gastric pH, +/- secretin test - Evaluate other potential causes of raised gastrin : PPIs, H Pylori / infection, atrophic gastritis and pernicious anaemia - Follow recommendations for PPIs - do not stop suddenly, especially if symptomatic +/- evidence of peptic ulceration Insulinoma* suspected/known - 48 - 72 hour fast, C-peptide, Pro-Insulin and β-hydroxybutyrate Stimulation / secretion tests may also be undertaken * If inherited disorder present/suspected - Screen as per disorder e.g. MEN1, VHL, TS, NF1
Endoscopy	Follow up as per disorder e.g. MEN1, VHL, TS, NF1
Scans	Contrast CT / MRI *Gallium-Dotatate PET/CT (SRS SPECT/CT if Dotatate PET n/a) FDG-PET – if High Grade / rapidly progressing disease. nb if available GLP-1 scan may be of more benefit in Insulinoma
Pathology (tissue examined in the laboratory)	Differentiation and cellular morphology - Synaptophysin - Chromogranin - Ki67 - Gut hormone - p53, SSR and lymphovascular markers (optional)

Treatment

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For information on all treatments currently utilised in the care of NET patients, please read the Treatments section in our NET Handbook - Your Guide to Life with a Neuroendocrine Tumour.

Follow-up

Grade 1 & 2	3 - 9monthly intervals in first 2 years - then at intervals dependent on presence / absence of disease / functionality (see below) - min annual CT + bloods (EUS / functional 3 yearly unless recurrence suspected) G3 : 2 - 4 monthly on treatment / potential for treatment
Grade 3	2 - 4 monthly on treatment / potential for treatment
By type	Gastrinoma : Routine + B12, ionised calcium, PTH, Gastrin - with annual assessment for Cushing syndrome Insulinoma : Routine + Fasting glucose, Insulin, C-Peptide, Pro-Insulin, β-hydroxybutyrate Others e.g. VIPoma, PTHRPoma, etc. If no metastatic disease : 3 - 6 monthly then annual follow up with specific biomarkers, CT/MRI (EUS/functional 3 yearly unless recurrence suspected) If metastatic disease present : 3 - 6 monthly on treatment/ potential for treatment : with specific biomarkers, CT/MRI (EUS +/- re-biopsy and / or functional imaging in progressive disease) If inherited disorder present/suspected : follow up as per disorder e.g. MEN1, VHL, TS, NF1

For more information, please read:

THE NET HANDBOOK - Your Guide to Life with a Neuroendocrine Tumour

This is a comprehensive 158 page guide produced just for you. We would really appreciate it if you were able to purchase a copy but understand that this is not possible for everyone...We want everyone to benefit from this handbook.

GET YOUR COPY TODAY!

You can buy from our online shop for £7.50 (P&P included) OR email or call us for a free copy. You can also read it online on our website.

We are here to help

A diagnosis of cancer is one of the greatest challenges you can face. It is normal to feel anxious, frightened and worried about the future. But when you're dealing with a NET, there's no need to 'go it alone'. From diagnosis and throughout treatment and beyond, our team and our services are here to offer guidance, support, education and information to anyone affected by NETs every step of the way - whether it's over the phone, on our website or a chat in person.

The NET Patient Foundation is the only charity in the UK dedicated to providing support and information to people affected by NETs. Here are some of the services we offer:

Helpline – 0800 434 6476

Our free, confidential helpline is for anyone who has questions about NETs. Your call will be answered by one of our nurses or trained staff members with experience of NETs.

Discussion Forums

The discussion forums are easy to use. If you're feeling anxious or just need to hear from someone else who has been there they offer a way to gain support and reassurance from others in a similar situation to you.

Patient Education Meetings

We run information and support sessions for people living with NETs. These meetings include talks from some of the country's top NET specialists.

NET Natter Groups

NET Natter meetings are informal support groups which offer an opportunity to meet with others in your area who are affected by NETs – patients, supporters, friends and family.

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