The NET Journey

Diagnosis

5 - 7 years is the average time to get a diagnosis.1

What to look out for?

Common symptoms (although not always present at the same time) are diarrhea, flushing, cramps and stomach pain, palpitation, wheezing and breathlessness.2

Tests you are likely to face can seem daunting:

- Personal & family medical history
- Fine needle biopsy
- Tumour marker tests
- Blood and urine tests
- Ultrasound
- Computed tomography (CT) scan
- Endoscopy & endoscopic ultrasound
- Magnetic resonance imaging (MRI)
- Echocardiography
- Bone scan
- Positron emission tomography (PET)
- Bronchoscopy
- Lung function tests

Your care team can be broad:

- GP
- Surgeon
- Oncologist
- Endocrinologist
- Nuclear medicine physician
- Gastroenterologist
- Radiologist
- Dietician

Meet your multi-disciplinary team

Consultation

Prepare questions in advance
If you wish, you can do some research up front
Take someone with you to the appointment
Take notes during the visit
As it may take time to receive the results of the tests, consider asking if the consult can be broken into smaller sections to facilitate understanding of the disease. See Table of NETs on symptoms.

Ask about treatment options.
Learn to spot side effects.
Talk to your friends and relatives.
Understand how lifestyle changes can help.

Why so long?

NETs are relatively uncommon2,3 so not well known by GPs
They are frequently misdiagnosed, as many of the symptoms are also shared with more common ailments and conditions2
They can cause no symptoms at all2,3

Getting treated & Living with NETs

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