



# The NET Journey

Getting an accurate diagnosis of a neuroendocrine tumour (NET) can be a long journey<sup>1</sup>

## 1 Diagnosis

5 - 7 years is the average time to get a diagnosis<sup>1</sup>

5-7<sup>1</sup>  
YEARS

### Why so long?

NETs are relatively uncommon<sup>2,3</sup> so not well known by GPs  
They are frequently misdiagnosed, as many of the symptoms are shared with more common ailments and conditions<sup>2</sup>  
They can cause no symptoms at all<sup>2,3</sup>



### 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<sup>2</sup>

Read more about symptoms & diagnosis >

### Types of tests<sup>2,4</sup>

- 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

Tests you are likely to face can seem daunting



Learn more about the types of tests >

## 3

## Meet your multi-disciplinary team

### Your care team can be broad<sup>4</sup>

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

Get the most from your care team >

### Getting the most from your care 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
- Ask for roles to be explained
- Write down the names, roles and contact details of your care team
- Keep asking if you don't understand the disease, the follow up or the treatments

## Consultation

## 4

## Getting treated & Living with NETs

- Ask about treatment options<sup>4</sup>
- Learn to spot side effects<sup>4</sup>
- Talk to your friends and relatives
- Understand how lifestyle changes can help<sup>4</sup>

Hear how other patients live with NETs >

## Find out more

Living with NETs an online resource developed by Ipsen that provides information about neuroendocrine tumours (NETs, which you may also hear referred to as carcinoid tumours, GI-NETs, GEP-NETs, pancreatic NETs and lung NETs) and support for those living with neuroendocrine cancer.

[livingwithnets.com](http://livingwithnets.com)



### References:

1. Modlin IM, et al. J Natl Cancer Inst 2008;100(18):1282-1289.
2. Mamikunjan G, et al. Neuroendocrine-Tumors - 4th-Edition. Inglewood, CA: Inter Science Institute; 2009.
3. Warner R. A review of carcinoid cancer: The Carcinoid Foundation. July 2012 (updated). <https://www.carcinoid.org/for-patients/general-information/a-review-of-carcinoid-cancer/>. Accessed May 2018.
4. Cancer.NET. Neuroendocrine Tumor Guide. <https://www.cancer.net/cancertypes/neuroendocrine-tumor/view-all> Accessed May 2018.

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