SPOTLIGHT ON
NEUROENDOCRINE
CANCER

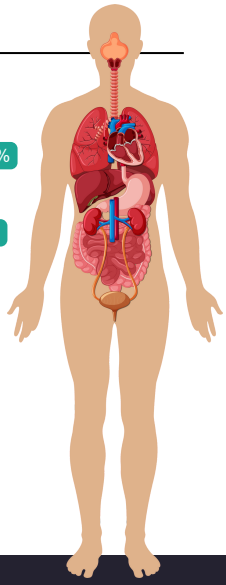
Neuroendocrine Cancer UK
Incorporating The Ann Edgar Trust

# NEUROENDOCRINE CANCER

## An overview for GPs

### KEY FACTS

- **The incidence of neuroendocrine cancer has increased by 371% (1995-2018), and it is now the 10th most prevalent cancer in England and the second most prevalent GI cancer.** (1)
- **Neuroendocrine cancer is easily missed.** There are challenges to diagnosing it because individual symptoms of neuroendocrine cancer may mimic or be masked by more common conditions such as IBS, anxiety, menopause and asthma. There is an average time to diagnosis from the first consultation of 3 years. (2)
- **Neuroendocrine cancer has a huge impact on patients' Quality of Life** (and their families) due to cancer and hormonal symptoms, relative rarity of diagnosis, information and diagnostic barriers and delays, alongside an often incurable, uncertain prognosis. (3)
- **Diagnosing patients earlier is life-changing because there are treatments that can improve symptoms as well as prognosis even where metastatic or secondary cancer exists.**
- It is a cancer that starts in the neuroendocrine cells scattered throughout the body. Like nerve cells, neuroendocrine cells receive messages; like endocrine cells, they can release hormones. Therefore, a diagnosis of neuroendocrine cancer can lead to symptoms both as a consequence of the tumour site and hormone secretion.
- More than 50% of all cases will have advanced disease (Stage III & IV) at the time of diagnosis. (4)



Lung / Bronchus: 20-30%

Digestive System: 60%

Stomach: 5%
Pancreas: 10%
Small Intestine: 5-25%
Colon: 13%
Rectum: 10-25%

Other Locations: 15%

Skin
Thymus
Ovary

**Neuroendocrine cancers may develop almost anywhere in the body, most commonly within the respiratory or digestive tracts (GI tract /pancreas).**

**The likely locations of Neuroendocrine Cancer. (*5*)**

**Any cancer diagnosis is devastating, and then you have the added confusion and bewilderment of dealing with a rarer, less well-known cancer; a lack of information, and an abundance of unanswered questions.**

**Visit Our Website**
www.neuroendocrinecancer.org.uk

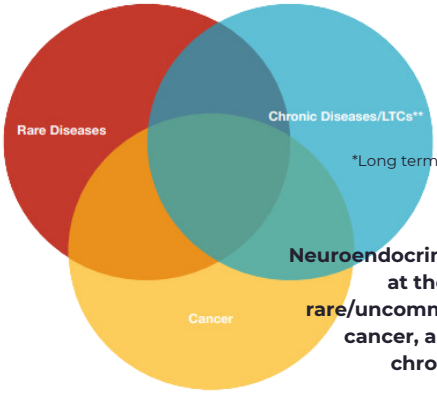
SPOTLIGHT ON
**NEUROENDOCRINE CANCER**

# WHAT IS IT?

NEUROENDOCRINE NEOPLASM (NEN) IS THE UMBRELLA TERM FOR NEUROENDOCRINE CANCERS THAT ENCOMPASSES:

| Neuroendocrine Tumours (well-differentiated cancer) = NETs | Neuroendocrine Carcinomas (poorly-differentiated cancer) = NECs |
|---|---|

- Neuroendocrine cancers (NC) have a higher prevalence than incidence: incidence ~ 9 per 100,000,1 prevalence ~ 48 per 100,000. In an average practice of 10,000 patients, approximately five patients will live with and beyond a diagnosis of NC.
- Neuroendocrine cancers may develop almost anywhere in the body, most commonly within the respiratory or digestive tracts (GI tract /pancreas).




**Neuroendocrine cancer sits at the interface of rare/uncommon diseases, cancer, and, for many, chronic diseases.**

## SYMPTOMS OF ABDOMINAL NEUROENDOCRINE CANCER
(GEP-NENS: GASTRO-ENTERO-PANCREATIC NEUROENDOCRINE NEOPLASMS)

Alongside Red Flag symptoms for pancreatic adenocarcinoma (PDAC), bowel or stomach cancer, for example, indigestion/heartburn, ulcer, pancreatitis, altered bowel habits, PR bleeding, etc.

The presence of:

- Malabsorptive diarrhoea
- Constipation
- Abdominal bloating and pain
- Subacute bowel obstructive symptoms
- Wheeze
- Palpitations
- Dry skin flushes (not menopausal sweats)
- Fatigue
- "I don't feel right".

**may indicate neuroendocrine cancer.**

### COMMON DIFFERENTIALS INCLUDE:

- **Reflux/gastro-oesophageal reflux disease (GORD)**
- **IBS / functional bowel disorder/disorder of gut-brain interaction**
- **NB new onset IBS unlikely > 50 years of age**
- **IBD**
- **Menopause**
- **Anxiety**

Approximately 40% of those with primary pancreatic and 30% of those with small intestinal NC will have functioning tumours. Other primary sites may also show syndromic symptoms. MEN1, 2a & 2b disorders need to be excluded in pancreatic NC: Up to 75% of those with MEN1 will develop 1 or more pancreatic NCs.

**Visit Our Website**
www.neuroendocrinecancer.org.uk

SPOTLIGHT ON
**NEUROENDOCRINE CANCER**

# SYMPTOMS

## SYMPTOMS OF LUNG NEUROENDOCRINE CANCER

Alongside Red Flag symptoms for lung cancer, such as persistent cough, and haemoptysis. The presence of:

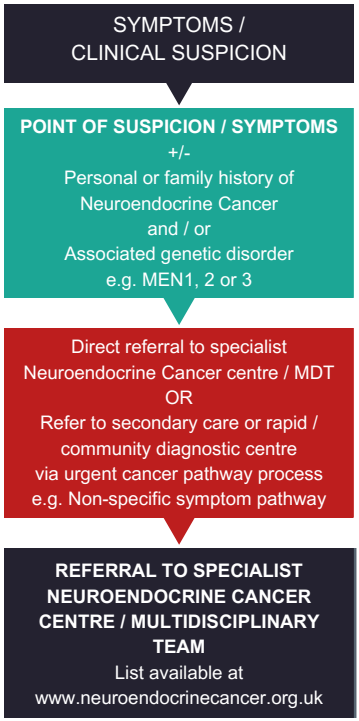
- Asthma-like symptoms
- Breathlessness
- A cough/chest infection that doesn't go away after two or three weeks
- Dyspnoea
- Chest pain
- Shoulder tip pain
- Persistent tiredness or lack of energy
- Loss of appetite or unexplained weight loss

**may indicate neuroendocrine cancer.**

Up to 6% may present with Cushing's syndrome and 5% with carcinoid syndrome.

## COMMON DIFFERENTIALS INCLUDE:

- **Asthma**
- **Allergies**
- **Bronchitis**
- **LRTI**




Created with support from GPs. For further information: RCGP website: e-learning course on Neuroendocrine Neoplasms

**I was told I had ME, IBS, and asthma and told to take up yoga to alleviate the palpitations and diarrhoea. I have huge confidence in my current team, but none in the diagnostic process. My life before diagnosis was miserable & I felt that no one took my distress seriously."**

SPOTLIGHT ON
NEUROENDOCRINE
CANCER

Neuroendocrine Cancer UK
Incorporating The Ann Edgar Trust

# QUESTIONS TO ASK YOURSELF
## when considering Neuroendocrine Cancer:

1. Is the presenting clinical picture consistent with or atypical for the suspected diagnosis?
2. Could symptoms be mimicking or be masked by symptoms of another health condition?
3. Does this patient keep coming back with their symptoms unresolved?
4. Is this patient suddenly coming in for repeated visits when they haven't been in for a long time?

*Remember, "three strikes and you're in". If a patient has presented for the third time with the same issue and you are no further forward, consider a referral into secondary care.*

**Listen to your patient.**

If a patient is concerned or feels something 'isn't right' it is important to consider this information seriously. Too many patients were diagnosed with anxiety – a condition that often post-dates initial presentation rather than pre-dates it.

**If you suspect neuroendocrine cancer, please refer your patient to secondary care,** adding in the referral letter: **"Does neuroendocrine cancer need to be excluded?"**

UKI NETS

For clinical information and advice about NETs and NECs, including expert guidelines, please visit the Clinical Practice page on the UK and Ireland Neuroendocrine Tumour Society's website: www.ukinets.org

Neuroendocrine Cancer UK
Incorporating The Ann Edgar Trust

If you have a patient with neuroendocrine cancer (NET or NEC), please signpost them to Neuroendocrine Cancer UK, a charity dedicated to providing support, advocacy, information and education to anyone affected by neuroendocrine cancer.

**The Neuroendocrine Cancer UK Stakeholder Group recommended "Neuroendocrine Cancer Pathway," launched in June 2023. Visit www.neuroendocrinecancer.org.uk for more information and the latest updates.**


References

1. White et al. 2022;23: 100510 The Lancet Regional Health – Europe. Incidence and survival of neuroendocrine neoplasia in England 1995–2018: A retrospective, population- based study
2. Basuroy et al. BMC Cancer 2018;18(1):1122. Delays and routes to diagnosis of neuroendocrine tumours.
3. Winter K, Bouvier C 2022, Open Conversations: Neuroendocrine Cancer and Mental Health Report, raremінds charity and Neuroendocrine Cancer UK
4. Genus et all. British Journal of Cancer, 2019 Impact of neuroendocrine morphology on cancer outcomes and stage at diagnosis: a UK nationwide cohort study 2013-2013.
5. Cuny et al. Endocrine-Related Cancer 25, 11; Role of the tumor microenvironment in digestive neuroendocrine tumors 10.1530/ERC-18-0025
6. Neuroendocrine Cancer UK, Barriers to diagnosis Survey



Office: 01926 883487
Helpline: 0800 434 6476

www.neuroendocrinecancer.org.uk