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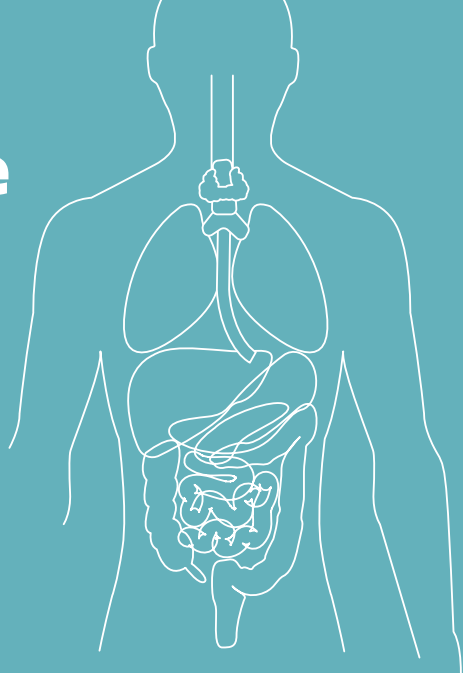


# Making sense of your **neuroendocrine cancer diagnosis**

***“NCUK has given me information, support and access to others who understand - without this I would probably be in a different place.”*** CRAIG - NCUK AMBASSADOR

# What is neuroendocrine cancer?

**Neuroendocrine cancer refers to a rare type of tumour that develops from cells of the neuroendocrine system. You may hear this cancer referred to as a ‘neuroendocrine tumour’, or NET, for short.**



Neuroendocrine cells are found all over the body, and their job is to produce the chemical messengers that we call hormones. These hormones affect how our organs work.

Neuroendocrine cancers are most commonly found in the digestive tract (i.e. from the mouth to the intestines), the lungs and the pancreas. However, there are several other less common areas where neuroendocrine cancers can form.

Symptoms depend on where in the body the cancer is. Those with lung neuroendocrine cancers may experience symptoms such as chest pain, coughing or chest infections, whereas those with intestinal neuroendocrine cancers may experience stomach ache, constipation or diarrhoea.

More information on neuroendocrine cancers can be found on the **‘Understanding neuroendocrine cancer’** page of the NCUK website, visit:

**[www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/understanding-neuroendocrine-cancer/](http://www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/understanding-neuroendocrine-cancer/)**

# Just diagnosed - what now?

**After you are diagnosed with a neuroendocrine cancer, you will have a lot of questions and may not know where to begin. There is a wealth of information on the NCUK website.**



The '**Just Diagnosed**' page aims to provide support that will help you come to terms with your diagnosis and learn more about what to expect, including:

- **Hearing the news**
- **Being prepared**
- **How NCUK can support you**
- **Speaking to a nurse**
- **Getting the right care**
- **Counselling service**
- **Local 'Natter' support groups**

Visit: **[www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/newly-diagnosed/](http://www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/newly-diagnosed/)** for all of this information and more.

*“My diagnosis was completely unexpected, and I was feeling really overwhelmed. I kept getting very tearful, and snappy with my husband and kids. It really helped talking with someone outside my family and friends about how angry and frightened I was. Although I'm still adapting, it's helped me get to a different place emotionally.”*

*CB, patient*



You may want to discuss your diagnosis with your GP. NCUK also provide **information for healthcare practitioners** to help them navigate this condition with their patients.

# Your care

**If you're diagnosed with a neuroendocrine cancer, a specialist, accredited, NET-specific Multi-Disciplinary Team (NET MDT) should review your case on an ongoing basis.**

The NET MDT will be made up of various clinical experts who specialise in neuroendocrine cancer. Referrals to specialist neuroendocrine cancer services work slightly differently across the UK. They also vary depending on who refers you (e.g. your GP, A&E staff, or other specialist).

It is likely that your case will be discussed at least in part within an MDT centre. **However, if this doesn't happen, it is important for you to discuss this with your doctor.**

More information on NET MDTs and what you can expect can be found on the 'Getting the right care' page of the NCUK website. Visit:

**[www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/newly-diagnosed/getting-the-right-care/](http://www.neuroendocrinecancer.org.uk/neuroendocrine-cancer/newly-diagnosed/getting-the-right-care/)**

**You can also find out more on the NCUK website about:**

- Treatments that may be recommended for you
- Diet and nutrition
- A guide to life with neuroendocrine cancer

**NCUK is there to support you from diagnosis to treatment and beyond.**



*“I'd been determined the diagnosis wouldn't make any difference to me, but I was exhausted and very low. I didn't really think 'just talking' would work, but counselling showed me that in accepting the things that have changed, life can still be good.”*  
CB, patient

# The NCUK Community

**After receiving a cancer diagnosis it's easy to feel isolated. This is perfectly normal. Many people find it helpful to hear from others who really understand what it's like to be diagnosed with, and live with, neuroendocrine cancer. There is a wide network of local support groups to help do that.**

You can visit the NCUK website to find one of the many local support groups, and to read about other people's experiences. In Scotland, local support groups are operated by NCUK's partners at **The Ann Edgar Charitable Trust (TAECT)**. Details can be found on their website, and on Facebook at **"NETs Scotland: The Ann Edgar Charitable Trust"**.

The following quotes are from stories shared by patients in the NCUK community. To read more, take a look at the **"Faces of NCUK"** section of the NCUK website.

*"Four years on from surgery and many tests later I am happy and doing well. I now help facilitate my local Natter group for people with neuroendocrine cancer as my way of helping support those struggling with this disease and a way of saying thank you to NCUK." RL, patient*

*"It was an immense shock to find that I had a life-threatening / limiting disease, and hugely stressful that there seemed to be so little information available to the patient compared to other cancers. I was so grateful to discover [the] Neuroendocrine Cancer UK website and forum." RL, patient*

*"...it is extremely important for us to share our neuroendocrine cancer stories as doing so goes a long way to alleviate the feeling of isolation that follows upon a diagnosis of an illness no one has heard of. Everyone always immediately looks for more information, right? It is re-assuring to read other's stories." RT, patient*

*"It was reassuring to hear other group members talking about 'living with their diagnosis' and made me realise that I am not alone with my own diagnosis." GH, patient*

**Family, friends & supporters can also join the 'Natter' Support groups.**

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*When I was diagnosed with Neuroendocrine Cancer in my small intestine, NCUK was a complete lifeline for me - I can quite confidently state that this organisation quite possibly saved my life. Without the sensible, kind and well-timed advice I was given, I would not have been able to access the specialist care and follow up I needed.*

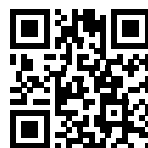
*LF, NCUK Service User*

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**NCUK**

**To visit the NCUK website or  
TAECT website, simply scan  
the QR code using the camera  
on your smart device.**



**TAECT**

*This leaflet has been developed by **Advanced Accelerator Applications (AAA)** in partnership with **Neuroendocrine Cancer UK (NCUK)** and **The Ann Edgar Charitable Trust (TAECT)**.*

*It aims to provide you with an introduction to your neuroendocrine cancer diagnosis and show you where to go to find more information and support.*

### **As a registered charity, NCUK's mission is**

*“To support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating neuroendocrine cancer research, increasing national awareness and influencing improvements in outcomes.”*

Neuroendocrine Cancer UK Registered Charity no. 1092386, The Ann Edgar Charitable Trust Registered Charity no. SCO42556  
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