



**Neuroendocrine  
Cancer UK**

Incorporating The Ann Edgar Trust



21 years of supporting  
the neuroendocrine  
cancer community



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## Why we fight for the Neuroendocrine Cancer community



I don't know what I would have done without you (NCUK) and the Natter support groups. You supported me in accessing specialist care. You have quite literally saved my life. And again now, you're here when I need you as you always have been.

[www.neuroendocrinecancer.org.uk](http://www.neuroendocrinecancer.org.uk)

## Neuroendocrine Cancer

A diagnosis of cancer is one of the greatest challenges anyone can face. Being diagnosed with a rare or uncommon cancer can have additional consequences, not least in terms of awareness, early diagnosis and access to expertise. Feelings of isolation, fear, uncertainty and anxiety are not uncommon.



**I've had enough of going from pillar to post, and feeling exhausted. My boss is really unsupportive with all the time I have to have off. I've got a young baby and my partner has just said she wants to split up. I keep thinking maybe it would be better if I was dead. I did think about just driving into a wall on my way home last week"**  
**Nick (31).**

### WHAT WE DO?

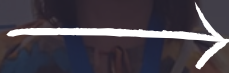
We were founded by patients and nurses to act as a bridge between hospital and home. Our purpose is to support and inform patients and families from diagnosis, enabling access to the best care and treatment whilst stimulating neuroendocrine cancer research, increasing national awareness, and influencing improvements in outcomes.



# WHAT WE HAVE ACHIEVED IN THE LAST 20 YEARS:

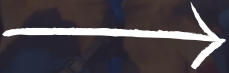
## ADVOCATING FOR ANYONE AFFECTED BY NEUROENDOCRINE CANCER

### Campaigns



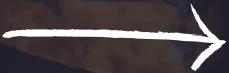
- Open Conversations (Mental Health)
- Spotlight on Neuroendocrine Cancer For Healthcare Professionals
- Ideal Patient Pathway
- Advocacy Research UK

### Education



- NCUK Nursing Academy
- National Education Webinar Series
- Virtual Handbook & Toolkit
- Podcast Series

### Support Services



- Free Psychotherapy Support
- Free Specialist Nurse Support
- Support Material for Every Hospital in the UK
- Peer-to-Peer Support Groups - 300 Groups in 2022

### Research



- Clinical Trial Support
- Data and Quality of Life Publications
- National and International Patient research Programmes

### Awareness



- Database of 10,000+
- Average 21,000 Website Views per Month
- 12,000 Social Media Followers
- World Neuroendocrine Cancer Day

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# The Need

It is without doubt that receiving a cancer diagnosis is traumatic, and patients are often left in a state of shock, confusion, sadness, and anxiety. For neuroendocrine cancer patients, the prospect of a cure is often minimal, and remission is unlikely. Unlike other cancers, even if there are no other signs of visible disease after treatment, there will be a point when the cancer returns.

Individuals with less common cancers like neuroendocrine cancer face disadvantages at every stage of their cancer journey. From the speed of diagnosis to treatment and research, people with rare cancers often receive a second-rate service.

Our vision is of a world where people know how to recognise, diagnose, treat, care for, and ultimately cure patients with neuroendocrine cancer. Our hope is that you will help us achieve that vision.

## Who are we reaching out to?

We are reaching out to any corporate business, whether large or small, to support our efforts in supporting individuals diagnosed with rare and less common cancers.

## WHAT COLLABORATION MEANS FOR YOU

Increased Staff Cohesion

Positive Marketing

Greater Brand Exposure

Our Continuous Involvement  
and Commitment

A Sense of Accomplishment  
Through Working Together

# What don't you know?

## THE FACTS

- Around 50% of neuroendocrine cancer patients are initially misdiagnosed
- Less than a third receive the correct diagnosis at first presentation
- One in four are told their symptoms were due to anxiety, depression or were psychosomatic
- 80% fail to receive a diagnosis within one year



There are Centres of Excellence for Neuroendocrine Cancer across the UK - but no specialist commissioning in place to promote and safeguard the clinical and supportive pathway for those neuroendocrine cancer.

“When they said they found cancer in my bowel, I was terrified; when they said it was neuroendocrine cancer I was terrified and bewildered. Neuroendocrine Cancer UK helped me understand and took the terror away.

Cancer is scary; a rare cancer is both scary and confusing. Neuroendocrine Cancer UK helped me make sense of it all, and gave me hope, and friends for the journey. I don't know how I could have faced this without them. Bethann, NCUK Ambassador.

- Almost half are found with advanced disease (Stage IV) at diagnosis
- The mean time to a diagnosis is five years
- Less than 50% receive written information about their disease on diagnosis
- Less than 20% receive information about support services and organisations that can help.



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# Our Support Services

Supporting us not only increases research, but it aids us in the continuous development of our support services that help thousands of patients through this time.

## DEDICATED HELPLINE

We offer our specialist helpline, staffed by caring and knowledgeable professionals who are here to offer support and advice.

## INFORMATION

We believe that information is power, and that everyone impacted by neuroendocrine cancer deserves access to accurate, reliable information to make informed decisions about their care. That's why we're proud to offer a wealth of free, high-quality patient information on our website and YouTube channel.

## 'NATTER' SUPPORT GROUPS

We run regular face-to-face and virtual support groups across the UK. Alongside our Natter groups, we offer a range of online education 'Webi-Natter' webinars. These virtual events feature guest speakers who provide valuable insights and information on various topics related to neuroendocrine cancer.

## FACEBOOK GROUPS

We offer private Facebook groups for patients, supporters, and families affected by neuroendocrine cancer. These groups provide a safe space for people to connect, share experiences and offer mutual support.

## COUNSELLING

Our counselling service offers a safe and confidential space for patients, carers and families affected by neuroendocrine cancer to talk about their concerns and emotions with a trained counsellor.

## ONLINE EDUCATION EVENTS

Our National Education Webinar Series are free and interactive virtual events tailored to each devolved nation in the UK. Listen to the experts and access valuable information and insights on managing symptoms, navigating the healthcare system, and improving overall quality of life.



## OUR MISSION

Our purpose 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.

## OUR VALUES

Equality of care for all neuroendocrine cancer patients in the UK

- Excellence in support, care, treatment and research
- Fair allocation of national resources and inclusion in national policies and strategies for all cancer types
- Collaborative working and building accessible, approachable fraternity
- Honesty, transparency and integrity to promote confidence and trust in the charity.



## ARE YOU READY?

Together we can transform lives, build an equitable and sustainable care structure and give our community the attention they deserve through research, education, awareness and support.



GET IN TOUCH



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Visit our website for more  
information about  
Neuroendocrine Cancer UK

[WWW.NEUROENDOCRINECANCER.ORG.UK](http://WWW.NEUROENDOCRINECANCER.ORG.UK)



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