

Support the Neuroendocrine Cancer Community



Why we fight for the Neuroendocrine Cancer Community.

Working together.



**Neuroendocrine
Cancer UK**

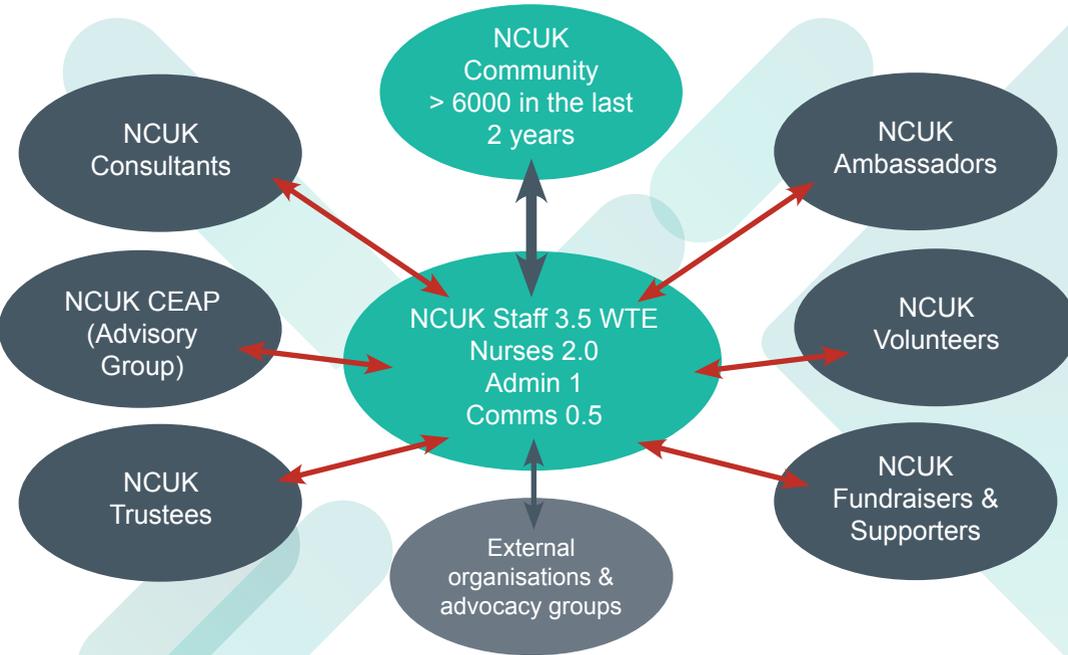
(Formerly NET Patient Foundation)

Registered Charity No: 1092386

www.neuroendocrinecancer.org.uk

WHO ARE WE?

Not a stand alone organisation.



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.

We work hard as an evidence-based advocacy group, collecting real-life data from the community to drive change in both commissioning for Neuroendocrine Cancer treatments and clinical practice. Our advocacy role is focused on having true impact within a community unaware of the needs of Neuroendocrine Cancer patients. By sharing our knowledge and patient experience we can collaboratively create positive change. We want to enhance awareness and self-confidence within the patient community so they can make informed choices and ask questions. It is vital that the patient voice helps facilitate best practice, that alongside having an input into drug research and development, there is also a safe platform for sharing experiences and peer support.

THE NEED:

It is undoubtable 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, specifically, the prospect of a cure is often nil, and remission 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.

As patients frequently wait too long for their diagnosis, they can often be treated for the wrong disease meaning their cancer pathway begins with feelings of extreme frustration.

After treatment patients have to address the gravity of their diagnosis at home, and often without regular access to the support of experts.

Therefore, patients frequently suffer from feelings of abandonment, and struggle to know in whom to confide. Indeed, if their cancer is particularly advanced, they will face the possibility of dying. From our experience, the complexity of Neuroendocrine Cancer means that friends and family often struggle to comprehend their suffering.

People with a less common cancer like Neuroendocrine Cancer are disadvantaged at every step of their cancer journey. From the speed of diagnosis through to treatment and research, people with rare cancers often receive a second-class service. It is time for a more consistent approach by ensuring that people are treated equally, that they get the specialist treatment they need and that they are properly supported to live their lives as fully as possible. Policy makers, health professionals and commissioners need to acknowledge the differences in patient experience and to take positive and meaningful steps to address them.

Our vision is of a world in which people know how to recognise, diagnose, treat, care for, and ultimately, cure patients with Neuroendocrine Cancer.



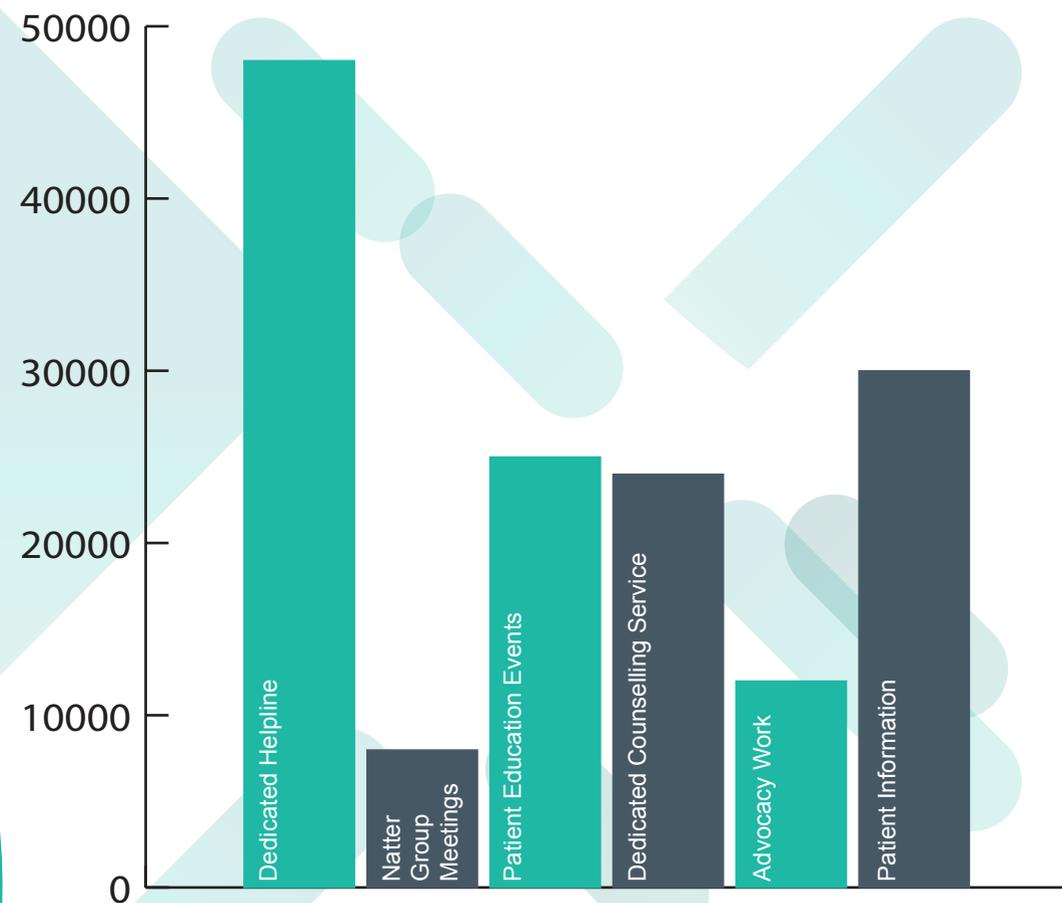
HOW YOU CAN HELP:

Support Our Services:

- Our dedicated freephone nurse helpline and email services are available to patient and supporters
- Local and online Natter support groups
- Our free to attend patient education events, wellbeing days and national annual Summit
- Our dedicated Neuroendocrine Cancer counselling service
- Our MIND the Gap© campaign, which is focused on helping Neuroendocrine Cancer patients carry not only the physical, but the psychological burden of disease
- Our extensive patient information resources, which we provide free of charge to hospitals and cancer support organisations to ensure accurate information is provided for all patients across the UK
- Our website which is core to our communication and education pillar
- Our awareness and media programme - keeping the community engaged and informed
- Our research - we undertake in-house research as well as supporting external clinical trials across the UK.

NCUK YEARLY SERVICE SPEND:

(£)



CAN YOU:

1. Make us your Charity of the Year?
2. Encourage Employees Fundraising?
3. Sponsor one or some of our services?
4. Set up Payroll Giving to NCUK?
5. Donate a Gift In Kind?

"When they said they found cancer in my bowel, I was terrified; when they said it was Neuroendocrine I was terrified and bewildered...the NCUK helped me understand, and took the terror away... Cancer is scary; a rare cancer is both scary and confusing. NCUK helped me make sense of it all, gave me hope, and friends for the journey. I don't know how I could have faced this without them"
Bethann - NCUK Ambassador



THE FACTS:

The Patient Experience:

- Around 50% of Neuroendocrine Cancer patients are initially misdiagnosed
- Less than a third receive the correct diagnosis at first presentation
- 1 in 4 are told that their symptoms were due to anxiety, depression or were psychosomatic
- 80% fail to receive a diagnosis within 1 year
- Almost half are found with advanced disease (Stage IV) at diagnosis
- Mean time to a diagnosis is 5 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

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 with Neuroendocrine Cancer.

'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)



BENEFITS OF BEING A CORPORATE CHAMPION:

- Great potential for positive brand exposure
- Help with your profile and recognition
- Increased staff cohesion
- Team building opportunities
- A greater sense of accomplishment through working together to reach a fundraising target
- A free will service through Bequeathed.org
- NCUK's continuous involvement and commitment
- Knowing your support shows you can see beyond the obvious, commit to promoting equality and champion the voice of those less common or rare.



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 an 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.



“When I was diagnosed with Neuroendocrine Cancer in my small 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.”
NCUK service user.

Contact Us

Neuroendocrine Cancer UK

74 Upper Holly Walk, Leamington Spa, Warwickshire CV32 4JL

Office: 01926 883 487 | Helpline: 0800 434 6476 | hello@nc-uk.org

www.neuroendocrinecancer.org.uk

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