
Neuroendocrine Cancer UK
The invisible cancer.
Missed. Misdiagnosed. Misunderstood.
How delays, misdiagnosis and the unequal treatment of neuroendocrine cancer in the UK are costing lives.
Supported by
AMEND
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Mental Health for the Rare Disease Community
UKI NETS
UK and Ireland Neuroendocrine Tumour Society

About Neuroendocrine Cancer UK (NCUK)

- We are a charity dedicated to supporting people affected by neuroendocrine cancer, putting patients, families and carers at the heart of everything we do.
- We know how isolating it can be to live with neuroendocrine cancer. Whether diagnosed with a neuroendocrine tumour (NET) or neuroendocrine carcinoma (NEC), many people struggle to find reliable information and genuine understanding.
- Founded 26 years ago by patients, families and healthcare professionals, we provide compassionate support, trusted information, raise awareness and fund vital research.
- Today, we are the leading voice for neuroendocrine cancer in the UK, supporting everyone affected, whether newly diagnosed or living with the disease for years.
- We campaign on behalf of our community to ensure neuroendocrine cancer is understood and prioritised, through education, outreach and by influencing health policy.
- Our research is helping to progress greater understanding, faster diagnosis and is moving us closer to a cure.
- We do not receive any funding from the government, NHS or larger cancer charities. Our work is made possible entirely by the generosity of our community, individuals and organisations who give their own time and money to support our mission.

Read more about our work and future priorities in our five-year strategy.

Foreword.



Lisa Walker
Chief Executive
NCUK

For over 25 years, we have supported people living with neuroendocrine cancer, and those who love and care for them.

We have listened to their experiences, shared their stories, provided trusted information, and driven progress through advocacy, education and research.

We are grateful to the healthcare professionals with specialist expertise and knowledge in this field who continue to support patients and actively champion progress in care. Meaningful progress has been made, and that has made a real difference.

But neuroendocrine cancer is still not recognised or well understood by the wider healthcare community or the public. Its complexity means it's frequently misdiagnosed. It can take on average, four and a half years to get a diagnosis.[1]

Delays to diagnosis and inconsistent care cause serious and lasting harm. Precious time is lost, allowing the cancer to progress before people receive the treatment they need. Patients and families describe these experiences as isolating and frightening, leaving them without support when they need it most. This is unacceptable and requires urgent attention.

Neuroendocrine cancer remains largely invisible. The cost of late diagnosis and years of prolonged treatment is carried not only by patients and families, but by the NHS itself. This is why we need to make neuroendocrine cancer visible through earlier diagnosis and better understanding.

On this World Cancer Day, we are proud to have the support of our colleagues in UKINETS, AMEND and Rareminds, whose partnership strengthens this report.

We are united in our focus on raising awareness and achieving earlier diagnosis, so that people receive timely treatment and support that can change their lives.

> **Delays to diagnosis and inconsistent care cause serious and lasting harm.**

1 Basauroy et al. BMC Cancer 2018. *Delays and routes to diagnosis of neuroendocrine tumours.*



Professor Martyn Caplin
Professor of Gastroenterology and Neuroendocrine Cancer
Royal Free Hospital (European Centre of Excellence)
and Patron of NCUK

Every year, I meet patients who must come to terms with the consequences of a delayed diagnosis.

These delays lead to unnecessary anxiety and confusion as patients try to understand this complex cancer and where they stand with their care. More concerning is that a potentially operable disease becomes inoperable due to the delays to diagnosis. This has a direct impact on survival, the severity of their symptoms and on clinical outcomes.

The sooner a patient is diagnosed, the more treatment options are available, even if the cancer cannot be removed surgically.

Smaller volumes of neuroendocrine cancer are generally easier to manage than more advanced disease, and larger tumours are more likely to cause significant symptoms, regardless of where they are in the body. Delays increase both the physical and emotional toll on patients and limit clinical options.

Our community of patients, families, researchers and clinicians stands together this World Cancer Day to highlight the importance of early diagnosis.

As incidence rises, this report aims to act as a catalyst for better awareness and calls for vigilance at every level, whether you are a concerned relative, a practice nurse or a specialist clinician.

While no clinician can know everything, and our NHS continues to deal with significant pressures, awareness, open mindedness and careful listening can make a meaningful difference.

Timing matters. Supporting earlier diagnosis and availability of the correct diagnostic tools can improve patient pathways, reduce avoidable strain on the NHS, and prevent people waiting months, or even years, for answers.

Together, we believe progress is possible.

With greater awareness, we can achieve faster diagnosis, improve outcomes and make better use of NHS resources. This report represents an important step towards better outcomes for everyone affected.

Lisa Walker *Martyn Caplin*

Executive summary.

Every year, around 6,000 people in England are diagnosed with neuroendocrine cancer –

that's one person diagnosed every 90 minutes.[2]

Although neuroendocrine cancer is an umbrella term for a group of individually rare cancers, it is less rare than official data suggests. Diagnoses have risen steadily – rates increased 371% between 1995 and 2018 – and they continue to climb.[3]

Delayed diagnosis remains one of the most significant challenges. Patients visit their GPs 11 times on average before they receive a diagnosis. Over half are diagnosed at an advanced stage (Stages 3 & 4), limiting treatment options and increasing the physical, emotional and clinical burden of the disease.[4]

At the heart of this is a lack of awareness and understanding. Neuroendocrine cancer represents a complex and diverse group of cancers that can take different forms and be difficult to recognise. It is easily missed and challenging to diagnosis because symptoms can vary and mimic other common conditions such as IBS, asthma, anxiety and menopause.

For many, this disease must be managed as a chronic, life-limiting condition, with symptoms that affect the quality of life long after diagnosis. While effective treatments exist, prolonged diagnostic delays and inconsistent referral pathways mean too many patients are unable to access specialist care.

The impact is often compounded by its invisibility. Many patients appear well, even with advanced disease, leading to symptoms being underestimated or dismissed. This can deepen isolation and further delay treatment.

Another challenge for patients in England, is restricted access to therapies that could slow disease progression and reduce symptoms. In some cases, the same treatments are available elsewhere in the UK or are approved only for specific primary tumour sites.

This report sets out the challenges patients face, the urgent need for earlier diagnosis and improved access to specialist care and treatment options. It highlights critical gaps in understanding, outlines the consequences of delays, and reinforces the importance of referrals to our neuroendocrine cancer specialist centres (see below) with the expertise needed to treat and manage this complex group of cancers.

Earlier diagnosis can be life changing. Even when the cancer has spread, treatments are available that can improve symptoms and prognosis.

Our report aims to offer clarity and hope to those facing avoidable delays, limited options and prolonged uncertainty.

What is a neuroendocrine cancer specialist centre?

Across the UK, more than a dozen accredited centres deliver specialist multidisciplinary care including advanced diagnostics, treatments and clinical trials, regardless of a patient's location or circumstances. Access to this care significantly improves outcomes, survival rates and quality of life.[5] However, unlike other cancers, there is no national referral pathway to ensure timely access to these centres after diagnosis.

2 White et al. (2022), *Incidence and survival of neuroendocrine neoplasia in England 1995-2018*, The Lancet Regional Health–Europe.
3 White et al. (2022), *Incidence and survival of neuroendocrine neoplasia in England 1995-2018*, The Lancet Regional Health–Europe.
4 NCUK, *Barriers to Diagnosis* Survey, January 2021.
5 Panzuto et al. (2025), *The importance of education and training in NENs: challenges and opportunities for multidisciplinary management.*

What is neuroendocrine cancer?

Neuroendocrine cancer is a type of cancer that begins in the neuroendocrine cells, which are found throughout the body. These cells have the ability to release hormones that can regulate many body functions. When they become cancerous, their growth rate and normal function is disrupted.

The most common neuroendocrine cancers tend to originate from the gastrointestinal tract, pancreas or lung.

Most neuroendocrine cancers occur sporadically. This means that there is no known genetic link to how or why they have developed. However, there are a number of rare inherited genetic conditions that may increase someone's risk of developing a neuroendocrine cancer.

The most common symptoms include unintentional weight loss, increasing fatigue, pain, diarrhoea, bloating, wind, heartburn, asthma-like symptoms, flushing and a persistent cough.

Medically, neuroendocrine cancer can be referred to as neuroendocrine neoplasms (NENs).

There are two main subtypes of neuroendocrine cancer.

Neuroendocrine tumours (NETs)

- NETs typically grow more slowly than NECs and many other cancer types. Symptoms can start intermittently and gradually increase over time. Those with a NET diagnosis may face living with this cancer as a chronic incurable condition, undergoing regular surveillance and monitoring.

Neuroendocrine carcinomas (NECs)

- Less common but more aggressive cancers. Symptoms tend to appear suddenly and persistently. Those with a NEC may follow a more familiar cancer journey, which can be less certain and less survivable.

Correctly identifying NETs vs NECs is critical as it significantly affects prognosis and treatment decisions.

Five-year survival rates for NETs exceed 65% but fall to less than 10% for patients with NECs.

Treatment.

For NETs, it depends on the tumour type, location, stage, growth rate, hormone activity and whether it has spread or is functioning i.e. producing excess hormones or chemicals. Treatment is tailored to each patient and can include surgery for early-stage tumours and systemic treatments like somatostatin analogues, chemotherapy, targeted therapies and radiotherapy.

For NECs, platinum-based chemotherapy is the standard first-line treatment and clinical trials are encouraged. Surgery is only considered in early stage cases where the tumour can be fully removed.

The aim of any treatment is to carefully balance effectiveness with potential side effects and long-term consequences.



Neuroendocrine cancers start anywhere in the body and symptoms vary greatly between people, which makes early detection difficult.

Approximately **70% of patients have NETs**
Just under **30% have NECs**



Data spotlight.

On average **it takes 4.5 years to be diagnosed from the first symptom**[6]

On average **patients visit their GPs 11 times before a diagnosis**[7]

More than 50% of patients are diagnosed at advanced stage (Stage 3 or 4)

As of January 2026, **no national diagnostic pathway exists** for neuroendocrine cancer

There are approximately **6,000 people diagnosed every year with neuroendocrine cancer**

30% of people experience their first neuroendocrine cancer symptom before the age of 50

More than 36,000 people are living with neuroendocrine cancer in the UK at any one time, making it more common than those living with stomach cancer and pancreatic cancer

6 White et al. (2022). *Incidence and survival of neuroendocrine neoplasia in England 1995-2018*, The Lancet Regional Health–Europe.

7 Basauroy et al. BMC Cancer (2018). *Delays and routes to diagnosis of neuroendocrine tumours.*

Consequences of late or missed diagnosis.

Every missed or delayed diagnosis carries consequences – for patients and families facing months or years of uncertainty, and for the NHS in absorbing the cost of repeated appointments, tests and referrals.

Clinical impact.

- By the time a diagnosis is reached, more than half of patients will already have cancer that has spread to other parts of the body. This can mean fewer treatment options, the need for more invasive treatment, and a higher financial burden on the NHS.
- **The cost of treating a patient at Stages 3 & 4 is approximately £200,000 – £300,000 higher than treatment at Stages 1 & 2.** These figures relate to treatment costs only and exclude surveillance, monitoring, or clinics.[8]

Living with the 'invisible cancer'.

- Many patients appear well because they don't look like a stereotypical cancer patient and may not undergo chemotherapy. This often leads to misunderstanding or dismissal, as others fail to recognise the seriousness of the disease.
- Limited awareness and persistent misconceptions can make it harder to access both physical and mental health support.

Impact of uncertainty on emotional and mental health.

- Patients often grapple with emotional distress due to delayed diagnosis, misdiagnosis, and the unpredictable nature of their illness. They often feel dismissed or not believed by doctors, then doubt themselves.
- Many live in fear of symptom changes, 'scanxiety' (anxiety about scans), possible progression, and deep loneliness – feeling like nobody understands what they are going through.
- Some have to wait until their disease has worsened to warrant treatment, adding to uncertainty.

Physical and financial challenges.

- A delayed diagnosis can result in more severe symptoms and side effects as treatment can be ongoing and complex. Many people then face a life of regular surveillance with frequent hospital visits and scans.
- Fatigue, hormone-related symptoms, pain, and other complications can reduce independence and quality of life. Some patients are no longer able to work, while others struggle with everyday tasks such as showering or cooking.

8 White et al (2021) *Evaluating cost-effectiveness in the management of neuroendocrine neoplasms.* Based on data on NHS tariff payment system in: *NHS Improvement Resources. NHS Improvement. 2019*

In their own words.
Four people about their lived realities.

“I was so fatigued I was on my knees. I had to choose whether to eat or have a shower.



Kerie Ivory, 52
from Buckinghamshire

“It’s hard living with a slow growing, creeping cancer – I’m constantly waiting for the tumours to grow big enough to get treatment that is appropriate for me. It’s devastating knowing I have cancer and we are not treating it. A lot of other cancers have the kitchen sink of treatments thrown at them. I’m forced to live with this disease rather than eradicate it.

Mother of two, Kerie Ivory, was diagnosed in 2012 with small bowel neuroendocrine cancer (specifically, Neuroendocrine Tumour (NET)) and a primary tumour in the ileocecal valve, which has spread to her lymph nodes.

It took 15 months of symptoms and GP visits before she was diagnosed. It’s thought she’d had the cancer for around four and a half years pre-diagnosis. Her initial GP told her categorically she didn’t have cancer. It was only when she changed GPs that her cancer was discovered. She was forced to give up work in 2022 due to severe fatigue caused by the cancer.

She says: *“Previous to diagnosis, my first symptom was a persistent cough which was misdiagnosed as rhinitis, post-nasal drip, asthma and reflux. I kept going back and forth to my GP, who dismissed my symptoms. By then I was so fatigued I was on my knees. I had to choose whether to eat or have a shower. When they found I was anaemic I wasn’t convinced this was the only thing wrong with me. I thought, ‘I’m a healthy young woman, this cannot be it’. And then my bowel symptoms got worse. I was getting severe bloating, wind and stomach pain. My stomach would be flat in the morning then over the day it would balloon. I looked five months pregnant by the evening. I was misdiagnosed with IBS but my symptoms continued to get worse. Finally, I was referred for a colonoscopy, during which the scope couldn’t get through – there was a tumour on the ileocecal valve which caused bowel obstruction. It was a relief to know that something had finally been found. The subsequent MRI found enlarged lymph nodes.*

I’ve had several surgeries to remove lymph nodes, some of my small and large intestines, as well as the ileocecal valve and appendix, a section of my liver and my gall bladder. My latest scans say that there are a couple more lesions in my liver, and areas have lit up on my spine. There were six lesions in my spine in the last scan. I have to prepare myself for more scans and wait to see if these lesions grow. I cannot relax knowing there are new tumours forming.

I was devastated about having to give up work due to severe fatigue. I have to limit what I do every day. Sometimes it may only be one thing.

My children have found it hard to accept – they understand it’s never going away and that at times it will grow and need treatment.”



Craig Speirs, 46
from Glasgow

“My diagnosis took nearly five years of appointments with my first GP for a range of symptoms. These visits didn’t get me anywhere and I was even told there was nothing wrong with me and that I had to go home and calm down as it was a result of stress from work. My cancer was invisible to the doctor.

Craig Speirs is a dad of two and has neuroendocrine cancer of the small bowel which has spread to his liver. He has carcinoid syndrome and carcinoid heart disease as a result of the cancer, which has resulted in two major heart surgeries. He expects he will need further surgery in the future to survive.

“One of my thoughts was whether to get married to Angela? Could I bring her into this new chaotic life?

He says: *“I was presenting a range of symptoms over the five years that I was going back and forth to the GP. I had bowel issues, flushing, heart palpitations and frequent diarrhoea. I would need to go to the toilet 10-15 times daily. I would take a change of clothes with me everywhere I went. I didn’t want to leave the house.*

I changed GP and instantly there was a difference, she listened to me. From there I had a series of tests and then in 2013 I was diagnosed. I’ve had my gall bladder removed and I have injections of Lanreotide (a synthetic hormone) every three weeks. Over the last 12 years, there have been a few challenging periods in my treatment. I had open heart surgery to replace my valves due to carcinoid heart disease and a second heart surgery about 18 months later.

Despite treatment, I unfortunately still suffer with symptoms daily. Over the years I’ve become better at handling this, but it still physically affects me. During a flushing episode, my whole body is covered in a red rash and I feel pins and needles on my feet, hands, and face. It also affects my breathing which becomes asthma-like. I’m closely monitored by my cardiologist as we know that in time, I will eventually need further heart surgery as my tumours continue to release these hormones.

I get scan anxiety. You worry about every scan, thinking the next one will be your last. That period between having a scan and waiting on the results can feel like a lifetime. I would go into every appointment expecting the worst.

The diagnosis meant that I was managed out of work by my employer, at a time when I really needed the support from them. I became a stay-at-home dad as treatment really didn’t allow me a new career at that point. For others looking at this life, it’s probably not normal.

One of my thoughts was whether to get married to Angela. Could I bring her into this new chaotic life. Over the years I’ve seen the hurt on her face every time I need more treatment, and this never gets any easier.

When I went through my two heart surgeries, there was a large risk of not getting through the surgery. I wrote letters to my children, Adam and Rhianne, and to my wife Angela, should the worst happen.”

...I checked my NHS app and saw a note saying I had a prognosis of months. It was summer and I genuinely thought I wasn't going to see Christmas.



Melanie Lucas, 49
from Somerset

The hardest part is the uncertainty – not knowing how long I have or what might come next affects every decision. But being supported, listened to and treated as a person, not just as a diagnosis, has helped me focus on living well for as long as possible. I'm learning every day how to do this..

Melanie Lucas was diagnosed with neuroendocrine cancer in her lung, with metastasis along the lining of the lung and diaphragm. She is not eligible for surgery and her cancer is not curative. Her doctors believe she may have been living with the tumour for up to 10 years before it was discovered.

She says: *I had a dry cough which hadn't gone after a couple of weeks. I felt completely fine, but my chest felt tight and I worried it might be Covid-related. I was starting a new job working with the public, so I thought I should get it checked out.*

The doctor examined me and said it was probably nothing to worry about. Because my mum had non-small cell lung cancer and COPD, he agreed to send me for an X-ray for reassurance. Six months earlier I had asked another doctor about tests because of my family history and was told that as a non-smoker I would never get lung cancer or COPD and shouldn't worry.

When the X-ray results came back, my GP phoned to say something had shown up on my lung and there was shadowing near my heart. After further imaging, I was told it looked like advanced lung cancer.

While I was waiting for appointments, I checked my NHS app and saw a note saying I had a prognosis of months. It was summer and I genuinely thought I wasn't going to see Christmas. I put my summer clothes on Vinted and started making a list of practical things I needed to sort out. The strange thing was, I felt better than I ever had. I'd just changed careers from a desk job to gardening and now I was being told might have months to live.

During my biopsy, the lovely radiologist said, 'It is something, but I don't think it's lung cancer.' A week later I got the call confirming it wasn't lung cancer but a neuroendocrine tumour of the lung. I was relieved it was slow growing, but I still had incurable cancer.

Apart from that cough, I had been completely asymptomatic. My lung function test scored 90%, which is above average for my age.

I started on Lanreotide injections to slow tumour growth and later had oral chemotherapy. I showed a good partial response, with some shrinkage but slight progression elsewhere. The injections are uncomfortable, but manageable. I've also added complementary therapies, which help me feel I have some control.

The biggest adaptation is living by a different calendar with cycles of tests, treatment and results. I've returned to self-employment because being in employment and living with cancer and all that it entails is just too hard.

One of the biggest lifelines has been discovering NCUK. Living with neuroendocrine cancer can feel isolating, especially when many healthcare professionals don't fully understand it. The charity community has been lifesaving.

As a GP, I'm sorry to say, I missed my own cancer.



Gordon Brown, 62
from Ashby De-La-Zouch

As a GP, I'm sorry to say, I missed my own cancer. I had been experiencing many seemingly benign symptoms but I never thought they were a result of neuroendocrine cancer. I did go to the hospital a couple of times complaining about abdominal pain/diarrhoea but nobody did a scan. I'd ask my GP colleagues for advice but everyone, including myself, felt that the symptoms were not significant enough.

Gordon was diagnosed in December 2021 with small bowel neuroendocrine tumour, metastasis in the liver/pancreas, as well as carcinoid syndrome which gave him carcinoid heart disease. For about three years prior to diagnosis his symptoms included severe abdominal pain and diarrhoea, as well as abdominal bloating. He started getting urticaria (hives) when he exercised, as well as experiencing acute tiredness. He had a couple of episodes of collapse, which was misdiagnosed as anaphylaxis, when really it was neuroendocrine crisis – a severe, life-threatening reaction in people with neuroendocrine tumours (NETs). His consultant believes he was probably having symptoms far longer – around five years.

He says: *"During the three years I was experiencing symptoms of tummy issues, it was infrequent and as I'd had IBS for years, I didn't think anything of the diarrhoea and bloating. It was whilst I had those episodes of collapse, that I was feeling acutely tired – it was during Covid and I was working hard. I'd get heart palpitations, I'd be out of breath. I'm a keen cyclist but I was trailing behind my peers. I suffered weight loss and facial flushing. One day I was feeling the fat around my torso and stumbled across my enlarged liver. That's when I got a GP partner to get an urgent CT scan.*

I was lucky that my local hospital in Coventry is a centre of excellence for neuroendocrine cancer, and I was immediately referred.

When I first got the diagnosis, I thought I was going to die. My consultant advised me I had a life expectancy of approximately 12 years, which sounds a lot but you can't guarantee it so I had a lot of worry. It made me much closer to my loved ones.

In April 2022, I had a heart valve replacement and in August the same year I had surgery to remove the cancer in the small bowel, liver and pancreas. I now have Lanreotide, a hormonal injection, which stops tumour progression. The injections give me diarrhoea for a few days and the heart disease means that I'm not as fit as I used to be. Thanks to the surgery I'm almost back to normal.

What I've learned from the experience is that if things are getting worse or you begin to get different symptoms and you're over 55, it's time to be referred. It can be a slow growing cancer so it may take a long time for you to start noticing new symptoms. There's not one cardinal symptom attached to this disease so it's important to raise awareness and I think it's more common than we think due to a high level of misdiagnosis."

A clinician's perspective.



Professor Raj Srirajaskanthan
Consultant Gastroenterologist
King's College Hospital (European Centre of Excellence)

"Because they often look well, my patients frequently battle the isolation of a hidden illness.

"In my years as a NET clinician, I've sat across from thousands of patients, and while every story is unique, they often share a hauntingly similar prologue.

A large number have undergone a long and circuitous journey to their diagnosis, commonly being misdiagnosed with irritable bowel syndrome, asthma, or menopause. This period of not knowing is often marked by a sense of being unheard, as patients struggle to reconcile their debilitating symptoms with 'normal' test results.

The turning point occurs when they are finally referred to a specialist NET Centre. The relief is palpable; they describe it as finally finding a team that speaks their language. In our multidisciplinary meetings, we don't just look at a scan; we look at the whole person.

We coordinate surgeons, oncologists, and specialist nurses to ensure that the patient is no longer the one responsible for bridging the gaps between different doctors.

Managing NETs is often a marathon, not a sprint. Many of my patients have been undergoing treatment for over a decade. This longevity brings its own challenges – the 'scanxiety' of regular check-ups and the burden of chronic symptoms that others cannot see.

Because they often look well, my patients frequently battle the isolation of a hidden illness. Yet, witnessing their resilience as they navigate life is wonderful to observe."

Could it be Neuroendocrine Cancer?

Neuroendocrine cancer is often called **'invisible cancer'** because symptoms are non-specific, affect multiple body systems, and are frequently misdiagnosed.

Symptoms checklist.

Look for patterns, not just individual symptoms.

For the public: Ongoing symptoms from more than one group? Ask your GP if neuroendocrine cancer has been considered.

For healthcare professionals: Consider neuroendocrine cancer in patients with unexplained, multi-system or treatment-resistant symptoms, particularly with repeat presentations.

Think Jess' Rule: Reflect. Review. Rethink.

Neuroendocrine Cancer UK

Digestive & abdominal

- New onset symptoms of **IBS** in people aged 50+
- Persistent **bloating** or wind
- **Gastric** disorders including **heartburn**
- **Abdominal pain**, discomfort or cramping
- **Altered bowel habit:** diarrhoea/constipation/fatty stools (steatorrhoea)

Respiratory

- Persistent **dry cough**
- **Asthma** symptoms
- Unexplained **wheeze** or shortness of breath

Hormonal & flushing

- **Skin redness** without sweating (dry flushing)
- **Palpitations**
- **Menopause** symptoms
- **High/low blood sugar** (hyper/hypoglycaemia)

General

- **Fatigue**
- **Headache**
- **Allergy-like** symptoms
- **Anxiety** and low mood symptoms
- Unintentional **weight loss**

Help us make the invisible visible.

By raising awareness together, we can support earlier diagnosis and improved outcomes across the UK.

For healthcare professionals:

- **Be aware of neuroendocrine cancer.**
  Keep it in mind when speaking with patients.
- **Listen carefully.**
  If someone keeps coming back with persistent symptoms, there may be more going on.
- **Remember Jess' Rule.**
  Symptoms need to be resolved or explained before a patient is discharged.
- **Look beyond appearances.**
  Not everyone with neuroendocrine cancer looks unwell, even at Stages 3 & 4.
- **Use the tools available.**
  Share our checklist with your colleagues, visit our **online resources** and use these to support earlier diagnosis.

For patients, families and the public:

- **Trust your instincts.**
  You know your body better than anyone.
- **Keep the conversation going.**
  If symptoms don't improve, it's okay to see your GP again. Keep a diary of your symptoms so you can talk them through together.
- **Speak up and spread the word.**
  Talking about neuroendocrine cancer helps others get diagnosed sooner.

Earlier recognition means better outcomes for everyone, as well as our NHS.

Share this report and symptoms checklist on social media, in GP surgeries, community centres, local services and workplaces.

Supporting people affected by neuroendocrine cancer is at the heart of everything we do.

As we don't receive any funding or grants from the NHS, the government or larger cancer charities, we rely on the generosity of our community to sustain and grow our services.

Visit our website today to find out more.









Neuroendocrine Cancer UK

www.neuroendocrinecancer.org.uk

Support our vital work today:
www.neuroendocrinecancer.org.uk/donate