

DRAFT FOR BOARD REVIEW · NOT FOR CIRCULATION

WORLD NEUROENDOCRINE CANCER DAY · 10 NOVEMBER 2026

The invisible cancer

Missed. Misdiagnosed. Misunderstood.

Why neuroendocrine cancer is so often missed in New Zealand, what the delays cost patients and whānau, and how earlier diagnosis changes what comes next.

WHO WE ARE

About Neuroendocrine Cancer New Zealand

- We are a national charity dedicated to helping people living with neuroendocrine cancer. We put patients and whānau at the heart of everything we do.
- Living with a cancer that no one has heard of is lonely and difficult. These cancers are complex, range from slow growing to very aggressive, and patients need trusted information and genuine understanding.
- Founded in 2012 by a patient, we bring families and healthcare professionals together to provide education, raise awareness and support vital research.
- We are the leading voice for neuroendocrine cancer in New Zealand, supporting everyone affected, whether newly diagnosed or living with the disease for years.
- We campaign for neuroendocrine cancer to be better understood and prioritised, through education, outreach and by influencing health policy.
- Our support for research is accelerating progress towards faster diagnosis and treatments that cure.
- We are 100% donor funded by the generosity of our community, individuals and organisations who get behind our mission.

FOREWORD

Bringing this cancer out of the shadows

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

Since 2012, Neuroendocrine Cancer NZ has walked alongside people living with neuroendocrine cancer, and the whānau, friends and carers who support them. We've listened to their experiences, shared their stories, provided information they can trust, and pushed for change through advocacy, education and research.

We are grateful to the healthcare professionals with specialist knowledge in this field, who keep backing patients and championing better care. Thanks to our collective efforts, New Zealand has gone from no specialist scanner and no PRRT to some of the best access to scans and PRRT in the world – in under a decade. Real progress has been made, and it has made a real difference.

But neuroendocrine cancer is still not well recognised or understood, by the wider healthcare community or by the public. It's complex, and that means it's often misdiagnosed. Research shows it still takes more than four and a half years on average to get a correct diagnosis.¹

Delays, misdiagnoses, and inconsistent care cause serious and lasting harm. Precious time is lost while the cancer keeps progressing, and people miss out on the treatment they need. Patients and whānau tell us they live with

isolation and fear, and that they're left without support just when they need it most. This is unacceptable and needs urgent attention.

Neuroendocrine cancer is still largely invisible. Late diagnosis and years of prolonged treatment take a toll on patients and their whānau, and on our health system too. That's why we need to bring this cancer out of the shadows, through earlier diagnosis and better understanding.

This World Neuroendocrine Cancer Day, we're proud to shine a light on raising awareness and getting people diagnosed sooner, so they can get timely treatment and support that can change their lives.



Dr Michelle Sullivan

Chief Executive, Neuroendocrine Cancer New Zealand

DRAFT PLACEHOLDER

New Zealand clinician foreword – name and words to confirm

A short foreword from a New Zealand neuroendocrine specialist, ideally from the national NET MDM: what a delayed diagnosis costs clinically, why an earlier one widens the treatment options, and a call for vigilance from whānau, practice nurses and specialists alike.

Pull quote from the clinician foreword

NAME · ROLE · HOSPITAL OR SERVICE

400+

Every year, more than 400 people in New Zealand are diagnosed with neuroendocrine cancer – that's more than ovarian, liver or oesophageal cancer and about the same number as diagnosed with brain cancer each year.

SOURCE TO CONFIRM

Neuroendocrine cancer: what Kiwis need to know

Neuroendocrine cancer is an umbrella term for a group of individually rare cancers, but it's likely more common than the official numbers suggest. Diagnoses have been climbing steadily, and they're still heading up.

Too often, it's missed

Getting diagnosed late is one of the biggest challenges. Research overseas shows people with neuroendocrine cancer symptoms visit their GP an average of eleven times before anyone puts the pieces together.² The consequence of delayed diagnosis is that the cancer is often at an advanced stage (Stage 3 or 4), which limits treatment options and adds to the physical, emotional and clinical load.

At the heart of it is a lack of awareness. Neuroendocrine cancer is a complex, varied group of cancers that can look very different from person to person. Symptoms can mimic everyday conditions like IBS, asthma, anxiety and menopause, so it's easy to miss.

For many people, it's something to be managed long term, with symptoms that affect quality of life well beyond diagnosis. Effective treatments do exist, but long waits for a diagnosis and patchy referral pathways mean too many people never get to see a specialist.

It doesn't help that the disease can be invisible. Plenty of people look well even with advanced disease, so their symptoms get brushed off or underestimated. That can be isolating and push treatment back even further. Access to therapies that could slow progression and ease symptoms can also be a hurdle, and some treatments are only funded for particular 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 shines a light on the gaps in understanding, spells out what delays cost people, and backs the case for getting patients in front of specialists who really know this group of cancers.

Earlier diagnosis is a game-changer. Even when the cancer has spread, there are treatments that can improve symptoms and outlook. We hope this report brings some clarity and hope to anyone facing avoidable delays, limited options and a long wait for answers.

WHAT NEW ZEALAND HAS GOING FOR IT

New Zealand's best weapon – a national NET MDM

Any patient anywhere in the country can have their case referred to the NET MDM by their specialist or their GP.

New Zealand's national neuroendocrine tumour (NET) multidisciplinary meeting (MDM) is a regular collaborative forum where leading specialists from diverse fields such as pathology, radiology, oncology, endocrinology, surgery and nuclear medicine review complex patient cases to design individualised treatment strategies. Getting access to this level of expertise makes a real difference to patient outcomes and ensures the best care reaches people in the most remote corners of the country.

In under a decade

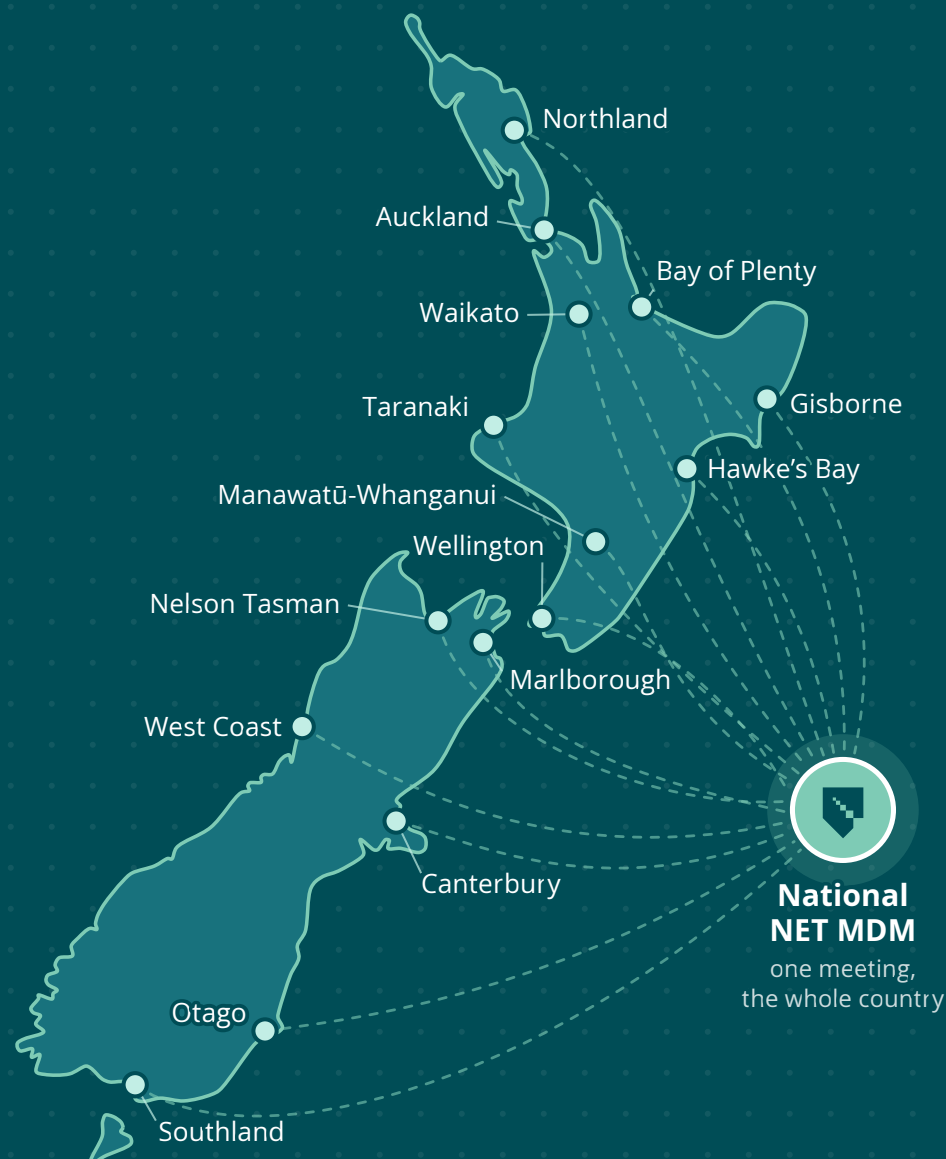
New Zealand has gone from no specialist scanner and no PRRT to some of the best access to scans and PRRT in the world.

Not Your Usual Suspects

Our GP education module, accredited by the Royal New Zealand College of GPs: neuroendocrinecancer.org.nz/knowledge-hub/gp-education

Still to fix

Some treatments are only funded for particular tumour sites, and patchy referral pathways mean too many people never get to see a specialist.



Schematic. Regions are shown generally, not as specific hospitals.

What is neuroendocrine cancer?

All neuroendocrine cancers begin in neuroendocrine cells, which are found all over the body. These cells release hormones that help regulate lots of bodily functions. When they turn cancerous, their growth and normal function get disrupted.

The most common neuroendocrine cancers start in the gut, pancreas or lungs. Most happen sporadically, meaning there's no known genetic link. However, there are a few rare inherited conditions that can raise someone's risk of developing a neuroendocrine cancer.

The most common symptoms include unexplained weight loss, growing tiredness, pain, diarrhoea, bloating, wind, heartburn, asthma-like symptoms, flushing and a cough that won't go away.

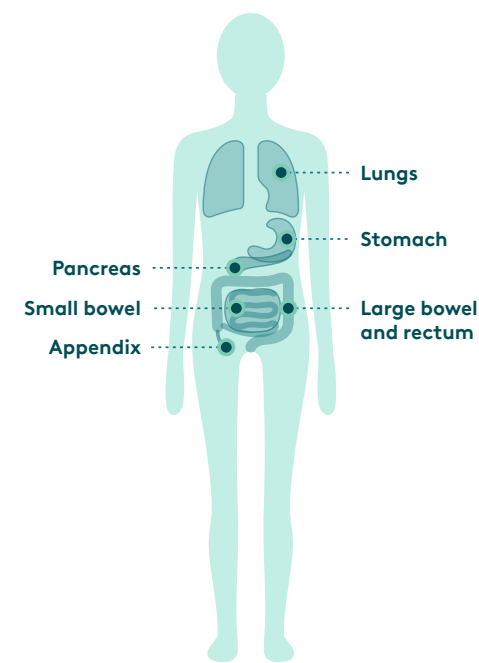
There are two main subtypes and getting the classification right really matters, because it shapes both prognosis and treatment.

Neuroendocrine tumours (NETs)

Usually grow more slowly than NECs and many other cancers. Symptoms can come and go at first, then build gradually. For many people, a NET means living with a chronic, incurable condition, with regular check-ups and monitoring.

Neuroendocrine carcinomas (NECs)

Less common but more aggressive. Symptoms tend to show up suddenly and stick around. Someone with a NEC may go through a more typical cancer journey, which can be less certain and harder to survive.



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

The figure is schematic.

70%

Approximately 70% of patients have NETs

30%

Just under 30% have NECs

TREATMENT

Tailored to each person

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.

DATA SPOTLIGHT

What the numbers say

IN NEW ZEALAND

4.7 years

On average it takes 4.7 years to be diagnosed from the first symptom (4.5 years globally).¹

15%

For 15% of patients, it takes ten years or more to get a correct diagnosis.¹

400+

More than 400 New Zealanders are diagnosed every year with neuroendocrine cancer.

[SOURCE TO CONFIRM](#)

4,000

An estimated 4,000 Kiwis are living with neuroendocrine cancer in New Zealand at any one time.

[SOURCE TO CONFIRM](#)

FROM INTERNATIONAL RESEARCH

11

On average patients visit their GPs 11 times before a correct diagnosis.²

More than half

of all patients are diagnosed after the cancer has spread around the body.³

30%

of people experience their first neuroendocrine cancer symptom before the age of 50.⁴

Common misdiagnoses include irritable bowel syndrome, gastritis, anxiety, allergies, asthma and menopause.

What delays cost

Every missed or delayed diagnosis carries consequences. For patients and families it means months or years of symptoms and uncertainty. For our healthcare system it means mounting costs of repeat appointments, tests and referrals.

CLINICAL IMPACT

More than half

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.³ This can mean fewer treatment options, the need for more invasive treatment, and a higher financial burden on our health system.

Living with the mental and emotional weight

Many people carry a lot of emotional distress due to delayed diagnosis, misdiagnosis, and the unpredictable nature of their illness. They commonly report feeling dismissed or not believed by doctors, and start doubting themselves.

All patients live in fear of symptoms getting worse, 'scanxiety' (anxiety about scans), the possibility of the cancer worsening, and deep loneliness – feeling like nobody understands what they are going through.

Some have to wait until their disease has worsened before treatment can be started, which only adds to the uncertainty.

Living with the 'invisible cancer'

Many patients look well. They don't fit the picture of a typical cancer patient and may not have chemotherapy. This can lead to misunderstanding or dismissal, because others don't realise how serious the disease is.

Limited awareness and lingering misconceptions can also make it harder to get physical and mental health support.

Living with the physical and financial struggle

A delayed diagnosis can mean more severe symptoms and side effects, and ongoing treatment that is more complex. Many people are then faced with a life of regular surveillance, with frequent hospital visits and scans.

Fatigue, hormone-related symptoms, pain, and other complications can chip away at independence and quality of life. Some people can no longer work, while others struggle with everyday tasks like showering, cooking or leaving the house.

Two people about their lived realities



Removing the tumours didn't just save my life, it gave me back a sense of myself that I didn't realise I had lost.



Lou

Read Lou's full story at neuroendocrinecancer.org.nz

In March, Lou was tramping one of NZ's toughest Great Walks. By April, twelve steps to her front door were a struggle. The cause: a 15 cm pancreatic NET, a second tumour on her kidney, and symptoms she'd spent years putting down to menopause.

Lou is a 54-year-old Māori woman of Kāi Tahu, Kāti Māmoe, Waitaha and Ngāti Hikairo descent.

In March 2026, Lou and her partner were tramping the Humpidge Track, feeling fit and strong, with the Milford Track with whānau planned four weeks later. Then in April, severe leg cramps and breathlessness set in. Blood tests showed she was anaemic, and a week later she was rushed to the ED after vomiting large blood clots.

A CT scan found a 15 cm pancreatic neuroendocrine tumour, and a second 7 cm tumour on her left kidney. The good news: neither had spread, and surgery was possible. In May, she had a seven-hour operation.

"Hope and fear seemed to exist side by side, and I quickly discovered that you can never underestimate the emotional roller coaster that comes with a cancer diagnosis."

Recovery meant more than healing. Lou was managing significant pain, adjusting to a large scar, and grieving the loss of parts of her body. "I hadn't expected to mourn my organs, but I did."

Looking back, the signs had been there for years. She'd been told she had IBS, and put the fatigue, the slower rowing and the short temper down to menopause and getting older. "I accepted these changes as part of getting older, never imagining they were being caused by two tumours growing inside me."

She had even stepped away from her career, and struggled with hopelessness she couldn't explain. Since surgery, the IBS, the anxiety and those dark thoughts have gone. "Removing the tumours didn't just save my life, it gave me back a sense of myself that I didn't realise I had lost."

Lou and her partner chose not to Google anything, and relied on Neuroendocrine Cancer New Zealand for information. She hopes her story encourages others to listen to their bodies and ask more questions.

Suzanne

Suzanne was told she had small cell carcinoma. Months later, a second look at her biopsies revealed something far rarer: atypical pulmonary neuroendocrine carcinoma.

In February 2013, Suzanne was enjoying a month with family in Melbourne when a nagging pain in her femur and a rare bout of indigestion sent her back to her GP. Within days, she learnt she had cancer in her femur and liver, and it had spread widely through her body. She'd had breast cancer surgery in 1999, so she was no stranger to oncology appointments.

Chemo made no difference. Then a cousin in Sydney emailed an article about the Peter MacCallum clinic, which led Suzanne to an Auckland specialist. When her Dunedin biopsies were re-examined, the diagnosis changed.

"Total disbelief, never heard of such an outlandish cancer."

Suzanne doesn't blame her Dunedin team, who had never seen it before, though she admits her sense of humour got a workout. "If I could claim ACC for wrongful diagnosis I would."

She has since developed carcinoid syndrome, despite being told she never would. "I'm re-writing medical history. They love me."

Getting access to newer treatments has been a fight, and Suzanne has taken on Pharmac and her insurer along the way. Her disease has now become less stable, and her specialists are hopeful of containing it.

"I refuse to allow this cancer to dominate my life though some days it is difficult... I am not defined by cancer."

Read Suzanne's full story at neuroendocrinecancer.org.nz

DRAFT PLACEHOLDER

New Zealand clinician perspective – name and words to confirm

A first-person piece from a New Zealand NET clinician, ideally someone who sits on the national NET MDM. The UK report uses this page for what specialists see: the long road many patients take to a diagnosis, the relief of reaching a team that knows the disease, and living with a cancer that others cannot see.

Pull quote from the clinician perspective

NAME · ROLE · HOSPITAL OR SERVICE

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.

Look for patterns, not just individual symptoms.

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

FOR THE PUBLIC

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

FOR HEALTHCARE PROFESSIONALS

Look beyond the Usual Suspects and consider neuroendocrine cancer in patients with unexplained, multi-system or treatment-resistant symptoms, particularly with repeat presentations.

Neuroendocrine Cancer New Zealand offers a medical education module "Not Your Usual Suspects" that is accredited by the Royal New Zealand College of GPs.

neuroendocrinecancer.org.nz/knowledge-hub/gp-education

By raising awareness together, we can support earlier diagnosis and longer, better lives for patients all over New Zealand.

IF YOU'RE A HEALTHCARE PROFESSIONAL

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 it might not be one of the Usual Suspects.

Consider if a neuroendocrine cancer diagnosis might fit unresolved or unexplained symptoms.

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.

YOU CAN TAKE ACTION TODAY

Share

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

Donate

Donate to support our work. We don't receive any government grants or other funding and rely entirely on the generosity of our community to sustain and grow our services.

neuroendocrinecancer.org.nz/donate

Find out more

Supporting people affected by neuroendocrine cancer is at the heart of everything we do. Visit our website today to find out more.

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

SOURCES

- 1 INCA (International Neuroendocrine Cancer Alliance), SCAN 2025 – Survey of Challenges in Access to Diagnostics and Treatment for Neuroendocrine Cancer Patients. New Zealand patient results, from *SCAN 2025 – a New Zealand reading* (Neuroendocrine Cancer New Zealand, 2026).
- 2 Basuroy R, et al. (2018). Delays and routes to diagnosis of neuroendocrine tumours. BMC Cancer. As cited in Neuroendocrine Cancer UK, *The invisible cancer* (2026).
- 3 Neuroendocrine Cancer UK, Barriers to Diagnosis Survey, January 2021. As cited in *The invisible cancer* (2026).
- 4 Neuroendocrine Cancer UK, *The invisible cancer* (2026).

[ORIGINAL SOURCE TO CONFIRM](#)

New Zealand incidence figures. More than 400 diagnoses a year, around 4,000 people living with neuroendocrine cancer, and the comparison with ovarian, liver, oesophageal and brain cancer are awaiting a confirmed New Zealand source.

[SOURCE TO CONFIRM](#)

This report is a New Zealand adaptation of *The invisible cancer*, published by Neuroendocrine Cancer UK in 2026. With thanks to our colleagues there.

SUPPORT OUR WORK TODAY

neuroendocrinecancer.org.nz/donate