

2000kms apart - working together.

How a team of Australian Neuroendocrine Cancer Nurses are delivering a National Supportive Care Service for People living with Neuroendocrine Cancer.

Introduction

When someone is diagnosed with cancer, information, resources and specialist support are essential and should be accessible. Yet there remains disparity.

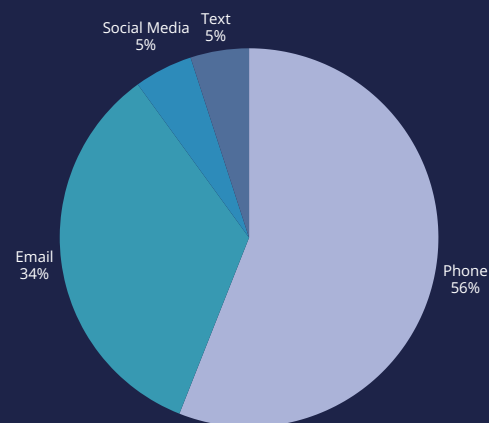
Access to supportive care can be dependent upon the type of cancer, a persons postcode or the system of healthcare they engage with.

NeuroEndocrine Cancer Australia's team of specialist cancer nurses are located across Australia providing accessible supportive care for people with neuroendocrine cancer and their families.

Aims

- ✓ Eliminate barriers to specialist cancer supportive care
- ✓ Ensure supportive care from specialist cancer nurses is within reach for all people with neuroendocrine cancer
- ✓ Empower people with neuroendocrine cancer through evidenced based information, knowledge and resources
- ✓ Fill the void between the supportive care people seek and the supportive care currently offered
- ✓ Be responsive to the needs of people with neuroendocrine cancer

How people contact the service



2500 + contacts to and from the service during 2024 CY

Neuroendocrine cancer is relatively unknown in the public domain. When people are faced with a diagnosis, limited information and support is commonly reported, leading to significant distress.

We created an online version of the validated National Comprehensive Cancer Network's Distress Screening tool to evaluate the impact of the neuroendocrine cancer nurse service (NCCN 2024).

Description

Team

Located and working remotely across Australia, a small team of cancer nurses provide information, resources and support to people with neuroendocrine cancer and their families.

The role is dynamic and diverse, requiring high level specialist clinical knowledge and communication skills .

While physical distance between the team exists, working together via phone and through online platforms, ensures continuous collaboration to deliver a cohesive service.

Support Available

- Telephone support line
- Online Ask the NET nurse enquiry
- Facebook Private Support Group
- Website
- Fact Sheets
- Information Booklets
- Explainer Videos
- Medical Alert Cards
- Patient Forums
- Living with NETs Education Program
- Navigation and signposting to other supportive care services
- Support Groups in person/online
- Advocacy

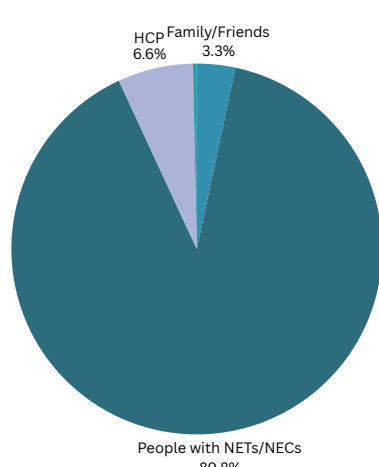
Service Strengths

- Nurses with specialist neuroendocrine cancer knowledge
- Responsive and on demand
- Australia wide service
- Multiple access points
- Capacity to also support health care professionals
- Nurses located in multiple states ensuring an understanding of state services

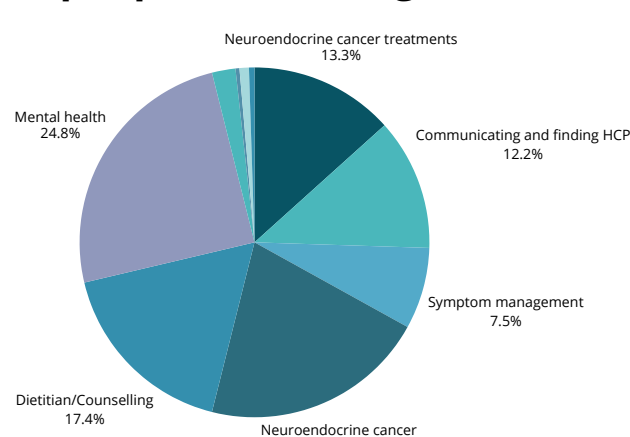


Outcomes

Who is contacting the service



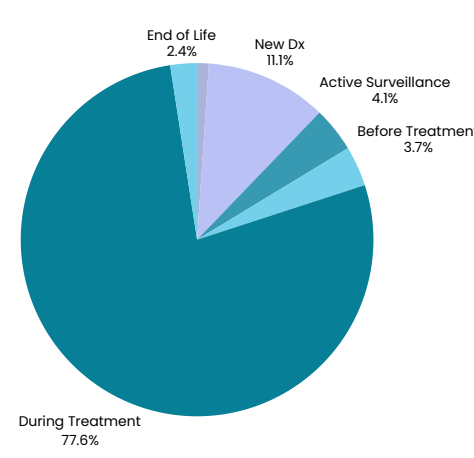
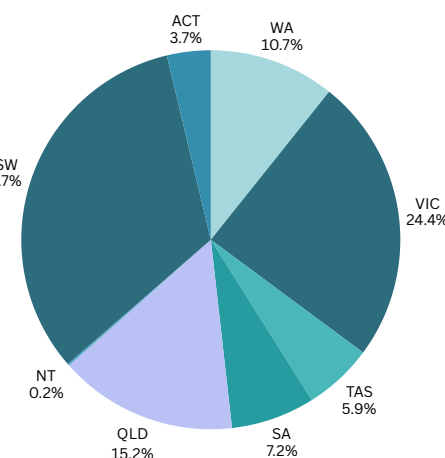
Why are people contacting the service



NECA Statistics for current 2024/25 FY

Outcomes

Location & timepoint people contact the service



Highlights

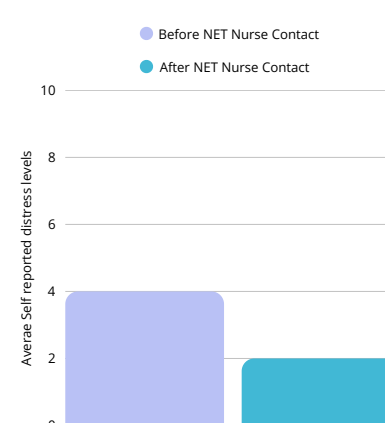
The nurses offer support that traverses the gap between a persons existing understanding, knowledge and experience, and what they are seeking to understand about neuroendocrine cancer.

After 2 years of living with neuroendocrine cancer, I finally found someone who understood the character of the cancer and they gave me valuable, helpful information.

Feedback - Service Evaluation NECA 2025

Service Evaluation

Evaluation of self reported distress levels before and after people contact the nursing service indicate when people with neuroendocrine cancer have access to education, resources and support through our specialist nurse support service, distress levels are reduced.



Reference https://www.nccn.org/docs/default-source/patient-resources/nccn_distress_thermometer.pdf

Conclusion

People with neuroendocrine cancer often find themselves isolated in a search for resources and supportive care. The Australia wide Neuroendocrine cancer nurse service is reducing the existing supportive care disparity. The service is experiencing continued growth and has the capability to complement existing health care services. By bridging the existing supportive care void, more comprehensive support of people with neuroendocrine cancer is achieved.